

Identification of Internal and External Stressors in Parents of Newborns in Intensive Care

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Perm J 2013 Summer;17(3):36-41

<http://dx.doi.org/10.7812/TPP/12-105>

Abstract

The purpose of this study was to identify parents' self-reported stressors as they experience their baby's course in the neonatal intensive care unit (NICU). Miles, Funk & Carlson (1993) Parental Stressor Scale: Neonatal Intensive Care Unit was used to survey 119 parents of neonatal infants, born at 24 weeks to full term, in the 28-bed level 3 NICU of a mid-Atlantic, Magnet-designated acute care hospital with 665 licensed beds. The newly developed Grosik, Snyder, Cleary and Tidwell NICU External Stressors and Stress Reduction Scale (2006), a 5-point Likert scale, was also used. Intrapersonal and interpersonal stressors were categorized as internal (occurring within the NICU) and extrapersonal (occurring outside the NICU) as external stressors. The findings were used to develop a new practice in the NICU to help reduce parental stressors.

Introduction

Our family-centered neonatal intensive care unit (NICU) is home to our hospital's smallest and sometimes sickest patients. For parents, the NICU experience is an unanticipated journey filled with stress, emotional turmoil, strains on relationships and, at times, depression. Parents struggle to restore balance to their lives as they navigate the NICU experience, hoping for the best.

The NICU journey is life changing; parents' lives become unharmonious. The birth of a baby is supposed to be a happy event, but for parents with an infant in the NICU, it is marked by fear, sadness, guilt, and anger. Stress arises when individuals perceive that they cannot adequately cope. According to the criteria in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR),¹ NICU hospitalization is a traumatic stressor.²

The stress experienced by these parents has been compared to a posttraumatic stress response and has been investigated in numerous research studies.^{3,4} Although it is clear that the NICU experience is stressful, it is important to keep in mind that the perception of stress changes during the different stages of the infant's stay.⁴

Background and Significance

Until recently, the NICU gave little consideration to the need to assess what external stressors affect parents. The concept of stress is well known, however its causes and effects are unique to each of us. This study is important because the highest prior-

ity in the NICU is the health and well-being of the neonate. To achieve this priority and to provide holistic family-centered care, the NICU staff must acknowledge and have a better understanding of the parents' experience. It has been well documented that the NICU journey is stressful for parents.^{5,6} Multiple studies have evaluated the NICU internal stressors that affect parents during and after the NICU stay. To date, there has been little exploration of the external stressors that parents have to endure while their baby is in the NICU. The lack of data regarding external stressors strongly supports the need to implement an assessment of outside stressors affecting NICU parents.

Purpose

The purpose of the study was to ascertain what internal stressors play a role in determining the NICU experience for parents, as well as to assess external stressors. The DSM-IV-TR states that "posttraumatic stress disorder is a psychological disorder that follows exposure to a traumatic event involving the threat of death or serious injury to the individual or another that is accompanied by feelings of horror, helplessness, or intense fear."^{1,3} Every year in the US more than 480,000 babies are born prematurely, creating insurmountable stress and emotional burden on families.⁷ Once aware of these stressors, NICU staff can implement interventions to help parents restore a sense of balance. To that end, we sought to identify both the internal and external stressors affecting families with babies hospitalized in the NICU for more than 1 week.

Methods

Literature Review

Stress directly affects parents' ability to cope when faced with the challenges of having a critically ill neonate in the NICU.⁸ Parental anxiety may be reduced when the NICU staff recognize parental stress early and implement proper interventions.⁹ A NICU that provides a parent-friendly atmosphere allows parents to adapt more successfully to the NICU environment.¹⁰ Stressors experienced by parents do not differ according to class, sex, or level of education.⁸ The NICU setting, therefore, has been recognized throughout previous studies as a stressful environment for parents. It has been recognized that the NICU team should provide families with emotional support; bedside nurses are in a unique position to reduce heightened parental anxiety and are depicted as the most influential in that regard.¹¹

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Parents feel a sense of loss and begin grieving when their baby is admitted to the NICU.¹² These parents experience emotional struggles and their dreams are devastated. Specific nursing interventions can reduce stress for parents so they can begin the healing process.¹² When nurses understand parents' views and propose strategies that promote effective collaboration, the level of stress decreases in the NICU environment.¹³ There are many factors that play a role in parents' adaptation to stress. An important strategy recognized to decrease parental stress is to incorporate parents into NICU team meetings.¹⁴ Early engagement with families allows the NICU team to extract pertinent information about parental concerns and issues, and hopefully to decrease parental uncertainty.¹⁴ An understanding of the parents' experience is an impetus for forming or modifying effective strategies and optimizing outcomes for both the neonate and the parents. When parents are supported and understood, they can accept their new reality and aspire to new dreams.¹²

If caregivers have a better understanding of parental stress, they can provide services and resources to help parents cope with having a critically ill newborn in the NICU.¹⁵ The birth of a sick infant causes psychological distress and trauma to parents.¹⁶ Studies have found that early crisis intervention for parents and continued therapy throughout the NICU stay are beneficial for reducing symptoms of trauma.¹⁶ In addition, the scope of the baby's illness or the length of stay made a difference in how this time period was perceived.¹⁷ Many families reported that this period was an acute crisis for the family unit; families have described it as very traumatic.¹⁷

The term *stress* is often used for any factor in a person's life that causes change. Stress can present emotional, physical, social, or economic demands. Relatively few studies have addressed the effects of outside demands associated with NICU admission.

Recently, outside stressors have been recognized as affecting the NICU experience for parents. Using the Parental Stressor Scale: Neonatal Intensive Care Unit (PSS: NICU),¹⁸ one study concluded that further investigation of "practical worries and daily hassles" was needed.¹⁹ The birth of a premature baby, events in the NICU, and the NICU environment can be so stressful it can lead to family decomposition and posttraumatic stress disorder.²⁰

The health care team in the NICU plays an essential role and is considered a major source of parental support.¹⁷ Interventions provided by the NICU staff that concentrate on stress reduction can create new modalities to determine the staff's effects on the parents. Encouraging parents to address and to understand their emotional distress helps them cope, restores optimism, and generates hope. It was noted that when parents are prepared for NICU admission, they experience less stress.²¹ This can be difficult to accomplish because many patients are admitted to the NICU on an emergency basis that precludes sufficient time to educate parents. Neonatal nurses must adopt evidence-based interventions that decrease family stress and enrich family coping. Significant stress experienced by parents can lead to disruption in the family's equilibrium.¹⁵ A hospital-based stress-reduction support group for parents has been shown to be beneficial.²² When given the opportunity to discuss problems and concerns, parents reported having less stress, anxiety, and depression. Nurses can help decrease parental stressors just by listening and providing a foundation that strengthens parents emotionally.²⁰

Parents have little time to prepare for traumatic stressors related to NICU admission.² During the crisis, families with an organized network of social support fare better than families who remain isolated.² In comparison, other studies have found that trauma caused by a NICU experience may have significant



Abington Memorial Hospital
External Stressors Scale
 Grosik C, Snyder D, Cleary G, & Tidwell B (2006)

Below is a list of various activities that might describe your experience outside of the hospital environment. If the item reflects something that you have experienced, then indicate how much the experience was stressful or upsetting to you by circling the appropriate number or N/A if not applicable.

1. Being discharged from the hospital before my baby	N/A 1 2 3 4 5
2. Child care for siblings while you are visiting the baby	N/A 1 2 3 4 5
3. Meeting daily needs of my other children, for example: time spent together, homework, extracurricular activities	N/A 1 2 3 4 5
4. Meeting the daily necessities of the home, for example: housing, groceries, meals, laundry	N/A 1 2 3 4 5
5. Meeting your work obligations	N/A 1 2 3 4 5
6. Meeting your financial obligations	N/A 1 2 3 4 5
7. Meeting your transportation needs	N/A 1 2 3 4 5
8. Communication with your spouse/significant other	N/A 1 2 3 4 5
9. Impact on your spouse/significant other on your feelings and emotional needs	N/A 1 2 3 4 5
10. Impact of your family and friends on your feelings and emotional needs	N/A 1 2 3 4 5
11. Preparing to take the baby home	N/A 1 2 3 4 5

Figure 1. Abington Memorial Hospital External Stressors: Stressful experiences outside the hospital.

influences on the parent-child relationship.¹⁶ This information facilitates an individualized approach to NICU family stress and development of strategies to manage stress. One theory is that parents have a hard time coping because they do not feel empowered.²³ Encouraging parents to be part of the team improves their sense of belonging, leads to greater engagement in the care of their baby, and decreases their fear.²³

Conceptual Framework to Define Stressors and Prevention Interventions

Stress is a complex phenomenon conceptualized in various ways. The term *stress* is often used to describe perceived stressors, such as anxiety, depression, anger, and fear.¹⁹ There is no clear definition of stress, and researchers continue to seek a greater understanding of it. The assessment tool PSS: NICU was used to explore the sources of perceived stress—the stressors—or situational variables (eg, the infant, the event, and the

environment).¹⁹ Neuman’s Conceptual Framework focuses on the wellness of the client system in relation to environmental stress and reactions to stress.²⁴ The environment is described as all the internal and external factors that influence the client system. Wellness is described as a secure condition that is intact and harmonious. Neuman’s Conceptual Framework can be applied to NICU parents because they have had interruptions in their equilibrium because of stressors. Stress is categorized as intrapersonal (occurring within the client), interpersonal (occurring between individuals), or extrapersonal (occurring outside the client).²⁴ This health care focus was adapted in this study to more clearly identify external stressors of NICU parents and to determine what preventive interventions have the best outcomes.

Instrumentation

We used the PSS: NICU after obtaining permission from its originator, Margaret Miles. The design of this scale emphasizes 4



Abington Memorial Hospital
Stress Reduction Scale
 Grosik C, Snyder D, Cleary G, Tidwell B (2006)

Below are some possible techniques used to reduce stress. Please rate on a scale of 1 to 5, with 1 being the least effective and 5 being the most effective technique for coping.

1. Researching your baby’s condition	N/A 1 2 3 4 5
2. Exercise	N/A 1 2 3 4 5
3. Professional counseling	N/A 1 2 3 4 5
4. Prescription medication	N/A 1 2 3 4 5
5. Herbal or nonprescription medications	N/A 1 2 3 4 5
6. Confiding in friends or family	N/A 1 2 3 4 5
7. Speaking to other parents with babies in the Special Care Nursery	N/A 1 2 3 4 5
8. Personal prayer, counseling by clergy, or attending religious services	N/A 1 2 3 4 5
9. Other _____	

Figure 2. Abington Memorial Hospital External Stressors and Reduction Scale: techniques to reduce stress.



Abington Memorial Hospital
Study Demographics

<p>Age</p> <input type="checkbox"/> Under 20 <input type="checkbox"/> 20-25 <input type="checkbox"/> 26-30 <input type="checkbox"/> 31-35 <input type="checkbox"/> Over 35	<p>Living Arrangements</p> <input type="checkbox"/> Rent <input type="checkbox"/> Own home <input type="checkbox"/> Live with family member <input type="checkbox"/> Live with mother/father of baby <input type="checkbox"/> Other	<p>Income (Optional)</p> <input type="checkbox"/> Less than \$20,000 <input type="checkbox"/> \$20,000 to \$40,000 <input type="checkbox"/> \$60,000 to \$80,000 <input type="checkbox"/> Over \$80,000
<p>Marital Status</p> <input type="checkbox"/> Single <input type="checkbox"/> Engaged <input type="checkbox"/> Married <input type="checkbox"/> Separated <input type="checkbox"/> Other	<p>Sex</p> <input type="checkbox"/> Male <input type="checkbox"/> Female	<p>Education (check highest level) (optional)</p> <input type="checkbox"/> Junior High <input type="checkbox"/> High School <input type="checkbox"/> College <input type="checkbox"/> Graduate School <input type="checkbox"/> Professional School (Physician, lawyer, dentist, etc)

Figure 3. Abington Memorial Hospital Study Demographics.

dimensions of the environment and experiences in the NICU: sights and sounds of the unit, effects of the infant's appearance, change in parent role, and relationship with the staff.¹⁸ The PSS: NICU scale has been used consistently for over 20 years to assess parental stress within the NICU environment.

We used an additional assessment tool, the NICU External Stressors and Stress Reduction Scale (Figures 1 and 2). Included in Figure 1 is a compilation of family responsibilities that might increase stress for parents outside of the hospital environment. Figure 2 is a list of stress-reducing techniques that parents might use. These tools were used to evaluate parental external stressors and the mechanisms parents used to cope with stress during the NICU stay. Parents used these instruments to rate their stress caused by external stressors with a Likert scale.

Data Collection

Each Monday, qualified parents were asked by the administrative assistant to complete the research package. The package included four questionnaires: an internal stressor questionnaire, the external stressors questionnaire, the stress-reduction techniques, and the demographic information sheet (Figure 3).

Sample

A convenience sample of 119 participants were recruited from the parents of infants who had been admitted to the level 3, 28-bed NICU of a suburban Philadelphia 665-bed community teaching hospital. The institutional review board of Abington Memorial Hospital approved this study. The consent form was explained to parents, and those who consented were enrolled in the study. Inclusion criteria were admission of baby to the NICU and length of stay greater than 1 week. The exclusion criterion was length of stay shorter than 1 week. Mothers and fathers were asked to participate separately, within 7 days after the infant's admission to the NICU.

Out of the 119 respondents, 60.5% were mothers. Of these, 37.1% were between age 25 and 30 years, 30% were older than age 35 years, 78.6% were married, and 58.6% owned their homes. The annual income of 36.5% of the women who participated in the study was >\$80,000, and college was the highest level of education completed for 67.2%. Fathers were 39.5% of the respondents. Of these, 29.8% were age 25-30 years, 29.8% were age >35 years, 68.1% owned their homes, and 40% had a yearly salary >\$80,000. For 40.0%, college was the highest level of education completed (Table 1).

Results

Analysis of Internal and External Stressors and Stress-Reduction Themes

The purpose of this study was to evaluate the internal and external stressors related to the NICU experience that contributed the most to parental stress response during the NICU stay.

Stressors were categorized as internal or external. Additional analysis focused on the extent to which the study participants' responses reflected the most common coping mechanisms for families. Internal stressors were those occurring within the NICU and external stressors occurred outside the NICU (Table 2). Internal stressors were further classified as intrapersonal or interpersonal; external stressors were not further classified.

Stress levels reported by parents were scored from 1 to 5 on a Likert scale for each question. With regard to intrapersonal stressors, the highest stress scores were related to parents observing their baby in distress or appearing significantly ill (Table 2). Parents' responses to interpersonal stressors with regard to the environment identified the noise of alarms and machines as most stressful. Furthermore, a personal struggle of separation and helplessness was manifested in scores regarding the parents' relationship with their baby in the NICU (Table 2). These findings are consistent with earlier studies evaluating internal stressors to the NICU family. External stressors were more varied and surrounded separation from the baby at maternal discharge and the day-to-day obligations of parents toward their other children

Table 1. Demographic characteristics of respondents, N = 119

Variable	Women, % (n = 72)	Men, % (n = 47)
Percentage of sample	60.5	39.5
Age, years		
Response rate	97.2	100.0
<20	0.0	0.0
20-25	15.8	8.5
26-30	37.1	29.8
31-35	17.1	31.9
>35	30.0	29.8
Marital Status		
Response Rate	97.2	97.9
Married	78.6	84.8
Single	11.4	2.2
Engaged	8.6	13.0
Separated	1.4	0.0
Other	0.0	0.0
Living Arrangement		
Response rate	97.2	100.0
Own home	58.6	68.1
Rent	27.1	23.4
Live with mother or father of baby	8.6	4.2
Live with family member	4.3	4.3
Other	1.4	0.0
Yearly salary, \$		
Response rate	72.2	85.1
<20,000	3.8	5.0
20,000-40,000	27.0	17.5
40,000-60,000	17.3	22.5
60,000-80,000	15.4	15.0
>80,000	36.5	40.0
Education Completed		
Response rate	93.0	100.0
Junior high school	0.0	2.1
High school	13.4	32.0
College	67.2	40.4
Graduate school	15.0	23.4
Professional school (physician, lawyer, etc)	4.4	2.1

NICU = neonatal intensive care unit.

The highest-scored stressor ... was "seeing my baby stop breathing."

and jobs (Table 2). Stress-reduction scores were strongest in the realm of preexisting support systems of family and friends, and, interestingly, a new support system of families that had had a similar NICU experience (Table 2). These questions and the responses improved caregiver awareness of parental stressors in the NICU and new approaches to stress management for families. A pilot program to respond to the identified coping technique of parent-to-parent contact was instituted using scrapbooking as an activity to bring former and current NICU parents together. This approach was preferred by families, as neither the former nor the current NICU parents wanted a formal counseling session. This approach was most productive in offering parents one stress-reduction technique that could be instituted and fostered by hospital staff. During these ongoing parent sessions, speaking to other parents with babies in the NICU was found to be a very effective individual strategy. In addition, this approach increased caregiver awareness of parental stress and was used to develop a new practice for parents to cope with the internal and external stressors in the NICU.

Stressors and stress-reduction techniques	Mean score ^a
Interpersonal stressors	
Sights and sounds	
Having a machine (respirator) breathe for my baby	3.45
The sudden noises of monitor alarms	3.16
The constant noises of monitors and equipment	2.66
Relationship with baby	
Being separated from my baby	4.27
Feeling helpless about how to help my baby during this time	3.83
Not being able to hold my baby when I want	3.78
Intrapersonal stressors	
Baby's appearance and behavior/treatment in the NICU	
Seeing my baby stop breathing	4.43
When my baby seems to be in pain	4.05
Seeing my baby suddenly change color (for example, becoming pale or blue)	3.95
Extrapersonal stressors	
Being discharged from the hospital before my baby	4.06
Meeting daily needs of my other children (homework/activities)	3.44
Child care for siblings while I am visiting the baby	3.33
Meeting financial obligations	3.07
Stress-reduction techniques	
Personal techniques	
Confiding in friends or family	3.64
Personal prayer	3.50
Speaking to other parents in the NICU	3.32
Researching my baby's condition	3.00
Techniques implemented in the NICU	
Parent-to-parent interaction	3.30

^a Based on 5-point Likert scale: 5 = highest stressor/reduction; 1 = lowest stressor/reduction.
NICU = neonatal intensive care unit.

Summary

Families who are expecting a baby have preconceived thoughts about the birth and future of their child. For NICU parents, fantasies fade and plans start to unravel as they find themselves dealing with fear and uncertainty. Parents try to cope but are often unprepared for this experience. Parents in the NICU can feel overwhelmed and experience hopelessness and despair. "Establishing strong, trusting, therapeutic relationships is essential if nurses are to provide effective family-centered care to infants and their families."¹³ A trusting relationship between families and the health care team is essential for reducing parental stress.

A review of the literature demonstrates that multiple studies have evaluated internal stressors and long-term effects of the NICU journey. The lack of data regarding external stressors strongly supports the need to implement an assessment of outside stressors that affect the NICU parents' experience. Once stressors have been identified, interventions can be developed to improve the family-centered approach to care. The importance of supporting parents during their infant's hospitalization cannot be overestimated. Attention needs to be paid to the external factors as well as the internal factors. As caregivers, we need to continue to expand our knowledge. The information gained will allow the holistic, family-centered philosophy to flourish. With stressors identified, strategies can be implemented to establish preventive interventions at the primary, secondary, and tertiary levels of care as parents and their infants transition from the NICU to the home environment and back into the community. ♦

Acknowledgments

Special thanks to our research administrative assistant, Barbara Tidwell. Leslie Parker, ELS, provided editorial assistance.

Disclosure statement

The 2006 Innovators' Circle Research Grant award of \$7000 was used to support the research reported in this article: the research was supported by Abington Memorial Hospital, Abington, PA. The project is the recipient of The Permanente Journal 2009 Service Quality Award.

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Micro-Adults

Children are not simply micro-adults,
but have their own specific problems.

— Béla Schick, MD, 1877-1967,
Hungarian-born American pediatrician