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Abstract

Problem: A Neonatal Early Discharge (NED) program is a supported process where preterm infants leave hospital before they have established full sucking feeds, and are gavage fed by their parents while they transition to breast and/or bottle feeds. While there is some evidence in the literature describing the outcomes of this process for preterm infants, there is even more limited evidence of the effects and outcomes of these NED programs on parents.

Objective: To summarize and critically appraise the literature regarding the effects of neonatal early discharge on parents.

Method: A literature search was conducted for English language publications since 2007 using Medline, Cumulative Index of Nursing and Allied Health Literature (CINAHL), PsycINFO and Google Scholar. A total of 20 primary articles met the inclusion criteria for the review.

Conclusion: An integrative thematic synthesis identified four themes: establishing parenting skills/confidence, bonding with the newborn, psychological distress, and the need for support and resources. Findings suggests that parents have various concerns regarding discharge from the neonatal unit, and therefore support from health professionals and family play a crucial role during the experience. There were also various external factors such as socioeconomic status and cultural differences which impact on parents differently, and it is therefore challenging to draw definite conclusions. This warrants further research in the area.

Statement of significance

Problem or issue: The increasing survival of preterm infants has placed pressure on healthcare services to consider alternate care models. Neonatal early discharge is one model where stable preterm infants requiring gavage feeds are sent home in the care of their family. Little is known of the impact of this model of care on parents.

What is already known: Previous research of the effects on parents of having a preterm baby have focused on the in-hospital period and the long-term consequences. Discharge of stable well preterm infants from the neonatal unit has various effects on parents, including stress.

What this paper adds: Neonatal early discharge facilitates bonding between parents and their preterm baby. These parents need to develop specialized skills to care for their infant at home, such as gavage feeding. Support from hospital staff, especially neonatal nurses/midwives, and other families, helps parents to cope with their baby and manage their psychological distress.

Introduction

Over the last two decades the rate of preterm births has increased significantly throughout the world.¹ In industrialized countries, the rate of survival over this same period has increased substantially due to socioeconomic improvements, and advances in obstetric and neonatal care.² The Neonatal Intensive Care Unit (NICU) is an environment of advanced medical technology improving infant survival, but one that is also known to limit parents' interactions with their newborns, often preventing them from providing basic care for their infants.³ This, among numerous other effects, commonly impairs the establishment of bonding and attachment between the infant and family, and may also affect the infants' future growth and development.⁴ While care in the NICU has contributed significantly in decreasing mortality of preterm infants over the years, studies have found that the transition from the neonatal unit (NNU) to home is not necessarily an easy journey, especially for parents.⁵

The model of care for preterm neonates has changed over the last two decades. Traditionally, after stabilization in the NICU, neonates stayed in special care units until they were fully breast- or bottle-fed and were then discharged into the care of their families.⁶ In 1989, a formalized program of Neonatal Early Discharge (NED), also referred to as an Early Discharge Program (EDP) was recommended in the United Nations Convention on the Rights of the Child (United Nations Human Rights, 1989). Such programs were thought to unite families sooner, allowing for earlier establishment of bonds and family adaptation.⁶ A NED program is an opportunity for a smoother transition between the neonatal unit and home.⁵ In contrast to standard discharge from the NNU, preterm infants on NED programs go home requiring gavage feeding or supplemental oxygen therapy. The early discharge of infants receiving gavage feeding in conjunction with breastfeeding or bottle feeding in the family's own home has been found to be safe and feasible.^{7, 8}

Research has shown that, following preterm birth, infants and their families require extra support such as intensive medical treatment and psychological support.⁶ There have been numerous studies on the effects of preterm birth and discharge of a preterm infant on parents. However, little is known about the effects on parents following NED. A descriptive article from Bathie and Shaw⁹ outlined the potential benefits when a

neonate is sent home on a NED program with a nasogastric tube in situ. Although NED programs were found generally to receive good feedback from families, studies are still being conducted regarding the appropriate discharge process to assist parents through the transition from hospital to home. An effectively planned hospital discharge would guarantee the continuity of the preterm infant's care at home.⁴ However, Sneath¹⁰ found that healthcare professionals and parents may have differing views about how best to prepare families for the early discharge of their baby.¹¹

The purpose of this review was to locate, critically appraise and synthesize the literature published about the parental experience and outcomes of NED programs, as well as the role of health professionals and support systems in fulfilling the needs of parents following their neonate's early discharge from the NNU. The literature search strategy and critical appraisal approaches, collation of themes and discussion of the findings, limitations and conclusions of this review are described.

Literature review method

Search Strategy

A literature search was conducted identifying publications describing NED programs and their effect on parents. The search was completed during May 2017 – April 2018 using electronic databases predominantly used to disseminate nursing and midwifery research (Cumulative Index of Nursing and Allied Health Literature (CINAHL), Medline and PsycINFO) as well as the internet search engine Google Scholar. Key terms included: “neonate” or “preterm infant”, “early discharge”, “neonatal intensive care unit”, and “psychological adaptation of parents”.

Inclusion criteria included English language papers published in the period of 2007-2018 and included content about parental experiences following neonatal discharge. The eleven-year period was used as limited relevant research was available within a five-year period. All research methods were eligible and only primary peer-reviewed research were included. Additionally, the bibliographic mining technique was applied, utilizing the reference lists of each relevant article. The outcomes for these searches are shown in Table 1.

Titles and abstracts were screened for relevance, with 24 full text articles being read. Nine articles were excluded due to irrelevance, language limitation or not meeting the selection criteria, leaving 15 articles. Five further articles were subsequently located in the reference lists of include articles, which resulted in a total of 20 articles in this literature review. The search process is summarized in Figure 1. A summary of the articles can be found in Table 2. Each article will be hereafter referred to as their number in Table 2.

Critical appraisal

Critical review guidelines for qualitative and quantitative studies were adapted from Schneider et al.¹² These guidelines were used to critically appraise the studies, identifying their weakness and strengths and the results are summarized in Tables 3 and 4. Following the critical appraisal, all 20 identified articles demonstrated appropriate rigor or trustworthiness and remained in the review.

Analysis of literature

A thematic/narrative analysis process was used to synthesize the findings.¹³ The selected articles were examined using descriptive coding techniques and each research article was interrogated for the findings and points of interest that directly related to the review question. A list of codes was generated, and common codes were grouped together. During this process, codes were checked for meaning and context to ensure category development was consistent and faithful to the primary sources.¹³ The primary researcher presented codes and categories to the team for discussion and refinement. Following discussion and cross checking between the literature, codes and categories, overarching themes were developed and agreed upon by the team.

Findings

A narrative review was written to reflect the themes arising from the thematic analysis of the synthesized data from the 20 articles. Only 3 studies specifically addressed the phenomenon of interest, i.e. the effects of neonatal early discharge from the NNU on

parents,^{6,27,29} while the other studies focused on the effect on parents of a traditional discharge from the NNU. These latter papers remained in the review as they offered useful insights into the impact and needs of parents upon discharge of preterm infants, which are even more relevant when planning early discharge. The effects on parents were able to be categorized into 4 themes: establishing skills/confidence; bonding with their newborn; psychological distress; and the need for support and resources. Some studies also highlighted other barriers for neonatal discharge which then lead to further considerations regarding discharge planning.

Most studies (n=16) were qualitative in nature and featured interviews of parents after their infants were discharged from a neonatal unit. Studies were conducted in countries such as the United States of America, Spain, Brazil and some European countries. Accumulatively, this review included 850 mothers' or couples' experiences of neonatal discharge.

Establishing parental skills/confidence

Parents were found to have very low confidence in caring for their newborn preterm infants at the time of discharge.^{14,15,22,23,30} These included basic parenting skills such as how to care for the infant on a daily basis and how to recognize if the infant was doing well or not. The parents in some of these studies were not aware of the supplies they might need once their preterm infant came home, or the post-discharge plan of care.^{4,5,14,15,30} Some studies also highlighted parents' concerns about not knowing how to interpret their baby's cues that may indicate their well-being, such as breathing patterns, weight gain and colour changes.^{4-6,11,14,23-25,29} This skill was thought to be essential for early discharge of a preterm infant, and parents with other children even found their experience in the NNU to be helpful in relearning these skills.^{3,26}

Most of the neonatal units in the studies had a formal discharge education plan which included teaching and guidance from staff for a period of time before the actual day of discharge.^{4,14,15,30} Some parents were appreciative of this because it gave them time to become familiar with their infants' needs; they learned to interpret their baby's cues and therefore learned how to respond appropriately in the security of the neonatal unit environment. As a consequence, they gained confidence in their capacity to take

responsibility for their infants at home. Positive feedback and hearing the neonatal unit staff say that their infant was doing well increased parents' perception of their infant's readiness for discharge.^{4,6,7,11,14,17,21,22,24,25,28-30} Parents felt they gradually attained a primary role in their own and their infants' lives, rather than being on the sidelines, and their control and independence were strengthened by the preparation for their infant's discharge.^{5,6,11,15,16,21}

However, despite nursing staff's efforts in teaching parents how to perform some procedures for their infant, some studies found that parents still doubted that they knew everything necessary to care for their preterm infant at home.^{4,16,18,22,28-30} Some parents feared doing something wrong or harmful to the infant, and this anxiety was especially heightened by the fact that they felt that leaving the supervised and highly specialized setting of the neonatal unit seemed inherently riskier and more uncertain.^{19,21,22,28} For parents from neonatal units whose babies were followed up at home after discharge by other community healthcare workers (HCWs), parents perceived that after the months of support from nursing staff and other NNU staff, this support was taken away and replaced with care from HCWs whom they did not know.^{19, 22} Some parents recommended better continuity of care, even if it involved a multidisciplinary approach (including physicians from different specialties, nurses, social workers, speech therapist, nutritionist) with attunement to the family's needs.^{11,14,22,29}

Bonding with their newborn

One of the most significant effects of neonatal discharge was the enhanced bonding between parents and infants. Several parents did not feel as though their infant was really theirs until they took them home. Only when at home did they feel like a proper family.^{4-6,21,22,24,29} In addition, early discharge of the preterm infant also helped reduce the possibility of family fragmentation which may result from a longer hospital admission, and may also affect other siblings negatively.^{6,27,29} Once home, parents took responsibility for infant care and subsequently perceived that their parenthood was closer to normal, giving them much more freedom as compared to when their babies were in the NNU.^{4- 6,21,22,24,26,29,30}

Mothers, more than other members of the family, seemed to be affected the most by the positive effects of bonding with the new infant. On discharge, mothers experienced feeling great joy by having their babies with them 24 hours a day, without the schedule restrictions, and having contact in the intimate, warm and private space at home, where they could feel, see, touch their babies, embrace and feed them and do everything they and their babies needed and wanted.^{4,5,16,28,25} Mothers described a self-governed role, in which they experienced their infants as becoming more their own.^{5,17,26,28}

Several studies stated that mothers went through pendulating emotions from feeling emotionally exhausted, to feeling relieved, from experiencing an insecure, to a secure bond. Failure to establish a bond early during hospitalization meant that some mothers could not establish a bond with their babies once at home. These mothers expressed a feeling of helplessness caring for their infants at home after hospital discharge.^{16,25} Discharge from the neonatal unit meant a change in conditions under which attempts were made to establish a maternal-infant bond. The mother had left the regime that focused on her infant's survival and physical well-being in the neonatal unit, and now experienced a new expectation about creating a good relationship with her infant for the future.^{5,17,30} Experiencing a sense of subordination in relation to the staff and the regimen in the neonatal unit made some mothers insecure in their relationship with their infants.^{4,5,17,29}

Socioeconomic circumstances also influenced the experience of parent-infant bonding, such that adolescents, working fathers and Indigenous parents had particular challenges. Specifically, these included cultural barriers, short maternity leave, far distances between hospital and home, the cost and inconvenience of transportation or temporary housing, and a lack of access to specialized/emergency care in rural areas outside cities.^{11,23,24,29,30}

Psychological distress

The experience of coming home was very different between families. Some saw it as easy,^{6,19,30} but most families experienced ambivalence and ended up paying an emotional price inclusive of significant stress.^{6,19,30} Parents described the burden of

responsibility as very large, overwhelming or anxiety-inducing.^{6,19,30} Many experienced mixed feelings in the first few weeks at home. Negative feelings manifested as worry, nervousness and frustration, while positive feelings included happiness, optimism, excitement and unconditional love. Mixed feelings were defined as simultaneously conflicting feelings included happiness, frustration, stress, fear, excitement and uncertainty.^{4,19,21-23,25,26,28,29}

Leaving the well-regulated, highly specialized environment of the neonatal unit left parents filled with fears, insecurity and uncertainty.^{5,6,11,14,18,19,23,26-28} Parents faced additional stress factors in the process of having a hospitalized preterm infant, including the higher chances of the infant dying, especially for those whose future seemed more uncertain.^{16,19,23,28-30} Studies concluded that neonatal discharge, early or otherwise, did not modify parental concerns about issues such as sudden infant death syndrome, or reduce requests for help with understanding and adapting to the uncertainties of prematurity. Support through structured discharge programs did not prevent normal reactions but could contribute to reducing the intensity of the emotional experience.^{6,18,22,23,28-30}

Parents voiced a number of concerns about their abilities to manage once at home. Among many, these included balancing work and family, sleep deprivation due to the around-the-clock care for their infant, their knowledge gap as primary caretakers of the infant, and competing demands with other existing children and responsibilities.^{11,18,26-28,30} They could not rest because every 2 to 3 hours they had to care for and/or feed their baby.^{6,16,19,23} In order to address the stress and uncertainty inherent in caring for a preterm infant, parents found that physical activity or exercise, shifting their mental perspective, reconnecting with their infant and reaching out to their social support system helped them to cope.^{11,18,26,27,30}

Even though coming home from the neonatal unit elicited mixed feelings for the anxious parents, many stated that it was also a positive experience, with the benefits outweighing the anxiety. Mothers were able to look back at their infants' early struggles and frame their experiences in a positive light – that because they overcame them, they felt they would be able to cope with other difficult challenges in the future.^{5,6,19,22,28}

The need for support and resources

One of the biggest facilitators during the discharge process for parents was the help from, and communication with the nursing/midwifery staff in the neonatal unit. Although some parents described feeling frustrated about the restricted visiting hours in the neonatal unit, the amount of information they received concerning their infant's condition, or last minute or delayed discharge notification, many parents appreciated establishing relationships with the neonatal unit team and learning from them.^{4,5,11,19,24,29,30} Information provided by the neonatal unit staff and healthcare providers about how to care for their baby affected the mother's perception of her own competence which shaped her psychological and physical support needs.^{4,11,19,30} This information would usually come in the form of parental involvement with supervised direct care in the neonatal unit which gave parents greater confidence and reduced their fear at the time of discharge.^{4,6,11,14,19,21,22,24-26,29,30}

Parents looked upon the discharge nurse/midwife as an authority figure and a supervisor. Nurses/midwives were seen as the ideal healthcare professionals to help parents prepare for discharge, since they were the ones with the most interactions and experience caring for their infant.^{4,6,19,24,11,27,30} Some parents spoke of the difficulty of maintaining a sense of continuity of carer because of nurses'/midwives' shift work.^{14,22,24,29} Nurses/midwives were described as being well suited to preparing parents for discharge as they were able to follow the family's evolution throughout the hospitalization and were more attuned to the family's needs.^{14,22,24,29} Nurses/midwives were also shown to play a key role in empowering women during the process of acquiring their maternal role. Positive feedback from the neonatal unit staff enhanced parental readiness for discharge.^{4,11,14,19,21,26,27}

Some studies also highlighted that parents wanted information specific to their infant's health condition and preferred to speak directly with healthcare professionals. Parents expressed their preferred method of communication regarding discharge as face-to-face conversations, as these allowed them to ask questions and clarify elements they did not understand. They also appreciated written material to supplement information already discussed in person, including books about preterm infants (often stored in the neonatal unit to read while visiting their infant), as well as clinical specialist

nurse/midwife-led support and information sessions and online resources.^{4,11,14,18,23,24,30}

Other parental needs included unrestricted visiting hours to promote mother-baby contact, allowing the extended family to participate in caring for the preterm infant, and telephone communication with nursing personnel to support families when they first took their babies home.^{11,16,18,23,29} Parents expressed their appreciation for one-to-one bedside teaching of caring for their infant, home follow-up visits, and a multidisciplinary approach such as a local community-based program consisting of an interdisciplinary team of physicians, nurses/midwives or a dietician that followed the infant's development and progress post-discharge.^{11,14,18,26,29,30}

Other important sources of support for parents are extended families and friends. Many parents relied on the social support they received from their family, partner and friends.^{18,22,24,26} Although they did not feel totally confident about caring for their baby at home, they felt they would be supported by other people and other families with experience in caring for small babies, which helped them to minimize their fears and anxiety.^{17,18,22,24,26,28}

Discussion

The literature findings highlighted four main themes of parental effects of neonatal discharge, both early and traditional. These included issues around building up parental skills or confidence, bonding with their newborn, psychological distress and the need of support and resources from family, hospital staff and the community. It is obvious that these issues were all inter-dependent upon each other, where, when accumulated, they contributed to the parents' experience of their infants' discharge.^{4,10,27} These findings are consistent with the anecdotal findings suggested by Bathie and Shaw.⁹

That being said, it is crucial to acknowledge that parents need time and space to bond as a family, both physically and emotionally.^{6,21,27,29} As bonding in the hospital environment during their infant's hospitalization may be difficult for some parents,^{4,6,21,22,24,29} hospital staff play a role in creating a space and opportunities for

parents to bond and interact with their preterm infant as much as possible. Despite parents being able to foster their relationship with their baby in the comfort of their own home, parental confidence, psychological stress and bonding challenges may still persist.^{4-6,11,14-19,21-30}

Support and resources from hospital staff and the community played a major role in helping parents cope with the three other effects of neonatal early discharge. Building up parental skills and confidence in caring for a newborn infant required support from not only hospital staff, but also from extended families, local community and other parents with more experience. Continuity of care should, as best as possible, be implemented considering also each family's unique needs, resources and skills.^{6,20} While hospital staff are better equipped to assist parents during the discharge planning process and the days leading up to discharge,^{4,11} local community follow-up teams included in NED programs,^{6,27} and extended families and friends played an important role in supporting parents following discharge.^{18,25,26}

As with all studies there are limitations. The most significant limitation of this review was the lack of published studies in the English language describing the parental experience of NED between 2007 and 2018, and therefore the findings may not be truly representative and unique to parents' experience of NED as compared to neonatal discharges in general. It is possible that early discharge may accentuate the intensity of effects on parents found in this review. In addition, the studies only focused on very specific and narrow groups of the population due to language barriers. While NED programs do currently exist in some health facilities, there are minimal studies exploring the effects and outcomes of these programs. This warrants further research to assist health facilities in shaping appropriate support for parents getting ready to take their infants home early from the NNU.

Conclusion

The purpose of this review was to find, critically appraise and then synthesize the literature published about the parental experience and outcomes of NED programs. Only three studies were identified that were specific to NED programs. However, taking the broader approach of neonatal discharge we found four main themes related

to the parental experience. Despite the difficulties associated with the neonatal early discharge process, support from, and communication with healthcare professionals, especially neonatal nurses/midwives, is critical in making a difference to parents' experience of early discharge. Further studies are needed to explore the effects of different social factors such as socioeconomic status, education and cultural differences.

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