

INTRODUCTION

Psychosocial program standards for NICU parents

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This article provides a rationale for and brief description of the process of developing recommendations for program standards for psychosocial support of parents with babies in the neonatal intensive care unit (NICU). A multidisciplinary workgroup of professional organizations and NICU parents was convened by the National Perinatal Association. Six interdisciplinary committees (family-centered developmental care, peer-to-peer support, mental health professionals in the NICU, palliative and bereavement care, follow-up support and staff education and support) worked to produce the recommendations found in this supplemental issue. NICU parents contributed to the work of each committee.

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BACKGROUND

A neonatal intensive care unit (NICU) is akin to a trauma center for all participants. Fragile babies struggle to survive and grow. Parents and families worry constantly while trying to maintain optimism and hope. Staff attempt to avoid burnout while both encouraging distraught parents and acknowledging the times of poor prognosis. Distress is the companion of everyone.

Although the title of this supplemental issue of *Journal of Perinatology* involves psychosocial support for NICU parents, the recommendations go beyond parents. The reader will find numerous studies documenting the NICU experience as a potentially traumatic event;¹ primarily to parents, but also to babies² and staff.^{3,4} In the ideal NICU, psychosocial support of both NICU parents and staff should be goals equal in importance to the health and development of babies.

In January 2014, the National Perinatal Association convened a broad group of approximately 50 thought leaders and stakeholders—physicians (both neonatology and obstetrics), nurses, nurse practitioners, nurse midwives, developmental care specialists, psychologists, social workers, public health experts, parent support group leaders and parents—to develop interdisciplinary guidelines for psychosocial support services for parents whose infants require care in NICUs. The workgroup consisted of representatives of 29 professional groups and parent groups. NICU parents were involved in each of the six committees. The 50 work group members represented 22 academic institutions.

The committees gathered research citations, communicated by e-mail and phone, and many members attended a summit on 15 October 2014 in St Louis, MO, USA. On 1 May 2015, the recommendations were sent to the organizations represented by workgroup membership (and other organizations) for review and potential support. The listing of a supporting organization in this issue does not imply that the organization agreed with each and every recommendation. Support entailed agreement with the overall tenor of the recommendations and does not indicate official guidance from the supporting organization. Whenever possible the recommendations follow from the research citations.

Some recommendations have an evidence base that is modest. In these cases, the workgroup has relied on consistent personal experiences that the recommendation is simply 'the right thing to do'.

The workgroup fully understands that some of these recommendations will be difficult to implement, especially in an era when health-care organizations, governmental groups and insurance companies are struggling to accommodate to the realities of the marketplace. The recommendations are a road map for how NICUs should be transformed; and, in some cases, multiple suggestions are provided for achieving a goal. Provision of comprehensive family support, which involves (a) family-centered developmental care by the health-care staff, (b) active parent-to-parent support within the NICU and (c) ready availability of services provided by mental health professionals, should be a goal for all NICUs. A recent transformation for NICUs has been the construction of single bed rooms.⁵ The research on single bed rooms has demonstrated mixed effects on both mothers and babies.^{6–8} One very interesting aspect of the advantages of the single bed room is a recent study in one hospital showing that this change in the architecture did not lead to a direct beneficial effect upon the baby, but rather the beneficial effects were mediated by increased maternal involvement.⁸ Many of the recommendations of the workgroup focus on the optimization of the mother/father/baby relationship to ensure that families get the healthiest start possible.

Multiple guiding principles can be found throughout these recommendations. One is that comprehensive psychosocial support requires interdisciplinary collaboration. Every discipline has a role to play in interacting with each other for the maximum benefit of babies, parents and staff. A second guiding principle is continuity of care. Whenever possible, psychosocial support should begin during the antepartum period. This support should continue through the NICU stay and into the post-NICU period.

Another principle is reflected in the recognition that there are a variety of emotional responses to potentially traumatic experiences.¹ Four primary trajectories of emotional recovery

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have been documented in the general trauma recovery literature.¹ Many of these trajectories have been found in research on NICU mothers.^{9,10} These trajectories are resilient, chronic, recovered and delayed.¹ Resilient refers to continuous low-intensity symptoms of emotional distress and adaptive psychological functioning. Chronic refers to high-intensity symptoms and maladaptive functioning for the duration of the crisis. Recovered refers to initial symptoms of moderate intensity that decline over the course of time. Delayed refers to initial levels of symptoms of moderate intensity that increase in intensity over time. Many readers will have observed the different trajectories in NICU parents. The emotional reactions of NICU parents should be monitored over time and appropriate levels of support offered.

These trajectories of recovery dovetail with a fourth principle, layered levels of care as represented in the 'pediatric psychosocial preventative health' model of care.¹¹ A 'universal' level of care should be available to all parents. This universal care level is best addressed with family-centered developmental care along with active parent-to-parent support. A higher level of 'targeted' care should be provided for families identified as being at risk for emotional distress. Both professional and paraprofessional levels of 'targeted care' should be delivered by NICU staff. 'Clinical' care is emotional care provided for NICU parents with acute or diagnosable conditions by mental health professionals both within the NICU and through outside referrals.

Clinical levels of care are clearly needed in the NICU.^{12–15} Multiple research studies (using interviews or questionnaires) have reported elevated symptoms of depression in 39 to 63% of NICU mothers during the first postpartum year.¹⁴ Studies of post-traumatic stress disorder report that 9 to 53% of NICU mothers score above threshold on post-traumatic stress disorder questionnaires or interviews.^{9,10,14,15} The few studies of NICU fathers also show elevations in depression and post-traumatic stress disorder symptoms that are distinctly greater than the 1-year prevalence rate for the general population.¹⁴ Research has also shown the beneficial effects of psychosocial support programs (ranging from parent support groups to systematic psychotherapy in the NICU) on the well-being of NICU parents. These reports are elaborated in the following articles in this journal issue.

Although the need for clinical care has clearly been demonstrated, many readers will recognize that much of the distress NICU parents feel can be lessened by the health-care team, using sound principles of communication. These principals include: (a) acknowledging, (and, when necessary) clarifying or reinterpreting parents' concerns; (b) fully sharing medical information on a regular basis and (c) empathetically delivering 'bad news'. Clarity and continuity of communication between parents and the health-care team is a key, as is the management of transition points and handoffs among caregivers. Psychotherapy researchers have long recognized that therapeutic benefits come not only from the specific techniques of therapy, but also from the general components of communication found in caring relationships (for example, compassion, empathy, understanding and acceptance).¹⁶

Some of the recommendations involve giving guidance to NICU parents about the risk for future psychological distress. Such guidance should not imply that all parents are at risk for psychopathology.¹

Rather, psychosocial programs should both normalize the levels of distress felt by almost all NICU parents and offer targeted and clinical levels of care for parents at risk. NICU mental health professionals should take into account multiple risk factors in

counseling parents about their future possibilities.¹⁴ The recommendations in this issue do not indicate an exclusive course of action. Clinical judgment should be used in all communications with parents.

Readers may also wish to access an Internet-based tool kit that provides useful resources for both parents and professionals. Parents will find resources to help them get through a NICU stay, as well as how to start and maintain a parent support group; professionals will find more information on perinatal mental health issues and their management (www.support4NICUparents.org).

CONFLICT OF INTEREST

SL Hall has a consulting agreement with the Wellness Network, but this organization had no input or editing rights to the content included in the guidelines. The remaining author declares no conflict of interest.

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APPENDIX A: WORKGROUP ON PSYCHOSOCIAL SUPPORT OF NICU PARENTS

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Academy of Neonatal Nursing
Association of Women's Health, Obstetric and Neonatal Nurses
Council of International Neonatal Nurses
Healthy Mothers, Healthy Babies Coalition, National Premature Infant Health Coalition
March of Dimes
National Association of Neonatal Nurses
National Association of Neonatal Therapists
National Association of Pediatric Nurse Practitioners
National Association of Perinatal Social Workers
National Perinatal Association
Nurse Family Partnership
Oklahoma Infant Alliance
Special Care/Special Kids
Transcultural Nursing Association

Parent Support Organizations that Participated in the Workgroup

Eden's Garden
Graham's Foundation
Hand to Hold
NICU Helping Hands
St. John's Mercy NICU Parent Support (NICUPS)

Parent to Parent of Salt Lake City
Preeclampsia Foundation
Premie Parent Alliance
Zoe Rose Memorial Foundation

APPENDIX B: ORGANIZATIONS THAT SUPPORT THE RECOMMENDATIONS

The following is a list of organizations that agreed to support the spirit and general content of the *Interdisciplinary Recommendations for Psychosocial Support of NICU Parents*, with the understanding that their support does not imply agreement with each and every recommendation. The *Recommendations* should not be considered official guidance from any of the supporting organizations.

Professional Organizations

Academy of Neonatal Nursing
American College of Nurse-Midwives
Council of International Neonatal Nurses
Marcé Society for Perinatal Mental Health
National Association of Neonatal Nurses
National Association of Pediatric Nurse Practitioners
National Association of Perinatal Social Workers
National Association of Neonatal Therapists
National Perinatal Association
Nurse Family Partnership
Society for Maternal Fetal Medicine
Transcultural Nursing Society
University of North Carolina at Chapel Hill Center for Maternal and Infant Health

Family Support Organizations

Canadian Foundation for Premature Babies
Eden's Garden
European Foundation for the Care of Newborn Infants
Graham's Foundation
Hand to Hold
Hope for HIE
NICU Helping Hands
Postpartum Support International
Preeclampsia Foundation
Premie Parent Alliance
Premie World, LLC
St John's Mercy NICU Parent Support
The Tiny Miracles Foundation
Zoe Rose Memorial Foundation