Interdisciplinary Recommendations for the Psychosocial Support of NICU Parents

Guest Editors

Sue L. Hall, MD, MSW, FAAP and Michael T. Hynan, PhD
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A workgroup of multidisciplinary professional organizations and neonatal intensive care unit (NICU) parents was convened by the National Perinatal Association. Six committees (family-centered developmental care, peer-to-peer support, mental health professionals in the NICU, palliative care and bereavement, 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. The workgroup consisted of over 50 members representing 22 academic institutions, 28 professional groups and 8 parent groups. Many participants met at a summit held on Oct. 15, 2014 in St. Louis, MO. The recommendations were subsequently reviewed by multiple organizations. The introduction lists the organizations supporting the recommendations.

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INTRODUCTION

Psychosocial program standards for NICU parents

MT Hynan1 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.


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 28 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...
have been documented in the general trauma recovery literature. Numerous studies have found that NICU mothers experience high levels of anxiety and depression, and that these symptoms can persist for extended periods after discharge. Some of these trajectories have been found in research on NICU mothers. These trajectories are resilient, chronic, recovered and delayed. 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. 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. 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. 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. 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. 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 principles 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).

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. 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. 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.support4NICU/parents.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.

ACKNOWLEDGEMENTS
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REFERENCES
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- 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

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

Recommendations for involving the family in developmental care of the NICU baby

JW Craig1, C Glick2, R Phillips3, SL Hall4, J Smith5 and J Browne6

Family involvement is a key to realize the potential for long-lasting positive effects on physical, cognitive and psychosocial development of all babies, including those in the neonatal intensive care unit (NICU). Family-centered developmental care (FCDC) recognizes the family as vital members of the NICU health-care team. As such, families are integrated into decision-making processes and are collaborators in their baby’s care. Through standardized use of FCDC principles in the NICU, a foundation is constructed to enhance the family’s lifelong relationship with their child and optimize development of the baby. Recommendations are made for supporting parental roles as caregivers of their babies in the NICU, supporting NICU staff participation in FCDC and creating NICU policies that support this type of care. These recommendations are designed to meet the basic human needs of all babies, the special needs of hospitalized babies and the needs of families who are coping with the crisis of having a baby in the NICU.


BACKGROUND

The provision of family-centered care has been endorsed by the American Academy of Pediatrics and many other health-care organizations. However, gaps have been demonstrated between the goals of family-centered care and its actual practice. Family-centered developmental care (FCDC) takes family-centered care one step further by involving the family as an essential contributor to the provision of individualized, developmentally supportive care of their baby. FCDC provides the strong supportive foundation families in the neonatal intensive care unit (NICU) need to optimize the lifelong relationship between themselves and their babies, as well as to optimize the baby’s physical, cognitive and psychosocial development. Embracing families as decision-making partners and collaborators in their baby’s care has long been recognized as an optimal way of caring for babies in the NICU. A primary goal of FCDC is to minimize the lasting negative effects that a baby’s illness may have on parent–baby interactions. Reaching this goal can be accomplished through identification of individual infant/family vulnerabilities and strengths and then finding ways to address these characteristics in the antepartum period, continuing through NICU admission, and on to NICU discharge and the transition home.

Fully implementing FCDC requires a global change in culture and in the behavior of the many professional disciplines working within the NICU, and FCDC demands an expansion of the historic role of the NICU health-care team. One way for NICU teams to develop and expand their FCDC practices is through the implementation of quality improvement initiatives. This article presents key areas that these initiatives should address: (a) parent support, (b) staff support and (c) NICU policies.

The following recommendations for developmentally supportive care are critical components of standard medical care providing for the basic human needs of all babies. The recommendations address the special needs of babies who are admitted to the NICU as well as the needs of families who are coping with the crisis of having a baby in the NICU.

SUPPORTING PARENTS’ ROLES AS CAREGIVERS OF THEIR BABIES IN THE NICU

Historically, the model of care for the NICU baby included almost complete separation from the mother and the family, with the baby enveloped in technology and cared for by highly trained personnel. After the baby was ‘cured and ready for discharge’ the family was notified to take their baby to home. While separation of babies from mothers has a profound negative effect on the baby’s physiologic stability, as well as psychosocial well-being and brain development, the current model of care for the NICU acknowledges that the effects of a premature birth or hospitalization of a sick newborn are not only experienced by babies but also by parents and families. This separation is especially true for very low birth weight babies and their families, as these babies spend significant time away from their parents and are at high risk for long-term developmental and behavioral problems. Parents of premature babies often lack support and opportunities to engage in parenting while in the NICU, leading to frequent misperceptions of their baby’s behavioral cues and even labeling of their babies as ‘difficult’. The separation of parents from their baby in the NICU combined with parental mental health issues such as depression, post-traumatic stress disorder, anxiety and other stress-related conditions can adversely affect the parent–baby relationship resulting in adverse outcomes for the baby’s social and emotional development and behavioral and cognitive functioning. This separation may render the preterm baby, especially one who is very low birth weight, to be at risk for abuse and maltreatment following hospital discharge.

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Parents of premature and sick babies must develop and maintain an appropriate understanding of their babies’ needs in order to be prepared for home caregiving.\textsuperscript{11,12} Studies by O’Brien et al.\textsuperscript{24} in Canada and Ortenstrand et al.\textsuperscript{25} in Sweden, in which families were fully integrated into the NICU team and actively provided much of their babies’ care, showed many benefits to both parents and babies. Mothers had lower stress scores and felt more knowledgeable and confident, while babies had improved weight gain and a higher rate of exclusive breastfeeding at discharge in the O’Brien et al.\textsuperscript{24} trial. The length of stay was shorter for babies in the Ortenstrand et al.\textsuperscript{25} trial. Phillips et al.\textsuperscript{26} found that supporting mothers in the NICU to respond to their babies’ behavior in an effort to support attachment led to significantly higher rates of breastfeeding at 8 weeks after birth.\textsuperscript{26}

Several studies have revealed a link between infant stress in the NICU and the corresponding changes in brain architecture. Smith et al.\textsuperscript{27} demonstrated that when neonates were exposed to increasing numbers of stressors in the NICU, the babies had regional alterations in brain structure and function, as determined by magnetic resonance imaging, as well as abnormalities in motor behavior on neurobehavioral examination. However, when parents of premature babies are shown how to recognize their baby’s behavioral, social and physical cues, parents facilitate their baby’s developmental and physical progress, further reflected by changes in the brain’s structure. Milgrom et al.\textsuperscript{28} found that when parents participated in a 10-session training program to help them reduce their preterm babies’ stressful experiences, their babies’ brains showed improved cerebral white matter micro-structural development, again as determined by magnetic resonance imaging. In another study, preterm babies who received 8 weeks of skin-to-skin contact with their mothers demonstrated accelerated functional brain maturation as assessed by electroencephalogram, when compared with babies who did not receive such contact.\textsuperscript{29}

Further work by Milgrom et al.\textsuperscript{10} evaluated the impact of an extended intervention using the enhanced Mother–Infant Transaction Program, called PremieStart, on both mothers and their babies born at < 30 weeks gestation. The goals for mothers who participated in this training were to recognize and minimize stress responses in their babies. Mothers who participated were found to be more sensitive to their babies and were appropriately responsive to the identified stress behaviors. Their babies displayed fewer stress behaviors at term equivalent age and showed more advanced communication development at 6 months corrected age. This latter finding gives promise that the intervention may provide an early benefit to cognitive and pre-linguistic development. White-Traut et al.\textsuperscript{31} demonstrated that when mothers received information on how to provide their babies with simple, developmentally appropriate multi-sensory stimulation through the ‘Hospital to Home Transition—Optimizing Premature Infant’s Environment’ program, their babies had better weight gain during the hospital stay and were less likely to see a health-care provider for an illness in the 6-weeks post-NICU discharge.\textsuperscript{21} Parents also benefited when they were supported to improve interactions with their babies. Melnyk et al.\textsuperscript{13} found that parents who participated in the ‘Creating Opportunities for Parent Empowerment’ program during their NICU stay reported less stress while in the NICU and less depression and anxiety at 2 months’ corrected infant age than did mothers who did not receive the intervention. Babies of participating mothers also had a shorter length of stay in the NICU.\textsuperscript{13}

Taken together, these studies provide a strong basis for interventions that support parents in the parenting role and guide parents in developmentally appropriate interactions with their preterm and sick babies. These interventions have the potential to lessen the adverse impact of environmental stressors to which NICU babies are exposed, ultimately lessening the chance of poor developmental outcomes. In addition, positive benefits of reduced stress and improved parent mental health outcomes ultimately can further improve parents’ relationships with their babies.

Recommendations for supporting parents’ roles as caregivers of their babies in the NICU:

1. Parents should be incorporated as full participatory, essential, healing partners within the NICU caregiving team. As partners within the medical team, parents should:
   (a) Assume the parental role through provision of hands-on care to their baby including early, frequent and prolonged skin-to-skin contact as is medically appropriate, with coaching, guidance and support from the NICU staff;\textsuperscript{33}
   (b) Participate in both medical rounds and nursing shift change reports;\textsuperscript{13,28}
   (c) Honor both Health Insurance Portability and Accountability Act (HIPPA) and safety concerns while in the NICU; and
   (d) Have full access and input to both written and electronic medical records.

2. Parents and family members should be supported to engage in developmentally appropriate care in order to become competent caregivers and advocates for the neuroprotection of their babies.\textsuperscript{11,13,33} Components of parent support should include guidance on how to:
   (a) Provide comfort and security through consistency of their presence for their baby whenever possible;
   (b) Understand the behavioral communication of their baby so as to best interpret and respond to the baby’s needs;
   (c) Create and sustain a healing environment with respect to sensory exposures and experiences;
   (d) Provide supportive positioning and handling for their baby, including supportive oral feeding experiences, skin-to-skin contact (kangaroo care) and infant touch;
   (e) Collaborate with NICU staff to minimize their baby’s stress and pain in the developmentally-unexpected environment of the NICU;
   (f) Safeguard their baby’s sleep, recognizing the importance of sleep to healing, growth and brain development;
   (g) Optimize their baby’s nutrition with breast milk and breastfeeding whenever possible; and
   (h) Protect their baby’s skin and its many functions, including its role as a conduit of neurosensory information to the brain.

STAFF PARTICIPATION IN FCDC

Commitment by leadership throughout the health-care system to an interdisciplinary model of care is essential for successful implementation of FCDC in the NICU, including administration, medical and nursing teams, and all other hospital staff who provide supports and services to babies and families in the NICU.\textsuperscript{3} The needs of babies, families and staff are better met with an integrated team approach to achieve optimal outcomes. Recommendations for staff participation in FCDC:

1. A culturally appropriate and warm welcome for families should accompany the admission of each NICU baby. Basic introductory resources written in the primary language should be provided and continued throughout their NICU stay. When parents are able to be with their baby, the following should be reviewed with them: hand hygiene practices, staff roles and simple explanations of equipment. However, before medical equipment is explained, the focus should be on promoting baby–parent interaction. Emphasis should be placed on the critical importance of the parents’ presence to the short- and long-term outcomes of their babies, and parents should be

assured of unlimited, around-the-clock information and access to their baby.
2. Staff should be educated on principles and methods of implementing FCDC, including the above topics in ‘supporting parents’ roles’ #2.3
3. Staff communications with parents and families should be regular, understandable (free of medical jargon), personalized, consistent and carried out in a culturally proficient manner.36
   The quality of staff communication with parents and families, as provided by every member of the care team, is a key to ensure success of FCDC.

NICU POLICIES TO SUPPORT FCDC

Because of advances in medical technology, the survival rates of sick and premature babies have greatly increased.37 Moving beyond mere survival, the focus of FCDC is on quality of life, neuroprotection and successful integration of the vulnerable baby into a healthy family unit.35 This requires integrated relational care, which must begin at delivery or as early as possible during the antepartum period.38 A team of professionals trained in the developmental support of the parent–baby dyad, such as infant developmental specialists, specially trained nurses, doctors and psychologists, along with neonatal therapists including occupational therapists (OT), physical therapists (PT) and speech language pathologists (SLP) must be involved in delivering this care as part of an interdisciplinary team.11,39–41 Using an integrated, neuroprotective, family-centered, developmental care model, specially trained neonatal therapists should provide individualized therapeutic interventions in the NICU.41 Attention to the experience of the baby and family requires a system-wide approach,7 and the inclusion of multiple disciplines as a standard of care.

Recommendations for NICU policy to support FCDC:

1. A policy of unlimited, open access for parents should ensure around-the-clock information and access to their baby, including medical rounds and nursing shift changes. Parents should not be viewed or referred to as ‘visitors’, but rather part of the care team.
2. Clear policies and procedures should promote the participation of parents’ support system; including the baby’s siblings, grandparents, extended family and parents’ friends, recognizing the importance of their involvement to the family’s well-being.19,42
3. Support to the family should begin whenever maternal or fetal conditions and diagnoses are identified that could lead to an NICU stay. This support should include an antenatal consultation with the NICU health-care team, including the developmental specialist or neonatal therapists (OT, PT and SLP),11,39–41 as well as an anticipatory lactation consultation.
4. Optimal family support in the NICU should include provision of:
   (a) Tangible resources; such as a family lounge, sleeping rooms, showers, laundry, kitchen, computers and a family room in which to practice caring for the baby before discharge. Learning materials about infant development and care practices should be created in understandable language and provided in either written or digital form (in the form of videos or apps), as parents may desire;
   (b) Psychosocial support for parents from every professional group providing care in the NICU including the neonatologists, nurse practitioners and nurses, social workers, psychologists, neonatal therapists/developmental specialists (OT, PT and SLP), lactation consultants, hospital chaplains and the palliative care team;41
   (c) Expanded family support inclusive of grandparents and siblings, as well as childcare while parents are caring for their baby in the NICU;42
   (d) Peer-to-peer support1 (see also ‘Recommendations for peer-to-peer support for NICU parents’, this issue); and
   (e) Referrals to resources within the community; such as mental health services, smoking cessation resources and services for parents who may have inadequate housing, transportation, food or clothing, as facilitated by the perinatal social worker or other staff members.43
5. In the case of a baby’s death, an interdisciplinary palliative care and bereavement team should provide services to support the baby’s parents and extended family (see ‘Recommendations for palliative and bereavement care in the NICU: a family-centered integrative approach’, this issue).
6. Preparing for the transition from the NICU to home should begin at the time of the baby’s admission (see ‘NICU discharge planning and beyond: recommendations for parent psychosocial support’, this issue). Parents should be provided with:
   (a) Anticipatory guidance and education about criteria for discharge;
   (b) Education about Back-to-Sleep and Shaken Baby Syndrome and other issues related to baby’s safety;
   (c) Opportunities to develop competence and self-efficacy in the care practices needed for their baby at home;
   (d) Follow-up resources including referral appointments to appropriate care providers, which may include home nursing visits, developmental care specialists (OT, PT and SLP) and breastfeeding support; and
   (e) An assessment of their social support system, their risk for postpartum depression or other emotional distress44 and the safety of their home environment as needed.

7. Quality improvement projects on FCDC should become an integral part of the care provided.2
8. Hospital committee structure and NICU policy development should include family advocates as regular members.

SUMMARY

The transformation envisioned in the family-centered, developmentally supportive model of care incorporates the family fundamentally and consistently into the care of their baby, recognizing parents as important collaborative members of the NICU team,1,11,45 and embracing their roles as facilitators of their baby’s development. Family involvement is a key to realize the potential for long-lasting positive effects on their baby’s physical, cognitive and psychosocial development. It is imperative that NICU policies for parent support and staff support for FCDC be in place to offer the standard of care necessary for optimal outcomes of both baby and parent. Parent support should begin as soon as maternal or fetal concerns are identified that could lead to an NICU stay. Incorporating parents as full participants in their babies’ care should include provision of information regarding (a) developmental care principles and (b) infant-communicated behaviors indicating stress and/or stability. Staff should be educated on principles and methods of implementing FCDC. Additionally, NICU policies and procedures should support the participation of parents as part of an interdisciplinary team. Finally, hospital committee structure and NICU policy development should include family advocates as regular members. Quality improvement projects on FCDC should become an integral part of the care provided.

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 authors declare no conflict of interest.
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REVIEW

Recommendations for peer-to-peer support for NICU parents

SL Hall1, DJ Ryan2, J Beatty3 and L Grubbs4

Peer-to-peer support provided by ‘veteran’ neonatal intensive care unit (NICU) parents to those with current NICU babies is a legitimate and unique form of support that can complement or supplement, but not replace, services provided by professional NICU staff. Peer support can be delivered through hospital- or community-based programs that offer one-to-one in-person or telephone matches, or support groups that meet in-person or via the Internet. Issues in program development, volunteer training and program operation are discussed. Recommendations for offering peer support to all NICU parents as an integral component of family-centered care and comprehensive family support are presented.

INTRODUCTION

Parents who experience a complicated pregnancy or the birth of a baby born prematurely, with congenital anomalies or an illness, face an unknown situation with their baby’s hospitalization. The highly specialized care their baby may require leaves families struggling as they cope with parenting from a distance, not feeling like parents and hesitating to become involved. This new experience leaves parents with a sense of powerlessness, feeling uninformed and intimidated because of their lack of familiarity with the neonatal intensive care unit (NICU) environment. Families have a vital role in ensuring the health and well-being of their NICU babies, and emotional, social and developmental support of both babies and families are integral components of neonatal health care. Parents of NICU babies have the opportunity to be better prepared if they have the emotional support and aid of other parents who have been through a similar experience.

Parents with infants in NICUs are well known to be at increased risk for postpartum depression, post-traumatic stress disorder and anxiety. Each of these conditions can disrupt parent-infant bonding, leading to adverse childhood outcomes including worse cognitive, developmental and behavioral functioning. Psychosocial support is critical in mitigating the risk factors for developing these conditions. Although professional mental health staff such as social workers, and to a lesser degree psychologists, may be available to deliver services to NICU parents, not every family may need or want formal support. However, parents may actually experience increased stress from their usual informal support networks because their friends and family may not fully comprehend the NICU experience, and friends and family may also be grieving along with the parents. NICU parents may also be physically isolated from their traditional support networks, increasing the potential benefit for receiving peer support services while in the NICU.

Peer-to-peer support (‘peer support’) is a well-established modality for improving outcomes in people with a wide range of risk factors and diagnoses. In a NICU setting, peer support and parent mentoring are provided by volunteer parents who have had a similar experience (‘veteran parents’) and who have received training; programs can either be hospital-based or be community-based. The rationale for peer support is that it offers a shared experience in which one NICU parent can best understand what another is going through. This shared experience allows for acceptance without judgment and provides a foundation of respect between parents. Peer support programs in NICUs can serve to foster a feeling of safety and comfort among parents; parents can share their fears, get validation for their feelings and gain perspective. Such programs can also serve as a platform for parents’ questions and provide encouragement for parents to become advocates for their babies and themselves.

There is now a growing body of evidence of the benefits that peer support provides to parents of NICU infants and special needs children. Parents who receive peer support have been found to have increased confidence, problem-solving capacity and adaptive coping, perception of social support, self-esteem and acceptance of their situation. Further, parents feel more empowered and interact with, nurture and care for their infants to a greater degree during more frequent visits to the hospital, leading to a shorter length of stay for their infants. Parental stress and anxiety, as well as depression, are all reduced. Peer support therefore offers a ‘legitimate’ and ‘unique form of assistance that is not typically met by the formal service system’ and one that cannot come from any other source. The support provided by volunteer mentors from externally developed peer support organizations should never duplicate or replace formal/professional support provided to parents by NICU staff; it can, however, supplement and complement internal professional services offered by the hospital. Pediatricians and other health-care professionals should facilitate and encourage peer support as recommended by the American Academy of Pediatrics in 2012. As a core principle of family-centered neonatal care, it should be an integral component of every NICU family support program.

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TYPES OF PEER-TO-PEER SUPPORT

The support for families in the NICU can be as unique as the families themselves. All types of support can be provided by mentors from peer support organizations, whether they are hospital-based or community-based; support provided may be emotional, informational or tangible, which might include concrete physical, financial or material assistance. A variety of models for providing peer support exist, and many parent support organizations offer blended models in which parents can utilize more than one—and sometimes even all—modalities. Frequency of contact and duration of contact during the NICU stay and beyond to home are dependent on each program and on individual participants.

In-person support or telephone support

In this model, veteran parents are closely matched on as many dimensions as possible (language, culture, baby’s diagnosis, family makeup and so on) with current NICU parents to serve as their mentors or ‘buddies’. Through the relationship that parent mentors establish with new NICU parents, they can normalize the parents’ situation and help them accept it by modeling a positive attitude. Mentors can reduce parents’ isolation, sometimes even serving as substitute family and friends. This may be particularly important to low-income parents who may not have well-functioning support networks of their own. The support is provided in non-medical language that is easier for parents to understand than that provided by the healthcare team. Mentors can also give parents practical advice, help them resolve day-to-day problems and help them access other services. Although parents may feel that they need to ‘hold it together’ when dealing with the medical team so that they appear capable, having a support person not affiliated with the medical team allows parents to let their guard down and express their true emotions. Within the frequently changing NICU landscape, a parent mentor can provide a parent with continuity of care throughout their NICU experience and even beyond.

One potential shortcoming of this model of support is that it may be difficult to ensure that all matches between mentors and parents are good ones, especially when parents are non-English speaking and/or from different cultures. Communication styles, parenting styles, outlook on life and parents’ vision of the future may differ in a particular match. Matches may also become problematic if the mentor parent has not experienced what current parent is going through, especially if the mentor’s child is doing better than the matched parents’ child. For any of these reasons, matches may need to be changed.

Providing peer support by telephone, instead of in-person, may offer several advantages to stressed NICU parents who may not have time or the ability to meet with their peers and friends. Connections between mentors and parents can occur more spontaneously and with greater flexibility. Mentors’ around-the-clock availability, when parents need them, gives parents a feeling of dependability. In addition, telephone support is private and non-stigmatizing. It can be effective for low-income mothers with diverse ethnic backgrounds, and is easily accessible to all regardless of socioeconomic status or geographic location. Another important benefit is that parents do not need child care in order to make use of telephone support.

Finding appropriate matches for telephone support relationships may be difficult, just as with in-person matches. Parents may ultimately not find their match to be helpful, and either party can lose their match’s phone numbers that can end the relationship or mentor parents may be negligent in following through. Alternatively, parents with babies in the NICU may simply be too busy to utilize phone support. Among the studies on the value of in-person or telephone peer support for NICU parents, mothers were the primary recipients of support services; there is minimal research on how fathers might utilize and respond to peer support in the NICU. This should be an area for future research.

Parent support groups

Parent support groups can be run by a veteran parent in collaboration with a NICU staff medical (nurse or doctor) or mental health (social worker or psychologist) professional; or groups can be run by parents only or professionals only. However, groups have greater stability and longevity if they are jointly run by a parent and a NICU staff person. Group participation further leads parents to visit their baby more often in the NICU and to show greater interest in their baby’s development after discharge. In the group, parents also get coaching on how to interact and collaborate with baby’s medical team and learn how to communicate more effectively about their baby’s and their own needs. Parents get insight into their feelings, feel less isolated and have the opportunity to interact with others who are in a similar situation.

Another benefit that may be seen when NICUs offer support groups is that the NICU staff can become more responsive to the needs of families through hearing about parents’ concerns.

However, not all parents find value in group support; participating in a group may actually increase some parents’ stress. They may not feel comfortable sharing in a group setting in front of strangers, and may not want to hear other parents’ stories about the complications their babies encountered.

It can be challenging to establish and maintain group attendance, especially in smaller NICUs. Groups may be poorly attended by new mothers who are depressed, and parents whose babies have shorter stays may not feel the need for group support. Other barriers to parents’ use of support groups include their lack of child care and/or transportation and the inconvenience of evening meetings for some parents. For all these reasons, outreach from either NICU staff or veteran parents is required to encourage parental involvement. Parents may be more likely to attend groups if the groups are identified as being primarily educational in nature, rather than ‘support groups’. If professionals run support groups, then it is important that they allow participants to learn from each other by giving up their role as expert. Changes in hospital staffing, or lack of commitment of group leaders to continue the group in spite of obstacles, may lead to a group’s dissolution.

Internet support groups

Parents of NICU babies are increasingly turning to Internet support groups and web pages, with the profusion of parent support organizations that now have an online presence. These sites may be monitored by veteran parents and/or by health-care providers including social workers or nurses, although there is potential for the presence of professionals to inhibit parental exchanges.

A key benefit to Internet support is that parents can access support on sites tailored to their needs anytime and from anywhere, which may be particularly beneficial to parents who reside in rural areas, and to young single mothers and those who are socially isolated. Variables that can inhibit face-to-face communication, such as differences in gender, age and social class, are reduced when parents interact on websites. Parents have access to both information and support, and if they are socially sensitive, they can anonymously read others’ posts. The
collective knowledge of the group is available to all, regardless of their participation level. Information can also be imparted through live chats online; these can be moderated by professionals, increasing their value. Many parents find Internet support sites to be especially helpful after NICU discharge.

There are several potential drawbacks to parents’ use of Internet support sites. Emotionally charged or negative interactions, including abrasive or non-supportive posts, may occur as a result of the reduced social presence people have online. Information that is shared between parents may be misleading or unreliable, especially if the site lacks professional oversight to ensure that discussions between participants are medically sound. Veteran parents need to make it clear that they are not medical providers and that parents should consult their child’s own doctor for medical issues.

**BARRIERS TO PARENTS’ ACCESSING PEER SUPPORT**

The size and budget of a NICU most often determine what level of formal support can be provided to families as well as whether the NICU can embrace a peer support program and whether it is hospital- or community-based. Even when peer support programs are offered to NICU parents, many families still encounter barriers to accessing them. Each family’s needs may vary, making it difficult for a peer support program to provide a best fit for all. Redundancy of professional and peer support services may lead to underutilization of the latter, and inadequate cultural awareness on the part of staff as well as their limited availability to do outreach may also reduce families’ access to peer support services.

Some NICU families may not feel justified in using support services. This may be the case if they are experiencing a shorter NICU stay, if they have a full-term baby in the NICU or feel their baby is not having major health issues or if they do not feel the need for support until they have been in the NICU for a longer period of time. Parents often do not want to leave their baby’s bedside to access support; time constraints may be another limitation. Transportation issues, especially for mothers who have undergone a cesarean delivery, or financial difficulties can further impede parents’ ability to access hospital-based peer support services. In addition, parent’s lack of awareness of available services may limit their use.

**ISSUES IN PROGRAM DEVELOPMENT**

Veteran parent support is grounded in the experiential knowledge of parents who have effectively coped with parenting a NICU baby over time and at home. Veteran parents offer shared common experiences and know the stress associated with a baby’s diagnosis, have weathered the many transitional times and have sifted through services so that they have practical knowledge of available resources. The goals of peer support programs should include the following: to provide informal psychosocial support to all families whose babies have been admitted to the NICU; to increase both parents’ coping and parenting skills so they gain the confidence they need to feel that they are part of the NICU team and the competence to care for their baby; to provide information to families about hospital and community resources for their baby and family and to assist families in making the transition from hospital to home. An ideal peer support program would provide services to parents beginning in the antepartum period, when appropriate, and continuing through their baby’s NICU hospitalization and after discharge. Services would also be extended to siblings and grandparents, and to bereaved parents.

To implement a peer support program within a hospital setting, the need must be identified, collaborative commitment from hospital and administrative personnel received, a coordinator secured, and veteran parent mentors recruited and trained. Veteran NICU parents who did not receive peer support themselves and/or hospital personnel who are aware of the benefits of a peer support program may identify the need. The choice of a coordinator could either be a hospital employee (usually a nurse or social worker) or a veteran NICU parent from the hospital. Guidelines related to utilization of volunteers within the patient care setting need to be established and agreed upon before implementation of the program. Recruitment and training of volunteer parent mentors should be done by a professional such as a social worker and/or a parent leader as an ongoing process. Diversity of the NICU population should be reflected in the diversity of the parent mentors to allow for greater capacity in matching NICU parents with mentors. The NICU experience of parent mentors should have been at least 1 year before starting mentorship, and any unresolved issues with their own NICU experience need to be addressed before serving as a parent mentor. Parent mentors working in a hospital setting usually need to be screened and approved by the hospital’s regular volunteer program as well, to provide them with official volunteer standing in the hospital. Once a program is begun, ongoing collaboration between hospital and parent mentors is necessary to maintain a successful program, and institutions need to prioritize their commitment to the program so that even if key personnel leave the NICU environment, the parent support program will continue. For more detailed information about how to start a volunteer peer support program, see the document ‘Starting a Parent Support Group’ (www.support4nicuparents.org).

**VOLUNTEER TRAINING**

Programs utilizing veteran parents to provide peer support to NICU families, regardless of whether support is provided in-person, by phone or Internet, should offer a comprehensive training program designed to equip parent mentors with the skills needed. Content of training may include:

1. Defining the roles of a parent mentor:
   a. To actively and empathetically listen and encourage NICU parents without trying to solve their problems or give them advice;
   b. To assist parents in identifying and utilizing their current support systems;
   c. To offer emotional and informational support;
   d. To encourage advocacy for their baby;
   e. To empower parents to step into their parental role as an essential member of their NICU baby’s care team; and
   f. To identify when to ask for help and where help is available for parents that mentors are supporting.

2. Defining expectations of a parent mentor:
   a. To maintain confidentiality: the manner in which each hospital handles the sharing of patient information should be communicated;
   b. To treat all parents with respect, regardless of their cultural, racial and ethnic backgrounds, socioeconomic status and religion; and
   c. To make a time commitment for the program.

3. Development of essential skill set:
   a. Basic communication and reflective listening skills;
   b. Understanding the expected and normal emotional responses of NICU parents, and responses that indicate parents might be at risk for more serious mental health issues;
   c. Understanding the dynamics of grief and loss; and
   d. Knowledge of hospital and community resources.
Parent mentor training should be offered to groups of 8 to 12 parents whenever practical, allowing for a group that is small enough to result in intimacy but large enough to stimulate conversation and interaction. Demonstrations and observations, role-play, practice interviews and videotaped interviews can be utilized as training methods. Mentors should be encouraged to reflect on their own NICU experience and consider how it may affect their provision of support to NICU parents. Ongoing supervision of peer mentors is recommended to ensure that both group facilitators and individual mentors are supported and provided guidance when needed.

ISSUES IN PROGRAM OPERATION
NICU parents should be offered peer support soon after admission, usually within the first 3 days, and many NICUs offer a program brochure at the time of the baby’s admission. Parents may also request support at any time, and hospital or volunteer staff may personally reach out to parents. Parameters for matching volunteer veteran parents with current parents include the baby’s gestational age and diagnosis, parents’ age, family size, structure and lifestyle, education and income level, language and ethnic background and geographic location. The more similarities between the NICU experiences of matched parents, the faster and easier it is for a support parent to establish rapport with the new parent. Matches on the dimensions of culture and language are important determinants of satisfaction for non-English speaking mothers. Current NICU mothers who have a history of substance abuse, child welfare issues, domestic violence or psychiatric illnesses probably will be matched with veteran mothers who do not share those same experiences. However, trained parents can establish supportive relationships with parents of different backgrounds because of the commonality of the NICU experience, a fact that sets parents apart from NICU professionals. All parent matches should be followed up to determine their suitability, and the opportunity to change mentor/buddies should be available.

Multiple challenges may be encountered when starting a peer mentoring program. NICU staff may believe that their care is already family-centered; or staff may be overly focused on technology and medical care of the baby, concerned that a parent-run program will adversely impact their work, or skeptical that parents can meet other parents’ needs. In addition to overcoming the NICU staff’s cultural resistance and desire to maintain the status quo, other potential barriers in the NICU environment include lack of space, limited time and resources to support volunteers, staff concerns about the safety needs of the baby and privacy concerns of the family. To ensure the quality of programs offered, continuous quality improvement processes should be implemented.

SUMMARY
Peer-to-peer support has a legitimate role in the spectrum of providing psychosocial support to NICU parents, and should be institutionalized as an integral component of family-centered neonatal care that is available to all families with infants in the NICU.

RECOMMENDATIONS
1. Every parent of every baby admitted to a Special Care Nursery or NICU should be offered peer support from a ‘veteran’ NICU parent mentor during their baby’s hospital stay. Ideally, this opportunity would be a part of a NICU’s comprehensive family support program.
2. While in-person peer support during the baby’s hospital stay may be viewed as best practice, peer support can be offered to parents in a variety of different ways including email or phone support, group support or through an online community support site for NICU families.
3. Peer support in any form is best started in the antepartum period when appropriate (as when mothers are hospitalized during the antepartum period), continued through the baby’s NICU stay, as well as after baby’s discharge from the NICU. Having a consistent peer mentor throughout a NICU parent’s journey may be desirable.
4. Parents whose baby expires should be offered the opportunity to be paired with a bereavement mentor who has also experienced a neonatal loss.
5. Peer support is one element of a comprehensive family support program. Other elements should include:
   a. An institutional and administrative champion for peer and family support;
   b. A facilitator/coordinator who could be:
      i. A hospital employee (psychologist, social worker, nurse, pastoral care, physician),
      ii. A trained parent and/or family support specialist,
      iii. A former NICU parent or volunteer from one of the many non-profit peer-to-peer parent support organizations across the country;
   c. A menu of types of support available (individual and/or group in-person support, email, phone and online support);
   d. Parent education classes and written materials, as well as social activities;
   e. Staff education to promote understanding of NICU families’ psychosocial needs, family-centered care practices and methods of communicating and providing support (see ‘Recommendations for enhancing psychosocial support of NICU parents through staff education and support’, this issue).
6. Any family support program that utilizes peer volunteers should provide training to the volunteers to ensure that they are capable of carrying out the peer support role in a responsible and culturally sensitive way that is fully compliant with both Health Insurance Portability and Accountability Act (HIPPA) regulations and hospital policies.
7. In NICUs without the resources to develop a local and comprehensive family support program of their own, parents should be referred to regional or national parent support organizations that have been evaluated by their NICU staff. Resources for parent support can be found at websites of the following organizations: the National Perinatal Association’s Family Advocacy Network (www.nationalperinatal.org/parent supportgroups), the Premie Parent Alliance (http://preemieparentalliance.weebly.com/#!/), the March of Dimes (www.shar yourstory.org), the Canadian Premature Babies Foundation (www.cppbf-fbpc.org) and the European Foundation for the Care of Newborn Infants (www.ecni.org).
8. Peer support organizations working with NICU families should consider offering support services to members of the baby’s family including siblings, grandparents and others, as needed and desired.

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 recommendations. The remaining authors declare no conflicts of interest.

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Recommrdsations for peer-to-peer support for NICU parents
SL Hall et al


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This article describes recommended activities of social workers, psychologists and psychiatric staff within the neonatal intensive care unit (NICU). NICU mental health professionals (NMHPs) should interact with all NICU parents in providing emotional support, screening, education, psychotherapy and tele-services for families. NMHPs should also offer educational and emotional support for the NICU health-care staff. NMHPs should function at all levels of layered care delivered to NICU parents. Methods of screening for emotional distress are described, as well as evidence for the benefits of peer-to-peer support and psychotherapy delivered in the NICU. In the ideal NICU, care for the emotional and educational needs of NICU parents are outcomes equal in importance to the health and development of their babies. Whenever possible, NMHPs should be involved with parents from the antepartum period through after discharge.

**BACKGROUND**

Numerous research studies have documented elevated levels of emotional distress in parents during the hospitalization of their baby in a neonatal intensive care unit (NICU) and thereafter.1–5 Many of these studies have reported clinically elevated levels of postpartum depression (PPD) and post-traumatic stress disorder (PTSD). Although not all NICU parents have these disorders, it has been estimated from research in the NICU that 20 to 30% or higher of NICU parents experience a diagnosable mental disorder during the first postpartum year.6 An additional proportion of NICU parents will experience subclinical levels of symptoms. These symptoms have many harmful correlates, including: (a) interference with parental trips to the NICU, (b) disturbances in both mothers’ and fathers’ developing relationship with their baby and (c) later impairments in the growth and development of their baby and child.7–16

Layered levels of emotional support should be available to all parents in the NICU,17 including systematic support and education of parents in the developmental needs of NICU babies (see ‘Recommendations for involving the family in developmental care of the NICU baby’, this issue). Peer-to-peer support provided by trained volunteers should also be offered to all parents, with in-person support as a best practice (see ‘Recommendations for peer-to-peer support for NICU parents’, this issue). This combination constitutes a ‘universal’ level of care for all parents.17 For parents with more risk factors and/or those displaying acute distress, NICUs should provide support from social workers, psychologists, psychiatrists, pastoral care staff and NICU staff trained as paraprofessional counselors (i.e., ‘targeted care’).17 NICUs should also have referral mechanisms in place for psychological and psychiatric treatment outside the NICU for those parents whose symptoms require ‘clinical’17 levels of care beyond the capabilities of the NICU. Whenever possible, support should begin in the antepartum period and be carried through the after discharge period (see ‘NICU discharge planning and beyond: recommendations for parent psychosocial support,’ this issue).

The following are recommended best practices for supporting the emotional well-being of parents while in the NICU and preventing a deterioration of psychological functioning during the potentially traumatic NICU experience.18,19

**RECOMMENDATIONS FOR NICU MENTAL HEALTH PROFESSIONALS**

1. All NICUs with 20 or more beds shall have at least one full-time masters’ level social worker and one full-time or part-time doctoral level psychologist embedded in the NICU staff. NICUs should also consider having full-time or part-time psychiatrists and psychiatric nurses on staff. Larger NICUs should have proportionally more NICU mental health professionals (NMHPs) on staff. There is a growing trend toward employing psychologists in NICUs, and some NICUs have had psychologists on staff for decades (http://www.nationalperinatal.org/psychologists). Funding streams for NMHPs, including third-party reimbursement, vary state by state. NICUs are encouraged to investigate sources of funding for mental health services with...
their hospital administrators, specifically chief financial officers and medical billing professionals.

2. All NICUs should provide at least one comfortable area for group discussions among parents (e.g., parent lounge) and one comfortable room per 20 beds for confidential discussions between NICU families and NMHPs.

3. The ‘Standards for Social Work Services in the NICU’ of the National Association for Perinatal Social Workers (NAPSW) are endorsed, along with the NAPSW standards for social workers regarding PPD and perinatal bereavement (http://www.napsw.org/about/napsw-code-of-ethics-and-standards.html).

4. The roles of social work and psychology can overlap regarding activities such as counseling, screening, providing staff education and teaching parenting skills.

5. Procurement of benefits and services for families from outside agencies should continue to be one of the roles of social workers. Social workers, psychologists and psychiatric staff should have dedicated time to provide verbal therapeutic support to all parents and family members. NMHPs are essential members of the NICU care team and should interact with all NICU parents/caregivers and family members. Collaboration among social workers, psychologists and psychiatric staff is strongly encouraged to provide support to both parents and NICU staff. Some hospitals have shifted case management responsibilities to nurse case managers, so social workers can provide necessary support for both families and NICU staff.

6. Roles of psychologists, psychiatric staff or advanced clinical social workers (when within the scope of their credentials) can include:

   a. Conducting research in the following areas:
      i. Use of assessment devices, test interpretation and outcome evaluation.
      ii. Identifying risk for the development of psychological disorders in NICU parents.6
      iii. Parent–infant attachment and therapy.
      iv. The effects of parental emotional distress on both the parent–child relationship, the parental couple and the long-term outcomes of the child (both physical and emotional).

   b. Providing the following clinical services for families:
      i. Assessments, test interpretation and outcome evaluation.
      ii. Differential diagnoses of psychiatric disorders and recognition of subclinical symptoms.
      iii. A variety of treatment approaches, including interpersonal therapy, short-term dynamic therapy, cognitive therapy, behavior therapy, couples and family therapy, mindfulness training and infant mental health.

   c. Educating NICU staff about both the centrality of the parent dyad–infant relationship in all interactions and communicating with families who are: (a) guilt and shame-ridden, (b) distressed and angry, (c) possibly struggling with substance abuse, (d) bereaved and (e) coping with prior traumas and perinatal losses including multiple trials of assisted reproductive technology and miscarriages.

   7. Social workers, psychiatric staff and psychologists who work in NICUs should provide support to staff as well as to families (see ‘Recommendations for enhancing psychosocial support of NICU parents through staff education and support’, this issue). Supporting roles include acting as liaisons between staff and families along with direct educational support by discussions of family dynamics and family–staff interactions. These discussions should occur in a variety of settings including rounds, case conferences, faculty meetings, debriefing sessions, and so on. Such support is necessary to minimize burnout, compassion fatigue and secondary traumatic stress. Pastoral care staff can also be instrumental in providing this support.

Clinical judgment of NMHPs is paramount in making decisions about implementing recommendations regarding screening, treatment and referral. These judgments should take into account the diversity of families’ ethnic, religious and social relationships. Special circumstances may require adaptation of these recommendations.

NMHPs should endeavor to create a family-centered culture of understanding and responsiveness for the NICU staff (medical, administrative, custodial, volunteer, and so on) that recognizes, normalizes and supports NICU parental emotional distress. Ideally this culture should permeate the NICU staff and be readily apparent to NICU families. Within this culture, care for the emotional and educational needs of NICU parents is outcomes equal in importance to the health and development of their babies.

RECOMMENDATIONS FOR LAYERED LEVELS OF SUPPORT FOR NICU PARENTS AND FAMILIES

1. The family-centered NICU environment should include an active peer-to-peer support organization, ideally with a position for a paid parent support coordinator embedded in the NICU staff. NMHPs should work closely with the parent support coordinator providing training to recognize parental emotional distress and perinatal mood disorders.

2. All NMHPs should strive to meet with all parents/caregivers to screen and identify parents at high risk for emotional disorders and those with subclinical symptoms. Clinical judgment and a consideration of other risk factors should determine the outcome of a screen. When first meeting with parents and caregivers, social workers and psychologists should explicitly state that they meet and interact with ‘all parents’ so as to (a) normalize the likelihood of parental emotional distress, (b) avoid perceptions of stigmatization of distress and (c) initiate the process of providing emotional support. One goal of NMHP interactions with parents is to identify both: (a) parents with clinical levels of symptoms and (b) parents with subclinical symptoms, who are also at increased risk. A positive identification (or subclinical score) may not require referral to a mental health provider but should result in additional attention and targeted support while in the NICU. Increased levels of support can be given by embedded NMHPs as well as other NICU staff trained (a) to recognize symptoms of PPD, PTSD and other psychological problems and (b) to provide a first level of emotional support20 (e.g., listening visits).21,22

3. All NICUs with at least 40 beds should have parent education groups with a therapeutic orientation, which meet at least once a week. These groups should be led by NMHPs and should supplement any group meetings conducted by the parent-to-parent group.23,24 Parent education and support groups should meet at flexible hours to avoid infant feeding hours and so that working parents and grandparents may attend. Some NICUs have found that alternating between an afternoon and an evening (or weekend) works well. Group meetings and topics should be advertised at bedside and on bulletin boards. NICU staff receiving electronic messages can also be prompted to invite parents to meetings. Groups should be facilitated by NMHPs (and ideally cofacilitated by other NICU staff or trained parent volunteers). Experienced NMHPs and peer-to-peer volunteers have reported that labeling parent meetings as only ‘support’ groups may diminish attendance because of stigmatization and/or parents’ fear of exposure. Instead, announcing content, such as ‘Learn to Read your Babies Cues’, ‘Breastfeeding—Pumping May Be a Drag, but…’, ‘Tips for Surviving the NICU’ or ‘Dads—Your Special Role’, can help
increase attendance (along with the provision of food). Additional suggestions for parent support can be found at an online ‘tool kit’ developed by members of the supplemental issue workgroup (www.support4NICUparents.org).

4. All NICUs should have resources within the NICU and affiliated hospital for caring for the 20–30% (or higher) of NICU parents likely to experience a diagnosable mental disorder. 6 All NICUs should also have referral mechanisms in place for treatment outside of the hospital by social workers, psychologists, psychiatric nurses and psychiatrists. NICUs lacking a parent support organization or NICUs without NMHPs should ensure that referrals are available to all parents for emotional support. Possible resources include hospital parent advisory boards, community parent support organizations and outside referrals to mental health professionals. Research has indicated, however, that outside referrals are often not accomplished. 26–28 Families are often too stressed and burdened to keep appointments at outside facilities. Counseling and therapy conducted in the NICU are more likely to be successful with parents attending more often, and thus likely to gain therapeutic benefit. Some NICUs, with established psychotherapeutic programs, have also arranged for psychotherapists from Behavioral Health units in the hospital to offer therapy in the NICU on an outpatient basis. Research on psychotherapy conducted in the NICU has shown beneficial results. 29–32 Special attention needs to be paid to the parents that rarely come to the NICU. Although it might be that distances are too great and/or the burdens of other children are heavy, it also may be a symptom of significant depression and/or a traumatic reaction, as avoidance is a notable symptom of PTSD. Outreach needs to be done to engage these parents.

5. Using the NICU’s standards of confidentiality, NMHPs should strive to communicate the identified mental health needs of parents/caregivers with the obstetric care provider and the family’s primary care provider, pediatrician and other care providers.

RECOMMENDATIONS FOR SCREENING IN THE NICU FOR EMOTIONAL DISTRESS

1. NMHPs should strive to meet with all parents/primary caregivers within 1–3 days of admission to establish a working relationship, normalize emotional distress and evaluate risk factors for all forms of emotional distress. Hynan et al. 6 reported a table of replicated predictors of elevated scores for PPD and PTSD. Whenever possible NMHPs should use standardized measures for evaluation. There are many validated screens for PPD and PTSD. 6

2. Screening should be done within the first week (both mothers and fathers). 6 Screening for emotional distress is best done early to evaluate parents whose babies are in the NICU for only a few days. Parents with shorter stays have reported elevated levels of emotional distress. 33

3. NICU parent/caregivers should be rescreened later: (a) whenever deemed important and (b) within 48 h before discharge (for NICU stays > 1 week). Because levels of emotional distress change (see ‘Introduction: psychosocial program standards for NICU parents’, this issue), NICU parent/caregivers should be rescreened later.

4. Screening methods can include any of the following (in order of complexity): 6

a. quick screens for depression (2 questions) 24 and PTSD (4 questions), 25
b. validated PPD and PTSD questionnaires, 36–43

c. inventories, such as the Psychological Assessment Tool-NICU, 44 and
d. interviews, such as the Clinical Interview for Premature Parents. 13,45

5. Positive screens at a less complex level should be followed up with more complex screens. Choice of screening method is best left to the judgment of NMHPs, taking into consideration the general procedures in a particular NICU. Responsibility for administering less complex screens (a–c above) can be delegated to NICU staff, specifically those trained and supervised by an NMHP. Some NICUs have had success with having the bedside nurse administer screens. More complex interviews should be afforded by NMHPs. In any case, it is advantageous to have the person administering the screening be someone who has developed a positive working relationship with the parents, often a bedside nurse. 26 Simply leaving paper and pencil screens by the bedside is insufficient for adequate screening. NICU staff should be educated regarding the rationale for screening and typical follow-up. A single screen should be viewed as one piece of information, not a whole clinical picture. Screening by itself is a necessary, but insufficient, way of both meeting the mental health needs of families and evaluating the parent–infant relationship needs. (The Clinical Interview for Premature Parents interview is one method of exploring the parent–infant relationship). 13,45 Screening methods may need to be modified by concerns such as the education level of the parent, language, cultural tradition and so on. NICUs upgrading their psychosocial services for parents have faced questions of how to record information regarding screening results, therapy progress and referrals. These questions are especially relevant in children’s hospitals when parents are not the patients. Using hospital-based standards of confidentiality, we recommend that NICU staff and NMHPs make judgments on information storage, retrieval and communication that safeguards parents’ confidentiality as much as possible while (a) maximizing services to parents in the NICU and (b) facilitating the emotional well-being of parents after discharge. Suggestions for recording this information, as well as the implementation of other NMHP recommendations, can be found on the online ‘tool kit’ developed by members of the supplemental issue workgroup (www.support4NICUparents.org).

6. Screening should be incorporated into the NICU procedures as quality assurance.

7. Screening should only be implemented if there is psychological treatment available either within the NICU or through outside referral. NICUs without NMHPs may still use screening if outside referral networks are in place. In this case, NICU staff should be trained by someone with expertise in psychometrics, test interpretation and referral. If an NICU is not able to provide embedded NMHP staff on a full-time basis, part-time staffing by mental health professionals from other units of the hospital is essential.

8. Screening for emotional distress should be offered to parents returning with their babies for developmental follow-up visits.

Although some families manifest symptoms of depression, anxiety and PTSD during the NICU hospitalization, others may experience symptoms after the baby is discharged or as parents recognize that their child is not achieving expected developmental milestones. Thus, parents should also be screened after discharge by health-care home visitors and at developmental follow-up appointments. During follow-up visits, NICU parents should be educated about the vulnerable child syndrome and other possible conditions, as well as screened for possible abuse.
RECOMMENDATIONS FOR TELEMEDICINE SUPPORT

1. Telemedicine can be used for both screening and treatment, potentially increasing accessibility for families in low-resource settings.

2. Telemedicine services shall be conducted in accordance with accepted standards for training, providers’ credentials, confidentiality and HIPPA compliance, as developed (for example) by The American Telemedicine Association (http://www.americanetended.com/resources/telemedicine-practice-guidelines/telemedicine-practice-guidelines/clincial-guidelines-for-telepathology#.V0TXth0yo). Teletherapy and screening for NICU parents can follow the guidelines of the American Psychological Association (http://www.apapracticecentral.org/ce/guidelines/telepsychology-guidelines.pdf).

3. Many NICU parents use social media from Internet sites for both information and emotional support. NICU staff should familiarize themselves with web-based support sites to guide parents to reliable sources.

Many NICU parents are unable to come into the NICU on a regular basis. Impediments include long travel distances, lack of transportation, poverty, need for uninterrupted employment, childcare and (often ignored) mental health issues. NICUs with access to adequate information technology support should establish telemedicine services for both NICU babies and parents. Research has indicated that outcomes using telemedicine services are often equivalent to outcomes from face-to-face contact.

RECOMMENDATIONS FOR ANTENATAL SCREENING AND SUPPORT

1. When a NICU stay is anticipated, parent support coordinators and NMHPs should initiate a relationship with the family before the birth to provide both emotional support and prenatal screening for emotional distress.

Among women admitted for antepartum pregnancy complications, the prevalence of anxiety and depression symptoms is high. Evidence suggests that women with antenatal depression and PTSD are at increased risk of preclampsia and preterm birth.

SUMMARY

Evidence-based NICU care has been evolving over the past few decades. Research has documented that NICU parents have a variety of emotional responses to the NICU experience, ranging from resilience to psychopathology. Three variables are likely responsible for much of this variability: pre-existing mental health conditions, the severity of the baby’s medical condition and the level of emotional support for parents during the potentially traumatic NICU experience. The NICU staff can do little about the first variable, other than inquire about prior health conditions of parents and act accordingly. NICU care has historically been focused on the physical health of the baby, but the technological medical advances in the NICU may be approaching limits. Intensifying the focus in the NICU on the emotional well-being of parents is the next frontier. Evidence has also documented that this frontier has a great potential to (a) facilitate the growth and development of babies through a healthy parent–baby relationship and (b) promote the long-term emotional well-being of parents, babies and families. Movement towards this goal will also be aided by an NICU culture that values the emotional well-being of all staff, encouraged to work together in an interdisciplinary manner.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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Technological advances have increased our ability to detect a life-threatening, life-limiting or lethal problem early in pregnancy, leaving parents months to anticipate a death or a prematurely born infant. Babies can also be born with unanticipated problems that could lead to death. In either scenario, perinatal palliative care should be offered as a strategy for family support. Since the preponderance of professional training focuses on saving lives, many health professionals are uncomfortable with palliative care. This article’s purpose is to define best practices for the provision of family-centered perinatal and neonatal palliative care and provision of support to bereaved families experiencing anticipated and unanticipated life-limiting conditions or death of their infant. An overview of core concepts and values is presented, followed by intervention strategies to promote an integrated family-centered approach to palliative and bereavement care. The concluding section presents evidence-based recommendations.


INTRODUCTION

Palliative and bereavement care date back for decades. Dame Cicely Saunders used the term ‘hospice care’ in 1948 to describe specialized care of the dying.1 In 1997, the emphasis was on quality of life during the dying process.1 As technology pushed the age of viability for newborn infants downward, smaller, more medically fragile babies started surviving. Although survival for those infants <1000 g has improved, the overall neonatal mortality rate in 2011 was 4.04 per 1000 live births.2 Technological advances have also made it easier to detect a life-threatening, life-limiting or lethal problem early in pregnancy, giving families the chance to make an informed decision about continuing the pregnancy and planning for the birth process and beyond.

Perinatal palliative care gained prominence in the early 2000’s, when Catlin and Carter4 highlighted the need for a coordinated plan for delivering neonatal palliative care. Catlin and Carter recognized that palliative and bereavement care are often provided in a fragmented approach, with many disciplines operating in their own ‘silos’, each offering advice without knowing what else has been said to overwhelmed families. Unfortunately, the same fragmentation occurs in many neonatal intensive care units (NICUs) today, in spite of the fact that the American Academy of Pediatrics has outlined numerous practices for pediatric palliative care.4,5

Palliative care can now be offered to parents as an alternative to termination of pregnancy when a fetus is diagnosed with a life-limiting condition. It is a viable treatment option for babies born at the edge of viability,6 diagnosed with life-limiting conditions at birth or who become critically ill during a NICU stay and are not responding to aggressive medical management.7 Decisions to not initiate or to withdraw intensive care from a baby can be both ethically challenging8,9 and morally distressing.10–12

Arriving at such a decision through an interdisciplinary, family-centered team approach can shorten futile intensive care and minimize suffering of both babies and their parents.13 Several studies have shown that providing intensive care to babies with pre- or postnatally diagnosed life-limiting conditions does not prolong life.14,15 Hence, palliative care serves as an alternative to intensive care, continuing to provide quality care and grief support while honoring both the baby and the family. Identification of best practices and evidence-based guidelines to help health professionals provide the best possible palliative care in a compassionate manner is needed. This article’s purpose is to define best practices for the provision of family-centered palliative care for fetuses and infants and to support bereaved families experiencing anticipated and unanticipated life-limiting conditions or death of their baby.

CORE CONCEPTS AND VALUES

Palliative care is an approach that improves the quality of life of patients facing life-limiting conditions, and their families, through the prevention and relief of suffering by means of early, impeccable assessment and treatment of pain and other physical, psychosocial and spiritual issues.16 For this paper, palliation will refer to comfort care for the neonate who is facing a life-limiting condition, whether or not death is expected, and supportive care for the baby’s family. This care promotes quality of life and includes the family as an integral member of the health-care team.16 The setting for the care may be the acute care hospital, an ambulatory care facility in the community or the home.16 Palliative care is still an option that is offered unevenly and too late in many instances, and rarely delivered in an integrated approach. Bereavement care focuses on the grief process by providing interventions that support families after a fetal, neonatal or infant loss, with the goal of decreasing feelings of sorrow, psychosocial stress and social isolation.37 Grief support is encompassed in palliative care.

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Family is defined as a constellation of people who are related by birth, adoption, marriage or those individuals the parents designate as part of their family unit. The family constellation is crucial to provide individualized care that embraces a family-centered approach. Family-centered care is defined as delivery of services that revolve around the incorporation of the family in the development and implementation of interventions; it represents a family–professional partnership. The family is an integral part of the health-care team, and both work together to plan and implement palliative and/or bereavement care. Core values or key concepts that support palliative and bereavement care are compassion, commitment to the delivery of palliative/bereavement care, dignity, integrity, respect, information-sharing, parental decision-making, and teamwork.

Families may experience an anticipated or unanticipated loss. Although each loss requires a slightly different approach, the common guiding principles include providing family-centered, compassionate and individualized care. The family must be included in the decision-making process to the degree they deem themselves able to participate, guided by their understanding of their child’s best interest.

**UNANTICIPATED LOSSES**

When a family experiences an early loss such as from a miscarriage, ectopic pregnancy, fetal demise or the birth of an extremely premature infant, there is no opportunity to plan or prepare for the death. Perinatal loss needs to be recognized as a unique type of bereavement, and even early fetal losses or stillbirths will require bereavement care. Such losses disrupt a significant life milestone (pregnancy/birth/infancy) and can cause isolation from peers, inner conflict for the grievers and a reorganized sense of self-esteem. A child’s death is unlike any other loss, profoundly affecting parents individually and as a couple, as well as the family system and society. The family is likely to be in shock as they are forced to adjust from having the infant they anticipated to one born dying. In cases of unanticipated loss, palliative and comfort care may be offered as indicated.

The interprofessional team needs to be fully informed of parents’ choices so that care is coordinated and the family’s wishes are carried out. If a baby in the NICU is expected to die, then providers need to determine the family’s wishes for resuscitation of their infant, and whether they wish to sign a DNR (Do Not Resuscitation) order. Many families are unwilling or unable to face a decision that may make them feel as though they are responsible for ending their baby’s life. They may be more accepting of a plan to not resuscitate if asked to agree to AND (Allow a Natural Death). The term AND is used interchangeably with DNR and refers to the desire not to aggressively resuscitate an infant or intervene if a code occurs.

**ANTICIPATED LOSSES**

Advances in genetics and technology enable many families to know well in advance that their fetus has a potentially life-limiting condition. Prenatal genetics refers to the use of genetic testing and counseling during a pregnancy. Non-invasive genetic screening, offered very early in pregnancy, has become more accessible. Abnormalities in prenatal screening tests can lead to further evaluation, including both ultrasound and more definitive genetic testing to provide further information about the cause of fetal anomalies. This process can affect parents time to make decisions early in the pregnancy, such as whether they want to pursue medical interruption of the pregnancy, medical interventions such as fetal or neonatal surgery, or preparation for a fetal or neonatal death.

Antenatal consults should occur in the context of a family meeting with the specialists from both obstetrics and neonatology, the palliative care team and support provided by a NICU mental health professional. A coordinated, integrated team approach is needed so that the family gets a consistent message indicating that they are the architects of this plan to the degree they wish. Results of genetic and other diagnostic evaluations, and information about the condition of the fetus and its prognosis should be shared among the group. Options for palliative care as an alternative to termination of pregnancy can be presented to the family, and a plan of action created according to the family’s wishes.

Anticipatory grief is a term that is used when a death is anticipated or expected; it starts when the family recognizes that the outcome will not be what they anticipated. They experience the loss of their envisioned future as a family. Often, their usual social support system is inaccessible due to discomfort and to the absence of many cultural norms for acknowledging an anticipated loss. The family loses the rites of passage that make the baby more real and that facilitate bonding within the family unit such as having a baby shower or homecoming party.

A death that is anticipated before birth affords the family the opportunity to work with the health-care team to develop both a birth plan, which can specify their desires for how they want the birth to evolve, and a palliative care plan. The family’s participation in making these plans helps to provide them with a sense of control, and the plan honors their choices for their baby. When the birth occurs, the plans should be followed regardless of which health professionals are present at the time.

In either anticipated or unanticipated losses, efforts should be made to include the families as a part of the decision-making process without overwhelming them. Families need to be provided options for memory-making, and asked whether there is a ritual that is important to their culture or belief system that they wish to see happen. Parents may choose to keep a lock of hair, handprints and/or footprints, clay models of the newborn’s hands or feet, photos, a receiving blanket, and special boxes or envelopes for keepsakes. The key is to ask the family what they want while realizing they may not know. A plan for the death is just as important as a birth plan and should include the family’s plans for organ donation when applicable.

**DURING THE MOTHER’S AND BABY’S HOSPITALIZATION**

The goal for hospitalization at the baby’s birth is for the family to be as prepared mentally, physically and spiritually as possible. Specific information should be given to the parents to address their questions and concerns both before and after the baby’s birth. It is important to have a structured bereavement program that is available to staff at all times; written policies and standards for this program should be available to all hospital personnel.

If the mother is in one hospital after giving birth, and the baby in another, then information may be given to the father (or other family member) before the mother, leaving her with unanswered questions. Thus, all attempts should be made to keep the mother informed. It is also important to recognize that parents’ understanding of their baby’s condition may differ depending on the information they have received, their anxiety levels, their prior experiences with loss and the way the information is provided.

A mother who has given birth to a baby who has died or who is expected to die should be cared for with the utmost sensitivity. All staff that could potentially enter her room should be made aware of her loss. Mothers may even be offered the option to receive their postpartum care on a unit other than the usual mother/baby unit.

Although providing comfort with dignity, parents must be asked whether they have personal preferences, and staff should not assume that all of the family’s reactions are culture based. Giving families mementos or photographs related to their baby’s hospital stay provides them with options for remembering their
baby, although these may not be acceptable in some cultures. Photography is an important remembrance to some families, as photographs provide visual proof of the reality their baby’s life and are valuable in the mourning process. Photographs should be free to families and can be provided through a volunteer organization of professional photographers, a contracted photography company or families may prefer to take their own photographs.

Dressing the baby is important so that the family has a photo or mental picture of their child as a baby and not one that is naked, covered with tubes and wires. Families may choose to dress a baby in special clothes such as Angel Gowns, which are available for free to all hospitals upon request from a parent support organization. Parents should be offered peer-to-peer support, and those whose baby expires should be offered the opportunity to be paired with a bereavement mentor for such support (see ‘Recommendations for peer-to-peer support for NICU parents’, this issue). In hospitals without functioning peer support programs, parents should be referred, with their consent, to regional or national parent support organizations that have been evaluated by their NICU staff.

FAMILIES OF MULTIPLES
When one infant in a set of multiples has died or is actively dying, families face an emotionally complex and volatile situation. Families are grieving while balancing hope for a baby or babies who are still alive. In addition to providing the usual bereavement support, health professionals must also acknowledge that the parents may be conflicted, as these parents are experiencing joy and grief simultaneously. It is best to photograph multiples together and separately, even if one of the babies is alive, making sure to have a process to differentiate the babies from each other. This further acknowledges the specific grief.

DIFFERENCES BETWEEN FATHERS AND MOTHERS
Fathers may react differently from mothers to losses. In some cultures, fathers are viewed as the protector; if a baby dies, then the father may feel as though he has failed because he could not protect the family. Mothers may feel that they failed as a woman to produce a healthy child. Men and women may also grieve differently. The father may return to work and his social network sooner than the mother. He may want to process the grief alone and may be reluctant to share his feelings even with the mother of his child. Mothers often want to talk through their emotions and to process the death. Mothers may be more accepting of support groups and counseling than fathers. Differences in perceptions may never be shared between the parents unless they are encouraged to talk together with guidance from a health professional, clergy or parent support liaison.

DISCHARGE TO HOME BEFORE DEATH
The time after discharge of the mother and/or baby is an emotion-laden time for families. Medical technology used in the home may create a high degree of parental emotional stress. Parents of medically fragile and technology-dependent children have identified role conflict and care burden as sources of stress. If a family is taking their baby home to die, then their ability to cope should be assessed before discharge, including what support systems are in place and whether palliative and/or hospice care for families and neonates is available in their community.

For babies not expected to survive, plans should be developed for a home death with the participation of the family. Supportive contact for the parents should be available going forward, such as by hospice nurses who come to the home to assist the family with a dying baby, by support groups or by peer mentors that either meet face-to-face or in an online community.

FOLLOWING THE DEATH
Burial arrangements and final disposition of the infant’s remains are important (although difficult) topics to address, and hospital staff, particularly social workers, may open the conversation and provide information to families regarding their options or suggest the family designate someone to investigate services available in their community. Hospital services should be outlined verbally, and written information provided to the parents. A letter or sympathy card should be mailed to the family 1 to 2 weeks after the loss, signed by the health-care professionals who actually cared for their baby, as an important and personal gesture. The name of a grief counselor or a list of general bereavement support groups/agencies should be provided to the family, if it has not been already.

STAFF EDUCATION
Staff working with families facing or experiencing a perinatal loss must be educated on how to work with families under extreme stress and how to have difficult conversations. Several studies have shown that both nurses and physicians feel ill-prepared to have conversations with families regarding end-of-life issues. However, a number of educational and training programs have been developed for medical and nursing students and trainees, faculty and practicing health professionals.

STAFF SUPPORT
Palliative care work is stressful, and caregivers in both Labor and Delivery units and in the NICU are themselves at risk for burnout, compassion fatigue, secondary traumatic stress syndrome and/or post-traumatic stress disorder. It is important that staff have a chance to debrief and gain support when working with perinatal or neonatal loss, and have the opportunity to participate in bereavement interventions such as attending funerals or memorial services. If caregivers do not get emotional support, then they will have less to give to the families. Staff can be referred for counseling or obtain support from the pastoral care staff.

RECOMMENDATIONS
1. Parents who lose a baby before, during, or shortly after birth, or later in the NICU should be offered:
   a. Anticipatory guidance regarding the grieving process, including how mothers and fathers, and other family members, may grieve differently. This anticipatory guidance should begin antenatally if a life-limiting diagnosis has been determined.
   b. Participation in bereavement rituals, including those that meet their spiritual, religious and cultural preferences. These rituals may include a variety of practices and items that will help them remember their baby, such as provision of hand prints, foot prints and photographs. Smooth communication should be facilitated between parents and the staff of the NICU and obstetric units throughout the dying process; a perinatal social worker or other designated person can assist with this.
   c. Psychosocial support for all members of the family, including but not limited to grandparents and the baby’s siblings.
   d. Peer-to-peer support and/or referral to community or Internet support organizations (see ‘Recommendations for peer-to-peer support for NICU parents’, this issue).
e. Counseling regarding both the physical and psychological considerations of attempting another pregnancy.5
f. Post-hospital follow-up in a variety of forms, including individual contact by a staff member at various time periods as well as a conference 4 to 6 weeks after the baby’s death to review autopsy and other results that will help parents understand what happened to their baby.47

2. When intensive care will not be provided, a collaborative, interdisciplinary approach should be used to provide palliative care including bereavement care to any family whose fetus or neonate is facing a life-limiting condition or imminent death.48
3. Physicians and nurse practitioners should follow the guidelines outlined by the American Academy of Pediatrics when engaging in discussions with parents about whether to initiate or continue intensive care for a baby who may not survive:49 neonatal nurses and perinatal social workers should be included in the decision-making process as well.45,49 Intensive care should be provided only if it is believed that the baby will benefit from it. The best interests of the baby should be the guiding standard.4,6

4. In cases where there are disagreements between parents and the health-care team when making end-of-life decisions, particularly around the futility of further care for a baby, a bioethics consult should be obtained and/or the case presented to the hospital Bioethics Committee.4,50

5. Parents whose babies with life-limiting conditions survive to hospital discharge should be offered both practical and psychosocial support to help them prepare for discharge, learn how to both care for and cope with their baby at home,51,52 and/or they should be referred to a hospice with experience caring for infants. Their baby’s primary care provider, neonatal specialist, medical home or any subspecialists should be fully involved in making and carrying out home care plans and providing follow-up support.5

ANTENATAL RECOMMENDATIONS
Parents anticipating a perinatal loss should be offered:

1. An antenatal interdisciplinary conference to develop the following plans, which should be individualized according to parents’ desires and cultural, spiritual and religious beliefs:
   a. A birth plan, which should include parents’ preferences regarding the conduct of labor, the circumstances surrounding delivery and the care for baby and parents after the baby’s birth;
   b. A plan for the extent of resuscitation to be performed and whether to allow a natural death; and
   c. A palliative care plan as indicated and desired when babies are not expected to survive. This plan should include parents’ preferences on where the baby’s care will be delivered, how nutrition will be provided and how baby’s pain and discomfort will be managed.51,52

2. Encouragement to bond with their baby and to create memories throughout the pregnancy whenever feasible, recognizing the barriers parents may face in bonding.
3. Psychosocial support for all members of a family, including grandparents and the infant’s siblings.
4. Both practical and psychosocial support to help parents cope with their baby at home when infants with life-limiting conditions survive to hospital discharge.5

HEALTH SYSTEM RECOMMENDATIONS
1. All health professionals who work with pregnant women, neonates and their families should receive education and demonstrate competence in palliative and bereavement care that is appropriate within their scope of practice. This education should include training in how to communicate effectively and empathetically with families.5,21,33
2. Policies for palliative care and bereavement practices in any part of a health-care system should be in place and easily accessible to all staff, to ensure a standard of care for all families.
3. Palliative and bereavement care resources in the community should be available to anyone who is providing care to a neonate and family facing a life-threatening condition or imminent death or has experienced a loss, whether or not there is a palliative care team or program at a specific institution.
4. Hospitals should work in partnership with their local organ donation organizations to determine whether specific babies are eligible to become organ donors and to assess, in collaboration with the family, whether organ donation is the right choice for them.5

5. Health-care staff who provide palliative and/or bereavement care should receive psychosocial support and engage in self-care,4,9 to enable them to provide optimal care to the families they serve, as well as to prevent burnout, compassion fatigue or secondary traumatic stress.5 The perinatal social worker,44 NICU psychologist54 or pastoral care staff55 can be instrumental in providing this support.

CONCLUSION
A family-centered, integrated culturally driven plan of care can provide support for families experiencing an anticipated or unanticipated loss. The goal of palliative and bereavement care is to make the families and neonates as comfortable as possible. It is important to engage the family in the plan of care and to recognize that each family is different in how they wish to approach this situation. Palliative and bereavement care must be considered as standard care and treated as an expectation, not as optional additional services. Staff must also be supported, as palliative care and bereavement care are critical but emotionally draining aspects of perinatal/neonatal care. This article presents evidence-based recommendations for perinatal–neonatal, family-centered palliative and bereavement care.

CONFLICT OF INTEREST
The authors declare no conflict of interest.

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REFERENCES
REVIEW
NICU discharge planning and beyond: recommendations for parent psychosocial support

IB Purdy1, JW Craig2 and P Zeanah3

Parents will interact with a multitude of teams from various disciplines during their child’s admission to the neonatal intensive care unit. Recognition of the emotional stressors experienced by these parents is a first step in working to provide the crucial support and parenting skills needed for bonding and caring for their infant from admission through discharge and beyond. Family-centered care involves time-sensitive two-way communication between parents and the multidisciplinary team members who coordinate care transition by providing emotional, educational, medical and home visitor support for these families. To do this well, a thoughtful exchange of information between team members and parents is essential to identify psychosocial stress and ameliorate family concerns. Parents will need emotional and educational support and follow-up resources. Establishing individualized, flexible but realistic, pre- and post-discharge plans with parents is needed to start their healthy transition to home and community.


INTRODUCTION
Parents naturally experience many kinds of stress after the birth of a baby. Stress can be amplified by many factors encountered during their baby’s hospitalization in a neonatal intensive care unit (NICU), such as the baby’s appearance and behavior, exposure to medical lingo, advanced technology and the risk of their baby dying. This stress leads to a variety of reactions, including sadness, fear, anger, anxiety, grief, depression and helplessness. Parents of NICU babies commonly experience high stress after discharge with costly medical bills for childbirth and NICU hospitalization. Non-medical expenses related to loss of work, decreased income and limited job alternatives can also be sources of stress. The costs of caring for premature infants after discharge are not just financial but also emotional. Factors that drive emotional conflicts and undermine parents’ involvement include a lack of family-centered care, inadequate communication between staff and unwillingness for staff to alter their work regimen to meet parents’ schedules. Some parents become overwhelmed after discharge by their baby’s health problems, rescheduling appointments or seeing doctors unfamiliar with their baby’s history and condition.

The primary focus of NICU personnel has been trying to improve the survival and neuromorbidity of high-risk infants. By contrast, there has been a lack of attention given to parents’ psychosocial needs. As NICU infants and parents make up the family unit, the emphasis needs to broaden to include better psychosocial support for NICU parents with a goal toward improving developmental outcomes of the infants as well as the family’s functioning. Teams of interdisciplinary, multi-disciplinary and trans-disciplinary specialists need to unite to standardize best practices in discharge to prepare families for transition from NICU to home. Embracing dynamics of team collaboration ensures each family will receive state-of-the-art services in the NICU, during the transition to home and through the first years of life. Optimal team collaboration may require system-level changes. NICU teams need expert personnel dedicated to handling the intricate medical and social needs of the family unit to better develop parent–infant relationships before the time of discharge. NICU staff communication should encourage family involvement to prevent or minimize parental separation that disrupts parent bonding during a critical period of brain organization.

The following recommendations are offered as a guide for providing (a) emotional support, (b) parenting education, (c) medical follow-up care and (d) home visitations. These recommendations are based on prior evidence and guidelines referenced herein. The recommendations are meant to be fluid and flexible. Recommendations are also offered to help institutions establish policies and protocols to better prepare families during the transition to home and beyond.

EMOTIONAL SUPPORT
Psychological distress in NICU parents is associated with a deteriorating cycle that disrupts the parent–infant relationship, leading to subsequent impairments in child development and reciprocal negative effects on parents. Many parents report that NICU nurses and doctors do not understand their emotional condition. Evidence suggests that NICU parents undergo emotional strain due to poor communication experiences with NICU staff. These difficulties include a disrupted relay of information between units and shifts, parents not welcomed on rounds, limited visitation times and restrictive touch practices. Lack of good communication contributes to parents feeling lonely, abandoned and an unwanted presence. High levels of emotional stress are reported by parents of premature infants.

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parents for emotional distress should be a high priority in the NICU along with providing parents access to resources, handouts and contact information for parent support organizations and mental health care providers.15–29

In particular, mothers of preterm infants experience greater rates of depression than mothers of term infants, which can adversely affect their parenting abilities.16 Maternal distress early in a child's life has long-term effects on child behavior.15 Generally children of depressed mothers do not fare well, regardless of socioeconomic status, and need close pediatric follow-up.16 The literature suggests that early educational services can mitigate the adverse effects of maternal distress and even the effects of poverty on infant outcomes.16 Fathers are also at risk for emotional distress. Some return to work while bearing the emotional duty of caring for the mother, newborn baby and other children.17 Involving parents in their baby's care is a crucial step toward empowering and enabling their competence and confidence as caregivers. This empowerment must begin in the NICU and should be continued into the home.

All pre- and post-natal health-care in-patient and outpatient settings should have staff trained to identify families at economic, social and psychological risks, as well as providing the appropriate referrals.27 Psychologists in NICU or in the community are well suited to provide a wide range of clinical and consultative services and should have a role in individual and family assessments.27 Research on postpartum depression (PPD) found improved outcomes when management and treatment occurred within the practices that conducted antenatal screening.27 All providers should engage in family-centered care using staff who are trained and experienced in mental health care and psychological screening for stress, depression and other forms of emotional distress.27

Research identified inflammation as an underlying risk factor for depression and specifically PPD observed in new parents.30,31 However, breast milk feeding (BMF) can counter this inflammatory effect in mothers and improve stress and immunity.31 NICU staff should counsel parents about skin-to-skin care when the baby is stable. Professionals need to point out the vital role of family members in supporting BMF to improve stress, immunity and health outcomes.32,33 All perinatal and pediatric health-care workers should help parents establish pre- and post-discharge plans to overcome breastfeeding obstacles to decrease emotional distress.32,33 To sustain BMF from admission through infancy, professionals should help parents develop a BMF plan, access breast pumps and gain support from their family.32,33 Initiating family-based interventions such as skin-to-skin holding and BMF to support the developing parent–infant relationship can also alleviate known sources of stress in the parents once they take their baby home.18

PARENTING EDUCATION

NICU family-centered developmental care includes providing mentoring to parents at times that meet their schedules. Individualized encouragement is needed to prepare parents to assume a parental role and feel capable of providing home medications, special feeds, changing tubes, ordering additional supplies and initiating cardiopulmonary resuscitation if needed. Hospitals need to have designated NICU staff to mentor parents. Additionally, health-care teams in NICU, outpatient and at-home visits should be skilled at observing and assessing parent–infant interactions so staff can empower parents to respond to their baby's cues to support bonding. Educational tools such as the Newborn Behavioral Observation Scale are useful for professionals to gain and assess these skills.34

NICU parents need help preparing for their baby's transition to home and for potential readmissions.35 In addition to working with parents at the bedside or in a classroom, videos and websites are convenient methods of enhancing parents' knowledge and decreasing their stress.26,33,36 A three-step randomized trial of 781 infant–parent dyads examined a longitudinal parenting intervention. The first intervention was offered at 1 month after birth via educational booklets and DVDs on infant sleep and cry patterns, medical causes, settling techniques and parent self-care. At 2 months parents received telephone consults, and at 3 months parents participated in a parent group.36 These interventions decreased mothers' postnatal depression symptoms and decreased infant sleep and cry problems in frequent feeder infants.36 Family-focused care coordination using a combination of methods such as mail, telephone or telehealth is needed for at-risk families of medically fragile infants.

Parents' stress may escalate when approached about appointments and insurance authorizations for their baby's post-NICU care. Simply providing parents with names, addresses and phone numbers of specialists is an inadequate and unsafe referral method that may jeopardize babies' health and create extra stress. One to two parents and/or members of the family should receive individualized mentoring with checklists and outlines to cover all necessary care and education. Parents should be given a discharge folder that includes all teaching handouts, medication sheets, growth charts, supplies, follow-up appointment dates with phone contacts and a copy of the discharge summary. For the transition from NICU to community services to be seamless, the contact information and dates of scheduled appointments for the primary care provider (PCP) and all post-discharge specialists should be clearly documented in the NICU discharge summary. Utilizing the hospital's procedures regarding the sharing of information, the PCP and subspecialists involved should receive a copy of relevant information or be able to access it via the electronic medical record. High-risk infant follow-up (HRIF) clinics and home visitors (HV) should also be included in these communications. To facilitate the transition process, a staff member from the PCP's office should meet with the family before discharge to gain familiarity with their needs and to establish a supportive relationship.

Table 1 outlines tasks to be completed in preparing parents for transitioning to home. Discussion of these tasks should be provided in a culturally and linguistically appropriate manner so parents will be able to show competence in infant caregiving before transition to home.6 To promote best practices and minimize stress, NICUs should establish policies that include members of the discharge team serving as ‘parent champions’ to guide the family through the maze of referrals and to pre-schedule initial appointments.37 Whenever possible, staff should communicate with parents as ‘equals’ and team members during all communications.

MEDICAL FOLLOW-UP

Pre-discharge

Ideally, transition planning involves NICU discharge (DC) preparation by teams and good communication that begins at admission and continues beyond discharge. Team transition planning includes identifying the degree of medical, psychosocial, environmental and financial readiness of the infant-family unit.37 Weekly NICU multidisciplinary DC team meetings should provide opportunities for discussing these risks and the family's perspectives.37 In one study, families who were unprepared for NICU discharge reported more problems post-discharge with infant feedings and lack of basic supplies (nipples, bottles, formula, diapers and so on).38 The DC team should confirm that each family receives a clearly written discharge plan. The plan should include pre-scheduled appointments and contact information to providers who accepted their child and insurance coverage so parents can connect with providers for questions before the first scheduled visit.38 A NICU point person needs to communicate information
Table 1. Parent pre-discharge plan checklist

<table>
<thead>
<tr>
<th>Technical parenting skills</th>
<th>Home environment readiness</th>
<th>High-risk infant behavior: normal or abnormal</th>
<th>Anticipatory guidance plans</th>
<th>Family support services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Basic baby care</td>
<td>Order supplies and equipment needed at home</td>
<td>Normal newborn behaviors</td>
<td>What to expect and what to do at home—sleeping, crying, feeding</td>
<td>Pediatrician</td>
</tr>
<tr>
<td>Individualized special care (medications, equipment, tube changes)</td>
<td>How and where to acquire provisions for special needs</td>
<td>How newborns differ from sick or preterm infants</td>
<td>Parental mental health and self care (sleep, eat, parent support groups, websites, professional referrals)</td>
<td>Early intervention services (social worker, physical, occupational, speech and feeding therapists)</td>
</tr>
<tr>
<td>Cardiopulmonary resuscitation</td>
<td>Nurse assessment of home</td>
<td>Abnormal newborn behavior</td>
<td>Plans for coping with and soothing infants</td>
<td>Lactation support services</td>
</tr>
<tr>
<td>Patient advocacy tips</td>
<td>Community resources</td>
<td></td>
<td>Enriched environments</td>
<td>Breastfeeding during the</td>
</tr>
<tr>
<td>Red flag checklists</td>
<td></td>
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<td></td>
<td>first year</td>
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Car seat/bed use

<table>
<thead>
<tr>
<th>Car seat/bed use</th>
<th>Installation of car seat</th>
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<tbody>
<tr>
<td>Car seat tolerance for special needs babies</td>
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</table>

Family support services

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<tr>
<th>Family support services</th>
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<tbody>
<tr>
<td>Pediatrician</td>
<td></td>
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<tr>
<td>Early intervention services (social worker, physical, occupational, speech and feeding therapists)</td>
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<tr>
<td>Lactation support services</td>
<td></td>
</tr>
<tr>
<td>High-risk infant follow-up clinics</td>
<td></td>
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<tr>
<td>Home visitors</td>
<td></td>
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<tr>
<td>Public health nurses</td>
<td></td>
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<tr>
<td>Women, infants and children</td>
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</table>

Derived from Smith et al.9

Regarding parental emotional distress to alert other providers and assure documentation in the discharge plan.15 NICU DC teams that coordinate infant-family care plans should be responsible for scheduling the first referrals to outpatient providers.21,26 The DC team should assist the parents with establishing post-discharge plans and referrals to lactation and feeding specialists, mental health providers, social workers, PCP, HRIF clinics, specialists, visiting nurses and other community resources.39–45 These referrals ensure that supportive care resources are in place at discharge. Going through the medical checklist with parents also has benefits of increasing parents’ confidence and emotional preparedness.

Post-discharge

Health-care teams in NICU and outpatient settings should observe evidence-based recommendations from literature reviews, policy statements and statewide quality improvement projects for pre- and post-discharge and follow-up during early childhood.37–45 Trends in shortened NICU stays may decrease parent separation but can result in infants going home with unresolved medical problems.23,24 Earlier NICU discharge of children with special health-care needs (CSHCN) leads to families needing closer and more frequent health-care follow-up.37,38 Some state agencies mandate NICUs to provide HRIF programs to coordinate care of CSHCN, helping families bridge the gap between the NICU, home and the community. HRIF clinics are responsible for providing special medical, developmental, psychological and social assessments during the first 3 years of the baby’s life.37–42 Similarly, a medical home model ideally provides accessible, coordinated, culturally effective, family-centered care for CSHCN.43,44 Due to lack of funding, this model has not been widely adopted.44 Specialty health-care teams should work in partnership with another to optimize care and encourage strong parent–infant relationships.14

Many NICU graduates still have severe medical complications that impact growth and development, which can be a source of stress to parents caring for them at home. Nutritional screening using home baby scales and telephone consults to monitor growth to prevent failure to thrive (by advising families on nutritional and caloric adjustments) can decrease parent stress and improve patient outcomes. An important predictor of how the infant grows and develops after discharge is the quality of the infant’s psychosocial environment and parent–infant relationship.10 In addition to growth, several factors influence infant outcomes (gestational age at birth, brain injuries, variations in care management, parent’s socioeconomic status and maternal mental health).8 Table 2 presents parent challenges while in the NICU and during follow-up, potential barriers to success and examples of facilitators and resources for parents. Advising parents about the possible emotional challenges during their child’s first year and what conditions increase the risk for hospital readmission may help diminish some stress when it occurs.55

**HV SERVICES**

Congress created the Maternal, Infant and Early Childhood Home Visiting Program to support voluntary, evidence-based HV services for at-risk pregnant women and parents with children up to pre-kindergarten.48 The focus and timing of HV varies and can cover pregnancy, labor and early child health.46,47 Nurses conducting HV assessments may augment other services by including screening for depression and anxiety and providing an additional level of emotional support to families via techniques such as ‘listening visits’.24,25 HV programs may be funded by community resources, federal or local grants or insurance companies, based on family income criteria and consent to participate.30,47–52 Community-based HV programs may provide financially eligible families with parenting education and support services before delivery.

During NICU admission, if a family is already involved with a HV program continued involvement should be encouraged. If peer mentors developed supportive relationships with families, then it is desirable for mentors to continue involvement after discharge, if both parties are willing. If not, then HVs by NICU nurses or therapists or other appropriate referrals can be made. The importance of continuity of care for the NICU baby during and after discharge has long been recognized by hospitals and community health-care providers.24

Nurses report success in providing lactation support to families in the home to meet the AAP guidelines for continued exclusive breastfeeding during the first 6 months of life.49–51 The mission of visiting nurses may be the best option and environment for breastfeeding issues and infant support.49,50 Visiting nurses were also identified as a viable means of securing high-quality patient-centered outcomes and found to be as effective and safe for initial patient encounters post-hospital discharge as traditional office visits.52

HV programs vary in terms of their intensity, focus and resources; such services may be provided by other registered nurses, public health nurses, child development specialists or professionals with specialized training to provide education, guidance and assistance to families.24,25,48,51 Improving the parent–child relationship may counterbalance the distorted or aberrant parenting that may result when parents sense their
A concerted effort in understanding the continuum of parent-infant needs is essential to support healthy parent-infant relationships during the early years of the infant's life both within the NICU and post-discharge. A well-prepared family should receive anticipatory counseling about the psychological stresses that often occur throughout pregnancy and the first several years of life. Using a ‘team working with teams’ approach for discharge planning, the NICU professionals need to align with care coordination across disciplines. Working together, the care teams can help families build bridges from the NICU to the community. The ultimate goal for pre- and post-discharge care should be to communicate, identify, coordinate and refer families at-risk to appropriate mental health and psychosocial services before NICU discharge and while attending HRIF clinics, Primary Care Clinics, HV and other community programs. NICU teams handing off to community teams need updated evidence-based guidelines for recognition of potential barriers and facilitators to help parents be prepared to overcome obstacles and challenges to caring for themselves and their family.

Table 2. Resources for helping parents overcome barriers

<table>
<thead>
<tr>
<th>Parent challenges</th>
<th>Barriers</th>
<th>Facilitators and resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Establish parent-infant bond</td>
<td>Socioeconomic and cultural</td>
<td>Community transportation: Assists with trains, car pools, bus tickets and taxis</td>
</tr>
<tr>
<td></td>
<td>Short maternity leave</td>
<td>Community housing: Houses, shelters, hotels, etc.</td>
</tr>
<tr>
<td></td>
<td>Far distances between home and hospital</td>
<td>Child support: Child life, volunteers for play area</td>
</tr>
<tr>
<td></td>
<td>Transportation and house costs and conveniences</td>
<td>Food: Hospital cafeteria food pass, WIC</td>
</tr>
<tr>
<td></td>
<td>Medical NICU environment</td>
<td>Communication: 24-h NICU telephone access</td>
</tr>
<tr>
<td></td>
<td>Restricted NICU visiting hours</td>
<td>Family-friendly NICU environment: Skin on skin Kangaroo care for parents, low light and noise</td>
</tr>
<tr>
<td></td>
<td>Competing demands (children, work, school)</td>
<td>Psychosocial support resources: Utilize social workers, mental health professionals, psychiatrists and psychologists to screen and refer for stress and depression</td>
</tr>
<tr>
<td></td>
<td>Emotional and mental distress</td>
<td>Interpreters: Available by phone or in-person</td>
</tr>
<tr>
<td>Acquiring parenting skills</td>
<td>Communication (language, education level)</td>
<td>Educational materials: Provide written, video, website or bedside teaching</td>
</tr>
<tr>
<td></td>
<td>Lack of parental engagement</td>
<td>Offered in parent’s language and education level. Topics: self-care, anxiety, depression, optimal parenting, normal versus abnormal infant behaviors, health, hygiene, safety, illness prevention</td>
</tr>
<tr>
<td></td>
<td>Difficulties establishing lactation and breastfeeding</td>
<td>Red flag checklists: Establish what, why, when, where and who to call for emergency treatment</td>
</tr>
<tr>
<td></td>
<td>Insufficient human resources</td>
<td>Parent support groups: Hospital or community, websites, referrals, parent volunteers</td>
</tr>
<tr>
<td>Discharge and follow-up</td>
<td>Health insurance</td>
<td>Breastfeeding support: Lactation specialists, WIC, professionals trained to meet the baby friendly hospital initiatives and AAP guidelines</td>
</tr>
<tr>
<td></td>
<td>Administrative procedures for transfer of care to community</td>
<td>Parents advocate for patient safety: Children’s Hospitals’ Solutions—Patient Safety website</td>
</tr>
<tr>
<td></td>
<td>Special equipment</td>
<td>Pre-established discharge plans: NICU point personnel to identify family needs to provide special training. Pre-schedule appointments, phone contacts</td>
</tr>
<tr>
<td></td>
<td>Medications</td>
<td>Parent training check lists: Medication, feeding, special cares (tracheostomy, gastrostomy tubes, wounds), equipment (oxygen, suction, ventilation) and contact numbers to reorder supplies</td>
</tr>
<tr>
<td></td>
<td>Lack of access to specialized/ emergency care in rural areas outside the city</td>
<td>NICU follow-up programs: Post-discharge primary care, HRIF teams, early intervention and home visitor services for ongoing cares and support</td>
</tr>
<tr>
<td></td>
<td>Poor discharge follow-up coordination system for families</td>
<td></td>
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</tbody>
</table>

Abbreviations: AAP, American Academy of Pediatrics; HRIF, high-risk infant follow-up; NICU, neonatal intensive care unit; WIC, Women, Infants and Children services. Derived from Raffray et al.41

child is vulnerable and/or have negative perceptions of the child. A systematic review of studies on HV offers evidence of some benefits to improved parent-infant interaction with preterm infants. Unfortunately, due to methodological limitations, these studies have not shown any benefit to infant development, abuse/neglect, growth/nutrition or morbidity. Future research is needed to investigate potential benefits of HVs in medical cost savings or potential physiologic and psychological impact of positive parenting experiences. In particular, more research comparing HV with standard care for breastfeeding and PPD with other specific at-risk NICU populations is needed.

It is important that all health-care staff seek input and communication with other professionals and providers and community programs that are involved with these families. Postpartum Support International is one example of a worldwide network of support available across every American state and in 36 additional countries that offers training and access to care coordinators. Care coordination teams in NICU, HRIF, Medical Home, Primary Care and subspecialties should be knowledgeable about HV websites and availability of referrals to HV programs in their state to provide parents with assistance contacting these resources for help and to individualized referrals to resources that match family’s needs.

SUMMARY

A concerted effort in understanding the continuum of parent-infant needs is essential to support healthy parent-infant relationships during the early years of the infant’s life both within the NICU and post-discharge. A well-prepared family should receive anticipatory counseling about the psychological stresses that often occur throughout pregnancy and the first several years of life. Using a ‘team working with teams’ approach for discharge planning, the NICU professionals need to align with care coordination across disciplines. Working together, the care teams can help families build bridges from the NICU to the community. The ultimate goal for pre- and post-discharge care should be to communicate, identify, coordinate and refer families at-risk to appropriate mental health and psychosocial services before NICU discharge and while attending HRIF clinics, Primary Care Clinics, HV and other community programs. NICU teams handing off to community teams need updated evidence-based guidelines for recognition of potential barriers and facilitators to help parents be prepared to overcome obstacles and challenges to caring for themselves and their family.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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Recommendations for enhancing psychosocial support of NICU parents through staff education and support

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Providing psychosocial support to parents whose infants are hospitalized in the neonatal intensive care unit (NICU) can improve parents’ functioning as well as their relationships with their babies. Yet, few NICUs offer staff education that teaches optimal methods of communication with parents in distress. Limited staff education in how to best provide psychosocial support to families is one factor that may render those who work in the NICU at risk for burnout, compassion fatigue and secondary traumatic stress syndrome. Staff who develop burnout may have further reduced ability to provide effective support to parents and babies. Recommendations for providing NICU staff with education and support are discussed. The goal is to deliver care that exemplifies the belief that providing psychosocial care and support to the family is equal in importance to providing medical care and developmental support to the baby.


RATIONALE

The manner in which neonatal intensive care unit (NICU) physicians, nurses and other staff interact with parents greatly influences parents’ perceptions long after their baby has been discharged from the NICU.1 Although attempts are made to educate NICU staff, many feel less than fully prepared to respond to parents’ distress, meet their psychosocial needs and interact with them in ways that will enhance their coping both during their NICU stay and postdischarge.2 Moreover, NICU staff are themselves at risk for the adverse physical and emotional consequences of providing care in one of the hospital’s most stressful work areas. If staff are not sufficiently made aware of how to manage their own work stress, the consequences can include burnout, compassion fatigue, secondary traumatic stress syndrome and/or post-traumatic stress disorder. Staff may then become emotionally guarded or depleted, and unable to offer supportive care to emotionally vulnerable NICU parents.

Burnout syndrome was defined in 1988 as a ‘state of physical, emotional and mental exhaustion caused by long-term involvement in emotionally demanding situations’.3 Burnout stems primarily from conflict within the work setting, such as unhappiness over work conditions, salary or disagreements with co-workers or supervisors.4 It is reported that as many as 40% of hospital nurses exhibit symptoms of burnout,5 and rates of burnout by health-care workers (n = 820) reported in one review of 44 NICUs ranged from 7.5 to 54.4%, with rates being higher in non-physicians.6 Neonatologists are not immune to burnout, though. One study of 110 neonatologists found that 30% experienced high burnout and another 60 to 65% were in the ‘at-risk’ range.7 Among the factors associated with burnout in neonatologists are work experience of < 5 years, believing that living with a physical disability is unworthy and having recurrent death ideation.7

Factors contributing to stress and burnout among NICU nurses fall into three general categories. First, several aspects of the NICU physical and interpersonal work environment can be challenging. Working in physical surroundings often with inadequate lighting and excessive ambient noise,8 being overstimulated in the pervasive crisis atmosphere,9 experiencing interdisciplinary conflicts7 and facing verbal abuse from distressed families can add to levels of stress.10 Moreover, staff must manage this work environment for long hours while maintaining vigilance over their patients and promoting a calm environment for families, as well as a professional and caring persona.11 Workload issues constitute a second general category of stress, including dealing with excessive and unrealistic patient assignments because of inadequate staffing.10,12–14 Working mandatory overtime during periods of high census, or, alternatively, being forced to take days off during periods of low census.15 Providing patients and families with optimal care creates a third general category of factors. Poor communication skills may contribute to nurses’ feelings of inadequacy about their ability to provide necessary emotional support to families.5 Ethical dilemmas may create moral distress, such as when nurses are asked to carry out end-of-life orders to which they have a ‘conscientious objection’.16,17 Staying current with changing practices and technological advances is also challenging.11,13

Nurses who report being burned out experience greater difficulties in their personal lives;18 a variety of psychological complaints, higher rates of alcohol and drug abuse19–21 and compulsive gambling.22 Stressed nurses are also prone to experiencing a variety of health problems, including sleeplessness, headaches, muscle tension,13 immune dysfunction and...
gastrointestinal or cardiovascular disturbances.\textsuperscript{23} In addition, seasoned nurses with considerable work experience may have increased susceptibility to the cumulative effect of stressful experiences that can also lead to post-traumatic stress disorder.\textsuperscript{10}

High rates of burnout among nurses in general are associated with many adverse effects on patient care, including an increase in health-care associated infections,\textsuperscript{25} a decrease in recognition and reporting of errors,\textsuperscript{25} an increase in patient mortality\textsuperscript{14} and a decrease in patient-reported satisfaction.\textsuperscript{25} Hospitals whose nurses have high rates of burnout are more likely to experience increased rates of employee tardiness and absenteeism,\textsuperscript{19,20} as well as high rates of nursing turnover.\textsuperscript{27}

Compassion fatigue has been described as a unique form of burnout; the two conditions have overlapping symptoms, including physical, emotional and work-related symptoms.\textsuperscript{9,28} Although staff suffering from burnout are likely to withdraw from interpersonal interactions with patients and families, those with compassion fatigue are likely to become overinvolved and ‘try harder’ despite feeling emotionally exhausted.\textsuperscript{28}

Whether a health-care professional develops burnout and/or compassion fatigue, the result is the same. The provider may not be emotionally available to support the psychological needs of their patients and their patients’ family. Reducing staff burnout and compassion fatigue could lead to lower costs in treatment of health-care associated infections and to hiring and training new staff.\textsuperscript{29} Other benefits include the potential to improve employee morale, patient and family satisfaction,\textsuperscript{4,12} and ultimately patient survival.\textsuperscript{14}

The purpose of these recommendations is to define standards for education and support of NICU staff that will enable them to feel sufficiently prepared to provide psychosocial care and support to the family.

**RECOMMENDATIONS FOR STAFF EDUCATION**

Staff education relating to the psychosocial needs of NICU families and methods of providing support should be provided to all NICU staff. ‘All NICU staff’ refers to all disciplines that interact with NICU families on any level. Staff education should be provided during orientation and then periodically throughout the course of every year. Education of interdisciplinary groups should promote fruitful discussion and collaborative interaction.

**TOPICS FOR STAFF EDUCATION**

Normal responses to infant hospitalization

NICU staff should be made aware of the emotional impact of the NICU experience on parents and the ‘normal/expected responses to this abnormal and often unexpected life-changing event. Of the multiple emotional, psychosocial and situational stressors parents may experience, those related to their infant’s precarious health status are usually paramount. Parents may also experience a variety of unexpected and traumatic emotions related to their pregnancy and birth experiences leading up to NICU admission. Additional psychosocial and interpersonal stressors may include financial hardship, transportation and lodging challenges, and the strains of balancing family, home and work life.\textsuperscript{60,61} These stressors bring forth a variety of emotional responses that parents do not expect but which commonly occur; these may include shock, fear, guilt, anger, lack of control and jealousy of parents with healthier babies. Parents may also resent NICU staff who oftentimes spend more time with their babies than parents are able to. Furthermore, parents’ emotions render them less able to concentrate and to make decisions, compounding an already stressful situation. Given this, one important goal of the NICU staff should be to help parents normalize their common emotional responses.\textsuperscript{32}

Perinatal mood and anxiety disorders in NICU parents

The cumulative stresses faced by NICU parents confer higher risk for perinatal mood and anxiety disorders compared with parents of healthy, full-term infants. A comprehensive curriculum about perinatal mood and anxiety disorders experienced by NICU parents should incorporate the following topics: (a) information about depression,\textsuperscript{33–38} anxiety,\textsuperscript{34,37} and post-traumatic stress disorder\textsuperscript{35,39,40} in NICU mothers and fathers, including epidemiology and risk factors,\textsuperscript{41} adverse effects of these conditions on parent–infant attachment,\textsuperscript{42,43} and the physical, cognitive and emotional development of infants;\textsuperscript{32,44,45} (b) methods for screening for perinatal mood and anxiety disorders (see ‘Recommendations for mental health professionals in the NICU’, this issue); and (c) a review of efficacious treatments offered for parents in the NICU.\textsuperscript{46–48}

Family-centered developmental care

The American Academy of Pediatrics has called upon pediatric staff to embrace families as true collaborators in the care of their children. Parents should function as integral members of the health-care team and their views should be incorporated into care plans.\textsuperscript{49,50} Staff should be educated about methods for improving and expanding implementation of family-centered developmental care in the NICU, as found in ‘Recommendations for involving the family in developmental care of the NICU baby’, this issue.

Culturally effective care

An important component of staff education involves increasing awareness of how to provide care that is culturally effective\textsuperscript{51,52} as endorsed by the American Academy of Pediatrics.\textsuperscript{73} Respect for diversity regarding racial, ethnic, spiritual, educational, geographic and socioeconomic backgrounds, cultural and linguistic traditions, and care preferences comprise one of the general principles of family-centered care.\textsuperscript{49,50} Improving the quality of provider communication may be key in increasing the extent to which minority populations are involved in family-centered care.\textsuperscript{64} To achieve cultural sensitivity, staff should be encouraged to undergo an educational process that involves gaining self-awareness, learning to appreciate the differences and value of cultural practices other than one’s own and exhibiting behavioral flexibility.\textsuperscript{55,56}

Differences in preferences for care and satisfaction with care have been documented among parents of diverse cultural backgrounds in pediatric settings.\textsuperscript{57–59} Developing trust between families and their medical providers is an important element in communication and may vary among racial groups. Tang et al.\textsuperscript{60} reported that although African-American parents trusted their individual health-care providers in the NICU to the same degree as white parents, a greater proportion of African-American parents mistrusted the medical profession in general.

Parents who are recent immigrants, speak English as a second language, have low educational levels or have lower incomes are more likely to have low health literacy skills.\textsuperscript{61} Parents with any of these attributes are an especially vulnerable population and need information delivered in an understandable way. Methods to enhance parental understanding include providing written materials using terms that are easy to comprehend in their native language, asking parents to teach back what has been taught\textsuperscript{62} and providing opportunities to ask questions in an unhurried manner using an interpreter as needed. Information should also be provided within a cultural framework. For example, in some cultures, a family member other than the parents may make all
health-care decisions. For this reason, parents should be asked whom they prefer to be involved in making health-care decisions. To facilitate optimal communication, hospital staff who interact with non-English-speaking families should use trained, non-volunteer interpreters. Even when interpreters are used, cultural differences can still contribute to difficulties in communication with families.\textsuperscript{5,6,4} However, interpreters may be able to help the medical team understand the influence of cultural norms.\textsuperscript{52}

Self-care

Education should cover elements of self-care for staff so NICUs can become proactive in preventing and minimizing burnout and compassion fatigue,\textsuperscript{16} including: (a) education on management of work stresses,\textsuperscript{28} which include communication skills, techniques for boundary setting, ethics and knowledge of family system dynamics; (b) maintenance of work-life balance by giving attention to adequate nutrition, hydration, sleep, exercise and pleasurable activities that promote overall health and well-being\textsuperscript{28} and (c) management of life skills, including time management, budgetary management and stress reduction.\textsuperscript{13,28}

Competent communication

Research has shown that a mother’s perception of the support she received from her nurse correlates with her level of depression.\textsuperscript{36} Specifically, a one point decrease of a mother’s rating on the Nurse Parent Support Tool resulted in a 6% increased risk for depression.\textsuperscript{16} Equipping nurses with advanced communication skills is especially important as parents view nurses as a more frequent source of information\textsuperscript{52} and support\textsuperscript{7} than neonatologists. Multiple studies have shown that NICU parents have identified a need for improved staff–parent communication.\textsuperscript{5,6,6,6–68}

Although staff frequently speak with NICU parents, their efforts to communicate about the infant’s status do not always lead to parental understanding.\textsuperscript{1} De Wit et al.\textsuperscript{69} compared mothers’ understanding of their NICU infant’s illness to clinicians’ perceptions. Although most mothers understood at least one aspect of their infant’s diagnosis, mothers often believed that their infant was less sick than the clinician did. This discrepancy may have been the result of parents’ unrealistically optimistic expectations. Teen-aged parents of NICU babies may not fully grasp the information being communicated to them, often underestimating the critical nature of their infant’s illness, in part because they may be reluctant to ask providers to clarify technical language.\textsuperscript{70}

Each institution should have a communication curriculum that includes a number of topics. First, the curriculum should teach staff how to provide information about the baby’s diagnoses and expected course using simple, straightforward language void of medical jargon and presented in a warm, sympathetic manner.\textsuperscript{69} Staff can benefit from a number of suggestions as to how families would like to receive ‘bad news’. Instruction should include when and how to approach parents, and how providers should pace themselves during these discussions, speaking from an empathetic perspective and staying away from using medical jargon.\textsuperscript{52,71–76} Second, staff can learn how to interact with parents from the perspective of an expert coach and facilitator,\textsuperscript{77} so that parents can become competent in their baby’s care. This coaching can be carried out by using a teach-back method.\textsuperscript{82} Third, instruction should include segments covering how to provide psychosocial support to families in crisis, which starts by engaging in active listening to a family’s concerns and fears.\textsuperscript{10,73} This may require skills in conflict resolution\textsuperscript{10} or the provision of support to parents during palliative and bereavement care.\textsuperscript{78,79} Finally, the program should ensure that the health-care team knows how to involve families in making care decisions,\textsuperscript{80} including decisions about whether or not to resuscitate extremely immature neonates.\textsuperscript{81}

MODELS OF COMMUNICATION TRAINING

A variety of models for communication training of both NICU physicians\textsuperscript{73,82–86} and nurses\textsuperscript{87} exist. Each NICU should tailor their efforts to the size, composition and needs of their staff, balanced with the resources available to the hospital. Within these models, personalizing information for specific patients is likely to provide the greatest benefit.\textsuperscript{74} Most curricula combine practical and theoretical aspects to achieve these goals.\textsuperscript{90}

Providing increased and more sensitive communication

Janvier et al.\textsuperscript{76} suggested that parental dissatisfaction in the NICU was usually the result of inadequate communication leading to the family’s perception that their needs were not met, rather than inadequate medical care. This report noted that parents would like health-care professionals to introduce themselves, call their baby by name and not diagnosis, speak in lay person’s language (i.e., not use medical jargon), speak with one voice, know their baby, acknowledge their parental role and not label them as a difficult parent.

Audiotaping family conferences is a strategy that can help highlight and reiterate key issues for parents, who may have trouble processing information given to them during NICU admission. Koh and Jarvis\textsuperscript{71} found that the taped conversations between parents and neonatologists helped parents recall specifics of their infant’s condition and how to support their infant. Penticuff et al.\textsuperscript{88} familiarized parents with an Infant Progress Chart and used parent-provider care planning conferences to improve collaboration in the NICU. This approach increased parents’ understanding of their baby’s care, especially among young, low income, minority mothers. Johnston et al.\textsuperscript{93} reported improved parents’ satisfaction as a result of: (a) familiarizing a family with the NICU environment, its care philosophies and team members, (b) establishing contact between the family and members of the NICU team before the birth of the infant and (c) creating opportunities to dialog about an infant’s condition and the family’s concerns.

To increase communication between the principal medical provider (PMP) in the NICU and parents, Weiss et al.\textsuperscript{94} focused on maximizing providers’ engagement, availability, understanding, reciprocity and empathy. This process was accomplished by providing a short education module for PMPs; giving the parents a contact card with the PMP’s name, job description and contact information; and displaying a large poster of the faces, names and titles of the PMPs at the parents’ entrance to the NICU. A careful introduction of the program and the PMP, along with maintenance of weekly contacts and use of interpreter services, were deemed essential to the success of the program.

Many parents desire to attend family-centered medical rounds.\textsuperscript{58} Voos et al.\textsuperscript{95} reported that these rounds increased parental satisfaction with their baby’s health-care providers compared with attending traditional rounds. Parents can also be involved in nursing change-of-shift report to further enhance bidirectional communication.\textsuperscript{90}

Simulation training and interactive workshops

Simulation training (especially using ‘standardized patients’ or ‘role-playing’) is an effective method of staff education.\textsuperscript{84,86,96} Simulation provides a ‘safe’ environment in which participants can receive non-judgmental, supportive feedback from colleagues, enhance existing skills and develop new skills.\textsuperscript{97} The use of standardized patients has been an useful tool given the realistic, interactive nature of this technique.\textsuperscript{96} Scripts can be written to simulate emergencies, routine patient care or communication interactions that require specific techniques, such as delivering ‘bad news’. After the simulation, participants can review video-tapes of their interactions and perform a self-assessment.
Observers can also give feedback. Although most educators have moved toward simulation training, less expensive alternatives such as role-playing may be equally effective.98

A training format of longer duration is the Program to Enhance Relational and Communication Skills-Neonatal Intensive Care Unit (PERCS-NICU).97 This program consists of 10 to 15 workshops for interdisciplinary health-care providers. Facilitators included a neonatologist, a psychosocial professional and a family faculty member. The PERCS-NICU program was shown to improve communication and relational skills, increase confidence and reduce anxiety for NICU providers.97

The Neonatal Critical Care Communication84 was developed to teach advanced communication skills to NICU fellows and neonatal nurse practitioners. This evidence-based training involved didactic sessions, small-group role-playing with actors and reflective exercises during a 3-day retreat away from the hospital. The program increased clinicians’ self-perceived competence to face common communication challenges; however, no objective measures of improvement were used.

Listening visits
Listening visits (LVs), a nurse-delivered treatment for maternal depression, is a specific model of communication that can be provided within the NICU as an extension of family-centered care.99,100 The LV intervention is based on the idea that providing a woman with the opportunity to express her feelings with consistent social support reduces depressive symptoms. Each LV session lasts ~ 1 h and combines active listening with problem solving. A preliminary open trial has shown promising results for the effectiveness of LV within the NICU. Most NICU mothers who were eligible to receive LV from an NICU nurse opted to receive this intervention; LV recipients had significant improvements in mood.99 These results suggest that LV delivered at the infant-point-of-care by an NICU nurse are both an acceptable and effective treatment option to at-risk mothers who are not likely to access other forms of mental health care. The training for nurses to engage in the LV intervention with NICU mothers is easily taught.99,101

IMPLEMENTING STAFF EDUCATION: POTENTIAL BARRIERS AND FUTURE DIRECTION

Numerous barriers to the implementation of staff education programs may be encountered. Creating time for staff to attend educational programs is challenging, given long shifts, busy patient assignments and staff fatigue. Cost may also be a factor, both in creating and delivering educational programs, as well as in compensating staff for their time. Professionals who hold the narrow view that their caregiving responsibilities extend primarily to provision of medical care may not feel comfortable expanding their role to providing psychosocial care. These staff may not perceive the parents of babies they care for as their ‘patients’. Staff who feel overwhelmed by the acuity of the babies in their care may also feel that their responsibilities for medical care inhibit their ability to provide psychosocial support.

To overcome the barriers, the interdisciplinary leadership team must endorse the importance of staff education and be committed to its development. The NICU culture must realize the importance of psychoeducation concurrent with medical education. Staff education should be offered on both day and night shifts, and continuing education credits should be awarded to attendees. Ongoing education of staff should be fully integrated into a variety of other platforms including case conferences,72 case debriefings, morbidity and mortality conferences,72 ethics rounds, daily family-centered medical rounds, and so on. Administrators must consider the many benefits of providing staff education in communication skills; some of these include increased parent satisfaction, improvement in families’ functioning and less staff burnout/staff turnover.

Further research to develop improved strategies to enhance competence in communication skills, as well as to measure the effectiveness of the various communication skills training programs, is warranted.82,97,102,103

RECOMMENDATIONS FOR STAFF SUPPORT

Psychologists, social workers and other mental health professionals

Mental health professional (MHPs) who work in NICUs should provide support to staff as well as to families.104–106 Support may be accomplished through acting as a liaison between staff and families, and/or through discussions of family dynamics and family/staff interactions at a variety of settings.12 MHPs can also help staff become aware of signs of compassion fatigue, burnout, moral distress and other more concerning problems staff might experience related to the trauma of providing intensive care. MHPs can provide NICU staff with guidance and referral to on-site and community-based resources to address their mental health needs.

Pastoral care staff

NICUs should have a dedicated pastoral care person integrated within the care team.107 In addition to providing spiritual support to the families of patients, pastoral care staff should be available to support NICU staff in becoming more aware of their own values,108 particularly how their religious background and spiritual perspective may affect their interactions with patients. Pastoral care staff can participate in ethical consultations and decision-making, and help to address moral distress.109

Nurses

Nurses should support each other through mentoring relationships,68,110,111 team building activities10 and nursing recognition activities.3 Individual nurses and administrative leaders share the responsibility in preventing nurse burnout13 and compassion fatigue. Many of the factors associated with these conditions can be changed through a hospital’s commitment to reduce them.

Hospital or NICU-specific ethics committee and palliative care teams

An ethics committee should be available to help staff minimize the occurrence of moral distress, burnout and compassion fatigue.112 The ethics committee can give guidance to help staff and families negotiate end-of-life decision-making and determine guidelines for infant viability.113,114 NICU staff should receive both initial and ongoing training and education in ethics, particularly related to engaging in shared decision-making with parents around withholding of life-sustaining treatment,83 withdrawal of life-sustaining treatment, end-of-life care,115 and palliative care.116 Lack of formal training in palliative care may render NICU staff reluctant to become involved. Although NICU staff may feel confident in their palliative care delivery even without formal training, staff (and families) benefit from the guidance and support of palliative care teams in their discussions and interactions with families.116

METHODS OF STAFF SUPPORT

Debriefing sessions

A debrief session is an interdisciplinary meeting that can facilitate processing of emotions and provide support for NICU staff, especially when it is held shortly after a difficult case, including
those that are ethically and morally challenging, or the death of a patient. Sessions review the case and focus on the aspects of both medical and psychosocial care that could have been improved. Some staff members may prefer one-on-one debriefing from an NICU MHP staff, rather than meeting as a group. Because debrief sessions can elicit strong and sometimes opposing emotions and views, it is important to have a qualified professional leading the discussion. There are potential barriers to conducting debriefing sessions. Staff who want to attend may not be working when the sessions are held, or attendance may be limited by work assignments. Some may not choose to attend the session without encouragement, and some who do attend may not want to talk about tough issues. To remove access barriers and facilitate staff attendance, nurse managers should try to arrange patient assignment coverage and/or compensate staff who want to attend debrief sessions. Nursing and medical leadership should support debrief sessions to ensure that everyone has time to process their activities and feelings. Leadership may need to personally invite staff to attend to make sure that all are supported.

Encouraging participation in bereavement interventions
Offering staff the opportunity to participate in bereavement interventions during and after provision of end-of-life care, such as conducting remembrance ceremonies and giving time to attend funerals, can help them process the grief experienced when a patient dies.

Optimizing the physical environment
Ensuring an optimal physical environment, including one that conforms to standards for noise and lighting, and one in which communication and safety concerns of nursing staff are adequately addressed, will facilitate staff satisfaction. Although redesign of NICUs with some or all single family rooms has been driven largely by the desire to support optimal infant development, this transition has also been associated with reported decreases in job stress and anxiety among nurses. Factors contributing to decreased stress include decreased noise levels, reduced crowding and a perception of the work environment as being more private, less distracting, less hectic and less fatiguing. In addition, nurses working in single family rooms NICUs are less likely to experience burnout and more likely to rank quality of care higher. These attributes of single family room NICUs may make it easier for hospitals to recruit and retain their workforce. There are, however, potential drawbacks to the single family rooms. Staff and families may feel isolated, and staffing and nurse-to-nurse communication can become more challenging. Importantly, Pineda et al. found that infants cared for in single family rooms had lower language scores and a trend toward lower motor scores at age 2 years, suggesting a potential adverse impact of more limited sensory stimulation. Further research is needed to determine the optimal type of NICU design that will best meet the needs of staff, families and babies.

Ensuring support from nursing, medical and hospital administration
Focusing on staff training alone is insufficient, as it neglects employment practices and issues of management style that contribute to burnout. Making sure that channels of communication between nursing staff and their supervisors are clear will provide nurses with an outlet to access support. Nursing administrators can also provide support to nurses through attention to best practices in staffing, including ensuring adequate staffing and provision of breaks, as well as days off and orientation and mentoring of new nurses. Nurses may also derive support from the institution of ‘no-tolerance’ policies for families who become verbally or physically threatening.

Medical administrators should be cognizant of work force issues that impact physician burnout and should ensure adequate staffing of the NICU’s medical team. Allowing physicians to exercise control over their hours and schedule is an important predictor of lower rates of physician burnout. The importance of physicians collaborating with other members of the NICU team should be emphasized and promoted.

Hospitals should provide support for staff who develop post-traumatic stress disorder or other psychological distress as needed, either through personal therapy, support groups, on-site counseling via employee assistance programs, pastoral care or other professional resources within the hospital. Employee wellness programs may also provide additional support through nutrition, art therapy, massage, group exercise and/or stress reduction classes.

SUMMARY
NICU staff work in a stressful environment and must balance caring for fragile, high-risk babies with providing psychosocial support to the babies’ families. Educating all staff and providing them with tools to better understand parents’ needs, to provide culturally effective family-centered care and to enhance their communication skills can both decrease parents’ risks to experience perinatal mood and anxiety disorders and increase parents’ satisfaction with their NICU experience. Educating staff about self-care and also providing them with support in a variety of ways can help to minimize the occurrence of burnout, compassion fatigue and secondary traumatic stress disorder. When staff are better prepared to handle the challenges of supporting NICU families in distress, then staff, babies and families benefit.

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