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The NICU Experience

How Does It Affect the Parents' Relationship?

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ABSTRACT

There is much research about the negative effect of serious and chronic childhood illness on the parent's partner relationship. It is generally assumed that parents of newborns admitted to the neonatal intensive care unit (NICU) also share this risk of relationship strain. However, little research specific to the effects of the NICU on the parent's relationship exists. The focus of most research examining parents of NICU infants is the mother's emotional well-being. The effect on the father is rarely studied. Drawing from studies of other childhood illnesses, it is reasonable to hypothesize that the experience of a NICU hospitalization may also strain the parents' relationship, possibly to the point of dissolution. The implementation of family-centered care in the NICU has had promising outcomes, and it is hypothesized that family-centered care will minimize the emotional stressors that may lead to the dissolution of the parent's partner relationship.

Key Words: fathers, mothers, NICU, stress, support

ACCORDING TO THE LITERATURE, serious and chronic illness of a child increases the parent's risk of divorce and relationship dissolution.[1–4] Support is needed because children of single-parent homes have more risk for economic hardship and less investment in their long-term health.[1,5] Parents whose infants are in neonatal intensive care unit (NICU) may experience depression, anxiety, loss of control of their child, and may not feel like a parent until after discharge.[6,7] Despite the known risk of stress on NICU parents, there is scant research regarding the partner relationship and effective support.

With NICU admission rates rising since 1990, more parents than ever are in need of psychological support.[8] There is much research about the mother's emotional stress in the NICU, but the father has been largely neglected until recently. Even so, several emotional similarities and differences have been identified between the mother and the father. These differences emphasize the need to include fathers in future research, as it may increase the understanding of how the NICU can affect the partner relationship.

Research specific to the NICU parents' relationship is limited, but there are studies that explore how other childhood illnesses affect the parents' relationship. These studies may give further insight into how the NICU can affect relationships. Chronic conditions and childhood cancers may be comparable with prematurity and the NICU hospitalization. A chronic condition is identified as having a biological, anatomical, or physiological basis, lasting at least 1 year, and having long-term sequelae. All of these conditions begin with the shock of diagnosis and require long-term care. A geographical distance may also be created between the parents depending on the location of treatment centers in relation to their home. Parents of NICU infants are usually unprepared for the psychological stress of the child's condition and the physical experience of the NICU.[9] In addition, it is common for an infant in the NICU to be discharged with a chronic condition.[10] There are also many differences to consider with this comparison, with probably the most significant being that a NICU infant has never left the hospital and the parents have yet to experience their newborn as their own.

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Although there are many factors to consider with this comparison, the limited literature regarding the NICU parents' relationship creates a need that other studies be used to hypothesize about the effect of the NICU.

CHRONIC CONDITIONS AND CANCERS: THE EFFECT ON THE PARTNER RELATIONSHIP

The full effect of a child's illness on the parent's relationship is not entirely understood, but studies of chronic conditions and childhood cancers indicate a decrease in parent's communication, time together, and marital satisfaction.[11–13] Many studies have found a significant role strain as the parents each adapt to their new responsibilities.[11,12] Berge et al[11] found that marital satisfaction of the mother is negatively correlated with the severity of her child's chronic illness. The father has decreased marital satisfaction over time if his depressive symptoms increase.[11]

There is an abundance of literature regarding childhood cancer and the parents' relationship. According to Silva et al,[14] having a child with cancer has some positive and some negative effects on the parents' relationship. Increased marital satisfaction occurs when parents realize that they have the ability and resources to manage the cancer together. Decreased marital satisfaction occurs with high stress of the illness experience, little time to dedicate to the relationship, a weakened connection between the parents, and deterioration in intimacy and sexual relations.[14] In addition, work stress and role strain may lead to relationship issues and decreased marital satisfaction.[15–18]

A study by Yeh[19] states that while spouses expect support from one another after a child's cancer diagnosis, few parents are able to give the support they expect to receive. The mother notes that her role as a wife is entirely replaced by her role as a caregiver, and the father concentrates on providing an income to his family.[14] Some conflict may arise with these roles when the mother expects emotional support or help in caring for the child, and the father's focus is solely on work.[19] The inability to communicate also has a negative effect on the couple's relationship. Lack of communication is caused by increased stress, the burden of cancer treatment, the physical distance between partners, and the parents' emotional states.[14,17] These findings suggest a need to include a focus not only on the disease but also on the needs of the family.

In contrast to the popular belief that having a child with a disability leads to marital dissolution, McCoyd et al[20] report that this is only true in cases of high levels of caregiver burden, instability of the child's health, or that the expected assistance from the partner is minimal or nonexistent. Any sick child, whether he or she is in the NICU, is chronically ill, or has a diagnosis of cancer, will have unique levels of need and instability. This is important when assessing a parent relationship, as each individual case may have more or less emotional risks based on these aspects.

CHRONIC CONDITIONS AND CANCERS: THE EFFECT ON THE INDIVIDUAL PARENT

Although chronic conditions and cancers may have differences, there are similar patterns that emerge with the assessment of the individual parent's reaction on having a sick child. Understanding these patterns may provide some insight on the parent experience in the NICU. Both the mother and the father of a child with a chronic health condition or cancer have increased stress, anxiety, role strain, and depressive symptoms compared with parents of healthy children.[11,14,21] Although it is unknown whether these increased stressors are the cause, parents of a chronically ill child are also twice as likely to have chronic illness, activity limitations, and worse overall self-reported health.[21] Mothers and fathers respond differently to stressful situations. This may be due to cultural and societal gender roles and expectations.[22,23] When caring for a child with a chronic illness, the mother is more likely to report symptoms of depression and anxiety than her partner. The father is more likely to have difficulty discussing emotions and may try to maintain "normal" family function despite the additional burden of the ill child.[22,23]

The father of a child with cancer also has difficulty discussing his emotions and may experience inner conflict because of the social expectation to be strong and hold the family together.[14,17] A study by Clarke et al[22] reports that the father's direct physical involvement in a child's cancer care may positively influence marital outcomes, as it decreases the level of caregiver burden each parent experiences. This is an interesting finding because a father is reported to believe that his role is of the breadwinner and supporter of the family while his wife leaves work to provide childcare.[14,22] Parents of children with cancer endure significant role strain, as their perceived and expected roles in childcare and daily life change over the course of the illness. This strain may increase the risk of marital dissatisfaction.[24]

THE NICU EXPERIENCE: THE EFFECT ON THE PARTNER RELATIONSHIP

This literature search for how the NICU experience affects the parent's relationship is limited to US and Canadian studies performed in the last 10 years. Even with these minor limitations, there is little research

found in the major databases about the parents' relationship when a newborn is admitted to the NICU.

The literature shows that NICU parents experience anxiety, stress, role strain, and depression, similar to that of parents of a child with a chronic condition or cancer.[7,6,25–29] In the NICU, parents also lack privacy, may be excluded from care, and may receive no institutional support.[10] Similar to parents of a child with cancer, the NICU experience may limit parents' communication with each other. The infant's hospitalization may last months and parents might be separated from each other for a great portion of this period.[10] One study suggests that the unresolved parenting and spousal problems developed in the NICU may persist after discharge and can have a lasting effect on family function and daily life, including increased stress and depressive symptoms and difficulty in role adaptation.[7,30] With little literature specific to the NICU parents' relationship, one can only hypothesize that parents of NICU infants are at increased risk for marital dissolution similar to the parents of children with chronic illness or cancer.

THE NICU EXPERIENCE: THE EFFECT ON THE INDIVIDUAL PARENT

The mother and the father react differently to the NICU experience but overall, Feeley et al[26] state that anxiety levels in parents of very low-birth-weight infants are higher than what is expected. The mother's emotions have been the focus of many studies, and it is known that she experiences anxiety, guilt, loss of control, helplessness, fear, uncertainty, disappointment, alienation, sadness, and other negative emotions related to an unexpected parenting role and the poor health of her newborn.[6,7,25–31] The mother needs assurance, inclusion in care, and proximity and physical contact with her infant to help minimize these feelings. She also needs accurate and adequate information.[7,31–33]

Very little research has examined the experiences a father faces in the NICU, but he does have different challenges than the mother. Immediately after birth, the father reports having more concern about his partner's health than the child's.[34,35] The father seeks out information about his child's illness to better understand and provide care.[9,29] The father may feel as though he must assume new roles as a protector, overseer, supporter, and sole source of income. In an interview, one father stated that he felt like fathers were not allowed to cry, but instead needed to give support to the mother.[9]

The father also has more barriers to inclusion in the care of his child and often cannot spend as much time in the NICU as the mother because of work and other outside obligations.[36] The father may feel that he lacks control of the infant and his child's environment. This may be exacerbated by support systems for the father declining over time.[9,37] Sometimes, the father compensates for feeling a lack of control by concentrating on work or simply finding other things to do outside of the NICU.[7,9,29,38] This is similar to findings from research about chronic conditions and childhood cancers.[14,17,22,23] Overall, the father experiences similar psychological feelings as the mother, but his focus is on work instead of getting the support he needs.

FAMILY-CENTERED CARE IN THE NICU

According to Gooding et al,[10] family-centered care (FCC) focuses on patients in relation to their family. There are many aspects of FCC, including but not limited to the physical design of the NICU, parent education, breast-feeding support, kangaroo care (skin-to-skin holding), and policies supportive of parents' rights such as allowing unlimited parent presence, parent participation in rounding and nursing reports, and involving parents in the care of their child.[10] The literature shows that properly implemented FCC in the NICU decreases parents' stress, anxiety, and depressive symptoms and increases parents' confidence in caring for their child in the hospital and at discharge.[6,7,39–41] It is hypothesized that by decreasing the negative psychological effects of the NICU and increasing the confidence of both parents in caring for their child, the risk for marital conflict and dissolution may be decreased.

The recommended standards of NICU design have evolved to promote single-patient rooms to decrease environmental stimuli and nosocomial infections. Single-patient rooms also increase privacy and give parents a place to stay in the NICU.[42] One study from Sweden also found that single-patient rooms decreased length of stay ($P = .05$) and moderate to severe bronchopulmonary dysplasia.[43] Parental inclusion and education is encouraged with single-patient rooms and promotes feeling safe, having control, confidence, and connection with the child.[6,10,28,43–46] Breast-feeding and kangaroo care are also supported by single-patient rooms, and both interventions have been widely studied with respect to benefits for the mother and the baby.[10,42,47,48]

Although single-patient rooms are supportive of many aspects of FCC, they are also expensive and not always feasible. With this in mind, it is important for NICU nurses and staff to find other ways to encourage these aspects of FCC. Providing transport assistance, sibling support, photography, staff training on encouraging safe parent participation, continuing education of the mother and the father until discharge, and including parents in rounding are all FCC interventions that are easily performed even without single-patient rooms.[10]

Bedside nurses are in a position to encourage the parents to take full advantage of the opportunities FCC provides them. Supportive policies, especially allowing unlimited parent visitation, are needed to promote FCC.[10,49] Simply having policy allowing parent inclusion in care and rounding will not help, though, unless the parents participate. The nursing staff must encourage parents to hold their child, to participate in rounding and report, and to ask questions and learn as much as they can while they have access to the NICU resources. Hesitant parents must be identified and worked with to better understand why they feel hesitant and what can be done to make them more comfortable participating in the care of their newborn. Nurses must also identify the times during which both parents can be included in these education and family-centered interventions. A father's presence may be important in reducing the stressors that lead to relationship conflict and, as such, a father who is not often present should be further encouraged to find time to spend in the NICU and with the mother.

All of these aspects of FCC will promote parents as being members of the healthcare team rather than as bystanders. Including a parent relationship assessment at discharge and follow-up visits may also be beneficial in helping the parents overcome marital strain related to the NICU or having a sick child at home. Simply because parents are no longer in the NICU does not mean that they will not have more challenges to overcome, and healthcare professionals should be able to identify and address problematic families. Parent satisfaction with overall care is increased by FCC initiatives, and evidence has shown that the NICU staff also have improved satisfaction with their work.[10] Neonatal intensive care units participating in FCC programs have less nursing vacancies and an increased staff job performance.[46] Despite the overwhelming evidence of benefits, FCC is usually not fully and properly implemented in the NICU.

CONCLUSION

The literature suggests that parents of children with cancer or chronic conditions may have an increased risk of relationship dissolution. Because of psychosocial similarities, it is reasonable to hypothesize that having an infant in the NICU may also influence the parents' relationship. Emotional stress and the lack of the father's involvement in direct care may be predictive of relationship strain. Although the father may interpret his role as being the breadwinner rather than a caregiver, including the father in patient care and educational sessions may help him to feel more comfortable in a caregiver role and recognize the support system available to him. It is hoped that by using FCC interventions in the NICU, emotional stress can be minimized, both parents will have greater access to spending time with their child, and the risk of relationship strain and dissolution due to having a sick child will decrease. Although there is good evidence supporting the use of FCC in the NICU, it has not become a standard of care in many areas of the United States.

Nurses are recognized as the best teachers, guardians, and facilitators in the NICU setting.[50] Nurses provide emotional support to parents, promote family presence and participation in the NICU, and can create a welcoming environment for families.[7,50] Further nursing research into the effects of the NICU on the parent relationship and the benefits of FCC is needed to understand how it might specifically support the relationship. It is also hoped that further research will lead to a more widespread use of FCC in the NICU.

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