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Supporting Families as They Transition Home

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ABSTRACT

For families who are leaving the neonatal intensive care unit (NICU) or other intensive care and going home with their child, the transition is often accompanied by intense and complex emotions. NICU discharge readiness for infants reflects attainment of physiological maturity. However, discharge readiness for parents is defined as the masterful attainment of technical skills and knowledge, emotional comfort, and confidence with infant care at the time of discharge. Discharge preparation is the process of facilitating comfort and confidence as well as the acquisition of knowledge and skills to successfully transition home. A comprehensive approach to discharge/transition planning that includes psycho-social support and a focus on the caregiver–child relationship offers families the support they need and deserve at a critical time in their lives. After discharge, follow-up should occur in a medical home and be supported by the wide range of programs and services available to babies and families when they leave the NICU or other intensive care unit. It is important for hospital and community programs to establish strong relationships with each other and to be knowledgeable about each other's systems and services so that families can experience a safe and smooth transition home.

For families who are leaving the neonatal intensive care unit (NICU) and other intensive care settings and going home with their child, the transition is often accompanied by intense and conflicting feelings with parents reporting feeling excited, scared, and often quite unprepared. Despite the excitement of finally having the family together, many parents or primary caregivers experience a high level of stress and anxiety before, during, and after the transition from the NICU to home. They are leaving an environment where they trust their baby is being well-cared for and suddenly are carrying the weight of this responsibility themselves, while at the same time having to meet demands related to the needs of their other children and family members, their jobs, bills, insurance company interactions, and numerous other stressors. Throughout this manuscript, we use the term “parent”, but the discussion could apply to any primary adult who cares for a child, including guardians, grandparents, and foster parents.

Compounding these identified stressors is the fact that caregivers are at high risk for a wide variety of perinatal mood disorders (e.g., postpartum depression, anxiety disorder, post-traumatic stress disorder [PTSD]) which may or may not be recognized and addressed during their hospital stay.[34] These mental health issues can affect parents' ability to absorb and remember the information offered to them. Some parents may have a history of mental health problems or have experienced perinatal loss related to fertility issues, previous fragile infancies, or even mortality. These may all have a significant impact on caregiver well-being. Parents' emotional status can impact their belief in their own competence as a parent, which in turn will affect their attachment relationship with their baby.[10] Parental mental health problems can negatively impact their baby's development.[24]

The field of infant and early childhood mental health guides us to consider the caregiver and baby as a dyad, and whenever possible to promote and support a positive parent–child attachment relationship. Our goal in this article is to offer ideas and considerations about how keeping a focus on the parent–infant relationship during the discharge/transition process can promote optimal outcomes for both baby and caregiver and help mitigate some of the potential challenges they face. We aim to infuse an infant mental health perspective into the transition from the intensive care unit to home. We also outline some ways in which intensive care and community providers can work together to create a well-coordinated and integrated system of care which allows families to feel held, known, and cared-for as they make this much-anticipated transition.

Discharge Readiness of a Family

The goal of the following discussion is to combine infant mental health approaches with the logistics of discharge preparation for the family. It is well established that babies who have been hospitalized in a NICU are at high-risk for hospital re-admission,[15,17,30] and that a well-supported transition can reduce this risk. A comprehensive

Abbreviations: AAP, American Academy of Pediatrics; CCS, California Children's Services; CHSC, Child Health Specialty Clinics; FCC, Family Centered Care; HRIF, High Risk Infant Follow-Up; HRPP/NICP, Program High Risk Perinatal Program/Newborn Intensive Care Program; PTSD, post-traumatic stress disorder; NICU, neonatal intensive care unit; SWH, Smooth Way Home Program.

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approach to discharge/transition planning that includes psychological and social support and focuses on the caregiver–child relationship offers families the support they need and deserve at a critical time in their lives. How the discharge process occurs is vital to ensuring the competence and confidence of primary caregivers and a safe transition from NICU to home for infants and their families.

There are two related concepts involved in this transition process: 1) the discharge readiness of the family and 2) the integrated and coordinated transition back into the community. Discharge readiness for a family has two components, the discharge readiness of the infant and the preparation of the parents to care for their infant after the transition.

Discharge Readiness of the Infant

For the infant, the transition to home may occur when the infant achieves physiologic maturity and has completed all pre-discharge testing and treatment. To be ready for discharge the infant has to be able to maintain his or her temperature in an open environment, demonstrate consistent appropriate weight gain, be free of unsafe apnea, oxygen desaturation, and bradycardia events for at least 5 days, and have the ability to sleep with the head of the bed flat without compromising the infant's health and safety.[14,27] Offering parents information about the specific needs and status of their baby, and enlisting them as true collaborators in transition planning for their baby, have positive outcomes for parents and babies.[7,24]

Discharge Readiness and Preparation of the Parents

Parental discharge readiness is the desired *outcome* to discharge planning, and discharge preparation is the *process* by which it is achieved.[27] Parental NICU discharge readiness is described as the attainment of technical skills and knowledge, emotional comfort, and confidence with infant care by the parents at the time of discharge.[27] Parental NICU discharge preparation is the process of facilitating discharge readiness to successfully make the transition from the NICU to home.[27] A successful transition for the parents involves acquiring technical skills and infant care knowledge, preparation of the home environment where the infant will be joining the family, and management of the complicated emotions that can be associated with the pregnancy, birth, NICU hospitalization/discharge, and beyond.

A successful transition should involve an active discharge preparation program for parental involvement and training to ensure the ability to care for their infant at home as well as arrangements for ongoing medical care of the infant after discharge in a medical home by a physician or other health care professional who is experienced in the care of high-risk infants including an organized program of tracking and surveillance to monitor growth and development.[14,27]

Discharge Planning Using Family Centered Care (FCC) Principles

For parents, the transition to home is more complex. The parents will be the infant's primary caregivers and should be their primary attachment figures. Keeping this concept in mind, the discharge preparation program should be grounded in Family Centered Care (FCC). FCC embodies the concept that parents are an integral part of the care team who work in partnership with the medical providers on decision-making and providing care for the infant. The four central tenets of family centered care are family participation in care, information sharing, family collaboration and shared decision making, and dignity and respect for the family and their role in the infant's life.[9] FCC may ameliorate the stressors that families experience due to the separation from their infant, inability to experience a traditional parenting role, and the inclusion of multiple caregivers in daily care.[9,21]

Structured discharge education and support should begin early and be distributed throughout the NICU hospitalization to prevent the family from being overwhelmed with a large volume of content near end of the hospitalization.[27] Elements of the discharge educational program should be tailored to the family's specific circumstance and structured to include the skills and knowledge parents are expected to master.[27] Parents should be provided adequate opportunities to practice skills initially under direct supervision and then with supervisory support as needed. Repetition and return demonstrations (i.e., teach-back technique) can be used to increase parental retention of the education content.[27] The approach should offer frequent opportunities to evaluate progress and have the capacity for adjustment as necessary.

Discharge preparation programs are generally good at providing technical skills instruction. Often, technical skills like breast and/or bottle feeding; mixing formula; administering and storing medications; as well as infant care items such as bathing; diapering; temperature taking; dressing; caring for the skin, the umbilical cord and the genitalia; and safe sleeping positioning are the primary focus of the discharge teaching.[31,27] However, discharge preparation programs should also provide information about normal and concerning preterm infant behavior as well as abnormal signs and symptoms that should prompt the parents to seek advice from the medical home.[27]

As part of the transition home, parents will need to acquire food, clothes, other supplies, and explore available social support.[27] Awareness of these types of home environment needs can be communicated as part of a discharge preparation program. The discharge preparation program should also include anticipatory guidance designed to provide the family with a realistic idea of what their home life will be like (e.g., sleep deprivation, medical home visits, management of visitors, and other expectations) during the immediate and more long-term period following the transition home from the NICU.[27] The need for parental self-care is critical but not often discussed, planned for, or acknowledged as important during the transition process. Parents often report feeling guilty about taking any time at all for themselves. Lack of sleep can become a really critical issue.[4] Parents of NICU patients experience a combination of related emotional responses and alteration in sleep.[4] Sleep disturbance among parents of NICU infants has been demonstrated and associated with the occurrence of anxiety, depression, and fatigue.[4]

Discharge preparation should be individualized to the specific family such that it is racially, ethnically and cultural sensitive and responsive as well as appropriate for their sociodemographic and literacy level.[20,27] When discharge planning is done adequately, it can build and support parents' sense of confidence and competence in caring for their baby. These feeling contribute to a successful transition home but can be challenging to acquire during emotionally charged milieu of the NICU experience.[11]

As noted previously the discharge planning process can be heavily task and skill-oriented with parents being provided with significant and often overwhelming amounts of information. Commonly, less time is spent sitting down with the family to listen to how they are doing and what they are feeling. While the technical skills and knowledge are an essential part of discharge planning, it is also important for a successful transition to find out what the parents are worried about and/or don't understand. A comprehensive family assessment can aid in individualized education and preparation prior to discharge. Family assessment includes asking the family how they are doing and what they need. Some questions to keep in mind are the following: 1) What is the family structure and what are their cultural beliefs? 2) Are there language or learning barriers? 3) Are there any mental health, substance abuse, or domestic violence issues, either past or current? 4) What are their coping habits and styles? 5) Are there any financial or housing concerns? 6) What are the actual and perceived complexities of the skills required to care for the infant?

Some families have known risk factors for being unprepared for NICU discharge. These risk factors include but are not limited to substance abuse, inadequate prenatal care, teenage pregnancy, domestic violence, mental health issues especially anxiety or depression, limited English proficiency, and lower socioeconomic status or illiteracy[3,8,20,25,35] If one