



The Transformation of the Neonatal Intensive Care Unit: A Father's Perspective over 36 Years



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ARTICLE INFO

Keywords:

NICU
Support groups
Depression
Posttraumatic stress
Fathers
Psychologists

ABSTRACT

This article contains a perspective on the evolution of the neonatal intensive care unit (NICU) by a psychologist, who became the father of a premature baby in 1980. The perspective offered describes: a) parent support groups, b) research on emotional distress in NICU parents, c) the evolution of the NICU into neonatal intensive parenting units, d) fathers in the NICU, and e) psychologists in the NICU.

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The diagnosis of posttraumatic stress disorder (PTSD) did not appear in the Diagnostic and Statistical Manual of Mental Disorders until its third edition in 1980, the year my son, Chris, was born prematurely.¹ Chris spent 42 days in a neonatal intensive care unit (NICU) before coming home. I had taught abnormal psychology to undergraduate and graduate psychology students for years before his birth, and it was difficult to keep up with the growing research literature on stress. Then stress hit me like an on-coming train.

The following is my perspective on many related issues, all of which are informed by my activities in research and NICU parent advocacy: a) the evolution of NICU parent support groups throughout the world, b) research on PTSD and postpartum depression (PPD) in NICU parents, c) the emerging transformation of the NICU into a neonatal intensive parenting unit (NIPU), d) engaging fathers in the NICU, and e) the growing involvement of psychologists in the NICU.

I have never worked in a NICU, so readers should be aware that my perspective comes from four primary sources: a) my personal experiences as a NICU parent, b) stories told by other NICU parents and staff, c) published research, and d) attendance at perinatal conferences and board meetings. I suspect that many readers have their own versions of the “transformations” I describe.

My Family's NICU Experience

I knew immediately that Chris' birth by emergency caesarean section would have a profound psychological impact on my wife, Lauren, and me. But I did not know what that impact would be, and neither did the NICU staff or books I could then find. In the first year or so both Lauren and I were so busy managing everyday life that we had no opportunity (or time) to reflect on what we were going through.

I went 6 months without a haircut. Both Lauren and I had mild to moderate episodes of postpartum depression (PPD), but thankfully our university employers were supportive of our need to spend less time at work and more at home. I saw a psychotherapist for a few sessions. I was learning first-hand that an NICU experience for parents can be a potentially traumatic experience.²

Chris stayed in the only NICU in Milwaukee in 1980 after being transferred there from the birth hospital. That is where I first met one of the three neonatologists in Milwaukee at that time, John Glaspey. John attended Chris' birth, and I considered John my guardian angel while Chris was hospitalized. Through John Glaspey's encouragement, I touched Chris in the first hour of his life when I found the nerve to baptize him.

The County Hospital NICU (no longer in existence) had about 25 beds, and I did not realize at the time how fortunate our family was. I love small NICUs. After a week, Lauren and I knew every doctor and nurse that worked days and we had a primary care nurse. We formed relationships. Parents and grandparents were welcomed into the County NICU at any time of day, which was unusual in the 1980s; and if we happened to be present during rounds, we were encouraged to participate. Fortunately, the County Hospital was very considerate of parents, thanks to the philosophy and leadership of the neonatologists.

Over the years I have met many less fortunate parents who have suffered through large NICUs with complex staffing patterns. In the old NICU culture in the United States, staff cared for babies and parents were “visitors.” Parents in large NICUs often did not know who their doctor or nurse would be the day they “visited.”

Parent Support Groups

I knew intuitively that both emotional and practical support from parents, who had gone through the NICU before me, would be valuable. I learned of a support group in Milwaukee but when I contacted the

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group, the mother I talked with informed me that the group had stopped meeting. Currently, many NICUs have peer-to-peer support provided by veteran parents. This personal contact, I believe, is the most valuable source of emotional support for enduring the NICU experience and maintaining hope for the family's future. If hospital-based peer-to-peer support is not available, NICU parents can easily access community and Internet support groups and organizations.

Looking for support in the early 1980s, I found books written for parents of preemies, but the first books did not focus on psychological adjustment to the NICU experience. So I planned to write such a book. After 17 rejections, it was finally published.³ My book was welcomed as the first resource available that addressed the psychological issues of being a NICU parent. Current resources are available that are more relevant than my book to the changing NICU experience over the years (e.g.⁴).

The typist I hired for early drafts of my book informed me of an announcement of the first national meeting in 1984 of a group called Parent Care: Parents of Premature and High-risk Infants, International in Salt Lake City, Utah. Parent Care was formed when parent support groups in different cities found each other and united. Over the years of attending Parent Care meetings, my conversations with other NICU parents and lessons learned from conference sessions informed both my book and my psychological research agenda. I also was fortunate enough to receive guidance from the authors of the first two published books for parents of premature babies written by Sherri Nance⁵ and Helen Harrison.⁶

I was also one of the few psychologists in attendance at Parent Care meetings (and one of the few fathers). As a result, I was asked to speak at future meetings. In many conversations with NICU parents I noted that often parents would talk about having unexpected flashbacks to NICU experiences, which led me to think about PTSD in NICU parents and starting some research. My personal PTSD symptoms have been mild.

Parent Care stopped functioning in 1996, and some of my Parent Care associates found a welcoming new home in the National Perinatal Association (<http://www.nationalperinatal.org>).^{7,8} NPA prides itself on being multi-disciplinary and a convener of related organizations interested in participating in large-scale projects. The parent support component of NPA is the family advocacy network, which has worked with national and international organizations such as the Preemie Parent Alliance (<http://www.preemieparentalliance.org>) and the European Foundation for the Care of Newborn Infants (<http://www.efcni.org>).⁹ NPA also has excellent web-based resources for both NICU parents and professionals (<http://www.support4NICUparents.org>).¹⁰

Research on PTSD and PPD in NICU Parents

My academic research on aggression was going nowhere by 1985, so I decided to change my research focus. Parent members of Parent Care answered psychological questionnaires for me, and hospitals in three states allowed me access to NICU records. Over the years my graduate students and I published a series of studies using the Perinatal Posttraumatic Stress Questionnaire (PPQ) and other measures.^{11–15} Using different samples we found that mothers of high-risk infants scored higher on the PPQ and measures of depression than mothers that had delivered healthy, full-term babies. We also identified risk factors for emotional distress. In general, worse postnatal complications experienced by the baby predicted higher PPQ and depression scores in the mother. Over the years, I have been gratified to find that other researchers throughout the world have found the PPQ useful in their NICU work.^{16–19} More than seven research laboratories in the United States and four in other countries have reported on increased PPD and PTSD scores in NICU parents.

Recent research on psychological distress in NICU parents has now evaluated changes in PPD and PTSD during the NICU stay and afterward. Interestingly, this longitudinal research suggests that NICU parents show distinct patterns of recovery from the potential trauma of the NICU.^{17,18,20} These patterns are very similar to those observed in people

recovering from other potentially traumatic events, such as war or severe car crashes.² Some NICU parents suffer from high levels of PPD and PTSD during the NICU stay and afterward; others are fortunately more resilient and their symptoms are mild (but still uncomfortable). The remaining NICU parents have more moderate symptom intensity that can either improve or worsen over time.

Even though I made my academic career studying PTSD, I believe that PPD is more problematic for NICU parents. Depression is more prevalent than PTSD, and depressive episodes can re-occur throughout life. I am convinced that it is important to provide mental health services in the NICU (and afterwards) to potentially prevent the development of PPD and PTSD. These mental health services should include screening parents for emotional distress and offering access to psychotherapy by social workers, psychologists, and paraprofessional staff in the NICU and after the transition home.

The Transformation of the NICU to the Newborn Intensive Parenting Unit (NIPU)

At a Parent Care meeting in the early 1990s, Sheri Nance²¹ expressed an opinion that the goal of neonatology should change from, "getting the baby home in the best possible shape, to getting the family home in the best possible shape." Movement toward this goal has been facilitated by three more recent advances that will be articulated below.

The first advance was publication of "Interdisciplinary Recommendations for the Psychosocial Support of NICU Parents" by a work group organized by the NPA.^{22,23} Recommendations were provided by six groups, each containing a NICU veteran parent representative: a) involving the family in developmental care, b) peer-to-peer support in the NICU, c) mental health professionals in the NICU, d) palliative and bereavement care, e) discharge planning and follow-up, and f) NICU staff education and support.

According to these recommendations, all NICU parents should receive psychosocial support through both contact with veteran NICU parent volunteers and increased involvement as a family in providing developmental care for their baby. NICU parents more at risk for PPD and PTSD (because of screening results, life circumstances, and/or severe infant illness) would receive additional psychosocial support from NICU mental health professionals and specially trained NICU staff. A combined effort of the Vermont Oxford Network (<http://www.vermontoxfordnetwork.org>)²⁴ and NPA has begun to facilitate the implementation of many of the recommendations using quality improvement projects in hospitals within VON.

Improving the emotional wellbeing of NICU parents, however, is not an end point. The second advance comes from recognition that the principles of the field of "infant mental health" should be incorporated into NICU practices.²⁵ A "family in the best possible shape" should be defined as a family engaged in active, emerging relationships with their baby consistent with the practices of infant mental health. Emotionally healthy parents are a pre-requisite for a healthy, developing baby who, in turn, improves the wellbeing of the whole family.

The principles of infant mental health are part of the foundation of Vermont Oxford Network's (VON) advocacy of transformation of NICUs into NIPUs, which have an emphasis on the goals of "parenting" and optimizing the developing infant/parent relationships.²⁶ This change in labeling from NICU to NIPU is very important. NICU has traditionally implied care of the infant. NIPU implies care of the family through an emphasis on parenting and relationships.

The third advance in goals and terminology is occurring, with the emergence of "family-integrated care" in the NICU.²⁷ Family-integrated care maximizes the amount and kind of caregiving family members (primarily mothers) can provide during around the clock care for their baby. Nurses, in this model, function more as educator/guides and intervene only for procedures such as the administration of intravenous fluids and medications. Parents do everything else and

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