Discharge Planning in the Neonatal Intensive Care Unit
– A Literature Review

NU3S01 – Research

B.Sc. (Cur.) Children’s & General Integrated Degree Programme
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Abstract

The chosen topic for this literature review is discharge planning in the neonatal intensive care unit. A range of descriptive research articles using qualitative, quantitative and mixed methods will be critiqued and their findings examined. As indicated by the researched literature, the topics of parental preparedness, important aspects of preparation, parents’ feelings and concerns and support for families will all be discussed in depth under the following themes: preparing families for discharge and parental experiences of discharge.

Through reviewing the literature, it seems that some areas of education and preparation for parents are insufficient, especially feeding and recognition and management of infant illness at home. Although the majority of parents studied report feeling prepared for discharge it has been shown that high levels of anxiety are associated with discharge from the neonatal intensive care unit. The author concludes that research into the use of clinical pathways of frameworks in the discharge process, as discussed in some of the studies, could help develop a more effective, goal-oriented discharge process.
Introduction

The topic for this literature review is family discharge planning in the neonatal intensive care unit (NICU) which is a reasonably widely researched topic. Discharge planning has been described as ‘the development of an individualised discharge plan for the patient prior to leaving hospital, with the aim of containing costs and improving patient outcomes’ (Shepperd et al. 2010). It is a crucial component of making the transition from the acute care setting to the home (Smeltzer et al. 2008). A transition is considered ‘a passage or movement from one state, condition, or place to another that may create a period of vulnerability associated with changes in health status, role relations, expectations, or abilities’ (Meleis et al. 2000, as cited by Weiss et al. 2008 p.284).

The survival of very low birth weight (< 1.5kg) and very ill infants has increased due to advanced technology, new medications and a deeper knowledge of physiology (Bissell & Long 2003, Bain et al. 2003, Committee on Fetus and Newborn 2008). This means that these infants and their families must endure lengthy periods of hospitalization before they can be discharged home, sometimes with unresolved medical issues and special health care needs (Bissell & Long 2003, Committee on Fetus and Newborn 2008). It is the role of the nurse to prepare families, through the discharge planning process, to take on the full time care of their infant and ensure they acquire the skills necessary to do this (Hockenberry & Wilson 2007).

A recent clinical placement on a NICU prompted the author to explore this topic in order to find out whether families are being sufficiently educated and supported during the hospitalization of their infant, in preparation for discharge, and how discharge planning is being carried out.

In order to find literature on this topic the author searched electronic databases CINHAL, PubMed, British Nursing Index, Ovid as well as manual searches of library catalogues, however most of the literature was found through CINHAL. The following search terms were used: neonatal intensive care, discharge planning, discharge, transition home, parent, family, teaching, education. Of the research articles found, all are descriptively designed with a similar amount of qualitative, quantitative and mixed methods studies including a 2-part action research study and were of worldwide origin. The author restricted the search to the last 10 years (2000-2010) as this produced a sufficient amount of literature which is
relevant to the increased premature survival rates mentioned above. From the literature the following themes emerged and will be discussed in detail: Preparing Families for Discharge and Parental Experiences of Discharge.
Preparing Families for Discharge

Supporting and involving parents in the discharge process from the neonatal intensive care unit is of vital importance as it can reduce the risk of readmission and also give the parents confidence in caring for their premature infant at home (Smith et al. 2009). Parents are expected to assume full responsibility for their child’s care including feeding, medication and treatment regimes (Sneath 2009) as well as recognising signs and symptoms of infection or developmental issues (Mancini & While 2001). Discharge planning needs to be structured and take place throughout the entire hospital stay (Mills et al. 2006).

How prepared are parents?

In 2009, Smith et al. carried out a quantitative descriptive study in America to explore how prepared families are when it comes to the discharge of their infant from the NICU. 867 families and their discharging nurse rated the family’s preparedness using a 9-point Likert scale on discharge day. Although ‘it is unethical to recruit more participants than necessary in a study’ (Parahoo 2006 p. 277) the authors provided no justification for the very large sample size used. Families were questioned specifically on their technical (infant care skills) and emotional preparedness for discharge. Overall, 97% of families reported feeling prepared for their infant’s discharge, however 13% were ‘unprepared’ according to the Likert scale response of either the family or the nurse. This indicates that perhaps the families and the discharging nurse used different criteria to evaluate discharge preparedness which would diminish the reliability of the questionnaire (Parahoo 2006). The authors also admitted that the discharge nurse may not have been a reliable assessor of the families discharge preparedness as only 56% reported being familiar with the family. Limitations aside, this study highlights that the large majority of families were prepared to take their infants home from the NICU.

In a study conducted by Bain et al. (2003) which also looked into family preparedness for discharge, they focused on different aspects of the parents’ care for their infant. They carried out a mixed methods descriptive cohort study of 21 neonatal units in Scotland in order to explore parents’ perceptions of their preparation for discharge and to identify important areas of teaching in this process. Mixed methods are often used to study different aspects of one topic and explore phenomena from different perspectives (Parahoo 2006) which is clear from this study. 374 questionnaires were completed by parents two weeks after discharge, without any exclusion criteria in order to represent all parents’ views. The questionnaires were pilot tested in two centres prior to recruitment. A focus
group was also held with self-selected parents so they could express their views in more depth. The majority (86%) of parents felt they were taught what they needed to know, however when it came to feeding it seemed there was a lack of education and advice for parents. Only 31% were given the opportunity to practice preparing feeds in the hospital and 37% received information about when to increase feeds and recognising their baby’s hunger. An imbalance emerged between breast-feeding and bottle-feeding mothers and the support they received, with over 90% breast-feeding mothers gaining instruction on expressing milk, defrosting and storage of breast milk. These findings are in contrast with Smith et al. (2009) who found that a higher percentage of ‘prepared’ and ‘unprepared’ families felt confident with bottle feeding (97% and 91% respectively) than breast feeding (80% and 78% respectively).

**Important aspects of preparation**

As well as the importance of feeding education as discussed by Bain et al. (2003), Smith et al. (2009) found that families were more likely to be prepared for discharge if they felt confident with their baby’s breathing and heart rate, their health and maturity (e.g. feeding and weight gain) and their own readiness to take their infants home. They also concluded that ‘unprepared’ parents were lacking confidence in areas such as breast feeding, knowledge about medications and managing fever and illness at home. Recognition and management of infant ill-health was also a concern for parents in the small mixed methods study by Mancini and While (2001). Semi-structured interviews of 16 parents were carried out two days prior and six weeks post discharge, in order to obtain qualitative and quantitative data about the parents’ views of discharge planning in a NICU in England. A convenience sample was used and inclusion criteria were babies born at 30 weeks, or more, gestation and without major disabilities or requiring surgical interventions. 11 parents felt education about safety issues could be much improved and 13 parents felt the same about hygiene issues. Although this study has a small sample population considering the large and varied population of NICU parents (Parahoo 2006), it raises some important issues and areas of the discharge process in need of improvement.

Broedsgaard and Wagner (2005) found that additional interventions and support for parents contributed to their readiness for discharge. They conducted a mixed methods study of 37 families in Denmark with the aim of exploring parents’ experiences of an intervention to facilitate their infants discharge home from hospital. The data was collected through a pilot-tested, semi-structured questionnaire and focus-group interviews with some parents (n=18) after discharge. The main themes discussed were the role of the health
visitor (public health nurse) who’s visits to the NICU, multidisciplinary collaboration with the hospital and familiarity with the infant made the transition home easier for some parents; assignment of the same contact nurse for the whole stay who was an important source of support for the family; also, rooming-in with their infant for a few nights prior to discharge helped parents prepare for returning home. Although the authors admitted the small sample and lack of control group as limitations, this study successfully identifies interventions which contribute to the family’s independence by the time their transition home is complete.

Broedsgaard and Wagner (2005) also identified the mothers’ need for information to be repeated, which was satisfied by the availability of written informational materials. These findings differ greatly to Bain et al. (2003) who found that there was a lack of written information to support verbal instruction for parents on all aspects of care. This lack of written material was also expressed in a qualitative study by Hurst (2006) into parents’ evaluations of a support program in a NICU in America. Of the 477 participants in the support program, a subgroup of 48 parents completed surveys where the need for a library of articles and resource books, and more information in general, to be available to parents was expressed. Another qualitative study in which parents identified factors vital to a family’s discharge readiness was by Bissell and Long (2003) in England. In their study 10 sets of parents were interviewed to assess how they adapt to life at home with their baby. They needed to feel prepared and that the hospital had no more teaching or preparation left to offer, to have an understanding about their baby and believe they are well, and to have the confidence to manage at home independently.

Bain et al. (2003) suggest that the teaching of these essential skills to parents is often unstructured which can put the vulnerable baby and family at risk. In a broad 2-part action research study (Sims et al. 2006 & Mills et al. 2006) a number of potentially better practices (PBPs) to improve the NICU discharge process were developed and implemented in 6 NICU’s in America. The implementation of these practices was evaluated through hospital self-assessment tools, staff satisfaction surveys and internet-based parent satisfaction surveys. One of the main developments was the use of transition point checklists to provide a framework and spread out tasks in the discharge process over the entire hospitalization. The aim of this was to change the unstructured process described by Bain et al. (2003) and prevent overwhelming parents with information and education in the few days before discharge. Mills et al. (2006) also identified that discharges late in the day can cause frustration for families and limit additional admissions. Through their action
research study they implemented a discharge time of 11am with 73% success rate, which allowed families to get home early and settle in during the day, easing the transition home. Unfortunately the authors provided no information about the sample size of families who were affected by these interventions or the results from the staff and parents satisfaction surveys and also the development of these PBPs was carried out through a literature review and recommendation from a content expert, as opposed to research into people’s needs and experiences which, according to Parahoo (2006) is a main component of action research.
Parental Experiences of Discharge

It is vital to identify vulnerable families with additional needs in order to offer appropriate support, education and guidance to ensure a smooth and confident transition to life at home with their baby (Bissell & Long 2003). According to Mancini and While (2001) parents are the best informants for determining their infant’s need, therefore exploring their experiences and opinions is critical in ensuring the best possible discharge process for the family.

Attitudes and feelings

In 2007, Rabelo et al. conducted a qualitative study into the feelings and expectations of mothers when their premature babies are being discharged from an NICU in Brazil. A small sample of 11 mothers were interviewed where the following themes emerged: the moment of hospital discharge, maternal doubts, preparation and instruction for discharge and instructions sought after by the mothers. At the time of discharge, the mothers felt a mixture of feelings including joy, fear, anxiety and relief, with fear usually relating to other children and relations at home. Anxiety continues to recur throughout the literature as a central component in parent’s experiences (Bain et al. 2003, Bissell & Long 2003, Broedsgaard & Wagner 2005, Rabelo et al. 2007).

In a quantitative study carried out in Italy into maternal anxiety upon discharge of high-risk newborns from the NICU (Zanardo et al. 2003) it was found they experience higher anxiety levels at discharge time than a control group of mothers with healthy full-term babies. 100 mothers (plus 100 control group), of similar age and parity, completed the State-Trait Anxiety Inventory Y (STAI-Y) questionnaire less than two hours prior to discharge. This consisted of 40 statements about immediate feelings (state anxiety) and usual personality traits (trait anxiety) which were scored on a 4-point response scale. Trait anxiety levels were found to be similar in both groups however state anxiety levels in the study group were significantly higher than the control group at discharge time. In spite of this, the large un-selected population meant that the authors were unable base state anxiety levels on any demographic variables which may contribute anxiety levels at time of discharge, as well as length of hospitalization and infant morbidity.

The parents in Hurst’s (2006) study describe a sense of isolation and needed to know that they were not alone in their experience. Despite feelings of anxiety or isolation, it was clear from the parents in Bissell and Long’s (2003) study that the desire and excitement of going home with their baby outweighed the negative feelings or fears.
Concerns pre and post discharge

Mancini and While (2001) and Bissell and Long (2003) both qualitatively assessed parents views and concerns pre and post discharge. In Mancini and While’s (2001) study, areas of concern prior to discharge were infant development and recognition of ill health as parents expressed little satisfaction with the information given on this area. However, feeding issues were identified as a concern most frequently, both before and after discharge. Parents seemed to find difficulty settling into a feeding pattern after the strict regime of the NICU. These findings are reinforced Bain et al. (2003) and in Bissell and Long’s (2003) study where they also identified temperature control and safety; practical and organisational issues; and emotional support and role integration (particularly for fathers) as areas of parental concern prior to discharge. On the other hand, once parents were at home for about 2 weeks many of these worries dissolved as they gained confidence in their care and decision-making. Parent’s concerns about the actions to take if their infant becomes ill were also identified by Bain et al. (2003) through the findings that 90% of requested CPR skills training before discharge.

In the study by Rabelo et al. (2007) some of the mothers doubted their abilities to carry out tasks such as bathing, holding, feeding and changing their baby’s nappy as these activities are more complex when caring for a premature baby. Many of them reported a lack or absence of pre-discharge education and preparation and they emphasized their need for this. The mothers sought general information about everyday care at home and what to expect (e.g. elimination patterns). They suggested some form of manual or handbook on what they can expect and actions to take. This need for additional written information was also expressed in studies by Bain et al. (2003) and Hurst (2006).

Support

The feelings and concerns explained above can have devastating effects on parents such as impaired bonding with their infant and difficulties maintaining lactation and breastfeeding for mothers (Bain et al. 2003, Broedsgaard and Wagner 2005) therefore it is critical for NICU nurses to support these parents. The results of the Zanardo et al. (2003) study are significant as they identify that most mothers could benefit from pre- and post-discharge emotional support such as parent support groups or discussions with previous NICU mothers (Hurst 2006) to relieve their increased anxiety levels. In Broedsgaard and Wagner’s (2005) study they acknowledged that parents showed a strong need to express and discuss their experiences of their infant’s hospitalisation and life following discharge which wasn’t satisfied in their social networks at home. In Hurst’s (2006) study, a parent
support program offered a weekly parent support group, hospital visitation and 24 hour telephone support by a previous NICU parent. Of the 48 parents who completed the survey, 44 felt that their needs and wellbeing were important and 40 saw it as an imperative aspect of the NICU.
**Conclusion**

The purpose of this literature review was to find out whether families are being sufficiently educated and supported during the hospitalization of their infant, in preparation for discharge, and how discharge planning is being carried out in the NICU. It is clear from the literature that the majority of parents do feel prepared when being discharged home, however many areas of discharge planning seem to be lacking resulting in elevated anxiety levels for parents.

Feeding education has been found to be deficient and inconsistent between breast feeding and bottle feeding parents. This is reflected in the findings that feeding is the biggest concern for parents both before and after discharge. The other main concerns reported by parents in relation to discharge are the development of the infant, recognition and management of illness at home, safety issues, emotional support and role integration. A scarcity of written information to back up any verbal guidance on these important areas has been described in a number of articles.

Parents experience a range of emotions and feelings throughout their NICU experience, and especially when they are finally getting to take their baby home. It is now known that mothers of high-risk newborns suffer from considerably higher levels of anxiety at discharge time than mothers of full term healthy babies. For this reason, the support services and interventions such as pre-discharge visits from the health visitor, rooming-in with the baby, parent support groups and collaboration with parents who have gone through the whole NICU experience before, are invaluable in the discharge planning process. They have been proven to help parents prepare for discharge, make the transition easier and support them emotionally, dispelling feelings of isolation and loneliness.

In order for a successful discharge, parents need to be confident in their child’s wellbeing and feel that they are as prepared as possible and have no more to gain from the NICU in terms of education and preparation.

Overall, discharge planning in the neonatal intensive care unit is a multi-faceted process consisting of education, guidance and support for families throughout the whole hospital stay. From this literature review, it seems inconsistencies exist in this process resulting in parents’ insecurity around certain areas of infant care. Some of the researched articles discuss and suggest the use of clinical pathways or framework for discharge planning.
(Mancini & While 2001, Bain et al. 2003, Sims et al. 2006) however, there seems to be a lack of up to date research in this area. The author considers this would aid consistent and coordinated teaching and preparation in order for a successful discharge.
Reference List


