

REVIEW

NICU discharge planning and beyond: recommendations for parent psychosocial support

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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.

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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.¹ This stress leads to a variety of reactions, including sadness, fear, anger, anxiety, grief, depression and helplessness.^{2,3} Parents of NICU babies commonly experience high stress after discharge with costly medical bills for childbirth and NICU hospitalization.^{4,5} Non-medical expenses related to loss of work, decreased income and limited job alternatives can also be sources of stress.^{4,5} The costs of caring for premature infants after discharge are not just financial but also emotional.^{6,7} 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.¹ 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.⁵

The primary focus of NICU personnel has been trying to improve the survival and neuromorbidity of high-risk infants.^{1,8–10} 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.^{9,11,12} 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.^{13,14} 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.¹⁴ NICU staff communication should encourage family involvement to prevent or minimize parental separation that disrupts parent bonding during a critical period of brain organization.¹

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.¹⁵ Many parents report that NICU nurses and doctors do not understand their emotional condition.¹⁶ Evidence suggests that NICU parents undergo emotional strain due to poor communication experiences with NICU staff.¹⁶ These difficulties include a disrupted relay of information between units and shifts, parents not welcomed on rounds, limited visitation times and restrictive touch practices.¹⁶ Lack of good communication contributes to parents feeling lonely, abandoned and an unwanted presence.¹⁶ High levels of emotional stress are reported by parents of premature infants.^{16–19} Screening

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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 risk, 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 the 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 the parenting 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.¹⁹ 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.^{26,35,36} 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.⁹ 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.⁹ 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).⁹ 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

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

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 one 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.⁴⁵

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.⁴⁶ 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.^{20,47–52} 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 provision 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

Table 2. Resources for helping parents overcome barriers

<i>Parent challenges</i>	<i>Barriers</i>	<i>Facilitators and resources</i>
Establish parent–infant bond	Socioeconomic and cultural Short maternity leave Far distances between home and hospital Transportation and house costs and conveniences Medical NICU environment Restrictive NICU visiting hours Competing demands (children, work, school) Emotional and mental distress	<i>Community transportation:</i> Assists with trains, car pools, bus tickets and taxis <i>Community housing:</i> Houses, shelters, hotels, etc. <i>Child support:</i> Child life, volunteers for play area <i>Food:</i> Hospital cafeteria food pass, WIC <i>Communication:</i> 24-h NICU telephone access <i>Family-friendly NICU environment:</i> Skin on skin Kangaroo care for parents, low light and noise <i>Psychosocial support resources:</i> Utilize social workers, mental health professionals, psychiatrists and psychologists to screen and refer for stress and depression
Acquiring parenting skills	Communication (language, education level) Lack of parental engagement Difficulties establishing lactation and breastfeeding Insufficient human resources	<i>Interpreters:</i> Available by phone or in-person <i>Educational materials:</i> Provide written, video, website or bedside teaching 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 <i>Red flag checklists:</i> Establish what, why, when, where and who to call for emergency treatment <i>Parent support groups:</i> Hospital or community, websites, referrals, parent volunteers <i>Breastfeeding support:</i> Lactation specialists, WIC, professionals trained to meet the baby friendly hospital initiatives and AAP guidelines ³² <i>Parents advocate for patient safety:</i> Children's Hospitals' Solutions—Patient Safety website ³⁵ <i>Pre-established discharge plans:</i> NICU point personnel to identify family needs to provide special training. Pre-schedule appointments, phone contacts <i>Parent training check lists:</i> Medication, feeding, special cares (tracheostomy, gastrostomy tubes, wounds), equipment (oxygen, suction, ventilation) and contact numbers to reorder supplies <i>NICU follow-up programs:</i> Post-discharge primary care, HRIF teams, early intervention and home visitor services for ongoing cares and support
Discharge and follow-up	Health insurance Administrative procedures for transfer of care to community Special equipment Medications Lack of access to specialized/ emergency care in rural areas outside the city Poor discharge follow-up coordination system for families	<i>Pre-established discharge plans:</i> NICU point personnel to identify family needs to provide special training. Pre-schedule appointments, phone contacts <i>Parent training check lists:</i> Medication, feeding, special cares (tracheostomy, gastrostomy tubes, wounds), equipment (oxygen, suction, ventilation) and contact numbers to reorder supplies <i>NICU follow-up programs:</i> Post-discharge primary care, HRIF teams, early intervention and home visitor services for ongoing cares and support

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.⁴⁸ Unfortunately, due to methodological limitations, these studies have not shown any benefit to infant development, abuse/neglect, growth/nutrition or morbidity.⁴⁸ 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.⁵³ 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 individualize 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.⁶ 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 goals 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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