

Transition from hospital to home: Parents perception of their preparation and readiness for discharge with their preterm infant.

Abstract

Aims: To explore the experiences of parents with babies born between 28-32 weeks' gestation during transition through the Neonatal Intensive Care Unit (NICU) and discharge to home.

Background: Following birth of a preterm baby, parents undergo a momentous journey through the NICU prior to their arrival home. The complexity of the journey varies on the degree of prematurity and problems faced by each baby. The NICU environment has many stressors and facilitating education to assist parents to feel ready for discharge can be challenging for all health professionals.

Design: Qualitative descriptive design

Methods: The project included two phases, pre and post discharge, to capture the experiences of 20 couples (40 parents) whilst their baby was a NICU inpatient and then after discharge. Face to face interviews, an online survey and telephone interviews were employed to gather parent's experiences. Constant comparative analysis was used to identify commonalities between experiences. Recruitment and data collection occurred from October 2014 to February 2015.

Results/Findings: Overlapping themes from both phases revealed three overarching concepts: Effective parent staff communication; Feeling informed and involved; and being prepared to go home.

Conclusion: Our findings can be used to develop strategies to improve the neonatal intensive care stay and discharge experience for parents. Proposed strategies would be to improve

information transfer, promote parental contact with the multidisciplinary team, encourage input from fathers to identify their needs and facilitate parental involvement according to individual needs within families.

Relevance to clinical practice: Providing information to parents during their time in hospital, in a consistent and timely manner is an essential component of their preparation when transitioning to home.

Key words: Parents, Neonatal Intensive Care Unit (NICU), preterm, experience, perception, transition, discharge, multidisciplinary team

What does this paper contribute to the wider global community?

- Health care professionals working in a neonatal unit should determine whether parents feel that they have received effective education to prepare them for the transition from hospital to home.
- Information transfer is essential for the well-being of families; however information given by the neonatal team members may be overwhelming, require reinforcement and can be presented in an inconsistent manner.
- It is imperative that health care professionals understand the potential anxiety that parents feel prior to discharge, especially if the process is rushed due to organisational factors.

INTRODUCTION

Following the birth of a preterm baby, parents undergo a momentous journey through the Neonatal Intensive Care Unit (NICU) prior to arrival at their home. The complexity of the journey varies on the degree of prematurity and problems faced by each baby. Parental involvement through sensory input facilitates the process of bonding and includes touching, cuddling, nurturing and caring activities (Tracy 2000). Parent baby interaction is known to facilitate baby wellbeing and development (Feeley et al. 2013, Griffin & Abraham 2006). However, when a pregnancy becomes high risk or there is maternal complications resulting in preterm birth this process can be interrupted. Parental involvement in care lessens with earlier gestations and fragility of the baby (Mackley, Locke, Spear, & Joseph, 2010). The NICU environment has many stressors, and therefore, facilitating interaction and involvement as well as assisting parents to feel ready for discharge is an important responsibility for health professionals (Busse, Stromgren, Thorngate, & Thomas, 2013, Mackley et al., 2010, Melnyk et al., 2006).

BACKGROUND

Parental stress

Magnusson (1982, p. 234) defines stress as “an individual’s psychic and somatic reaction to demands that approach or exceed the limits of ... coping resources”. This stress response can impact parents’ ability to cope (Doucette & Pinelli 2006). An unexpected end to a pregnancy creates concerns for parents and evidence suggests parents experience increasing stress leading up to their impending birth (Melnyk et al., 2006). The emotional impact of an admission to the NICU differs within families; however parents consistently report experiencing anxiety, sleep deprivation, fatigue, depression, and helplessness (Busse et al., 2013, Mackley et al., 2010).

Differences between mothers and fathers

Transition from hospital to home

Parents, needs differ even though they are a partnership. The coping mechanisms of fathers and mothers can be different. An Italian study describes how differing approaches may be required to meet individual needs and reduce stress within the partnership (Matricardi , Agostino, Fedeli, Montiroso, 2013). Mothers are encouraged to breast feed, spend time at the bedside expressing milk and attending to care when the baby's condition allows. This presence facilitates information transfer about caring for the baby before and after discharge. Furthermore, the spontaneity of bedside information transfer facilitates active involvement and builds knowledge. Handling the baby frequently enables the mother to become confident and competent to care for her infant (Gooding et al., 2011, Griffin & Abraham 2006). In contrast, fathers who return to work early after the birth to support the family, look after other children and attempt to retain some 'normality' may have limited contact time with the baby. This contributes to fewer opportunities to acquire similar knowledge to the mother which may increase their stress levels (Mackley et al., 2010). Fathers who are actively involved in care reported how involvement helped them gain confidence with their paternal role (Blomqvist Rubertson Kylberg, Jorsberg,&Nyqvist 2011). Similarly, another study revealed that promoting control over how and when parents, particularly fathers, attend to the needs of their baby enhances parent's confidence in their ability to transition from hospital to home (Feeley, Waitzer,Sherrard, Boisvert, & Zelkowitz ,2012)

Transition to discharge

Health professionals agree that discharge planning commences at the bedside after admission to the NICU (Smith, Young, Pursley, McCormaick, & Zupancic, 2009). Previous experience with parenting determines the basic needs of parents. However further studies from Germany and USA report heightened stress levels for any parent taking a baby home with complex medical conditions and follow-up appointments (Lopez ,Anderson,& Feutchinger, 2012, Schlittenhart, Smart, Miller, & Severstson,2011). Transitioning to

discharge involves formal and informal education. Parents are taught about feeding, infant well-being and signs of illness, sudden infant death syndrome prevention and immunisation requirements. Smith et al., (2009) discuss the need for classroom teaching about resuscitation and developmental care with instruction and practical simulation for parents. However barriers occur when parents are not able to visit or opt to spend time with their baby rather than go to a class in the NICU (Schlittenhart et al., 2011). In contrast, positive outcomes have been reported from a structured program in the United States aiming to enhance parental education facilitating readiness for discharge (Melnyk et al., 2006).

Reviewing international literature highlights factors influencing parents transitioning from NICU to their home; however, they do not report on parents' impression and perceptions of readiness before and after discharge. Furthermore, we have been unable to identify evidence involving NICU parental educational programs and their outcomes in Australia. In order to address the gap in knowledge around this transition period for parents, our project explored the discharge experience of parents with babies born between 28-32 weeks' gestation and their transition through the NICU to home.

METHODS

Design

A descriptive qualitative design was used to investigate the experiences of parents during their transition through the neonatal unit and their preparation and transition to home. Researchers work with vulnerable groups to produce knowledge that can be used as an impetus to make improvements. Practical information from participants who have lived the experience can provide an emic view to inform and facilitate change (Streubert & Carpenter 2011). In this instance, the qualitative approach to gathering data using in-depth interviews and an online survey has allowed researchers to identify unmet needs in collaboration with parents contributing to recommendations to improve the discharge planning processes.

Participants, recruitment and data collection

Parents with babies admitted to the Neonatal Clinical Care Unit whose gestation was between 28- 32 weeks were invited to participate by neonatal nurse researchers who were not directly involved in care of their baby. The final sample size of parents recruited was determined when data saturation was reached during the analysis process (Polit & Beck 2010). Exclusion criteria included parents with babies born with anomalies and/or not expected to survive, were non-English speaking, or were potentially difficult to follow-up due to involvement with the child and family protection services. Parents were given the option to withdraw from the project at any time. Recruitment and data collection occurred between October 2014 - February 2015 at the only tertiary maternity hospital in Western Australia (WA). During this period 98 potential sets of parents were reviewed for their eligibility. Twenty-one sets of parents were excluded due to exclusion criteria, nine were discharged prior to recruitment, and 13 declined to participate. Thirty-five sets of parents were missed due to back transfer to peripheral hospital prior to recruitment or first interview. Participation required both parents to consent. Twenty sets of parents were interviewed. All participating parents consisted of a mother and father. Same sex couples were not excluded and single parents were invited to participate if they had a support person; however, there was no participation of non-traditional couple pairs.

Parents were provided with a letter explaining the aim of the study and what was involved. Informed consent was obtained from each parent. Demographic data was collected during the interview process including parental ages, number of children, and family structure. Parents were asked if they had any previous experiences with a preterm baby through family or friends. Information about their experience was sought from parents at two intervals, pre- and post-discharge. Parents participated in a face to face interview in the pre discharge phase when their baby was 4-6 weeks old. Interviews with parents were conducted

separately to demonstrate the value of each person's experience without influencing or biasing their partners' experience.

For the project an open-ended question interview guide was developed (Table 1). Questions were asked about the transition to discharge process to guide responses. Free flow discussion with open ended questions encouraged parents to voice opinions and suggestions for change. The interviews were recorded using a digital audio recorder and transcribed verbatim. Findings from the pre discharge interviews governed the questions used for the online survey and telephone interviews for the post discharge phase which occurred at approximately four weeks post discharge. Parents were offered an online survey or telephone interview. The online choice allowed flexibility for the parents to complete the survey at their convenience. Twenty-five of the forty parents participated in the post discharge phase.

Free flow of information during interviews may be influenced by the credibility of the interviewer with the participant (Schneider , Whitehead, LoBiondo-Wood, & Haber, 2016). The two interviewers were clinical nurses and known to parents however they were not involved in direct care with any of the babies. We anticipate that this reduced potential bias from coercion and allowed parents to feel comfortable to share their thoughts or experiences.

Data analysis

Commonalities within the data were identified using a modified constant comparative method of analysis (Schneider et al., 2016). Comparing text within the interviews allowed saturation of themes and subthemes within parent's experiences during hospitalisation and the transition period. The process of data analysis began with two team members conducting a separate analysis of transcriptions. The remaining team members analysed cross-sections of the transcribed interviews highlighting similarities across tentative themes. Distributing the transcripts across five team members enabled each interview to be independently reviewed by three team members. This method of analysis facilitated the final negotiation and a consensus

agreement of themes and subthemes capturing parents' experiences. Regular meetings provided opportunities to discuss ideas derived from the text to reduce bias and ensure credibility to the analysis process. Phase one and two data were analysed separately to reflect parents' experiences across the two time periods. Member checking was used to ensure that participants agreed that themes reflected their experiences (Streubert & Carpenter 2011). Participants were emailed a short summary of the themes from each phase with six parents confirming agreement with the findings.

Ethical considerations

Confidentiality was maintained in accordance with the National Health and Medical Research Council Ethical Guidelines (National Health and Medical Research Council (NHMRC) (2007). Approval to conduct the project was provided from the Women and Newborn Health Service Human Research Ethics Committee (2014073 EW).

RESULTS

Participant profile

Twenty sets of parents consented to participate in the project providing 40 individual interviews. The mean maternal age was 29 years (21-42) and the mean paternal age was 32 years (21-43). Thirty-three were first time parents with seven having other children. Seventeen sets of parents were married and three were de-facto relationships. Five couples had previous personal experiences with preterm babies through family and friends.

Themes from pre-discharge phase

Themes and subthemes from the pre discharge and post discharge analysis are displayed in Tables 2 and 3 which include a theme statement and list of subthemes. The subthemes are explained in text with supporting quotes in italics and a parental coding system. Mothers were coded as 'a' and fathers as 'b' (1a-20b). Data analysis from phase one

revealed four major themes with eleven subthemes. Analysis for the phase two resulted in three major themes and five subthemes.

First Impressions captured how the physical environment met parents' expectations. Parents commented that the presence of 'high-tech' equipment was overwhelming, however the new, clean and well organised environment was appealing: *It felt very clinical but that was actually very reassuring (1a)*. Parents judged the clinical staff and assessed their competency based on their actions which determined whether they were perceived to be professional, friendly and supportive: *they're running around trying to do everything but they're so calm, they know exactly what they're doing. I felt really comfortable in that (1b)*. Furthermore, parents expressed mixed emotions after their initial admission. They described feelings of being overwhelmed and scared but were impressed by the well-equipped nursery and perceived competence of clinical staff which reassured them that their baby was in safe hands: *I was a bit emotional, crying and felt happy and sad but just a bit freaked out and overwhelmed basically (12b)*.

What do I Need to Know offers a description of information parents felt they wanted and needed. Most parents felt well informed about the care and progress of their baby however some reported not being given much information initially and needing to ask clinical staff for more information. In contrast, some felt there was 'information overload' and were not able to 'take in' all that was given to them: *we were still in a bit of shock...they were explaining things to us which was all good but sort of with me it went in one ear and out the other (14b)*. Mothers and fathers gathered information differently as mothers spent more time at the bedside facilitating more contact with the multidisciplinary team and information transfer. In contrast fathers had fewer opportunities to participate in the care of their baby and receive information directly from staff: *I went back to work like 2 or 3 days after and I was getting updates from (his wife) but only 'cause she was there all the time (18b)*.

Parents shared experiences where staff offered inconsistent or conflicting information which left them frustrated and confused: *sometimes I would do one thing that one nurse said and then another nurse would take over and they would tell me to do it differently (13a).*

However, differing staff opinions could also be beneficial as each staff member offered new information. Some parents felt a need to seek information beyond the hospital to address their needs, whereas some felt that hospital staff were the most trusted source of information.

Some parents searched the internet and found it helpful although others didn't trust this information or found it overwhelming or negative: *there's a lot of bad stories out there...I just concentrate on what the doctors say and just leave it at that...I wouldn't listen to anyone else (9b).*

Being Involved in my Baby's Care incorporated three subthemes that reflected a shift in care from nurse to parent. As their baby's condition improved, the parent's level of involvement and responsibility increased as their baby moved towards readiness for discharge: *in the first couple of days...it was a little bit difficult...but after that they've always been you know really good in letting us be involved in his care (19b).* Parents wanted nurses to understand their needs and felt that nursing staff should be aware where of their level of involvement with their baby and what continuing support was required. A father suggested this could be included in handover: *some of them could work on their communications a little bit better...not just handover on the baby's stats but handover also saying 'and the parents are like this and they can do this and they'll ask if they need help. (10b).*

Parents commented on barriers and interpersonal challenges with nursing staff that affected their involvement in their baby's care. Nursing allocations changed frequently and different opinions from nursing staff was frustrating for parents. Personality clashes between parents and the nurse was also challenging and not supportive of their involvement in care: *the only thing...that was frustrating to me was the difference in opinions coming from the*

nurses (13a) or another father suggested *nurses were great, obviously, you don't see eye to eye with everyone (2b)*.

Getting Ready to Take my Baby Home clarified information that parents did or did not receive prior to discharge. Some parents indicated that there did not seem to be a lot of information given to them about the discharge process. Other parents were not concerned they felt that staff would provide information closer to the time of discharge. Most importantly parents wanted to be informed exactly when discharge would occur: *it's still very early...I'm told that we'll find all that out later on... to be honest I'm still trying to just deal with now (4a)* and another participant shared that *a bit more consistency in giving us an idea of when we might be going home. That would just generally allow us to relax a bit more (5b)*.

Themes from post-discharge phase

Preparing to go Home captured how methods to transfer information to parents on caring for their baby varied. Information transfer at this time was aimed at teaching parents the necessary skills to feel comfortable in caring for their baby at home. Most parents suggested they felt well prepared for home: *The hospital was amazing in preparing us for discharge. We learnt a great deal about looking after our babies and didn't expect to be as prepared as we were (18a)*. Parents shared how their independence grew during their hospital stay: *we'd been in NICU so long that (we) often cared for him without much nurse intervention (5a)*, and in some cases the nurses were regarded as role models: *we picked up many helpful tips and hints from the nurses about caring for our baby (11a)*.

Discharge Day revealed how parents felt on the day of discharge. Some felt rushed leaving the hospital and would have liked more notice and a better plan from the staff: *better idea about timeframes of discharge would have been good...It is easier to have a plan and then change it than to not have a plan at all. It often felt like we did not have a plan at all (5a)*. Others shared their emotions around not knowing when their baby would be discharged

and others had felt anxious because the experience was so rushed as the NICU had been their 'home' for many weeks. *It happened very quickly which was a little daunting (14a)*. In addition another mother noted ... *I felt a little bewildered when our transfer happened...I felt very rushed and I did start to panic as I was leaving the place that had been my second home (16a)*. Comments referring to uncertainty about the actual day of discharge appeared frequently in the interviews. One parent was told different days over a period of weeks: *we were told a different day every day for around 3 weeks its extremely emotional to keep getting hopes up just to be let down (9a)*. However, others felt rushed *It was maybe a bit rushed. The doctors and nurses kept saying maybe a week but then we got there one day and they said we could take him home (10b)*.

Arriving Home encompassed five subthemes. Most parents felt prepared to care for their baby at home however some explained they did not feel mentally or physically prepared: *taking care of a newborn baby was very daunting...I felt like the house was unprepared for it even though I had everything that I was told I needed (4b)* and another mother shared: *I actually felt very under prepared compared to how I was with my other two (children), in regards to having enough blankets, rompers etc (15a)*. Parents described how being organised and physically prepared was not always enough: *(I) felt very organised but nothing can fully prepare you for bringing baby home (14a)* and one father noted that *Lucky my wife was there! I wasn't mentally prepared and I didn't feel he should be at home yet (15b)*.

Some parents were anxious about taking their baby home without the constant monitoring and support from nursing and medical staff: *anxious that we didn't have the nurses' help and constant monitoring and more. I tended to check on him very often to make sure he's OK (10b)*. Feeling apprehensive about leaving their baby alone was not unusual: *I was nervous not having the support of the nurses and medical staff. I did not want to leave my baby alone (1a)* and not having the supervision they were accustomed to: *there was some*

apprehension knowing there was no supervision from the nursing staff if anything perhaps went wrong (11b).

Other parents enjoyed the autonomy of caring for their baby at home, felt more comfortable and in control: *it was nice to get home and to do it by ourselves without being watched by the nurses all the time (6a)*. Another mother suggested that she was *happy to get into our own rhythm of feeding and sleeping. Happy to be able to learn our babies cues on our own (10a)* and one father noted how they were *more in control and able to care for him (5b)*.

New challenges became evident even though parents were relieved were in their home environment: *overwhelmed by all the 'jobs' that surrounded (the baby) and being really tired from a lack of sleep (11b)* and one mother shared how *it is certainly challenging as I only have the support of (my husband) on weekends. We are still trying to figure out a routine (13a)*. Caring for their baby at home without professional support gradually increased parental confidence: *We were so pleased to have her home but were then faced with new challenges such as feeding and sleeping...But we survived and with every day became more confident (11a)*. Parents noted how being home is different from hospital and only then did they realise what further information was needed: *it is completely different...there are things that they (hospital staff) don't tell you that you only come to realise (4b)*.

Building my Information Network was about parents becoming more independent and being able to identify what and where their community resources were. Initially these included the hospital home visiting nurse and the local child health or community nurse. *I had weekly visits from the health care nurse which helped with any worry's I had (14a)*. Parents also knew they could contact the neonatal unit for support especially after hours: *I would ring the nursery...when I needed help. Also (the Home Visiting Nurse) was wonderful for support*

(1a). However, after this immediate period the ongoing support of the local General Practitioner, the internet and family members were identified as useful resources.

Recommendations from parents

Parents suggested that staff would benefit from a guideline or checklist of achievements that individual babies were required to meet before discharge to assist with planning. Furthermore, they considered a need for improving the way health professionals communicate with each other and the parents. Continuity of clinical staff caring for their baby was recommended as parents felt better when they ‘knew’ the nurse who was providing care. Parents also shared that they should be informed that there is a non-threatening feedback process for them to express their concerns about staff or their experience. Phase two highlighted parent’s suggestions to have more opportunity to provide day and night rooming in care along with extending the home visiting nurse service. Parents living in rural areas felt a lack of support without the home visiting nurse and would have liked peripheral hospital staff and community support to be better organised.

Discussion

Our findings offer an insight into the experiences of parents with babies born between 28-32 weeks’ gestation, during their journey through the NICU and their preparation and transition to home. Conducting this project in two phases enabled a broader perspective to be shared across the spectrum of parent’s experiences. Concepts that underpin our findings reflect the relationship between staff and parents. Key concepts such as effective staff communication, information transfer and encouragement to be involved in their baby’s care influenced how parents felt they were prepared to take their baby home.

Effective staff-parent communication

Effective communication between clinical staff and parents emerged as a key finding across themes in the pre and post discharge phases. Information sharing has been found to

reduce parental stress and assist the health care provider identify educational needs (Burger King, & Tallet, 2015; Feeley et al. 2012). During the last decade, parents of babies admitted to neonatal units both within Australia and internationally have reported dissatisfaction with the amount and quality of information received from clinical staff (Arockiasamy, Holsti, & Albersheim, 2008, Enlow et al., 2014, Kowalski, Leef, Mackley, Spear, & Paul, 2006). Findings from this study and two previous studies in Australia and the United Kingdom (UK) reflect similar experiences whereby parents felt they were not fully informed or included in discussions about their baby's care or treatment along with timing of discharge (Burger *et al.*, 2014, Gardner, Barrett, Coonaan, Cox & Robertson, 2002). In addition, parents from the UK study were reported to receive conflicting information (Burger *et al.* 2014) which aligns with our WA parents noting information inconsistencies. Similarly, our WA parents reported feeling frustrated and confused when they received inconsistent or conflicting information. Canadian fathers reported confusion and felt they were not included as much as the mothers (Arockiasamy et al., 2008) with Swedish fathers also feeling uncomfortable with conflicting information (Blomqvist et al., 2011). Furthermore, interaction with clinical staff has been suggested as key to promoting communication that can enhance parental understanding through information sharing (Feeley 2012). Consistent with literature we found that mothers and fathers tend to gather information as fathers spend less time at their baby's bedside and miss opportunities to interact with clinical staff therefore receiving 'second-hand' information from their partner. Importantly, German fathers rated any primary interaction with clinical staff very highly. (Garten, Nazary, Metzke, & Buhner, 2013). Danish nurses have implemented strategies to improve communication with parents and have noted early positive outcomes (Weis, Zoffman, & Egerod, 2013).

Parents informed and involved

Some parents in our study reported confusion due to a notable lack of information in the early days after admission. They perceived their baby as fragile and they felt unsure of how to interact and care for their baby. These feelings are consistent with findings by Stacey, Osborn, and Salkovskis (2015) and Turner, Winfeild, and Chur-Hansen (2013) who suggest that parents felt unsure and confused when information transfer was absent or inadequate. Adama, Bayes, and Sundin (2016) reported that the relationship between knowing, being involved in care and confidence are consistent within international literature. Furthermore, being active in caring for their baby is essential for parents to learn and develop skills. Parents within this WA study wanted to do more during the transitioning phase and expressed that staff should understand their needs to facilitate more involvement.

Feeling prepared to go home

The importance of the journey from NICU admission to discharge must focus upon preparing parents for that monumental day when they go home with their baby. Formal and informal education should prepare parents with this goal in mind whilst also considering the unique needs of each parent (Goldstein 2012; Jefferies 2014). Our WA parents expressed how they learned skills from observing nursing staff which enabled them to become independent carers. Parents gradually learn skills and acquire knowledge with nurses' supervision and guidance: Facilitating opportunities to be the 'primary' care giver can build confidence and readiness for the transfer of responsibility to the parents (Griffin & Abraham 2006; Skene, Franck, Curtis, & Gerrish, 2012). The NICU environment changes frequently and parents expressed feeling rushed at the time of discharge often due to a requirement to make bed spaces available. This is consistent with reports from Griffin and Abraham (2006) where the need 'to free bed spaces' to prevent overcrowding created the rush that parents experience. More recently, Jefferies (2014) discusses the importance of ongoing preparation for discharge during the transition period to reduce parental stress and anxiety should this scenario occur.

WA parents in this project acknowledged that the skills they acquired in hospital will enable them to care for their babies at home and were also aware of community resources to access when discharged. Therefore, it appears that despite mixed feelings about not always being fully informed during their hospital stay, parents generally felt prepared to take their baby home.

Limitations

It must be acknowledged that our findings represent one Western Australian (WA) tertiary neonatal clinical care unit where the experiences of forty parents' transitioning to home have been reported. Additionally, all couples recruited represented a traditional parenting pair with mother and father although this was not an exclusion criterion. As such, our findings do not reflect the diversity within contemporary parenting models such as same sex or single parents. Qualitative analysis relies on data saturation applied to a specific group of parents. The intention of qualitative research is not to generalise findings but the potential transferability to other contexts is determined by the reader through the provision of rich description within the findings. Parents in this study were interviewed by researchers who work as clinical staff in the NICU. These nurses have specific training in the neonatal field and extensive experience working parents. During the study period, they were not responsible for direct care of the babies. However, even with this consideration, we can only hope that parents felt they were able to openly share their experiences around the care provided to prepare them for the transition from hospital to home with their preterm infant.

Conclusions

Our findings from this WA study reflect a necessity to develop strategies to improve the NICU transition and discharge experience for parents. These strategies should be aimed at improving information transfer, promoting parental contact with the multidisciplinary team

and encouraging interaction from both parents to allow staff to better identify and meet their unique needs as a new family.

Relevance to Clinical Practice

Exploring the experience of a group of parents transitioning from admission to discharge in an Australian tertiary care centre provided insight into parental experiences that can inform the development of strategies to improve parents' transition from hospital to home. In-depth interviews allowed parents to have a voice around their experiences that must be listened to. Learning from their stories reinforces the need to involve a multidisciplinary team approach to better address parents needs within NICU. Potential strategies should target an improvement in information transfer so parents feel well informed about the care their baby is receiving and better prepared to go home when discharge is imminent. For example, one strategy could be the creation of weekly meeting times for parents to meet with the multidisciplinary team and discuss plans for care transitioning to discharge. Further consideration could be given to the inclusion of fathers to identify and meet their specialised needs. Provision of hardcopies of information for parents is available; however, a file/folder for them to collect resources and store them in one personalised folder may assist them to plan and seek information tailored to their individual needs of their family. Finally, engagement with past parents who were consumers of care in NICU is another potential strategy whereby relevant information resources can be built with direct parental input.

REFERENCES

- Adama EA, Bayes S. & Sundin D. (2016) Parents` experiences of caring for preterm infants after discharge from neonatal intensive care unit: A meta synthesis of the literature. *Journal of Neonatal Nursing*. 22(1), 27–51. doi.org/10.101016/j.jnn.2015.07.006
- Arockiasamy V., Holsti L. & Albersheim S. (2008) Fathers' experiences in the neonatal intensive care unit: a search for control. *Pediatrics* 121(2) e215-e222. doi:10.1542/peds.2007-1005
- Blomqvist Y., Rubertson C., Kylberg E., Joreskog K. & Nyqvist K. (2011) Kangaroo mother care helps fathers of preterm infants gain confidence in the paternal role. *Journal of Advanced Nursing* 68(9), 1988-1996. Doi:10.1111/j.1365-2648.2011.05886.x
- Burger S., King J. & Tallet A. (2015) Parents’ experiences of neonatal care: Findings from neonatal survey 2014. *Patient Experience Journal* (7), 45-52.
- Busse M., Stromgren K., Thorngate L. & Thomas K.(2013) Parents' respnses to stress in the neonatal intensive care unit. *Critical Care Nurse* 33(4). Doi:.org/10.4037/ccn2013715
- Doucette J. & Pinelli J. (2004) The effects of family resources, coping, and strains on family adjustment 18 to 24 months after the NICU experience. *Advances in Neonatal Care*, (4), 92-104. Doi: 10.1016/j.adnc.2004.01.005
- Enlow E., Herbet T S., Jovell J., Lorch S., Anderson C. & Chamberlain J. (2014) Neonatal intensive care unit to home: the transition from parent and paediatrician perspectives, a prospective cohort study. *Journal of Perinatology* 34, 761-6. Doi: 10.1038/jp.2014.75
- Feeley N., Sherrad K., Waitzer E. & Boisvert L. (2012) The father at the bedside: patterns of involmment in the NICU. *The Journal of Perinatal and Neonatal Nursing* 27(1),72-80. Doi:10.1097/JPN.0bo13e31827fb415.
- Feeley N., Waitzer E., Sherrard K., Boisvert L. & Zelkowitz P. (2012) Fathers' perceptions of the barriers and facilitators to their involvement with their newborn hospitalised in the neonatal intensive care unit. *Journal of Clinical Nursing* 22(3-4), 521-530. Doi:10.1111/j.1365-2072.2012.04231.x.
- Gardner G., Barrett T., Coonan K., Cox H. & Robertson B. (2002) Parent support programmes in neonatal intensive care: researching the issues. *Neonatal, Peadiatric and Child Health Nursing* 5 (1) 20- 25
- Garten L., Nazary L., Metze B. & Buhner C. (2013) Pilot study of experiences and needs of 111 fathers of very low birth weight infnats in a neonatal intensive care unit. *Journal of Perinatology* 33,65-69. Doi: 10.1038/jp.2012.32.

Gooding J., Cooper L., Blaine A., Franck L., Howse J. & Berns S. (2011) Family support and family-centered care in the neonatal intensive care unit: origins, advances, impact. *Seminars in Perinatology* 35(1), 20-28. Doi: 10.1053/j.semperi2010.10.004

Goldstein L. (2012) Family Support and Education. *Physical and Occupational Therapy in Paediatrics* 33, 139-61. Doi: 10.3109/01942638.2012.754393.

Griffin T. & Abraham M. (2006) Transition to home from the newborn intensive care unit: applying the principles of family-centered care to the discharge process. *The Journal of Perinatal & Neonatal Nursing* 20 (3), 243-249.

Jefferies A. (2014) Going home: Facilitating discharge of the preterm infant . *Paediatric Child Health* 19 (1), 31-35.

Kowalski W J., Leef K H., Mackley A., Spear M. & Paul D. (2006) Communicating with parents of premature infants: who is the informant? *Journal of Perinatology* 26, 44–48. doi:10.1038/sj.jp.721140

Lopez G., Anderson K. & Feutchinger J.(2012) Transition of premature infants from hospital to home Life. *Neonatal Network* 31(4) ,207-214.

Mackley A., Locke R., Spear M. & Joseph R. (2010) Forgotten parent: NICU paternal emotional response. *Advances in Neonatal Care* 10(4), 200-203. Doi:10.1097/ANC.0b013e3181e946f0

Magnussen D. (1982) Situational determinants of stress: An interactional perspective. In Goldberger & S. Brenznitz (Eds.), *Handbook of Stress, theoretical clinical aspects*, Ch 15 (1st ed., pp. 231-253). New York: Free Press, Collier Macmillan,

Matricardi S., Agostino R., Fedeli C. & Montirosso R. (2013) Mothers are not fathers: differences between parents in the reduction of stress levels after a parental intervention in a NICU. *Acta Paediatrica* 102(1), 8-14. Doi:10.1111/apa12058

Melnyk B., Feinstein N., Alpert Gillis L., Fairbanks E., Crean H., Sinkin R., Stone P., Small L., Tu X. & Gross, S. (2006) Reducing premature infants' length of stay and improving parents' mental health outcomes with the Creating Opportunities for Parent Empowerment (COPE) neonatal intensive care unit program: a randomized, controlled trial. *Pediatrics* 118(5), e1414-e1427. doi:10.1542/peds.2005-2580

National Health and Medical Research Council (NHMRC) (2007) National *statement on ethical conduct in human research*. Retrieved April 2014 <http://www.nhmrc.gov.au>

Polit, D., & Beck, C. (2010). *Essentials of Nursing Research: Appraising Evidence for Nursing Practice*. (7th ed.). Sydney: Lippincott Williams & Wilkins.

Schlittenhart J., Smart D., Miller K. & Severtson B. (2011) Preparing parents for NICU discharge. *Nursing for Women's Health* 15(6), 484-494. doi: 10.1111/j.1751-486X.2011.01676.x

Schneider, Z., Whitehead, D., LoBiondo-Wood, G. & Haber, J. (2016). *Nursing and Midwifery Research: Methods and Appraisal for Evidence-Based Practice*. (5th ed.). Chatswood NSW: Elsevier.

Skene C., Franck L., Curtis P. & Gerrish, K. (2012) Parental involvement in neonatal comfort care. *Journal of Obstetrics, Gynaecology and Neonatal Nursing* 41(6):786-97. Doi: 10.1111/j.1552-6909.2012.01393. x.

Smith V., Young S., Pursley D., McCormaick M. & Zupancic J. (2009) Are families prepared for discharge from the NICU? *Journal of Perinatology* 29, 623-629. doi: 10.1038/jp.2009.58

Stacey S., Osborn M. & Salkovskis P. (2015) Life is a rollercoaster...What helps parents cope with the Neonatal Intensive Care Unit (NICU)? *Journal of Neonatal Nursing* 21, 136 -141 Doi: org/10.1016/j.jnn.2015.04.006

Streubert, J. & Carpenter, D. (2011). *Qualitative Research In Nursing: Advancing the Humanistic Imperative*. (5th ed.). Sydney: Lippincott Williams & Wilkins.

Tracy N. (2000). *Parents of premature infants: their emotional world*. London: Whurr Publishers Ltd

Tuner M., Winfield H. & Chur-Hansen A. (2013) The Emotional experiences and supports for parents with babies in a neonatal nursery. *Advances in Neonatal Care* 13, 438- 446. doi: 10.1097/ANC.0000000000000030

Weis J., Zoffmann. & Egerod I.(2013) Enhancing person-centred communication in the NICU: a comparative thematic analysis . *Nurs Crit Care*,20(6),287-298.<http://doi.org/10.1111/nicc.12062>

Table 1. Interview questions

Phase One: Pre Discharge (4-6 weeks old, still an inpatient)
<ol style="list-style-type: none"> 1. What were your impressions of the nursery after your baby was admitted? 2. As parents how informed were you in relation to what was happening to your baby? 3. What information was offered? 4. How was information offered? 5. As parents how involved did you feel in relation to what was happening with the care of your baby? 6. Have you referred to other sources for information about preterm babies? 7. What is your understanding of our discharge process, follow-up program and home visiting? 8. Do you have any recommendations for improving our preparation of parents for discharge with their baby? 9. Would you like to share any other thoughts or feelings?
Phase Two: Post Discharge (At home, 4-6 weeks post discharge)
<ol style="list-style-type: none"> 1. Looking after your baby in the hospital is different to being at home. When you arrived home with your baby, how did you feel? 2. How prepared did you feel to care for your baby in your home environment? 3. If necessary, where did you seek additional information to assist with caring for your baby at home? 4. How would you recommend we improve our preparation of parents for discharge home with their baby? 5. Would you like to share any other thoughts or feelings about the discharge process or the preparation for going home?

Table 2. Themes and Sub Themes: Transition from hospital to home pre discharge

Theme and subthemes	Description
<p>First Impressions</p> <p>Physical environment</p> <p>Judgment of the clinical staff</p> <p>Mixed emotions</p>	<p>This theme and subthemes reflects parents’ thoughts about the physical environment, judgment of the clinical staff and resulting emotions during their first visit to the NCCU.</p>
<p>What do I Need to Know?</p> <p>My need for information changes over time</p> <p>Mothers and fathers gather information differently</p> <p>Consistency in the information</p> <p>Where do I get the information I need</p>	<p>Parents wanted to feel informed about their baby's condition and needed this information to facilitate their involvement in the care of their baby. Being kept up to date with their baby’s progress was paramount for parents so they could appreciate and contribute to decisions in care.</p>
<p>Being Involved in my Baby’s Care</p> <p>I can do more as my baby grows</p> <p>Nurses need to understand what my needs are</p> <p>Challenges with nursing staff</p>	<p>Although parents wanted to be involved in their baby’s care, they were acutely aware that the level of their involvement was guided by their baby’s condition. Parents shared how they were pleased when opportunities arose reflecting an improvement in their baby’s condition that meant they could increase their involvement. However, the reality of being involved was daunting and having encouragement and support by nurses was highly valued though not always given.</p>
<p>Getting ready to take my baby home</p>	<p>Parents indicated that they had not received much information regarding the discharge process. Some had not heard term before or it was not well understood. Parents trusted the clinical staff would provide what they needed to know when the time was right.</p>

Table 3. Themes and Sub Themes: Transition from hospital to home post discharge

Theme and subthemes	Description
Preparing to go Home	The hospital staff taught parents how to care for their baby which assisted in preparing them to care for their baby on their own at home.
Discharge Day	Many parents felt rushed when the time finally came to leave hospital and would have liked more notice and a better plan from the staff.
Arriving Home Am I prepared? Feeling scared and excited Now we are in charge New challenges Building my information network	<p>Most parents felt prepared to care for their baby at home although some did not feel mentally and/or physically prepared. In addition, some expressed being anxious about taking their baby home without the constant monitoring and support from nursing and medical staff. However, others enjoyed the autonomy of caring for their baby at home and felt more comfortable and in control. Parents also shared how caring for their baby in their home environment resulted in being faced with new challenges. Finally, by using community services they were able to build a network for support and information.</p>