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Religious and Spiritual Journeys: Brief Reflections from Mothers and Fathers in a Neonatal Intensive Care Unit (NICU)

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Abstract

The birth of a child is often accompanied by elation and celebration, but when a birth results in admittance to the Neonatal Intensive Care Unit (NICU), the typical emotions of joy and celebration may be tempered with anxiety and fear. Parents with a religious and spiritual worldview may find their faith and spiritual lens is an important aspect of coping with their NICU experience. There is a dearth of literature on this issue, and thus a pilot study was implemented that included eight mothers and fathers of babies admitted to the NICU. Parents responded to a brief interview 4 to 6 weeks after discharge that focused on how their religious or spiritual worldview changed as a result of their NICU experience, how they coped with their premature newborn after discharge, and the perceived impact on their spousal/partner relationship. Results indicated that parents who presented to the NICU with a religious or spiritual background indicated their faith grew as a result of their experience in the NICU. Parents without a religious or spiritual worldview also reported being able to adequately manage their NICU experience and reported little to no change in their religious or spiritual lives. Further, parents reported they coped well after their babies' discharge from the NICU and had supportive spousal relationships. This pilot study supported assessment of religious and spiritual experiences as a salient aspect in NICU parents' lives. Further study is necessary to elucidate how religiosity and spirituality can be strengthened for families during this challenging time.

Keywords

NICU; Religion; Spirituality; Parents; Prematurity; Coping

The news of a pregnancy comes with a host of emotions such as joy and elation, but often there is a sense of anxiety related to the birth of a child. Most parents envision a problem-free pregnancy that results in a healthy child. However, some parents face an unanticipated challenge through a preterm birth. When their expectations of a problem-free pregnancy are not met, parents can experience emotional challenges both immediately following discharge and even years after leaving the intensive care setting (Doering et al. 2000; Montirosso et al.

2012) that may affect their parenting relationships (Doucette and Pinelli 2004) and stress levels (Linden et al. 2015).

The atmosphere of the Neonatal Intensive Care Unit (NICU) can be a challenging place for parents as they face the alarming sounds and sights associated with their child being a patient in an intensive care setting. This combination of a distressing intensive care setting and the difficult emotions surrounding the event can create challenges for parents of these babies (Doucette and Pinelli 2004; Meyer et al. 1995; Shaw et al. 2006). For instance, mothers tend to struggle with higher levels of anxiety and depression while their baby is in the NICU, possibly even meeting criteria for post-traumatic stress disorder following their child's NICU experience (Holditch-Davis et al. 2003). Although many parents find this unfamiliar setting alarming, some mothers find they function well in dealing with stress after a premature birth (Gray et al. 2012). Further, parents find social support by family and friends to be invaluable during this time (Pinelli 2000), which can reduce their anxiety and depression. However, parents may also draw on their own religious and spiritual worldviews and concomitant coping strategies in dealing with this unanticipated and unfamiliar stressor.

After a preterm birth, parents may feel that their religious and spiritual lives have been challenged and possibly reinforced. Although the existing literature is replete with evidence to support a direct link between individual psychological well-being and religiousness and/or spirituality (see Hayward and Krause 2014; Paloutzian and Park 2013), there are far fewer studies related to how family relationships are enhanced or degraded by religious and spiritual coping and beliefs (Mahoney 2010), but the field is beginning to flourish (see Mahoney and Cano 2014). An area of continued growth centers on distressed families or families who are struggling with a significant life event (see Mahoney 2010). Thus, exploring the nascent area of parents' religiousness and spirituality and links to managing the NICU environment is warranted.

Indeed, parents tend to indicate stressors related to their children as one of the most taxing of life experiences. Thus, having a child admitted to a newborn intensive care unit is a time when parents may find spiritual resources helpful in handling challenging decisions about their babies' health. Parents may also find that they need to lean on their religious or spiritual beliefs to cope with expectations of parenting that have been altered after their child has been placed in the NICU. At times, parents may find they are using both positive and negative forms of religious coping in a medical setting, sometimes simultaneously (see Pargament 1997). Positive religious coping strategies include focusing on God's love, using religious faith to stop worrying, or concomitantly experiencing feelings of anger toward God and questioning the power of God (Pargament et al. 2000; Pargament et al. 1998). Recently, emphasis on spiritual struggles has emerged, focusing on the depth of negative forms of religious coping and offering insights on the rich internal struggles related to doubts, anger, feelings of abandonment by God and/or religious institutions, and even belief in demonic forces (Exline et al. 2014). This emphasis on spiritual struggles may provide keen insights into parents' difficult feelings when their child is placed in the NICU.

Although family-centered interventions are commonplace in the NICU (Melnik et al. 1997), the complex interplay between the emotional and spiritual needs of families is generally

minimally addressed in the NICU. This lack of addressing the religious and spiritual needs of parents may result in parents struggling with existential questions and fears that require adequate support not only from therapists but also from spiritual and religious communities or pastoral counselors trained in psychospiritual integration. A lack of conversations about religious and spiritual traditions pervades Western healthcare, which does a disservice to many patients during trying times (Pattison 2007). One of the only studies to date related to spiritual integration and care in the NICU is a case study by Snodgrass (2012). This study involved a psychospiritual, family-centered intervention with one NICU mother that focused on the existential doubts and grief experienced by many parents in the NICU. This spiritually integrated psychological intervention was one of the first in that particular NICU with a spiritual component. Thus, in light of the dearth of research on the religious and spiritual needs of NICU families, more studies are needed to uncover the nature of the religious and spiritual worldviews of NICU parents. Further, exploratory research may ascertain if these parents find their religious faith is strengthened or weakened during times of crisis.

Consequently, the focus of this descriptive pilot study was to assess the foundational question of whether the religious or spiritual worldviews of parents were changed—and if so, how—after they experienced the NICU. We also sought to understand parents' views regarding how they generally coped after their infant's discharge from the NICU and how they felt the NICU experience had impacted their spousal/partner relationship. It was hypothesized that parents with religious and spiritual beliefs would find strength in their religious and spiritual lives that helped them cope with the NICU in an effective manner, due to the extant literature suggesting that positive religious coping methods (i.e., praying to God or looking to God for support) often result in more positive psychosocial outcomes such as gratitude (Brelsford et al. 2014), whereas negative religious coping or spiritual struggles (i.e., feeling angry or abandoned by God) tend to yield adverse personal results such as depression and anxiety (McConnell et al. 2006). Thus, parents who felt abandoned by or angry with God might find their religious and spiritual worldviews are deleterious for their psychological and relational functioning and those who had positive religious and spiritual beliefs and exercised strategies to feel closer to God might find their religious worldview is strengthened. In a similar vein, we also hypothesized that parents who reported the use of positive coping strategies would also indicate better spousal/partner relationship quality after discharge. Thus, the use of positive coping strategies through secular and religious means would be related to reports of stronger Divine and couple relationships.

Method

This qualitative study was part of a larger mixed-methods descriptive pilot study exploring links between NICU parents' religiousness and spirituality in relation to their relationship quality and mental health. The full feasibility study yielded responses from 52 adult parents of preterm infants born at the Penn State Milton S. Hershey Medical Center whose infants were admitted to the NICU between 2012 and 2014 with variable lengths of stay. The Penn State Hershey Institutional Review Board approved the study protocol, and parental consent was obtained prior to subject enrollment. Inclusion criteria were that parents be over 18 years of age with English fluency who had preterm infants born at 25–35 weeks of gestation

and admitted to the NICU within 48 hours of delivery. Parents were not approached to participate if their infant was born with a congenital anomaly or if maternal illness prevented the ability to obtain informed consent.

We employed the use of narrative inquiry for the qualitative portion of the study, which is a form of research that uses the collection of stories as its source of data (see Duffy 2007). Due to the brief format of our research, we felt that discovering the complexity of each interviewee's beliefs and experiences was best understood through exploration of their own stories (Dicicco-Bloom and Crabtree 2006).

The qualitative portion of this study yielded a total of 8 participants. Parents (either mothers or fathers) were contacted 4 to 6 weeks after discharge to complete a semi-structured interview focused on confidence related to parenting a premature infant, ways of coping with a premature baby, views on parenting, impacts of having a premature infant on the parental dyad (if one was present), and religious and spiritual implications, all after discharge. For the purposes of this study, the most salient question related to parents' religiousness and spirituality was, "How have views of your own religiousness and spirituality been impacted by your experiences in the NICU?" Secondly, questions related to each parent's relationship with their spouse/partner and general coping methods were presented: "How has your relationship with your baby's father/mother been affected by your NICU experience?" and "How do you feel you are doing in terms of everyday coping with life now that your baby is home from the NICU?"

For the full pilot study, there were a total of 24 parental dyads who responded to the questionnaires plus four parents who did not have a partner. All parents were contacted with three telephone attempts to provide additional information through a brief structured interview. As a result of the 28 phone calls that were made, the principal investigator or a trained graduate assistant conducted eight telephone interviews. Of the eight interviews, five contained content relevant to parents' religiousness and spirituality. Three of the respondents reported not having a religious affiliation or not having strong religious beliefs. Thus, these respondents indicated nothing had changed while in the NICU related to their religiousness and spirituality. However, five respondents reported a strengthening of their religious and spiritual beliefs.

The eight respondents to the semi-structured interview were comprised of five mothers and three fathers from the NICU, none of whom were from the same parental dyads. The mean age of the respondents was 31 years, ranging from 26 to 35 years of age. In terms of racial background, five respondents reported being Caucasian, two Latino, and one Asian American. Most respondents were married (six), while one was single and one was separated. The sample displayed a range of educational attainment, with two respondents indicating an education of between 9th and 12th grade, one respondent reporting having attended some college, two respondents reporting having a bachelor's degree, and three reporting having a graduate or professional degree. Respondents' religious affiliation included Catholic affiliation (3), Protestant background (1), Church of Jesus Christ of Latter-Day Saints religious affiliation (1), and no religious affiliation (3). In answering a separate question, three respondents reported not being religious and five respondents reported being

slightly to very religious. Further, one respondent reported not being spiritual and seven respondents reported being slightly to very spiritual.

Results

Due to the small sample size for this study, the narrative approach was used to highlight responses from each participant who endorsed a religious or spiritual worldview. Responses ranged from religion and spirituality being minimally or not at all impacted by the NICU experience to substantial impact being felt on the religious and spiritual realm of the individual.

For instance, one mother noted that she was not sure of her beliefs but attributed the positive outcome to her belief in God. She indicated: “I do not know my beliefs, but there is a God—there is a God. I did not know what was going to happen. I feel thankful. I take every day [one day] at a time and feel thankful to God for the outcome.” Another mother reported “Awesome. He [God] takes care of my baby. He [God] does everything for you.”

A more descriptive response from one mother was as follows: “Huge part of coming home from the hospital—only missed 3 weeks of church. I believe God has a special place for me—my son was God’s miracle. God built my relationship with Jesus Christ.” She further reported that when she told her boyfriend about the pregnancy, he decided to break off the relationship, but she indicated, “I was ready to move Jesus Christ beside me. Huge impact on my life—follow the path God has created for me.”

A father also reported reinforcement of his religious beliefs: “I felt more of an awareness of direct intervention on behalf of my baby and my wife. We have always been religious people, so we have not had any major changes, but [this experience] has reinforced our beliefs.” Another father expressed that his faith journey had been tested but was reinforced in a positive way after the birth of his twins. He indicated, “Having the boys has impacted [me] somewhat in that I am a little more spiritual. Say prayers with them every night. Cannot go to church now, not really allowed to expose the babies. However, they are a blessing having them through IVF [in vitro fertilization]. I felt like we were losing hope with the 5th IVF—then we were pregnant, which was a blessing.”

As indicated previously, three participants, two mothers and one father, reported no changes to their religious or spiritual worldviews. For instance, one mother who indicated being moderately spiritual but not religious reported that her spirituality was “not significantly impacted by the NICU experience.” A father who indicated he was not religious or spiritual reported, “I do not belong to any religious group, so no, I do not think so.” Finally, a mother reported, “I am not very spiritual or religious; that has not changed.” Thus, some parents who participated in this study did not report significant changes to their religious or spiritual worldviews as a result of their NICU experience, whereas those parents who had a religious or spiritual foundation reported a strengthening of those bonds.

All eight participants also responded to questions related to their relationships with their spouse/partner following discharge from the NICU. The question “How has your relationship with your baby’s father/mother been affected by your NICU experience?” was

posed, and responses from one father suggested an improvement or fortification of the relationship. He stated, “[Our relationship] has matured, the whole experience IVF, NICU, and now. Made us stronger. Being patient and understanding through a test [has] strengthened [our] relationships through bumps in the road.”

Another question focused on coping, and this same father was asked, “How do you feel you are doing in terms of everyday coping with life after your baby is home from the NICU?” He replied, “[We] are more attuned to each other’s needs, not expecting things, but supportive of each other.” In regards to coping, this father reported, “Mom is doing the best she can (used to run everyday), [she] is coping with that [and] trying to work out daily.” He indicated, “There has been less that I had to sacrifice. [I] do everything I have done previously. Now [I] spend more time with the boys, hard to spend time alone with each.” Another father endorsed his marital relationship as being “the same, only better. We may sometimes feel tired, like to have rest. More time to talk and more interests in common.” He also reported that their sleep was compromised, which affected their coping, but otherwise he was doing well with the newborn premature child.

Another father reported minimal change in his relationship with the baby’s mother. He stated, “She is sleeping more often, so we do not have much time alone. I do not think it has been particularly adverse.” This same father also remarked on coping with the NICU experience by stating, “It has not affected me as much as it has affected my wife. One more busy thing.” His comments suggest that his wife may be experiencing more challenges coping with a premature newborn.

A single-parent mother, when asked whether her relationship with her baby’s father had changed, reported, “It has not. He abandoned me, [I] had nothing and he dropped me off with the baby. [He] did not connect with me; if I was there he would leave.” She also reported, “[Now I] realize the value of life, now [I] realize small things are not a big deal. [I just] want to get home to my kids.”

Some parents reported positive relationships with the other parent and positive coping. For instance, one mother reported that her relationship with her partner was “good” and that she (her partner) “is very happy, likes to play with her [daughter] in therapy.” Thus, even though this baby had additional care after discharge, it was perceived as a positive from this parent’s perspective. Another mother reported, “I would not have been able to do it without him.” This reflected that she and her partner were a team in the process of dealing with a premature neonate. She also resonated with the previous mother by stating, “[I am coping] pretty good, occasional stress, but I get rest and cope better.” Another mother reported that she and her partner had planned their daughter and said, “It brought us closer. You plan kids and are ready for them, it will work out.” She also indicated, “I am doing good. I have other children—they have been a big help.” Finally, another mother also reported that the NICU experience “made us stronger—he was not at the NICU because of work—then we met each other and ate dinner together.” She reported she is coping well after discharge. She reported, “I did good. We went to breastfeeding classes at HMC [Hershey Medical Center] after she was a month old. Lifestyle changes [occurred].” Overall, most parents felt that they were coping well and that their relationships with each other were strengthened by the NICU

experience. It appears that the mothers tended to have greater changes in their lives due to being the primary caregiver to their premature infant, but this did not reflect an impediment to their spousal relationship, if present.

Discussion

This is one of the first studies to explore religious and spiritual changes in parents who experienced the birth of a child that resulted in admission to the neonatal intensive care unit (NICU). Results from this pilot study indicated that parents who had minimal to very strong religious beliefs tended to experience reinforcement of those beliefs, while parents who had no religious or spiritual beliefs saw minimal changes in their religious and spiritual worldviews. Thus, this pilot study explored data comprised of one open-ended interview question, but our results support that parents who have a religious or spiritual worldview find their sacred beliefs remain and are strengthened after a stressful life experience such as having a baby in the NICU. Conversely, the three participants with no religious or spiritual worldview did not report that their religious or spiritual worldviews had changed. Thus, these parents may have had few spiritual struggles while in the NICU setting.

In addition to spiritual coping, parents also discussed other methods of coping with a new baby in the intensive care setting. Some parents reported trying to exercise or spend time with each other or their other children in order to cope effectively with their premature newborn. All parents reported they were coping well with the transition to being home after spending time in the newborn intensive care setting. Thus, this sample of parents had lower levels of distress than some parents in the NICU.

Parents also reported on changes in their spousal/partner relationship after their baby was discharged from the NICU. For the majority of participants, there was a co-parent in the form of a spouse (seven out of eight respondents). These respondents appeared to lean on their partners for support even though they spent less time together than usual. One participant did not have a supportive partner, but she indicated she was faring well and felt her religious beliefs were a source of strength for her.

Indeed, the qualitative portion of this pilot study yielded a very small sample size. Further, the use of three open-ended interview questions could be expanded upon in future studies to provide insight on the processes that enhance or strengthen parents' religiousness and spirituality. However, due to the dearth of information related to changes in parental spiritual and religious beliefs while in the NICU, this study was a necessary first step. Although the sample for this study self-selected for participation, which may mean they were experiencing lower levels of distress than other NICU parents, their comments are valid as it reflects a meaningful cross-section of the family unit in the NICU. However, due to their lower levels of personal struggle, there may be fewer perceived moments of stress for these parents, which could mean they called upon their use of religious coping to effectively deal with the stressful situation or, conversely, that they did not feel a need to call upon spiritual and religious beliefs because coping with the situation was within the reach of their secular coping methods (i.e., talking to friends, being proactive, positive thinking, etc.). In addition, parents who did not utilize a religious or spiritual worldview may have been able to

better cope with their child in the NICU due to other sources of support, such as family or friends.

Moreover, if parents' perception that there was a stressor (through a primary appraisal) was met with the ability to adequately cope through a secondary appraisal processes (Lazarus and Folkman 1984), these parents may not have needed to call upon greater questions about life and death often related to faith experiences and ultimate existential questions. For instance, the participants in this study reported coping well with their newborns' discharge from the NICU and having minimal spousal/partner strife. Thus, a confluence of positive and protective strategies through general coping and support could have been enough to elevate these families to higher levels of functioning with fewer perceived problems after discharge.

Alternatively, it is also possible that "awareness" or self-reflection is an important factor that is expanded through one's practice of spirituality and religion. Thus, those who do not engage in spiritual and religious practices may not necessarily be coping better, but may instead identify less with their individual challenges in life due to this lack of reflection through a spiritual lens. We believe that future studies that assess both members of the parental unit, if available, will yield additional interesting findings. Our sample did not provide a dyadic structure within the interview portion of this study, thereby reducing the understanding of the sacred space within each parental unit.

Although this study had limitations, there were important findings that suggest religious and spiritual views can be sources of support for NICU parents. These religious and spiritual supports may occur in tandem with other forms of support (e.g., family, friends, nurses, and social workers), but may also be a separate entity and experience for those who consider themselves to be religious or spiritual. The religious and spiritual lives of families need to be addressed in healthcare settings, which tend to limit conversations that include crucial spiritually based worldviews (Pattison 2007). Chaplains are trained to address spiritual needs, but are not always trained to address psychological concerns that come with faith-based concerns and questions. Further, spirituality may in itself be a unique aspect of a person that is transformed in the face of a stressor (Pargament 2013). Thus, additional research is necessary to explore religiousness and spirituality in the NICU in order to find ways to support parents who may be struggling with their religious and spiritual journeys during hospitalization and after leaving the newborn intensive care setting. This information might lead to the development of robust psychospiritual interventions to support families while in the NICU and upon discharge.

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