Mars Rising: Music Therapy and the Increasing Presence of Fathers in the NICU

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Abstract

Fathers of premature infants have been primarily marginalized caregivers up until the last 20 years, but change in both the societal definition and expectation of fathers as well as tremendous evolution in the Neonatal Intensive Care Unit (NICU) and neonatal care towards integrative practice inclusive of music therapy has rendered a unique time in history. Fathers, now viewed as integral to optimal parenting outcomes, are well matched to the unique therapeutic offering of music therapy. In this article, three music psychotherapists have provided literature review across the helping professions as well as case studies to bring the complex role of NICU fathers into much greater salience.

Keywords: NICU, Fathers, Music Therapy

Introduction

The Neonatal Intensive Care Unit (NICU) has seen a rapid progression toward integrative family-centered care, simultaneous to an evolution in the socio-psychological perception of fatherhood to the inclusion of fathers as both primary caregivers and primary supports for their spouses. While the general climate of NICUs is matriarchal by nature, music therapy may be identified as a modality ideally suited to bridge any perceived gap.

The use of music [1-4] and music therapy [4-33] in the Neonatal Intensive Care Unit (NICU) is well documented, with various approaches drawing from established theories including attachment theory [5-13,15,24,34], developmental theory [18,20,21,35,36], family systems [11,15,21], and trauma theory [21,26,27]. Music therapy literature spans interventions with pain and procedural support [5,6,9,10,13,18], non-nutritive suck response [6,7,9,13,14,16], kangaroo care [7-13,21,28], self-regulation [5-28], anticipatory grief [9,13,21,26,27,32,33], and the sound environment [29,37].

To date, the efficacy for these interventions has focused primarily on the importance of the mother’s voice [1,12,22,24], yet the literature base examining the mother-father dyad in both music therapy [2,5-11,15,21,30,31], and the areas of social and behavioral psychology [38-51] is increasing. Specifically, there has been much emphasis placed on understanding the emotional experiences of fathers [52-60], fathers’ identity formation [61-70], partnering during pregnancy and childbirth [71,72], and the impact of stress and anxiety on fathers [58,72-77]. The magnitude of this social change has charged the helping professions to develop creative ways of empowerment and support for fathers in these critical multifaceted roles [78-80].

One multi-site study [6] involving 272 infants enrolled in a clinical trial, included a qualitative analysis that revealed themes of: lack of control, lack of clarity as to role, financial stress, and reaffirmed loss when seeing other parents with healthy babies, in the answers of 68 fathers to the question “What is the most stressful part of having a baby in the NICU? (see Appendix A). This research is one of the only music therapy studies to date that specifically evaluated the psychoemotional needs of parents and caregivers in addition to the developmental needs of the neonate. Its reported findings afford a lens on a topic that is invaluable to the growing body of work in the NICU internationally. The First Sounds: Rhythm, Breath Lullaby (RBL) model of NICU care [5,6,9,10,21,24], from which the study dovetailed, brings salience to the benefits of psychotherapy for mothers and fathers, as a critical entry point to the treatment of the neonate.
Medical Music Psychotherapy in the NICU

The use of psychotherapy to address issues of bonding [5,6,21,24,30,31], anticipatory grief [32], and trauma [26,27], is relatively new to NICU music therapy, and is supported by relevant literature in the fields of social psychology [58,71,72-76]. Within this approach, the therapist’s interventions are informed by the skilled use of transference, countertransference, assessment of other psychodynamics that can emerge when mothers and fathers are navigating the NICU environment through their respective identities, and the identification, creation, and use of live music and song-of-kin [5,6,21,24] as an affirmational resource [78].

The skill set necessary for therapists doing this work is elucidated in the first two case vignettes to follow, but to better understand the source of parental stress, and particularly that of the father in his role as one that is integral to the wellbeing of both the neonate and mother, the authors have first provided an overview of the NICU and the trajectory of care that ensues from premature birth.

Overview of NICU Milieu

The NICU, a specialized nursery that provides 24 hour care to sick or premature infants, is staffed with specially trained physicians, nurses, and health professionals who are experts in the treatment of premature and ill newborns. Levels of neonatal care often vary across hospital settings.

A well-baby nursery attending to healthy babies born close to their due dates, provides routine care, and can usually manage late preterm babies born after 35 weeks gestational age. Common conditions treated in the NICU include but are not limited to prematurity, congenital heart defects, intraventricular hemorrhage, NEC (necrotizing enterocolitis), anemia, hypoglycemia, jaundice, retinopathy, sepsis, feeding issues, and respiratory distress due to immature lungs. Depending on the severity of the medical condition a baby may spend days, weeks or even months in the NICU before meeting the milestones required to be discharged home. Some may need minimal support for a short period of time while others with multiple needs require multiple interventions and longer stays.

A Special Care Nursery, or Level 2 NICU can care for babies 32 weeks gestational age or greater with some issues associated with prematurity such as jaundice, feeding issues, or trouble maintaining adequate body temperature.

Level 3 NICUs can vary from state to state, registering as the highest level of care and functioning as a Level 4 NICU in others. All Level 3 NICUs can care for babies born at more than 28 weeks gestational age. They can provide respiratory support and deliver IV fluids.

Level 4 NICUs can care for micro-preemies born as young as 18 weeks gestational age providing the highest level of care, which may include a range of neonatal surgeries and interventions.

Well-executed developmental care is critical to optimize growth and development for preterm infants in the NICU of all levels [18-21,35,36]. Commonly placed in a single occupancy room or in a room with several other babies, neonates spend their first days, weeks, or months in enclosed temperature-controlled isolettes. Once able to maintain their own body temperature, they may move into an open bassinet or crib. In addition to such a physical barrier separating parent and child, there is a constant hum of machines, alarms, and frequent painful medical procedures. This environment is very different from a mother’s womb, and can be intensely startling to preterm infants. Therefore the execution of developmental care is to create an environment most similar to that of the mother’s womb. An ideal environment is characterized by: limited light and sound, sleep cycle preservation, constant access to the mother and father’s voice, and a feeling of containment [29,37].

Discharge requires the neonates’ ability to: maintain their body temperature in an open bassinet or crib for at least 48 hours; be fed by breast or bottle; and have steady weight gain for 2-3 days. In some cases they may have special needs that require an apnea monitor or oxygen to be continued at home. These infants also have intense developmental and social needs.

Fatherhood and Identity Formation

Across the globe, the designation of “daddy” be it “papi”, “abba”, “tata”, or “baa”, is imbued with a host of social meaning, responsibility, and expectation. This role of the “father” has justifiably conjured much interest in the social sciences in recent decades resulting in an ample body of research on the complexity of identity formation as discussed previously. Additionally, the growing interest in understanding the importance of partnering for successful parenting has placed due focus on the role of the father, far beyond the commonly held stereotypes of “the protector”, “the rock”, and “the provider”, and more as a position essential to well-being and family health [11,40-43,71]. These latter notions are certainly important, but display only part of the portrait of fatherhood that we are coming to recognize. The social changes that have occurred since the 1960s in terms of the nuclear family system have continued to challenge such social norms for the better, to the degree that fathers are not only encouraged to actively participate in parenting, but at times to even assume the primary role. This socially defined role of the father is particularly challenged when premature birth becomes reality. The plethora of feelings around loss, self-blame, shame, and uncertainty can contribute to the emotional burden of a father as much as for the mother, which may stand in juxtaposition to social expectation still firmly held in most parts of the world [38,41-44].
Certainly the emotional challenge when events don’t occur according to ‘the plan’, is felt within the parent dyad across gradations of experience, but while the anguish of a mother is visible to the world, lack of recognition of the father is a societal issue that is perhaps most threatening at this time [39,71]. Possible feelings experienced by a father when an infant is born prematurely or even stillborn may center on the unfulfilled relationship of the protector of the perceived unprotected. With bonding to the unborn infant occurring for some men as early as the first ultrasound photos, the rite of passage into fatherhood, and the formation of identity within the role of father can be established quite early, which lends further testament to the magnitude of loss that can be felt [39,59-61,71]. Unfulfilled relationship, compounded with the financial stress that is immediately thrust upon parents of a premature infant, places most fathers under tremendous pressure to assume socially expected roles, with very little opportunity to authentically experience their own feelings. Moreover, as men are less likely to seek support on their own, the tendency toward self-reliance for processing profound loss is often the norm [39,71]. This said, most fathers are eager to tell their story when given the opportunity to do so [71].

The Role of Fathers in the NICU

Fathers of premature infants face additional milieu specific challenges that may exacerbate the challenges of identity formation and maintenance discussed in the prior section. In most studies, fathers expressed the need to take part in the care of their baby and wish to be acknowledged as equally important partners as mothers. Being close and holding or having eye contact with their baby, usually attributed to mothers, are existent experiences that can help fathers in developing ‘feelings of proximity’ [57]. In a similar way, nearly all fathers portrayed seeing or touching their preterm babies shortly after birth as ‘beautiful’ or ‘enjoyable’ experiences [53]. Family-centered music therapy interventions that aim at fostering such moments of proximity may thus be critical for both mothers and fathers in the NICU [31,32].

Many fathers of preterm babies are exposed to increased levels of stress [53,55], emotional exhaustion [58] or experience difficulties in transitioning to fatherhood [55]. Two recent qualitative studies [54,56] show that fathers’ emotional experiences in the NICU are marked by anxiety, feelings of helplessness and worries about their babies’ development. Also, given the rapid and unpredictable trajectory of high-risk pregnancy and early delivery, fathers express difficulties in adjusting to what it really means to be a father of a preterm baby. The lack of time for preparing themselves for fatherhood, can compromise the emerging paternal identity. During the time of their baby’s hospitalization fathers might also experience differences in their role as parents. Some fathers report being regarded as a “second parent” [54], and express the challenges of being acknowledged and “seen as a natural part in the care” of their babies [56, p.145]. This perception might be setting-dependent however. In a large study with 111 fathers of very low birth weight infants [53], 93.7% of fathers reported no differences in the way they or their partners were integrated into the care of their babies.

These insights seem to reflect that fathers’ emotional experiences in the NICU are similar to those of mothers. This matches the results of another study [50], which found no differences in the needs of fathers and mothers of preterm infants. Yet, fathers might also face gender specific challenges. Fathers often feel torn between caring for, or choosing between the mother and the baby [56,57]. This scenario becomes particularly significant during the mother’s postpartum hospitalization, when many fathers report the importance of both the relationship with their partner, and the opportunity to express their worries and fears as essential for coping.

Contradictorily, in a separate study [53], 48.1% of the fathers reported abstaining from expressing such fears and concerns in order to protect their partners. This might suggest different coping mechanisms in mothers and fathers [51], and that fathers manage their emotions differently: “Long silences, a feature of many father’s accounts, suggest a hidden facet of emotion management, one that does not easily transcend into overt expression. The term ‘silent emotion work’ seems to be a useful label to capture these mutely endured emotions” [55, p.661].

Preterm birth may challenge fathers in their social role as the family provider; a role in which they are expected to be strong and to manage adequately their feelings. Simultaneous to this role-fulfillment however, fathers can experience an overwhelming emotional instability. Involving fathers directly in music therapy renders opportunities for direct participation in the care of their babies [2,3,6-11], which may ameliorate the impression of being a “second parent” [54]. This practice of inclusion may be especially important in societies that are based on more traditional gender roles and expectations. Here, the provision of opportunities for both parents to interact and communicate musically with their baby can alleviate the pressure of social stigma about roles, and also help to nurture feelings of unity and family. Such positive shared experiences can assuage many of the difficulties experienced by fathers in the NICU [79,80].

Casework

The following case vignettes have been drawn from the authors’ use of music psychotherapy to support the integration of three fathers in each of their respective NICU experiences. Notably, the first and second case vignettes are presented in first person by the therapists, while the third is
presented by the father himself. In all three vignettes, each father experienced himself as vital in a role that was given prominence by way of the affirmation and validation afforded within a therapeutic relationship.

Case 1: Cultural Factors

This first vignette portrays the work with a father of a preterm baby in a Level III NICU in Bogotá, the capital of Colombia. As I am originally from Austria, but living and working in Colombia, several cultural challenges arise in the work with parents of preterm babies. Examples of such challenges may relate to gender roles, culture-based expectations of social relationships or the meaning of music in therapy.

David was born at 28 weeks with multiple difficulties related to his early start in life. Therefore, it took him quite some time to be sufficiently stable to receive additional stimulation and Kangaroo Care. After 20 days, he and his parents Laura and Santiago were referred to music therapy for optimizing bonding and fostering self-regulation.

The first session took place with both parents while Santiago was providing Kangaroo Care for David. Santiago and Laura expressed their preference for “Vallenato” music, a very popular Colombian music style. Santiago proposed a song (“Esa”) by a renowned singer of this genre, Rafael Orozco. The session started with singing the chorus of the song with an improvised melody and instrumental accompaniment. Both parents expressed curiosity and joy watching the gestures of baby David who responded with opening his eyes and smiling to the music and singing.

The next few sessions were held with Santiago and the baby alone due to the mother’s necessity to care for their other child at home. Santiago was very proud of his son and expressed his affinity for music by explaining that he sang a lot for David during pregnancy. He also expressed his unfulfilled dream to become a “Vallenato” singer himself. We continued to work with his favourite song from the first session, which notably is a tribute to a wife in a marital relationship. However, the lyrics describe also very clear the role that a woman needs to fulfill for gaining and maintaining the love of her husband: being at home and caring for the children, not complaining when the family goes through difficulties, fulfilling immediately and unconditionally the wishes of the husband, and not resisting physical closeness when the husband expresses such a desire.

Because this differed very much from my own worldview and cultural socialization regarding gender roles and social relationships, some important questions came up for me: How important are the lyrics when singing for preterm babies?

What if the lyrics depict a worldview that is contrary to that of the music therapist? What role does culture and socialization play in music and how are social and gender roles transmitted and reinforced by music?

However, during the sessions I learned quickly that these questions were more important for me than for the father. Santiago connected much more with the aspect of love that he wanted to transmit to his son rather than with the implicit or explicit “cultural message” of the song. Yet, during the conversations with him after the singing, I also noted that it was an issue for Santiago to be surrounded by so many women in the NICU: the mothers, the therapists, the nurses, the physicians. Thus, I came to understand that he also needed to protect and articulate his culturally shaped experience of what it meant to be a man and a father. Expressing feelings of love and tenderness towards his son might just have been possible through a song that contains perspectives on masculine identity aligned with his own biography, history and culture. That he could use this song for communicating his feelings for David became also clear when I asked him why he liked to sing this song for David. He said: “It’s very beautiful and one can share beautiful things with music. It’s something beautiful. It’s a song that…well, yes, it is also a form of saying ‘I love you’, you know? So one feels…feels this same energy, the same thing, this peace, that your daddy loves you and your mommy too…”

When the mother Laura rejoined music therapy a few sessions later on, both sang together Santiago’s favourite song, which they visibly enjoyed. She did not make any remarks about the song other than she liked it.

While Santiago’s song choice provided an initial dilemma for me due to the implicit reinforcement of specific gender roles, for the parents this was not the case. Both Laura and Santiago identified with the aspect of love the song transmitted to their baby. For Santiago, it might have been a sort of musical anchor for maintaining and reaffirming his masculine identity aligned with his own biography, history and culture. That he could use this song for communicating his love for David in an environment dominated by women. Being able to work with a male music therapist may also have helped Santiago in sharing his story as a man and father and provide both comfort and companionship during hospitalization.

For family-centered music therapy approaches in the NICU it is crucial to take into account the cultural, historical and biographical aspects and expectations of social relationships and gender roles. Nevertheless, this is also a challenge. The music therapists own worldviews might be shaped by different circumstances than those of the parents. This requires an increased sensitivity and awareness of these differences and of the role that music plays in this regard, especially when working in foreign cultural settings. After all, music is always culturally embedded. Hereby, as a music

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1 The parents and baby described in this vignette were part of a larger study about family-centred music therapy in Columbia. Their names were changed in order to maintain anonymity. Informed consent was given.

2 Excerpt from an interview held with both parents after the therapy session.
therapist in the NICU, it can also be helpful to focus again on the more universal aspects of the work: fear, love, frustration, happiness, sadness or grief, all common experiences of many parents with preterm babies independent of their cultural background. And music can provide an opportunity to connect, express and contain these experiences in a meaningful and culturally coherent way.

Case 2: Song of Kin & Identity

This vignette is focused on work with the 34 year-old father of NICU twins Shae and Leah, born at 28 weeks with multiple complications due to small gestational age (SGA). While this work extended for over a month, music therapy allowed the father opportunities to connect to the reality of premature birth in his own way.

As established earlier, the fragility of life in the NICU environment requires a therapeutic approach that is palliative.[32,33] This occurs naturally from the moment music therapy services are involved, because emphasis on relationship is central, and sensibility within a milieu of uncertainty can be honed. Focusing simultaneously on the developmental needs of the neonate and the psychosocial needs of the family, music therapy fosters a sense of meaning and relationship in an environment where uncertainty can manifest in parental detachment and at times ambivalence about bonding. While this was not the situation of the parents in this case, I maintain this point as an important area of assessment for those working in the NICU.

In this case, both the mother Nicole, and the father Jamie presented as eager to embrace the challenges ahead in spite of the understandable anxiety that was residual from the turbulence of the pregnancy and the reality of having their infants in the NICU. While they were both receptive to psychosocial support through music therapy, it was Jamie who had expressed early on in the therapeutic relationship a need to connect and process the NICU experience through music, which was richly familiar and comforting. During the assessment he recalled both of his parents (college professors) singing to him when he was a little boy, and exposing him to the pop music of the time, specifically the Beatles. The beginning of Jamie’s story emerged during music therapy in which his emotional experience could be unconditionally heard and validated.

Preliminary work focused on providing recluse from the NICU environment that was housing Shae and Leah. Music therapy facilitated the space for Jamie to reconcile his genuine feelings with those induced by societal expectation as previously discussed. Subsequently, his affinity for music and a deep desire to support and empower his wife, as well as to be able to use music with his new babies, was required.

The following recording session occurred at a point when both Nicole and Jamie were regularly engaging in music therapy sessions at the isolette during Kangaroo Care. Both parents expressed interest in recording their music/voices to supplement the work of music therapists, understanding that such a recording could support psychological imprinting for the infants when Jamie and Nicole were unavailable. The process itself would additionally serve as a forum in which Jamie could continue to authentically express his feelings and experience varying degrees of cathartic release.

On the day prior to the recording session, the unanticipated discharge of Shae to home imbued Jamie’s presence with a dichotomy of feelings and conflict. The elation that Shae was out of danger was juxtaposed with the additional stress of dividing time between home and hospital, and ambivalence about taking time to do the recording to which he had been looking forward.

During the opening process of the recording session, I invited Jamie to express what was coming-up for him with the present shift in planning. His ease in self-expression was at times interrupted by his reflex-like displacement of his own emotional experience onto his wife. I remember thinking at the time that this reflex was a response to the repeated impact of social stereotyping[76] to which many fathers are subjected. Jamie appeared to catch himself at these moments, stop, and then reclaim the feelings that were in fact his. This process was held positively and unconditionally through the conscious use of my own countertransference as a father who only 5 years earlier had stood in Jamie’s shoes.

Jamie expressed relevant themes in his identification of song-of-kin [5,6,9,10,21,22] and was supported in his telling of the “story”. The song choices ensued from his process of introspection on the chronology of his own life; from being a boy, to becoming a young man, and eventually to becoming a father. Jamie’s singing of the Beatles’ “Blackbird” referenced his relationship with his own parents, while James Taylor’s “Sweet Baby James”, offered a personal connection, which when processed in the therapy, affirmed his deeper inner strength and resourcing. The session closed with Leonard Cohen’s “Hallelujah”, a song that reinforced spiritual strength as a young man approaching fatherhood with a sense of celebration.

Jamie sang each song with tremendous passion and sensitivity as my colleagues and I accompanied him on guitar. His voice floated effortlessly over the chord changes to the songs he had chosen as if he were singing directly to Nicole and their babies.

Following the recording and Jamie’s return to home to care for Shea, my colleague and I continued the session into the NICU where Nicole was nursing Leah. This continuity was intended to further support the bonding between Jamie and Nicole by including Nicole in the process. The recording itself would serve as a transitional object away from the NICU, as well as providing valuable legacy that could one day be shared with Shea and Leah. During this happy yet tumultuous time, it was conviction to the importance of music in both Jamie’s and Nicole’s lives, which allowed them to persevere in the
complection of the recording as they again moved toward a new definition of “normal”.

Case 3: The Story of a Domesticated Dad by James

We knew from conception that we were a ‘High Risk Pregnancy’ and that the odds of going full term with the twins we’d conceived after much time, patience, and professional help were remote. I heard it all, but I never truly understood.

At 24 weeks and 3 days gestational age, my sons were born. Deskin was first at 1 pound 10 ounces followed by Jake at 1 pound 5 ounces. All I knew was that I wasn’t ready. I was petrified. Of course being born so early and so small leads to many medical issues, things I was not nearly prepared to deal with. After two days of heroic battling by both my son Jake and his medical team, Jake passed away due to complications. Though I felt myself spiraling out of control into the well of despair, I knew then and there that I had to keep myself together, if not for me then for my wife and my son Deskin who needed me more than ever. But what can you do for someone so incredibly small and so unbelievably fragile? What could I give to this tiny person who was out in this big cold world? The answer hit me quickly like a ton of bricks. Everything was the answer; I could give him my heart, my soul, my love and protection every hour of every day. This little person needed a voice, he needed a shield and he needed a safe harbor in the storm that was to be his first experience with this thing called life.

Early on my wife and I had several long discussions upon the topic of having a family and we decided that since she had an already established career with good benefits, I would leave mine quickly like a ton of bricks. My wife wakes him every morning and reads to him before she has to go to work. An in-home nurse prepares his medications, feeds him the blended diet that I have prepared, and bathes him, after which I lotion and powder him. This is a wonderful bonding experience where I can show him how much he is loved. After Bath time, we bring Deskin downstairs for his therapies and playtime.

Deskin has several doctors that make up his at home medical team, so typically once or twice a week we take him to office visits to be examined and have alterations made to his plan of care. At least once a week we take him to his Kindermusic class to interact with other toddlers; followed typically by lunch; story time; and naptime with Deskin asleep on my chest. Later on it is typically more therapy around which time my wife usually makes it home and then we do bath time, along with medical care and bedtime. My wife and I then usually retire and I make us some late dinner. We spend an hour or two together before going to bed, and then the next day we do it all over again.

Conclusion

Premature births are generally unexpected and cause emotional, physical, and financial stress on the parents, siblings, and extended family members. A family centered care philosophy, focusing on inclusion as opposed to exclusion or marginalization of the father or partner is critical to amelioration of this affect. The normalization of the working mom, the stay-at-home dad, and successful

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3 The quote referenced by the father is often used colloquially. Its original form and source is “Music hath charms to soothe a savage beast, to soften rocks, or bend a knotted oak” – William Congreve, 1967, first line of the play The Mourning Bride
partnering, is manifesting in greater visibility of fathers in the NICU. To remain relevant, the paradigm of healthcare has shifted in its welcoming of innovation not only in terms of integrative care such as music therapy, but in terms of gender and role participation as well. Music Therapy is ideally suited to meet the growing presence of fathers in the NICU, by providing a culturally sensitive and normalizing forum in which fathers can connect to, and participate in the NICU environment. As illustrated in our case vignettes, music therapy functioning in a multitude of psychosocial ways can ensure such breadth and depth of care.

References


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Biographical Statements

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## APPENDIX

What’s the Most Stressful Part of Having a Baby in the NICU? Question #2 (6)

<table>
<thead>
<tr>
<th>Locus of Stress/Anxiety</th>
<th>Moms</th>
<th>Dads</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss/Fear/Uncertainty</td>
<td>204</td>
<td>68</td>
</tr>
<tr>
<td>Leaving hospital without baby/missing baby/baby isn’t home with me</td>
<td>109</td>
<td>42</td>
</tr>
<tr>
<td>Impatience for/Wanting baby to be home</td>
<td>33</td>
<td>2</td>
</tr>
<tr>
<td>Helplessness; not being in charge of baby’s care or able to do anything for baby</td>
<td>5</td>
<td>22</td>
</tr>
<tr>
<td>Lack of control</td>
<td>16</td>
<td>1</td>
</tr>
<tr>
<td>Not being able to be at the hospital all the time</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Leaving baby in the care of others/trusting baby’s care to others</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Not being able to hold/feed baby</td>
<td>2</td>
<td>1</td>
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<tr>
<td>Not feeling like a mom yet, because of separation</td>
<td>1</td>
<td>1</td>
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<tr>
<td>Concern about bonding while being separated</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Worrying about baby’s weight and lung problems</td>
<td>2</td>
<td>1</td>
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<tr>
<td>Seeing baby’s small size/vulnerability</td>
<td>1</td>
<td>1</td>
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<tr>
<td>Seeing baby in distress</td>
<td>1</td>
<td>1</td>
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<tr>
<td>Seeing daily fluctuations in baby’s health</td>
<td>3</td>
<td>1</td>
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<tr>
<td>Coping with daily unpredictability/treatment complications</td>
<td>1</td>
<td>1</td>
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<tr>
<td>Accepting baby’s illness and need for NICU</td>
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<td>2</td>
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<tr>
<td>Accepting that baby can’t breathe on her own</td>
<td>1</td>
<td>2</td>
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<tr>
<td>Having to trust the opinions of medical professionals</td>
<td>1</td>
<td>2</td>
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<tr>
<td>Feeling guilty for possibly having “caused” the situation</td>
<td>1</td>
<td>2</td>
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<tr>
<td>Questioning self as cause of premature birth (Was it something we did?)</td>
<td>1</td>
<td>2</td>
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<tr>
<td>Questioning decision-making</td>
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<td>2</td>
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<tr>
<td>Experiencing roller coaster emotions</td>
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<td>2</td>
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<tr>
<td>Fear of losing emotional control/becoming impatient</td>
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<td>2</td>
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<tr>
<td>Being scared</td>
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<td>2</td>
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<tr>
<td>Being tired/exhausted</td>
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<td>2</td>
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<tr>
<td>Fear of receiving bad news</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Pumping milk on schedule; scheduling pumping for other child</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Being able to produce enough milk/Not being able to nurse</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Being concerned for child(ren) at home (when mom remains/spends time in hospital)</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Coping with unsupportive husband</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Helping husband learn how to hold/care for baby</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Not being able to treat baby as a “normal” child</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Not being sure of/how to touch the babies</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>
1 Seeing other parents w/ their healthy babies
1 Seeing other families grieve
1 Feeling frustration for not understanding/communicating well in English

15 Delivery – Ante- and Post-Partum
2 Being unprepared for the experience (NICU/premie delivery)/expectation gap
1 Coping w/ expectation/reality gap
2 Accepting that delivery did not go as planned
2 Feeling disappointment w/ gap between expectation and reality
1 Accepting that 1st-borns (twins) must be confined to NICU
1 Learning about pre-eclampsia/premature birth only at the time it happened
1 Knowing too much (RN moms…)
2 Not understanding/Being unknowledgeable about NICU
1 Processing all the info that comes mom’s way
1 Not seeing baby at birth/not knowing where baby was
1 Wanting both children in same hospital room – close to each other

24 Future-focused
9 Coping with/worrying about the uncertainty of baby’s immediate future
7 Thinking about the future – the long-term consequences of baby’s NICU stay
3 Fear of death
1 Hoping that baby is healthy/on the right track
2 Wanting baby to be healthy
1 Wanting assurance that baby is okay
1 Thinking about how baby might be feeling

21 NICU Environment
9 Seeing the machinery hook-ups and all that the babies are put through
8 Noise (NICU alarms; screaming babies…)
1 Lack of privacy
2 Seeing sick babies all around/other NICU babies
1 Waiting for nurses’ response to requests for help

17 Separation/Visitation
1 Commuting to hospital (from as far as Virginia)
6 1 Not spending enough time w/ baby; not visiting as much as I’d like
2 Making multiple visits during the day
2 1 Not being able to visit
1 Not being able to see baby for first couple of days
1 Not being able to see babies when I want to (on my schedule)
1 Choosing to spend long hours at the hospital
1 Making time to see baby
1 Being required to exclude family (sibs/parents) from NICU visits
1 Feeling guilt when leaving

16 Routine Disruption and Resumption
8 Wondering if we’ll receive a call from the hospital w/ disturbing news
<table>
<thead>
<tr>
<th></th>
<th>Coordinating/Organizing home life with hospital life</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Thinking about how to organize home-life once baby is home</td>
</tr>
<tr>
<td></td>
<td>w/ family, other kids</td>
</tr>
<tr>
<td>2</td>
<td>Disruption of family routine</td>
</tr>
<tr>
<td>2</td>
<td>Coping with the ups and downs, the feeling of being on a roller coaster</td>
</tr>
<tr>
<td>1</td>
<td>Fear of losing patience/not knowing how to be a good dad</td>
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<tr>
<td>1</td>
<td>Anxiety about leaving other children at home to be w/ newborn in NICU</td>
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<tr>
<td>1</td>
<td>Not being together as a family (1st child)</td>
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<tr>
<td>1</td>
<td>Time away from the family</td>
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<tr>
<td>1</td>
<td>Anxiety about caring for baby at home</td>
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<tr>
<td>1</td>
<td>Thinking about preparing baby’s room for arrival at home</td>
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<tr>
<td>1</td>
<td>Helping other children understand what’s happening with new baby</td>
</tr>
<tr>
<td>2</td>
<td>Financial Stress</td>
</tr>
<tr>
<td>1</td>
<td>Needing to return to work</td>
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<tr>
<td>1</td>
<td>Being jobless and needing a job and the income from it</td>
</tr>
<tr>
<td>16</td>
<td>Financial concerns in general</td>
</tr>
</tbody>
</table>