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Rationale for Development of a Comprehensive Family Support Program for NICU Parents “The Business Case for Comprehensive Family Support”

INTRODUCTION

In December, 2015, a multidisciplinary workgroup convened by the National Perinatal Association published a Supplement Issue to the *Journal of Perinatology*, entitled “Interdisciplinary Recommendations for the Psychosocial Support of NICU Parents” (SL Hall and MT Hynan, Co-Editors). The six articles in the Supplement contained numerous recommendations for improving psychosocial support of NICU parents representing “best practices” as supported by research and/or expert consensus opinion.

While many of the recommendations can be implemented through quality improvement processes by multidisciplinary NICU teams, several require a strong administrative commitment and may also require commitment of additional financial resources to bring them to fruition. In particular, the hiring of a NICU psychologist, and the development of a hospital-based peer support program or incorporation of a community-based peer support program, are among the recommendations that require buy-in from both NICU and hospital administration.

This document was created to help NICU staff lay out the case for senior hospital management about why these two initiatives are important to providing holistic care and comprehensive family support in the NICU. In addition, program issues that need to be considered to allow for smooth integration of these vital services are highlighted, to provide a basis for further discussion and planning. These include an examination of institutional requirements, potential roadblocks, and how the value of such a program might be measured.

RATIONALE FOR DEVELOPING A COMPREHENSIVE FAMILY SUPPORT PROGRAM FOR NICU PARENTS

What does “Comprehensive Family Support” consist of?

- Ideally, comprehensive family support would include the following program elements:
 - NICU staff psychologist, in addition to social work staff which every NICU should already have
 - Peer support program, either hospital-based or community-based
 - Policies and procedures for family-centered developmental care
 - Policies and procedures for a palliative care program and bereavement support
 - Comprehensive discharge planning and post-discharge support services
 - Curricula for staff education, and support services for NICU staff

- A best practice would be to have a paid Family Support coordinator, particularly if the peer support program is hospital-based (to ensure its smooth functioning and longevity)

Why do NICU parents need comprehensive family support?

- NICU parents are well-documented to have higher rates of depression, posttraumatic stress disorder and anxiety disorders (PMAD = perinatal mood and anxiety disorders) than parents of healthy, term infants.
 - Parents may come in to the NICU with risk factors for impaired coping ability and development of mental health issues (such as history of prior perinatal losses including miscarriage and/or stillbirth, infertility, any type of high risk pregnancy, substance abuse, exposure to intimate partner violence, history of mental illness including previous postpartum depression, poor social supports), and the NICU experience may contribute to escalating distress.
 - When parents are distressed or depressed, their interactions with their infants may be impaired, and less sensitive and less attuned to their infant's needs, and this in turn leads to impaired social, emotional, cognitive and physical development in their infants.
 - Supporting NICU parents leads to improved developmental outcomes for their infants.
- Parents' own support network of family and friends may not be available and may not understand their situation, may not be supportive due to their own grief and concern, and may even make matters worse for the parents.

Why should hospitals offer comprehensive family support to NICU parents?

- Comprehensive family support of NICU parents may result in shorter length of stays for NICU babies due to their parents' increased competence at caregiving. This may ultimately result in lower hospital costs especially under DRG or bundled payment scenarios.
- Provision of comprehensive family support is likely to lead to lower hospital readmission rates for NICU babies, because parents will be more competent and confident at caregiving by the time of hospital discharge.
- The hospital can view the family support program as an "added value" program they are offering to parents. "In addition to your baby getting the best medical care possible, your family will also receive the care and support you need to help you through this difficult experience." This could be a distinguishing feature in a competitive marketplace; conversely, the absence of having a family support program could be a drawback in a competitive marketplace when other NICUs are already offering these services.
- In the upcoming era of "pay for performance," reimbursement rates may become tied to patient satisfaction scores, which should go up with provision of comprehensive family support.
- Since young women and mothers are key drivers of traffic to healthcare systems, ensuring that mothers have a positive experience is crucial in ensuring their loyalty in choosing the hospital for their family's future healthcare needs. These may include future visits with their baby to the Emergency Department, the Pediatric Intensive Care Unit, and future family visits to the Maternity Ward with subsequent pregnancies.
- Hospital management should consider how strengthening family support services aligns with the hospital's stated Mission and Vision.

HIRING A NICU MENTAL HEALTH PROFESSIONAL (PSYCHOLOGIST)

Why hire a NICU psychologist?

- NICU parents are not likely to leave their baby's bedside to go access mental health services in the community. Delivery of psychosocial support services at the point of care is the emerging model in behavioral health.
- A NICU psychologist can fulfill many roles, some of which can be interchangeable with NICU social workers:
 - Perform screening for emotional distress in parents
 - Identify and treat potential traumatic events
 - Provide one-to-one supportive and therapeutic services to parents, including trauma-informed care
 - Serve to "prevent fragmentation" in parents' lives and help them to create a coherent narrative of their experience
 - Provide support to parents through groups that are therapeutic and/or educational
 - Provide education to parents about infant development and infant mental health
 - Provide support to NICU staff
 - Provide education to NICU staff to help them understand expected reactions of NICU parents and how to best support parents
 - Work with the concentric and intersecting linked layers of relationships that all affect the baby's outcome: the parental couple, mother/father/baby, parents' nuclear family, intersecting relationships with nurses and then doctors and nurses
 - Conduct clinical research to further knowledge about epidemiology of mental health issues in NICU parents and efficacy of various therapeutic interventions
- Psychologists can augment the supportive services that social workers may currently be providing to parents with higher levels of distress and psychopathology, offering far more therapeutic interventions with families.
- Social workers may be required to fulfill some case management duties, leaving them less free to attend to parents' emotional and mental health needs.

Why should a NICU psychologist have a PhD rather than a Master's degree?

- A PhD psychologist uniquely offers the ability to conduct research, provide consultation across specialties and providers, lead out in program development, integrate developmental care with the mental health of parents, and also possesses a more varied and deeper knowledge of group and systems processes than a Master's level mental health clinician would.
- A doctoral level psychologist can function independently, have full access to the physicians by whom they are viewed as being on the same level, and provide them with corrective feedback, education, and support in their work. Mid-level providers and social workers are viewed differently by physicians and, thus, serve a different role.

NICU parents who receive emotional support show:

- Lower rates of symptoms of depression, posttraumatic stress symptoms, and anxiety.
- Increased responsiveness to their infants and improved bonding with their infants.
 - Greater empowerment in their roles as parents.

- Increased capacity to integrate and find meaning in the NICU experience.
- Improved ability to negotiate needs with their partners, family, and medical caregivers.

How can a NICU psychologist be helpful to NICU staff?

- An important role psychologists can play is to support NICU staff. This can be done by:
 - Providing staff education, including education of neonatal fellows
 - Helping staff understand parents' reactions and better interface with them
 - Helping staff process their experiences and better communicate between disciplines
 - Translating the psychosocial language of families into the biomedical language of the medical team
 - Providing debriefing sessions for staff to help them process difficult emotions around morally distressing situations or patient deaths
 - Participating in training of volunteer peer mentors
- Providing staff support should lead to lower rates of burnout among NICU staff; typical burnout rates among nurses and doctors working in NICU are around 40%.
- Reducing staff burnout can lead to the following positive results:
 - Reduction in medical errors
 - Reduction in hospital-acquired infections
 - Reduction in staff turnover, which can be expensive for hospitals
 - Improved employee satisfaction and morale
 - Improved patient satisfaction

What kinds of programmatic issues might need attention?

- Ensure all of the hospital's internal resources and relationships are already leveraged to provide supportive services to NICU families: e.g., Chaplaincy, allied behavioral health departments, social work, etc.
- Consider whether case management staff can relieve social workers of case management and discharge planning duties to free up their time to concentrate on evaluation and support of parents.
- Try to envision with whom a NICU psychologist would need to interface and collaborate (palliative care team, ethics committee, social work staff, behavioral health staff, peer support program staff, perinatology and antepartum staff, community follow-up agency staff), and get buy-in from these staff before hiring a psychologist.
- Consider whether any mental health "care extenders," such as psychiatric nurse practitioners, or any trained paraprofessionals including bedside nurses and nurse practitioners, can play a role in providing screening or delivering care and/or education to parents.
- Try to identify areas of role overlap such as between psychology, social work and other helping professions so that roles can be clearly defined, to enhance collaboration and to avoid "turf wars."
- How will NICU mental health staff chart in the medical record (if parents are not patients in the hospital) and how will they bill for service delivery? See document by the National Perinatal Association entitled "Information for NICU Mental Health Professionals" for suggestions about charting and about billing codes.

- Consider first focusing efforts of the NICU mental health professional staff on care of parents and families, and then later expanding their efforts to support of the NICU staff.

What resources might the hospital have to provide?

- Salary for new NICU mental health professional(s).
- Identification of chain of command (pathway for reporting to a supervisor).
- Office space for new employee.
- Consultation space/meeting room for mental health services and group meetings with parents.
- If an academic center, consideration of in which division/department the NMHP be included.

How can a hospital measure the value that a NICU psychologist provides to the program?

- There are currently no accepted measures to determine a psychologist's "value" to a NICU.
- Researchers will need to gather data on how psychological service delivery in the NICU impacts measures of infant and parental well-being.
- Hospitals can consider looking at the following measures as proxies for improved parental and infant well-being, and staff well-being, which might be expected to improve with a psychologist on staff:
 - Reduced length of stay of babies
 - Reduced total cost of NICU stay
 - Reduced rates of parental depression, posttraumatic stress disorder and anxiety disorder compared with historical controls (published rates) or reduce rates of these disorders on screening tests at NICU discharge compared with admission
 - Improved patient satisfaction scores
 - Reduced rates of self-reported burnout among staff
 - Reduced turnover among nursing staff, and reduced costs related to hiring and training new staff

DEVELOPMENT OF A PEER SUPPORT PROGRAM

Why do NICU parents need peer support?

- A veteran NICU parent is more likely to understand what the current NICU parent is going through, to a greater degree than a member of the NICU professional staff. Parents find acceptance without judgment from veteran NICU parents, those who have been through what they are now going through, and can talk with them in non-medical terms.
- Parents will have a consistent support person through multiple "hand-offs" of their care during their hospital stay and into the community, and continued access to their support person after their baby's discharge.

Why offer peer support to NICU parents?

- Peer support is a core principle of family-centered care.
- In 2012, the American Academy of Pediatrics recommended that health care professionals should facilitate and encourage peer support.
- Peer support is likely to indirectly result in improved scores on patient satisfaction surveys.

- Hospitals that already provide peer support to NICU parents report anecdotally that they are seeing fewer incidents involving “angry” parents in the NICU, fewer requests from parents to change their baby’s nursing assignment, and fewer phone calls back to the NICU after discharge.
- Using trained volunteer parents to provide support to parents can extend—but not replace—supportive services offered by the paid hospital staff such as social workers and psychologists.

NICU parents who receive peer support show:

- Increased confidence and well-being in their parental role
- Improved problem-solving capacity and adaptive coping
- Increased perception of social support, self-esteem, and acceptance of their situation
- Increased interactions and more nurturing behavior with their infants during more frequent visits to the hospital
- Reduced parental stress, anxiety, and depression

What kinds of programmatic issues might need attention?

- The NICU will have to decide what types of peer support services it wants to provide from among a menu of services (most hospitals offer a combination): one-to-one peer support relationships provided by volunteer mentor parents (in person, by email, or by telephone), and/or parent support groups.
- Another model is to employ Parent Hosts. For example, the NICU at the C.S. Mott Children’s Hospital in Ann Arbor, MI employs three graduate NICU parents who serve as “hosts” to new and incoming NICU parents. They are scheduled so one of them is in the NICU during extended hours most days. Their role is to orient and assist families with the hospital experience through peer support, personal comfort, learning tools, and helping to navigate the hospital environment.
- Support from administration of both the hospital and the NICU (both medical and nursing) is imperative to ensure success of the peer support program.
- Some NICU staff may be resistant, feeling that they are already offering adequate services to parents, not trusting veteran parents and not wanting their roles to be infringed upon. Making volunteers’ roles clear at the outset can minimize any friction.
- Concerns will likely be raised about whether volunteers can be entrusted to perform appropriately in the environment of HIPPA regulations. These concerns can be addressed by providing careful training and supervision of volunteers, specifically educating them about their responsibilities to maintain confidentiality related to HIPPA, and by having them sign a Confidentiality Agreement.
- Lines of communication between parent peer volunteers and NICU staff will need to be clearly outlined, especially including how the volunteers will interface with the bedside nursing staff and the NICU mental health professional staff. Identifying a key institutional point person for peer volunteers to relate to, whether it’s a paid Family Support Coordinator, a NICU staff psychologist or social worker, nursing director or some other person, will be important to the program’s smooth functioning.

What resources might the hospital have to provide?

- The hospital can start its own program which it can solely fund, or allow/encourage a support group already operating in the area with its own funding to come in to provide services. In the latter case, the hospital can be a good faith partner by underwriting some costs to the volunteer organization, either financial or in-kind contributions, or both. Examples of in-kind donations include meeting/work space for peer support staff and volunteers, and access to items like paper, copy machines, etc.
- For hospitals with large NICUs, funding a Family Support Coordinator position would be advisable to ensure smooth functioning of the program and to ensure its longevity.
- NICU staff members can collaborate and cooperate with the parent support organization, and offer their time to help with volunteer training, group educational and support meetings with parents, and other activities.
- Hospitals will want to require that all parent volunteers go through the hospital's volunteer training program, in addition to the peer support group's specific training program.
- See also the document by the National Perinatal Association entitled "Starting and Sustaining a Peer Support Program for NICU Parents," available on our resource website at <http://support4nicuparents.org/wp-content/uploads/2016/08/Starting-a-Peer-Support-Group-Aug-2016.pdf>.

References to support this document can be found in the December, 2015 Supplement Issue to the *Journal of Perinatology*, entitled "Interdisciplinary Recommendations for the Psychosocial Support of NICU Parents," SL Hall and MT Hynan, Co-Editors.

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Please feel free to email any of the contributors for questions, or if you want to discuss strategy for improving comprehensive family support in your NICU, or email info@support4nicuparents.org.

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