INTRODUCTION

Psychosocial program standards for NICU parents

MT Hyman1 and SL Hall2

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 roadmap 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

1Department of Psychology, University of Wisconsin-Milwaukee, Milwaukee, WI, USA and 2Department of Neonatology, St John’s Regional Medical Center, Oxnard, CA, USA.
Correspondence: Dr SL Hall, Department of Neonatology, St John’s Regional Medical Center, 1600 N. Rose Avenue, Oxnard, CA 93030, USA.
E-mail: suehallmd@gmail.com
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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

Co-Chairs
Sue L. Hall, MD, MSW, FAAP, Neonatologist, St John's Regional Medical Center, Oxnard, CA, USA.
Michael T Hynan, PhD, Emeritus Professor of Clinical Psychology, University of Wisconsin-Milwaukee, Milwaukee, WI, USA.

Participants in the Workgroup
Lisa Baker, PhD, LCSCW, PIP, Associate Professor of Social Work, University of Alabama, Birmingham, AL, USA.
Amy Baughcum, PhD, Pediatric Psychologist, Assistant Clinical Professor of Pediatrics, Ohio State University School of Medicine, Nationwide Children's Hospital, Columbus, OH, USA.
Jennifer Beatty, MSW, Program Director, Hand to Hold, Austin, TX, USA.
Joy Browne, PhD, PCNS-BC, IMH-E(IV), Clinical Professor of Pediatrics and Psychiatry, University of Colorado Anschutz Medical Campus, and The Children's Hospital, Aurora, CO, USA.
Tawna Burton, March of Dimes Family Support Program Coordinator, Intermountain Medical Center Health, Salt Lake City, UT, USA.
Rebecca Chuffo-Siewert, DNP, ARNP, NNP-BC, FAANP, Neonatal Nurse Practitioner, Department of Neonatology, University of Iowa Children's Hospital, College of Nursing, University of Iowa, Iowa City, IA, USA.
Robert Cicco, MD, Neonatologist and Associate Director of NICU, West Penn Hospital, Pittsburgh, PA, USA.
Jenene Woods Craig, PhD, MBA, OTR/L, Assistant Professor of Occupational Therapy, Brenau University, College of Health Sciences, Gainesville, GA, USA.
JaNeen Cross, PhD, MSW, MBA, LCSCW, ACSCW, Assistant Professor of Social Work, Widener University, Chester, PA, USA.
Barbara DeLoian, PhD, RN, CPNP, Pediatric Nurse Practitioner, Special Care/Special Kids, Castle Pines, CO, USA.
Jaime DeMott, Parent Volunteer, Graham's Foundation, Waterville, OH, USA.
Pamela A Geller, PhD, Department of Psychology, Department of Obstetrics and Gynecology, Drexel University College of Medicine, Associate Professor of Psychology, Obstetrics/Gynecology and Public Health, Drexel University, Philadelphia, PA, USA.
Cris Glick, MD, Neonatologist, Mississippi Lactation Services, Jackson, MS, USA.
Andrea Schwartz Goodman, MSW, MPH, Formerly Maternal and Child Health Director, National Healthy Mothers, Healthy Babies Coalition, Washington, DC, USA.
Erika Goyer, Education Director, Hand to Hold, Austin, TX, USA.
Lisa Grubbs, Founder and President, NICU Helping Hands, Fort Worth, TX, USA.
Nick Hall, Founder and President, Graham's Foundation, Waterville, OH, USA.
Becky Hatfield, Parent Support Specialist, Parent to Parent Program, University of Utah Hospital, Salt Lake City, UT, USA.
Amanda Hedin, Founder, Eden's Garden, Blaine, MN, USA.
Pec Indman, EdD, MFT, Certified Trainer for Postpartum Support International, San Jose, CA, USA.
Carole Kenner, PhD, RNC-NIC, NNP, FAAN, Dean and Professor of the School of Nursing, Health and Exercise Science, The College of New Jersey, Ewing, NJ, USA.

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Stephen Lassen, PhD, Associate Professor of Pediatrics, University of Kansas Medical Center, Kansas City, KS, USA.
Kristy Love, Director of Operations, National Perinatal Association, St Louis, MO, USA.
Sue Ludwig, BS, OTR/L, Neonatal Occupational Therapist, University of Cincinnati Medical Center, Cincinnati, OH, USA.
Laura B. Martin, MMEd, Director of Parent Communication and Engagement, Graham's Foundation, Waterville, OH, USA.
MaryLou Martin, MSN, RNC, Clinical Nurse Specialist/Nurse Educator, McLeod Regional Medical Center, Florence, SC, USA.
Heather McKinnis, Director, Preemie Parent Mentor Program, Graham's Foundation, Waterville, OH, USA.
Cheryl Milford, EdS, Psychologist in Private Practice, Cheryl Milford Consulting, Huntington Beach, CA, USA.
Kyle Mounts, MD, Wisconsin Association for Perinatal Care/Perinatal Foundation, Milwaukee, WI, USA.
Raja Nandyal, MD, Associate Professor of Pediatrics, The Children's Hospital at Oklahoma University Health Sciences Center, Oklahoma City, OK, USA.
Chavis A Patterson, PhD, Director of Psychosocial Services, Division of Neonatology, The Children's Hospital of Philadelphia, Assistant Professor of Clinical Psychology in Psychiatry, Department of Psychiatry, Perelman School of Medicine at the University of Pennsylvania, Philadelphia, PA, USA.
Raylene Phillips, MD, Assistant Professor of Pediatrics, Division of Neonatology, Loma Linda University, Loma Linda, CA, USA.
Carrie Piazza-Waggoner, PhD, Associate Professor of Behavioral Medicine and Clinical Psychology, University of Cincinnati, Cincinnati Children's Hospital Medical Center, Cincinnati, OH, USA.
Rachel Ponzek, BSN, RN, Neonatal Intensive Care Unit, Children's Hospital of Philadelphia, Philadelphia, PA, USA.
Laney Poye, Director of Community Relations, Preeclampsia Foundation, Melbourne, FL, USA.
Janet Press, RNC, BSN, CT, Perinatal Bereavement Services Coordinator, Crouse Hospital, Syracuse, NY, USA.
Isabel Purdy, PhD, RN, CPNP, NNP, CNS, Associate Clinical Professor of Pediatrics, Division of Neonatology, David Geffen School of Medicine at UCLA, Los Angeles, CA, USA.
Lisa Rafel, Musician, singer, composer, Founder of Resonant Sounds, Oakland, CA, USA.
Donna Ryan, DNP, RN, Assistant Professor in Nurse Education Program, Elmira College, Elmira, NY, USA.
Anne Santa-Donato, MSN, RNC, Director, Obstetric Programs, Association of Women's Health, Obstetric and Neonatal Nurses, Washington, DC, USA.
Sage Saxton, PsyD, Clinical Associate Professor of Pediatrics, Child Development & Rehabilitation Center, Oregon Health & Science University, Portland, OR, USA.
Jennifer Schum, RN, CPN, Regional Director of NICU Family Support-West Region, March of Dimes, Dallas, TX, USA.
Lisa Segre, PhD, Associate Professor of Nursing, College of Nursing and Department of Psychological and Brain Sciences, University of Iowa, Iowa City, IA, USA.
Nancy Green Selix, CNM, DNP, Assistant Professor of Nursing, School of Nursing and Health Professions, University of San Francisco, San Francisco, CA, USA.

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Joan Smith, PhD, RN, NNP-BC, Associate Professor, Goldfarb School of Nursing at Barnes-Jewish College, Advanced Practice Clinical Scientist, St Louis Children's Hospital, St Louis, MO, USA.
Keira Sorrells, Founder and Executive Director, Zoe Rose Memorial Foundation and Preemie Parent Alliance, Jackson, MS, USA.
Sharon Sprinkle, RN, MBA, MHA, Nurse Consultant Manager, Nurse-Family Partnership, Denver, CO, USA.
Zina Steinberg, EdD, Assistant Clinical Professor of Medical Psychology, Columbia University, New York Presbyterian Morgan Stanley Children's Hospital, New York, NY, USA.
Alison Stuebe, MD, Assistant Professor of Obstetrics and Gynecology, Division of Maternal Fetal Medicine, University of North Carolina, Chapel Hill, NC, USA.
Sarah Verbiest, DrPH, MSW, MPH, Executive Director, University of North Carolina Center for Maternal and Infant Health, Chapel Hill, NC, USA.
Eleanor Yost, MBA-HA, MSN, PNP, Director of Program Innovations, Nurse Family Partnership, Denver, CO, USA.
Paula Zeanah, PhD, MSN, Picard-Nursing Collaborative Chair, Director of Research, Cecil Picard Center for Child Development and College of Nursing and Allied Sciences, University of Louisiana, Lafayette, LA, USA.

Professional Organizations that Participated in the Workgroup
- 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)

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
- Preemie Parent Alliance
- Preemie World, LLC
- St John’s Mercy NICU Parent Support
- The Tiny Miracles Foundation
- Zoe Rose Memorial Foundation