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journal homepage: [www.nainr.com](http://www.nainr.com)Transforming NICU Care to Provide Comprehensive Family Support<sup>☆☆</sup>Sue L. Hall, MD, MSW, FAAP<sup>a,\*</sup>, Raylene Phillips, MD, ICBLC, FAAP<sup>b</sup>, Michael T. Hynan, PhD<sup>c</sup><sup>a</sup> Division of Neonatology, St. John's Regional Medical Center, 1600 N. Rose Avenue, Oxnard, CA 93030<sup>b</sup> Loma Linda University Children's Hospital, 11175 Campus Street, Suite 11121, Loma Linda, CA 92354<sup>c</sup> Department of Psychology, University of Wisconsin-Milwaukee, PO Box 413, Milwaukee, WI 53201

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## ABSTRACT

Parents whose babies are admitted to neonatal intensive care units (NICUs) are subject to a variety of stresses that increase their risk to suffer from postpartum depression, posttraumatic stress disorder, and anxiety disorders. Parental distress can adversely impact parent-infant bonding, which in turn can lead to worse outcomes for the child. An interdisciplinary workgroup convened by the National Perinatal Association (NPA) has published recommendations for psychosocial support of NICU parents. This article presents nurses, who are key players in quality improvement (QI) initiatives in their hospitals, with a QI approach to transforming care in NICUs to provide comprehensive family support using the NPA recommendations as a road map.

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Nurses who work in neonatal intensive care units (NICUs) witness, on a daily basis, the trauma that can engulf parents: when their baby is born very early; is found to have anomalies or conditions that will require surgery and even perhaps life-long care; and is struggling to hang on to life. Parents can also be traumatized when their baby born at term is taken away from them and brought to the NICU for what medical professionals might consider a relatively minor problem; to the parents, a NICU stay for their newborn is never a minor occurrence. Indeed, the trauma is real and can have long-lasting effects, not only on parents' mental health but also on the bonds they forge with their baby,<sup>1,2</sup> and ultimately on their baby's long-term physical,<sup>3</sup> cognitive<sup>4</sup> social/behavioral<sup>5</sup> and emotional development.<sup>2,6</sup> Adverse mental health outcomes in NICU parents include higher rates of postpartum depression (PPD),<sup>1,4,7</sup> posttraumatic stress disorder (PTSD)<sup>8–10</sup> and anxiety disorders<sup>4,7</sup> compared with parents of healthy, term infants.

While technological advances in the NICU continue to contribute to increased survival rates of fragile infants, not enough attention has been paid to the well-being of the whole family to ensure that when a baby is ready to go home, s/he is discharged to parents who have been provided enough care and support to demonstrate their resiliency and readiness to care for all their baby's needs. Although family-centered care has long been recognized as a caregiving model that decreases or ameliorates parental distress, its actual implementation in many NICUs has fallen short of the mark.<sup>11–13</sup> Parents report feeling left out of the caregiving process, excluded from

decision-making and dissatisfied about communication with their baby's providers.<sup>14–17</sup> Parents are still suffering, often in silence, sometimes for years after their baby has left the NICU. Some NICUs are beginning to move in the direction of providing family-integrated care,<sup>18,19</sup> another model which has the potential to transform NICU care through hands-on parental involvement; however, its adoption is not yet widespread.

Recently, an interdisciplinary workgroup convened by the National Perinatal Association (NPA) focused attention on the pressing issue of expanding psychosocial support of NICU parents, resulting in the publication of a sweeping set of recommendations.<sup>20</sup> The recommendations, which speak to all disciplines involved in delivering NICU care, include best practices based on evidence and/or expert experience. These practices have been culled from research literature and from policy statements of major perinatal professional organizations such as the Neonatal-Perinatal Section of the American Academy of Pediatrics (AAP), the National Association of Neonatal Nurses (NANN), and the National Association of Perinatal Social Workers (NAPSW). Recommendations were developed in six areas: 1) expanding family-centered developmental care,<sup>21</sup> 2) ensuring the availability of peer support for all parents,<sup>22</sup> 3) defining the role of mental health professionals in the NICU,<sup>23</sup> 4) ensuring that palliative and bereavement care services are widely available and that staff are appropriately trained,<sup>24</sup> 5) improving discharge planning and post-discharge support for families,<sup>25</sup> and 6) making it mandatory to educate NICU staff in communication skills and parent support techniques as well as self-care.<sup>26</sup>

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### Top Ten Recommendations to Create Comprehensive Family Support in NICUs

The large number of recommendations proposed by the NPA Workgroup can be distilled into ten essential recommendations to provide comprehensive family support as follows:

1. Policies are in place to guide how NICU staff will routinely mentor parents in the developmental care of their babies.
2. Parent participation in medical rounds and nursing shift change reports is welcomed and encouraged. Parents are involved as 24/7 members of the care team.
3. The NICU has, or is affiliated with, a parent-to-parent peer support program, which is offered to all parents. Best practice includes a paid position for a parent support coordinator.
4. NICUs with more than 20 beds have a dedicated master's level social worker *and* a full- or part-time PhD psychologist on staff or available by consultation to provide verbal therapeutic support to parents according to a layered levels of support model as well as to support staff as needed. Larger NICUs should have proportionally more NICU mental health professionals (NMHPs) on staff.
5. NICU mental health professionals 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. Screening of both mothers and fathers should be done within the first week and repeated when practical, especially before discharge and when concerns arise.
6. The NICU has policies for palliative and bereavement care, and staff have been educated in how to deliver this care.
7. A NICU point person is responsible for coordinating pre-discharge needs of families, including specific educational needs, scheduling of appointments, ordering home supplies and equipment, and communicating with follow-up providers. Planning for transition to outpatient care should begin at admission to ensure appropriate care continues beyond discharge.
8. At NICU discharge, every family is connected with some type of follow-up support, whether provided through a phone contact or in-person visit by a community-based public health home visiting program, a NICU nurse, therapist or developmental specialist or a continued relationship with a peer mentor. Post-discharge support should include screening for emotional distress and para-professional therapeutic support.
9. NICU staff regularly (once a year or more frequently) receive education on the psychosocial needs of parents and how to meet these needs, as well as education on self-care to minimize burnout.
10. A pastoral care staff person is embedded in the NICU staff team, to provide both parents and staff with support.

Taken all together, the recommendations can serve as a road map for transforming NICUs from places where medical care of the baby is the singular focus and care and involvement of the parents is merely an afterthought, to places where parents are fully embraced as active participants and essential members of the caregiving team and mentored in how to step confidently into their role as parents, thereby enhancing the well-being of the entire family. An important component of mentoring parents in the NICU is to recognize, address and normalize their distress as a common and expected response to their situation. But how can a NICU staff that would like to improve their practices for supporting families start this process?

### Quality Improvement Processes

Nurses have long been leaders and key players in quality improvement (QI) projects throughout U.S. hospitals, as noted in “Crossing the Quality Chasm,” the groundbreaking report published by The Institute of Medicine (IOM) in 2001.<sup>27</sup> Quality improvement initiatives in NICUs may be hospital-specific, or they may be carried out as part of larger efforts such as those sponsored by state or regional perinatal quality collaboratives, including the Vermont Oxford Quality Improvement Collaboratives.<sup>28,29</sup> Significant strides have been made through these multidisciplinary efforts in reducing nosocomial and central-line associated infections,<sup>30,31</sup> increasing rates of exclusive

breastfeeding,<sup>30,32</sup> improving care during the “Golden Hour” after a baby’s admission,<sup>33,34</sup> improving pain management for neonates,<sup>35</sup> reducing the incidence of Bronchopulmonary dysplasia in very low birth weight infants<sup>36</sup> and shortening length of stay for babies with neonatal abstinence syndrome.<sup>37</sup> Quality improvement work has also been done to improve provision of family-centered care.<sup>38,39</sup>

Many, if not most, nurses are already familiar with QI methods, such as those outlined by the Institute for Healthcare Improvement in their Breakthrough Series model<sup>40</sup> and in the Transforming Care at the Bedside model.<sup>41</sup> The importance of nursing involvement in QI initiatives has also been recognized by the American Nurses Credentialing Center as one of the practice pathway standards necessary to complete their Magnet Recognition Program®.<sup>42</sup>

In hospitals that have earned the “Baby Friendly” designation, nurses have been intimately involved in helping their own hospital practices transform by utilizing the plans laid out in the Baby Friendly Hospital Initiative.<sup>43</sup> The model described by The Baby Friendly Hospital Initiative can be borrowed and adapted to serve as an outline for encouraging development of comprehensive family support. As in all QI projects, a pre-assessment is the first step. A NICU leader, nurse manager, or QI team could engage other NICU staff in a self-assessment process to determine the degree to which support for NICU parents is truly comprehensive, as outlined in the Interdisciplinary Recommendations for Psychosocial Support of NICU Parents.<sup>18</sup> Once an assessment is completed, an interdisciplinary task force can be created. Suggested members could include neonatal nurses, neonatal nurse practitioners, neonatologists, neonatal therapists (occupational and physical therapists, speech/language pathologists, and respiratory care specialists), lactation consultants, chaplains, social workers, psychologists, child life specialists, palliative care/hospice teams, and even members of the housekeeping staff, reception secretaries and other ancillary services.<sup>44</sup> It would also be important to include nurses and other practitioners from the Labor and Delivery and High-Risk Obstetrical Clinic or inpatient services, as well as High-Risk Infant Follow-Up Clinic and community home visiting agencies that provide follow-up care to families.

Engaging these professionals will help ensure that continuity of support is provided to parents beginning in the antepartum period and continuing through and beyond the transition to outpatient care. It is also critically important to have NICU graduate parent representatives on the task force to bring the essential parent voice to the change process and to keep the focus on family-centered care as a core principle.<sup>28</sup> Ellsburly and Ursprung have written a good primer on QI methodology for neonatology which outlines the process in detail.<sup>45</sup>

Once a task force to improve comprehensive family support has been convened, members can decide where they want to focus their efforts first, and then develop work plans accordingly. A natural starting point would be development of a comprehensive family support policy, including mission and vision statements, which could set the tone and establish the unit’s culture and commitment to supporting families in as many ways as possible. This global policy would inform the development of other related policies, such as those addressing family-centered developmental care, palliative care, discharge planning, staff education and so on. After development of a global policy, the task force can then select specific projects from among the 86 recommendations made by the NPA workgroup,<sup>46</sup> design projects that meet their own NICU’s specific needs for improvement, or join family-focused projects being conducted by QI collaboratives in which they might already be involved.

Recruiting motivated nurses and other NICU staff to join teams for each project is important to create a sense of ownership and buy-in from staff. Teams then embark on the Plan-Do-Study-Act cycle.<sup>45</sup> In order to “plan,” staff will be required to answer the following questions: What will we do? Who will do it? When and where will it be done? During the “do” phase, pre-intervention data will be collected, specific changes will be implemented and then data collected again after the intervention is completed. Results will be analyzed during the “study” phase, and if results are not as hoped for, the team will go back to the

**Table 1**  
NICU Self-Assessment Tool.

Family-Centered Developmental Care	Yes	No
1. Are introductory resources and materials for parents available in multiple different languages to reflect the NICU's patient population?		
2. Are parents allowed and encouraged to attend and participate in medical rounds? Nursing shift change reports?		
3. Do the NICU staff regard parents as equal members of the caregiving team?		
4. Do NICU nurses view their roles with parents to be coaches and mentors in their baby's care?		
5. Do parents have unlimited access to be with their baby?		
6. Do parents have unlimited access to their baby's medical records?		
7. Does the NICU offer a curriculum to help parents learn behavioral signs of stress in their baby?		
8. Does the NICU have a dedicated specialist (Child Life Specialist or other person) to focus on providing resources for and coaching parents on developmentally appropriate support of siblings?		
9. Is the stress of grandparents acknowledged and addressed and is their special role as support to parents honored and encouraged?		
10. Are interpreters or an interpreter service readily available to staff and parents at all times?		
11. Do all staff receive training in provision of family-centered developmental care?		
<i>Peer-to-Peer Support</i>		
1. Does the NICU have a relationship with a peer support organization that actively reaches out to parents in the NICU?		
2. Have NICU and hospital administration worked through any concerns about HIPPA and the volunteers' roles?		
3. What types of peer support programs might work in your NICU?		
<ul style="list-style-type: none"> <li>• in-person contact</li> <li>• phone contact</li> <li>• groups</li> </ul>		
4. Does a NICU staff person work with the peer support organization to ensure volunteer training is comprehensive and on target?		
5. Is space provided within the NICU for parents and volunteer mentors to meet, either individually or in groups?		
6. Are sibling programs and childcare options provided for parents who wish to meet with a peer support person?		
7. Does the NICU have a paid position for a parent support coordinator?		
8. Does the NICU have a parent advisory board?		
9. Are graduate parents involved in the Quality Improvement process?		
<b>NICU Mental Health Professionals</b>		
1. Does the NICU have adequate/appropriate staffing of NMHPs?		
2. Do NMHPs initiate contact with mothers who are hospitalized in the antepartum area of the hospital?		
3. Does the NICU have a policy that NMHPs meet with all parents within 3 days of admission?		
4. Has the NMHP team decided who will screen parents for emotional distress and what method will be utilized for screening?		
5. Is there a policy for repeated screening?		
6. Does the NICU provide dedicated time for NMHP counseling for parents in the NICU?		
7. Are there regular education/support groups for parents supervised by NMHPs and other staff/parent volunteers?		
8. Does the NICU have a list of referral resources for outside counselors for parents in need?		
9. Do the referral resources include therapists from hospital behavioral health departments doing outpatient therapy in the NICU?		
10. Are telehealth services utilized? Is there a role for them?		
11. Does the NICU have policies regarding confidentiality of parental screening and therapy information that can be communicated to other health care providers?		
<b>Palliative and Bereavement Care</b>		
1. Do Labor and Delivery, the NICU, and well baby nursery share policies for palliative care?		
2. Does the Labor and Delivery service have a template for a Birth Plan for parents that are anticipating loss in the neonatal period?		
3. Are parents anticipating an early loss offered a multidisciplinary antenatal consult?		
4. Is there a list of bereavement interventions that can be offered to parents, and is it known to all staff in Labor and Delivery, the NICU and well baby nursery?		
5. Do the perinatal service areas of the hospital (Labor & Delivery and NICU) have a working relationship with an organization either locally or nationally that provides remembrance photography?		
6. Does the NICU team receive training in provision of palliative care?		
7. Does the NICU medical team receive training in how to deliver 'bad news'?		
8. Does the NICU have a working relationship with the local organ donation agency?		
<b>NICU Discharge and Follow-Up</b>		
1. Are NICU parents rescreened for emotional distress prior to their baby's discharge (if NICU stay has been > 1 week), and results communicated to follow-up providers?		
2. Does every family receive some type of home visitation or follow-up phone call after their baby's discharge?		
3. Does the NICU staff have a standardized checklist to review with parents before their baby's discharge?		
4. Does every follow-up provider receive a copy of the baby's medical record, or have access to the electronic medical record?		
5. Does the NICU staff make first follow-up appointments for babies so that parents are relieved of this stress?		
6. Are parents given written discharge information, appointments, and copies of their baby's medical record prior to discharge?		
<b>Staff Education and Support</b>		
1. Do all new nursing hires and NICU staff get education about how to provide paraprofessional psychosocial support to NICU parents within the first two months of starting their position?		
2. Does the NICU staff embrace a team spirit in terms of interdisciplinary cooperation?		
3. Do bedside nurses and physician/NNP staff self-report a low rate of burnout?		
4. Does the NICU staff regularly (once a year or more frequently) receive education on the psychosocial needs of parents and how to meet these needs, as well as education on self-care to minimize burnout?		
5. Do bedside nurses generally feel supported by nursing administration, particularly in terms of staffing patterns?		
6. Does the hospital offer psychological support services for staff who suffer from burnout or posttraumatic stress disorder related to patient care?		
7. Is the NICU physical environment optimal for promoting staff satisfaction? What could be improved?		
8. Does the NICU medical team follow a protocol for routinely communicating with parents?		
9. Is a member of the hospital's pastoral care staff embedded in the NICU team?		

“plan” and “do” steps. Once change has been achieved, perhaps in a pilot group, the project can be implemented on a broader scale in the “act” phase, and the team can also pick its next target for improvement. Staff training will necessarily be a critical part of the process. Continued monitoring of data from projects that have been successful is necessary to ensure gains are solidified. A checklist that can be used during the NICU’s self-assessment is shown in [Table 1](#).

### Specific Quality Improvement Projects

Ideas for specific quality improvement projects in each of the six areas of recommendations by the NPA Workgroup are shown below.

#### Family-Centered Developmental Care

1. Every parent is given written and verbal information about the benefits of skin-to-skin care and encouraged to hold their baby skin-to-skin as often as possible. Receipt of this information is documented in a predetermined location in the baby’s chart.
2. Increase the number of hours of skin-to-skin/kangaroo care parents provided per baby.
3. Increase the percentage of parents who participate in a curriculum to learn behavioral signs of stress, relaxation, and feeding cues in their baby.

#### Peer-to-Peer Support

1. All parents, including bereaved parents, are given information about peer support programs and are offered the opportunity to participate within 3 days of their baby’s NICU admission. This information is documented in a predetermined location in the baby’s chart.
2. The majority of NICU parents who utilize the peer support program find it to be helpful. (Questionnaire, see below for ideas)
  - a. My mentor parent provided me with emotional support. Y/N
  - b. My mentor parent helped me get through my baby’s NICU stay. Y/N
  - c. I felt my parent mentor was a good match for me. Y/N
  - d. I felt my parent mentor cared about my family and my baby. Y/N
  - e. My parent mentor really listened to my concerns. Y/N

#### NICU Mental Health Professionals (NMHP)

1. A NMHP staff person meets with every parent within 1–3 days of baby’s admission and documents this contact in a predetermined location in the baby’s chart.
2. Every NICU parent is screened for emotional distress within 1 week after their baby’s admission, and this contact is documented in a predetermined location in the baby’s chart.
3. A list of referral resources for emotional support of parents is created and continually updated.

#### Palliative and Bereavement Care

1. Every bereaved family receives a 1–2 week follow-up note from the NICU staff.
2. Every bereaved family is offered a multidisciplinary follow-up conference 4–6 weeks after their baby’s death.

#### NICU Discharge and Follow-Up

1. Every parent receives a folder with discharge information prepared specifically for them (containing care instructions, medication information sheets, appointments, and a copy of the discharge summary).
2. Parents feel prepared for discharge. Initiate a post-discharge survey.
  - a. I feel the NICU staff prepared me for how to take care of my baby. Y/N
  - b. I feel the NICU staff prepared me for the different emotions I might feel once I got home with my baby. Y/N
  - c. I was satisfied with all the appointments the NICU team made for me before discharge. Y/N

- d. I was offered an opportunity to room in to provide the care for my baby before discharge. Y/N
- e. I felt like I knew my baby well by the time she was discharged. Y/N

#### Staff Education and Support

1. All staff engage in education about psychosocial support for NICU parents on an annual basis.
2. Parents are satisfied with the communication provided by the NICU team. (Track patient satisfaction surveys or create your own.)

### Summary

In summary, creating a culture to promote comprehensive family support in the NICU can be beneficial to babies, their parents, and NICU staff as well. There is much that can be done to normalize the reactions parents have to their NICU experience, and many ways to improve care so that families feel optimally supported and empowered. Doing so has the potential to improve parents’ functioning while they are in the NICU and once they are home, enhance their bonds of attachment with their baby and improve their child’s ultimate outcome. While babies can survive without their families, optimal physical, cognitive and emotional development occurs only within the context of loving, positive interactions with their parents or emotionally-involved primary caregivers. Providing psychosocial support to families in the NICU should not be considered an optional activity, but should be the foundation upon which NICU staff provide excellent medical care. NICU staff who are educated in providing such support feel empowered in their caregiving roles and find reward in the improved well-being of families in the NICU.

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