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Talking Points About Starting a Peer Support Program

To start your hospital's own peer support program, or to get "permission" for a community peer support program to come into your NICU, you may have to convince your hospital's administrators of the need for this. Below are some "talking points" that you can use to make your case for the importance of having a peer support program in the NICU.

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. One of these is the development of a hospital-based peer support program or incorporation of a community-based peer support program.

This document was created to help NICU staff lay out the case for senior hospital management about why having a peer support program is 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.

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.

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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