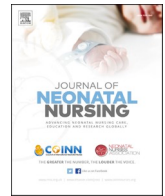




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Parents' experiences of transitioning to home with a very-low-birthweight infant: A meta-ethnography

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ABSTRACT

Medical-technological advances and neurodevelopmental care have improved the survival of extremely- and very-low-birthweight infants born before 32 weeks' gestation. After months in neonatal care, the infants are discharged, and parents exited but full of anxiety. This review is designed as a meta-ethnography, addressing parents' discharge experiences to comprehend the synthesised research, which includes 12 eligible studies. From the analysis, we constructed three themes: 'approaching discharge with both uncertainty and confidence'; 'discharge as a longed-for though disordering turning point'; and 'facing joys, worries and multiple challenges when at home'. The overarching interpretation was 'discharge as double-edged sword'. We conclude that bringing home very-low-birthweight infants is a joyful event, yet parents also experience discharge as never-endingly worrying, as a time filled with challenges to which parents must adapt and as necessitating continuous support from knowledgeable providers.

1. Introduction

Every year, about 15 million infants are born preterm, and this number is increasing, with global estimates showing that about 10% of all live births are preterm (World Health Organisation, 2018). Preterm infants born before 28 weeks' gestation are defined as extremely low birthweight (ELBW) and those born between 28 and 32 weeks as very preterm; these two groups are often named very-low-birthweight (VLBW) infants. In the last couple of decades, medical-technological advances have changed the design of neonatal intensive care units (NICUs), and family-centred neurodevelopmental care has increased the survival rates and improved the growth and development of VLBW infants (Maree, 2016). During the weeks or months of hospitalisation, parents worry about the early birth and the health condition of their VLBW infant. Thereafter, the transition to home puts further demands on the parents, as it signals the start of a life of unforeseeable

responsibilities and challenges.

1.1. Background

Parents' first sight of their VLBW infant is documented as distressing (Moghaddam et al., 2017; Widding and Farooqi, 2016; Ocampo et al., 2021): they find the early birth surreal, or they experience memory loss of what happened (Arnold et al., 2013; Fernández Medina et al., 2018; Sawyer et al., 2013). Mothers might have difficulty feeling like mothers (Fegran et al., 2008; Spinelli et al., 2016), having described themselves as feeling empty, stressed, in crisis and in long-lasting depressive moods (Baiá et al., 2016; Fernández Medina et al., 2018; Montirosso et al., 2014). Furthermore, parents are lacking sleep and are tired and worried about any changes in their infant's health status (Marthinsen et al., 2018). Conversely, other studies show that parents are found to develop resilience and to cope well overall (Lundquist et al., 2014; Rossman

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et al., 2013, 2017). Whether worried or resilient, parents of VLBW infants are vulnerable and need understanding and extra care (Baum et al., 2012; Greenfield et al., 2016; Kavanaugh et al., 2015). Confidence is shown to help parents love and care for their preterm infants (Franck et al., 2017). To encourage parents' confidence in their care, and because discharge and bringing baby home might have long-lasting effects (Ireland et al., 2019; Lundquist et al., 2014; Treyvaud et al., 2014), tailored guidance is crucial (Parascandalo, 2016; Ericson et al., 2017, 2018).

This review builds on the assumption that transition is a central concept in nursing, and it addresses concerns about facilitating transitions (Meleis, 2010). A transition denotes a life change, such as in health, relationship roles, expectations or abilities (Meleis, 2010; Suva et al., 2015); it occurs over time and requires individuals to incorporate new knowledge, alter behaviour and change the definition of the self in social and cultural contexts (Meleis, 2010). Thus, parents' discharge experiences after a long-term NICU stay with a VLBW infant involve a transition to a new life, and they involve changes to roles, knowledge, and behaviours (Meleis, 2015). During the NICU stay, parents adapted to the hospital routines, so any physical or responsibility changes thereafter might cause them uncertainty. Thus, the task of the neonatal and community healthcare staff is to facilitate this transition.

Parental experiences surrounding the birth of a VLBW infant have piqued researchers' interests. A review investigating studies of these parents' experiences of discharge and bringing baby home using a transition theory framework was not found. Therefore, this review aimed to synthesise published qualitative research about parents' experiences with and responses to their VLBW infant's discharge to home. We wanted to identify (a) parents' experiences of discharge to home and the transfer event, (b) parental challenges faced when at home with a VLBW infant and (c) synthesised findings suitable for neonatal nursing practice.

2. Method

The review was designed as a meta-ethnography according to Noblit and Hare's (1988) seven methodological phases. We complied with the eMERGe guidance to improve the transparency and completeness of our review reporting (Cunningham et al., 2019; France et al., 2019). With this approach, we tended to add useful, up-to-date and comprehensive evidence of what discharge to home means for parents of VLBW infants.

In the first of the seven phases, and before finally choosing a meta-ethnography, we discussed the chosen approach, the scope of the study, its relevance for knowledge development and challenges to come, such as theory, methodology, sample, time, resource, and practical issues.

In the phase 'deciding what is relevant to the initial interest: identifying and selecting study accounts to synthesise' (Noblit and Hare, 1988, p. 27), we systematically searched for reports in five databases: PubMed, CINAHL, PsycINFO, Web of Science and Scopus. In this phase, and to meet the aim, we narrowed the subjects to infants born before 32 weeks' gestation compared to a previously published protocol mentioning 37 weeks' gestation as a study limit (Aagaard, 2015). Thus, the search strategies developed focused on 'new-born extremely premature infant' OR 'very/extremely low birth infant/twin' OR 'VLBW' combined with 'transition experiences of going home' OR 'being discharged to home from NICU' using medical subheadings and free text words (see Table 1).

During the search process, a skilled librarian assisted us. Identical systematic searches took place several times, the last of which was in May 2020, thus synthesising knowledge from a decade of reports. Studies potentially eligible for inclusion, identified from the systematic searches, were screened by (HA and EH), first based on the title and abstract and then based on a full text reading according to the inclusion criteria: parents' experiences of discharge to home, the transfer event and challenges faced when at home with a VLBW infant. To assess

Table 1
Search strategy for Medline database.

Population	Phenomenon of interest	Context
Infant*	Attitude*	Intensive care units*
Premature*	Comprehen*	Neonatal*
Newborn*	Emotions*	Neonatal intensive care unit*
Very low birth weight*	Experience*	NICU*
Twins*	Emotion*	
Premature birth*	View*	
Premature infant*	Opinion*	AND
Newborn infant*	Percept*	
Baby*	Belief*	Patient discharge*
	Feel*	Discharge to home*
	Know*	Going home*
AND	Understand*	Early discharge*
	Adapt*	Patient discharge*
Family*		
Parents*	AND	
Single parent*		
Mothers*	Patient discharge*	
Fathers*	Discharge to home*	
Foster home care*	Going home*	
Relative*	Early discharge*	
Next of kin*	Patient discharge*	
Stepparent*		

methodological quality before inclusion, all studies considered eligible for inclusion were critically appraised using 'Checklist for qualitative research' (Joanna Briggs Institute, 2020) independently by two reviewers (HA and EH; Table 2). This appraisal demanded a careful and systematic reading and therefore contributed to familiarisation of the primary studies. One matter discussed in this phase was whether to include data from the result sections only, as argued by Ludvigsen et al. (2016), or to follow suggestions that data could be found in all studies' sections. We decided to include data from the results of the primary studies.

In the third phase, reading included studies, we first extracted and summarised the characteristics of the included primary studies (Table 3). Afterwards, data were imported to NVivo 12 (QSR International Pty Ltd, 2020), which allowed us to classify, sort and arrange information from the qualitative studies included in the review. We grouped and detailed topics, concepts, themes and meaning units. Thus, we became familiar with the phenomenon of interest, contexts, methods, and subject details.

In phases four, five and six, we determined how studies were related, combining study data into one another, and synthesising the combinations into a new interpretation. We read and reread, trying to determine how to unite and group topics and concepts into categories and themes with shared meanings, and we discussed the concepts and refined our themes among all authors.

Finally, in phase seven, we considered whether the translated data could be understood as either reciprocal (one study incorporates the concepts of another study), reputational (concepts contradict each other) or a line of argument (Noblit and Hare, 1988). We chose a line of argument because, through this detailed process, we identified interrelated aspects of the topic in all studies, and we assessed them based on three themes and an overarching interpretation. Our interpretation thus followed Noblit and Hare's (1988) argument concerning line-of-argument synthesis as being '... holistic in that it constructs an interpretation of all studies, their interrelations and context' (p. 63).

3. Results

As shown in Fig. 1 PRISMA flow diagram (Page et al., 2021), 781 reports in total were identified through our database search. After duplicates were removed, the titles and abstracts of 360 reports were screened, and 23 full-text articles were assessed. Finally, 12 reports were eligible for inclusion and constituted the review sample, representing

Table 2
Critical appraisal of eligible studies.

	Black et al., 2009	Nicolaou et al., 2009	Chang Lee et al., 2009	Hall et al., 2013	Turner et al., 2013	Garfield (2014)	Craig (2015)	Aydon et al., 2018	Berman et al., 2018	Petty et al., 2018	Granero-Molina et al., 2019	Fowler et al., 2019
1. Congruity between philosophical perspective and research methodology?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
2. Congruity between research methodology and research question or objectives?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
3. Congruity between the research methodology and the methods used to collect data?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
4. Congruity between the research methodology and the representation and analysis of data?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
5. Congruity between the research methodology and the interpretation of results?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
6. Researcher located culturally or theoretically?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
7. Influence of the researcher on the research, and vice versa, addressed?	N	N	N	N	N	Y	Y	N	N	N	N	N
8. Participants, and their voices, adequately represented?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
9. Ethical according to current criteria or, for recent studies, is there evidence of ethical approval by an appropriate body?	Y	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y
10. Conclusions in the research report drawn flow from the analysis, or interpretation, of the data?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Y: yes; N: no.

seven western and non-western countries. In total, 219 parents were interviewed, both during their NICU stay and at home. All eligible studies used a qualitative design and a qualitative analytic approach (Table 3). The critical appraisal showed that the eligible studies were transparent, informing the methodological aspects in the research process. However, the researchers' influence on the research was not mentioned in 10 of the 12 studies (Table 2).

The parental experiences of discharge and returning home resulted in an overarching interpretation that 'discharge is a double-edged sword', a metaphor pointing to the change and ambiguity parents experience surrounding the transfer from the hospital to bring baby home (Fig. 2). Three themes emerged, including 'approaching discharge with both confidence and uncertainty', 'discharge as a longed-for though disordering turning point' and 'facing joys, worries and multiple challenges when at home', whereas challenging experiences were supported by three subthemes: 'feeding and breathing as challenging', 'family life as challenging' and 'extensive hygiene as a social challenge' to enlighten the synthesis further. In the following, these findings will be elaborated.

3.1. Approaching discharge with both uncertainty and confidence

Approaching discharge with uncertainty refers to being ambiguous about discharge and bringing baby home, where discharge is at the same time joyful and worrying. One mother stated, 'I felt immense joy and happiness but at the same time a lot of fear because you're going home with a child that has problems' (Granero-Molina et al., 2019, p. e4). Some parents could be anxious about the lack of nursing and medical support nearby, and further reasons for worrying included visiting restrictions, such as limited visiting hours and access to their infant, living far away, little information and training, and not knowing the discharge schedule. Under these circumstances, discharge could feel overwhelming. Other parents really enjoyed returning home, where they were more comfortable.

During the NICU stay, many parents acquired the nurses' caring actions and attitudes. In some NICUs, the staff invited parents to group sessions before discharge, which involved reassuring parents of their confidence and readiness for discharge. Even so, parents could feel

Table 3
Characteristics of the eligible studies.

Author, year Country	Aim(s)	Professional and theoretical contexts	Design and data collection	Participants	Data analysis	Main findings
Aydon et al. (2018) Australia	Explore experiences of parents during transition and discharge to home	Neonatal care Stress theory	Qualitative descriptive Individual semi-structured interviews	40 parents, 20 mothers and 20 fathers with babies born between 28 and 32 weeks' gestation	Constant comparative analysis	Effective parent-staff communication; feeling informed and involved; being prepared to go home
Berman et al. (2018) USA	Explore parent perspective on discharge from NICU and build a parent-centred conceptual framework	Medical	Medical ethnography Telephone interviews 14 months–8 years after birth	15 parents (14 mothers and 1 father) of 18 NICU graduates discharged with tubes or monitors	Inductive and deductive content analysis	Communication; parent role clarity; emotional support; knowledge and training; financial resources
Black et al. (2009) USA	Analyse the phenomenon of becoming a mother and giving birth prematurely to a medically fragile infant	Nursing Life Course Theory, a sociological framework	Qualitative research, semi-structured individual interviews	34 mothers of babies with a mean weight of 1000 g	Content analysis	Coming home as a turning point
Chang Lee et al. (2009) Taiwan/UK	Explore mothers' parenting experiences when their premature infant was in NICU	Health Care/ Nursing	Qualitative research In-depth interviews	26 mothers of babies weighing less than 1500 g	Grounded theory	Causal conditions/context/ intervening conditions/action/ interaction strategies/ consequences
Craig (2015) USA	Investigate self-efficacy of caregiving and then lived experiences of parents post-NICU discharge	Occupational Therapy Bandura's self-efficacy theory	Qualitative research In-depth interviews	10 parents of babies born between 24 and 28 weeks' gestation	Qualitative phenomenology	Individual, environmental and social themes
Fowler et al. (2019) Australia	Explore experiences of mothers of extremely premature babies during NICU stay and transition home	Nursing	Interpretive description Telephone interviews	10 mothers from three Australian states with infants born at 24–27 weeks' gestation	Thematic analysis	Things got a bit dire; feeling a failure as a mother
Garfield (2014) USA	Examine concerns and coping mechanisms of fathers and mothers of very-low-birth-weight (VLBW) babies (less than 1500 g) in their transition to home	Medical	Qualitative research Inductive semi-structured phone interviews	15 mothers and 10 fathers of VLBW babies	Content analysis	Pervasive uncertainty; parents' coping mechanisms abound
Granero-Molina et al. (2019) E/RGH/UK	Describe the experiences of mothers of extremely premature infants following discharge to home	Nursing	Hermeneutic phenomenology Focus group and in-depth interviews	20 mothers of infants born at less than 28 weeks' gestation	Gadamerian-based hermeneutic research	The journey home; the difficulty of living with an extremely preterm infant
Hall et al. (2013) DK	Investigate experiences of being mothers of very preterm infants, their meaning of the hospital stay and experience of returning home	Neonatal nursing	Qualitative research In-depth interviews three times	5 mothers	Hermeneutic phenomenology	Being on a journey; at home at last – entering a new motherhood; being a responsive mother – the baby shows the way; being a preterm mother constantly worrying and comparing
Nicolaou et al. (2009) UK	Explore experiences of mothers concerning early interactions with their premature infants, their perceived support and their information needs	Community health	Qualitative research Semi-structured telephone interviews	20 mothers of babies with a median gestational age of 27 weeks	Thematic analysis	Hospitalisation as a barrier to interaction/anxiety regarding transition/transition preparation-emphasised medical information/sleepy and unresponsive baby/insecurity improvements over time/unfulfilling support from health visitors
Petty et al. (2018) UK	Investigate post-discharge experiences of parents of extremely premature infants	Narrative method Nursing	Qualitative research Semi-structured interviews in parents' homes	14 parents of babies born from 24 to 30 weeks' gestation	Constant comparative analysis	Emotional and mental health of parents; uncertain outcomes; ongoing health needs of the baby; educational needs of health professionals; parental support and preparation for transition home
Turner et al. (2013) AUS	Explore emotional reactions during the transition to home among parents of very preterm infants born between 24 weeks and 31 weeks 5 days' gestation	Medical Psychiatry	Qualitative research Telephone interviews	9 mothers	Thematic analysis	Anxiety and concern about the baby's readiness for discharge

uncertain about how to manage the 24/7 responsibility at home. One parent stated, 'I was nervous, scared, ...a little bit stressed as well, that the day finally came, and maybe that I was ill-prepared' (Turner et al., 2013, p. 441).

In cases where the VLBW infant was still dependent on technological support, such as oxygen or tube feeding, parents not only worried about caring, management and responsibility at home, but also about their daily life. Especially frightening was the immobility of the medico-

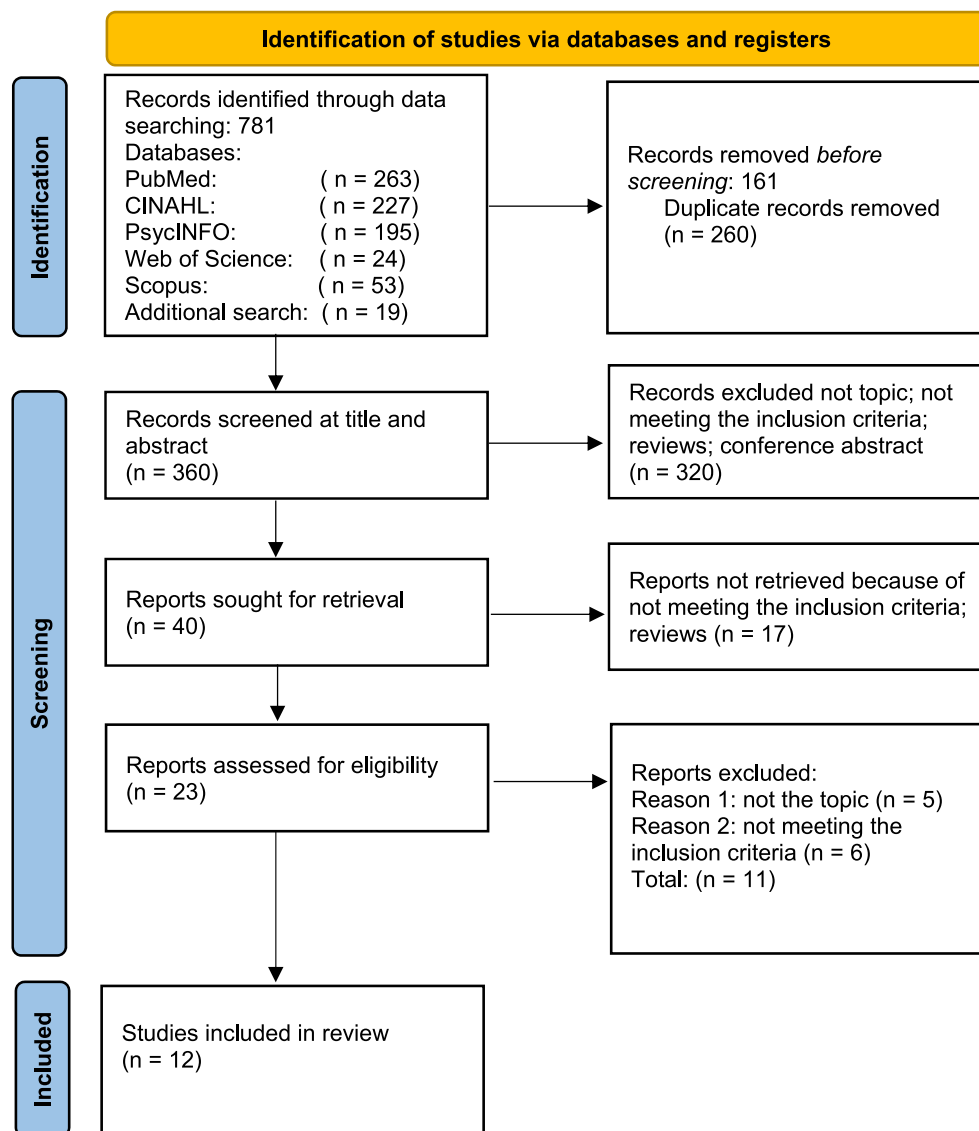


Fig. 1. Flow diagram for screening of primary studies.

technological devices in the beginning. One mother said, ‘She was on oxygen up ‘til about 6 weeks ago, so a good couple of months ... and it’s just so much easier now that she’s off the oxygen’ (Turner et al., 2013, p. 442).

The parents could feel confident if the nurses reassured them and reminded them to continue doing the things, they had done during their NICU stay. One mother of a set of twins born at 27 weeks’ gestation with a 54-day NICU stay stated, ‘The nurses always said: “We wouldn’t send them [twins] home if they weren’t ready to go home and if we didn’t feel like you were ready”’ (Garfield, 2014, p. 309). It was likewise a great help if, after discharge, parents were assured continuity of care and information between the hospital and community services.

3.2. Discharge as a longed-for though disordering turning point

Discharge as a disordering turning point refers to discharged parents being scared, puzzled, and confused following the actual transfer to home. For them, discharge was more than a transfer—it was the beginning of a new life: ‘Suddenly you are alone ... it felt good to bring him home, of course that is what anyone wants, but it was nerve-racking’ (Petty et al., 2018, p. 3). Leaving the comfortable and specialised setting of the NICU suddenly became scary; it exposed the parents to a

significant amount of responsibility. At discharge, the parents began to feel alone, rushed, confused, unable to cope or nerve-racked, as exemplified in the following quote: ‘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’ (Aydon et al., 2018, p. 274).

Parents felt at ease if the discharge schedule was clearly set, though they were distressed if there was no fixed plan or if discharge happened unexpectedly. One parent described it as follows: ‘My head was spinning. I got in the car, and I said to my partner, “I’m not going to cope. This is too much”’ (Turner et al., 2013, p. 441). Sudden changes could cause parents to question their own parental capability, as well as their infant’s readiness for discharge and capability to eat and breathe without professional assistance. One father stated, ‘Oh my gosh, what if something happens?’ (Garfield, 2014, p. 307).

3.3. Facing joys, worries and multiple challenges when at home

Life after bringing baby home was filled with joys, but also worries and challenges. At discharge, the VLBW infant was still fragile, and its health was a daily concern for the parents. Any small sign of well-being was a milestone that nurtured the parents’ expectations of their infant’s growth and development. This acknowledgement not only increased the

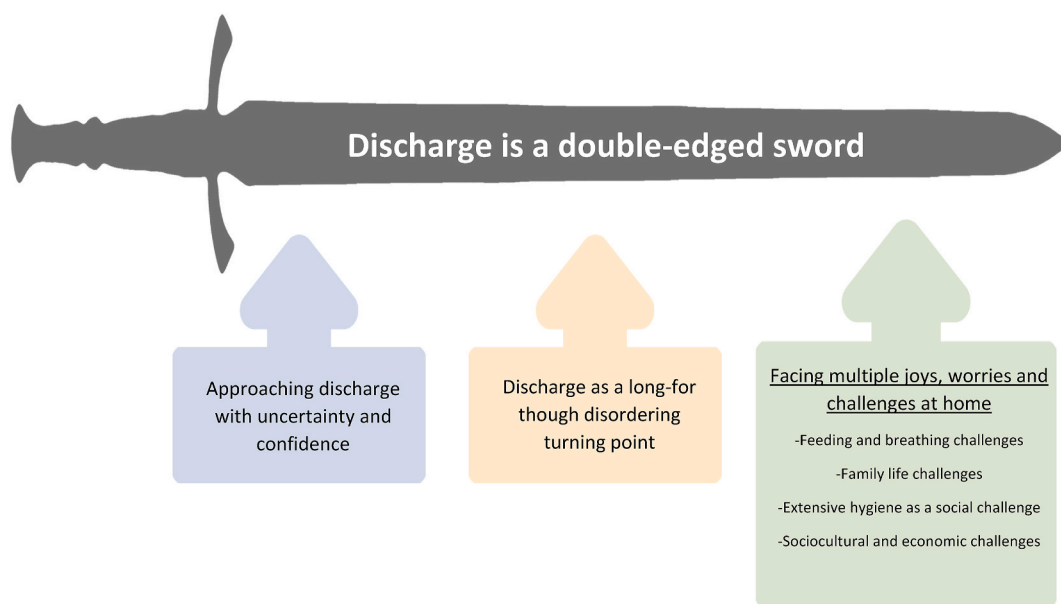


Fig. 2. The change and ambiguity parents experience surrounding the transfer and after returning home homecoming.

parents' knowledge base and parental maturation, it also stimulated attachment between infant and parents.

For first-time parents, the discharge to home was the true attainment of the new parental role, which led them to focus on themselves first as parents and then as parents of a VLBW infant. For second- or third-time parents, it was not always easy to acknowledge that their VLBW infant had different needs than their older siblings. Parents were taking over the main responsibility for caring decisions; they were coping with the VLBW infants' medical complications and avoiding readmissions; and, at the same time, they had to have positive expectations, be in control, focus on establishing a sensitive and loving parent–infant relationship, enjoy their infant's disposition and happily follow their progress and development. Thus, these parents faced challenges related to their infant's feeding and breathing, to family and social life, to extensive hygiene precautions and to financial and economic matters. In the following, we enlighten these challenges.

3.3.1. Feeding and breathing as challenging

During the NICU stay, most parents were trained in feeding their VLBW infant in different ways, such as through feeding tube, breast-feeding, or bottle feeding. Still, at home, feeding continued to be a significant challenge. The mothers had to develop their own feeding regimen, facing such challenges as learning how to care for a feeding tube, learning how to teach the infant to gradually suck milk from bottle or breast and learning how to cope with and handle the immature infant's unique breaks, necessary for breathing while sucking: 'My number one fear and concern was, "What if my baby stopped breathing?"' (Garfield, 2014, p. 308).

3.3.2. Family life as challenging

After weeks or months at the NICU, the parents really anticipated returning home, establishing—or re-establishing—the family and taking care of the new VLBW infant and, in some cases, older siblings. Even though parents felt well-informed before discharge, they could be surprised by how difficult it was to remember the information when at home. One father stated, 'We were so anxious when we got home?... It's like we never heard anything!' (Craig, 2015, p. 105). After discharge, the parents were concerned with each other's health and wellbeing, how to balance work and family and how to manage the sleep deprivation required of round-the-clock care for the VLBW infant. One mother stated, 'The sleep deprivation I experienced with two premie twins was

beyond anything I experienced ... Sleep deprivation really messed with my mental health' (Berman et al., 2018, p. 101). The mothers were much concerned with how their partners were balancing work and family, while the fathers were mostly concerned with the mothers' mental and physical well-being, especially how their spouses managed to rest between the frequent caring and feeding. To overcome these challenges, the parents could develop coping strategies, such as physical activity or reaching out to close friends, extended family or mothers from the hospital for emotional and practical support: 'I am still in contact with many mothers from the hospital and their experience has encouraged me and guided me in how I have to treat my son' (Granero-Molina et al., 2019, p. e5).

3.3.3. Extensive hygiene as a social challenge

The importance of the VLBW infant's health and well-being meant strict hygiene precautions, as the VLBW infant could easily contract an infection. Thus, health precautions for the infant had social consequences on the parents. On the one hand, parents were looking forward to re-establishing their social relations and discussing their infant and their experiences at the NICU. On the other hand, and to protect their tiny infant, they had to limit their social life and select with whom to interact after returning home. This smaller circle of acquaintances could be disappointing and could contribute to feelings of isolation. However, the strict hygiene principles made the parents cautious, and they took measures to protect their infant:

Since our NICU graduate baby [was ill], we've been really conscious of keeping him away from other kids who are sick, and I took my other son out of childcare. If friends invite us over, we ask if their kids are going to be sick, and if they are, we don't go. (Turner et al., 2013, p. 441)

3.3.4. Sociocultural and economic challenges

After returning home, parents could face pressure from friends, grandparents, community staff and others who did not understand the family's new and socially restricted life. In some cultures, the infant's health and the cultural postnatal rituals could be in conflict, both being just as important: 'I didn't practice my *Zuo Yue Zi* fully, but I feel that's fine ... I'd rather be with my baby and hold her in my arms ...' (Chang Lee et al., 2009, p. 331). Such ambiguity could easily escalate when grandmothers and other family interfered, despite the best intentions.

Parents could likewise encounter inexperienced community health-care professionals caring for VLBW infants, which could lead to feelings of loneliness and abandonment. One mother stated, 'I felt a little bit left alone with him. Health visitors would come around but ... they didn't know how to deal with a premature baby' (Nicolaou et al., 2009, p. 190). Such health care visits seemed to impede the progress of the mother-infant bond.

In cultures without a social security network, giving birth to a fragile VLBW infant, and the subsequent prolonged NICU stay, could negatively affect family income. Furthermore, economic challenges could be related to the mothers' choice to stay at home or work part-time—such decisions had financial implications. The birth of a VLBW infant and their subsequent discharge to home could thus have extensive and long-lasting economic and sociocultural consequences for the family.

4. Discussion

This meta-ethnography, based on 12 qualitative studies published 2009–2019, offers a comprehensive understanding of how parents of VLBW infants experience discharge to home, the transfer to home and life after returning home. From our analysis of studies from both western and non-western countries, we argue that the findings, presented as an overarching metaphorical interpretation of 'discharge is a double-edged sword', containing three themes and several subthemes, draw together clinically useful aspects of the parental discharge and return home experiences. Knowing of and acting on these findings is quite appropriate for neonatal nurses.

From the transitions theory perspective (Meleis, 2010, 2015), the meta-ethnography uncovers that for parents of VLBW infants, discharge is more than a transfer from the NICU to home. These parents' discharge experiences are interwoven in developmental, health-illness and situational transitions that are challenging for them. Both the transfer to home and life after returning home seem much welcomed, though filled with worry and challenges. Our findings thus concur with Green and colleagues' findings (2021) that the transition from the NICU to home with a VLBW infant is much different from returning home with a late premature infant; it includes stressful parental experiences, which the health care system must acknowledge and facilitate. We found that these transitions could be disordering; and returning home meant living with worry and multiple challenges that were not always easy to overcome. It is obvious that discharge programme interventions specially designed for mothers and fathers strengthen parental care of a VLBW infant (Ocampo et al., 2021). We would argue that facilitating support to reduce parental uncertainty at discharge after the birth of a VLBW infant and a long NICU stay is a primary nursing task.

Our theme 'facing joys, worries and multiple challenges' touches on the extensive life transition that occurs when parents bring their VLBW infant home. Feelings of being left with physicians and community nurses who are inexperienced with VLBW infant care was one challenge - the lack of collaboration between hospital and community healthcare providers, an aspect leading parents to feel abandoned by professionals after discharge, was another challenge among our findings. We would agree with Penny and Windsor (2017) that a high level of collaboration in neonatal healthcare services might give an impression of negotiation and participation. However, our findings pointed at the opposite. Therefore, neonatal nurses must observe the quality of their collaborations related to discharge. Collaboration is a rubric that meets current political and disciplinary agendas. As such, however, it might obscure the ambiguities that characterise pre- and postnatal care in neonatal practice. There seems to be a need for neonatal hospital and community staff not only to consider collaboration but also to adopt a critical attitude towards abstract expressions, such as collaboration.

Family-centred care (FCC) e.g. is another highly abstract concept that refers to an accepted mode of care for hospitalised children and their parents (Coyne et al., 2016). Neonatal and community nurses might acknowledge FCC but not always follow its intentions when

facilitating discharge and the return home for parents and their VLBW infant. Likewise, our findings show that the discharge to home can take place without proper preparedness for parents living far away, where visitation is restricted to special hours and information and training are far from optimal. Our review, as well as other studies (Smith, 2021), shows that a well-ordered discharge plan could be helpful for parents, easing their feelings of disorder and facilitate their transition.

A major challenge after returning home is feeding. Even though the parents practice feeding their VLBW infant during the NICU stay, feeding remains a primary worry at home, because feeding hours are still frequent and feeding affects the infant's breathing. We found that parents' worry about feeding is an essential though complex care issue; and this concurs with previous studies arguing that parents at discharge, worry much about their infant's food intake and about tube- and breastfeeding (Chang Lee et al., 2009; Larsson et al., 2017; Sisk et al., 2010). This worry continues over the years, necessitating prolonged support and understanding (Grundvig Nylund et al., 2019). Difficulty and worry in feeding the VLBW infant point to the need for timely readiness at discharge, early training of parents in feeding skills and repeated reassurance of their VLBW infant's unique feeding pattern; it concerns clarifying and discussing misunderstood information and supporting family self-management. Kornburger et al. (2013) suggest nurses, prior to discharge, to check caregivers' understanding of discharge instructions through a 'Teach-Back' assessment. Post-discharge recommendations for feeding exist, and nursing support is suggested to both parents (Francis et al., 2018).

Parents have other worries than feeding. Our theme 'approaching discharge with uncertainty and confidence' builds on the findings that discharge is an intertwining of joy and worrying, related to both longed-for-yet-frightening prospects of discharge to home and life at home. Our findings show that parents worry about approaching discharge, and they continue to worry about the transfer to home and how they and their tiny infant will manage. Worrying seems central and, in a way, shadows the joy and happiness of bringing baby home. We would argue that knowledge of the meaning of parental worry is an important matter in excellent neonatal care. We find parental worry to be a sign of both a healthy transition from the NICU to home and a healthy transition to parenthood.

According to the pedagogue and philosopher Max Van Manen (2002), worrying is embedded in lived relations of caring as, what he calls, care-as-worry. Van Manen (2002) further argues that worry is an active and necessary ingredient of parental attentiveness, functioning as the glue that keeps parents attached to their child's life, as parents never stop worrying because they love and care for their children. From this perspective, our finding that parents of VLBW infants face multiple worries about discharge and returning home demonstrates genuine parenthood. Though, because their VLBW infant needs frequent feeding and close observation, and because worrying demands much energy and parents might overinvest in their parental role, the worry could develop into exhaustion and burnout (Hubert and Aujoulat, 2018). We agree with these authors that to prevent such an unhealthy condition, parents—especially mothers—must be told that they are good enough, that the perfect mother does not exist, and that parental worry is a sign of adopting a loving and caring parental role.

At discharge from the NICU, they become parents 24/7 with total parental responsibility. From the perspective of transitions theory (Meleis, 2010), these parents acquire a new role as a parent, a mother or a father. In a way, their small and vulnerable infant takes them hostage (Van Manen, 2002) - the worrying is there forever.

Another matter concerns sensitivity. Easing a healthy transition and return home for parents of VLBW infants is possible when the involved nursing staff are sensitive and display patience. Being sensitive refers both to being aware of the self and to reacting to others' needs (Sayers and de Vries, 2008). Responding and reacting to others' needs mean being open, listening and observing in ways that are touching and comforting; they refer to promoting self-worth and demonstrating a

non-judgmental, knowledgeable and appropriate attitude (Sayers and de Vries, 2008). We find that sensitive postnatal and post-NICU debriefing is closely interwoven with postnatal care. We would agree with previous research (Steele and Beadle, 2010) that to prevent a gap in continuity after the VLBW infant is discharged to home, and for transitional care to be effective postnatal and post-NICU care, time, listening and information are required. Our suggestions have features that correspond to Green and colleagues (2021) concerning the need for parents of VLBW infants to describe the details of and their feelings about their experiences. To heighten the parental preparedness for discharge to home, or to help them wield their double-edged sword, there should be time for discussions of the future; confirmation about normality; a focus on sensory perceptions, smells, visions, noises, etc.; and identification of the worst thing that might happen. As modern technology and quality neonatal care contribute to an increase in survival among VLBW infants, their parents' well-being is just as important to consider. Discharge planning programmes might be most helpful if they are adjusted to local contexts (Smith, 2021), and because parental well-being has a clear impact on infant and family health, facilitating well-being for parents of VLBW infants is a primary goal in neonatal nursing.

5. Strength and limitations

All through the research process, we tried to be faithful to the messages of the primary studies and, at the same time, translate findings into a condensed and universally new understanding suitable for neonatal and community nursing. In the process, we kept in mind that a meta-ethnography is a systematic interpretation of forwarding evidence. One limitation is that we have not considered the meaning of culture and healthcare systems, which, as globally seen, differ significantly. Reflecting on such matters would have strengthened the review but could also have had ethical implications, such as over-interpretation of the data from the primary studies. The eMERGe guidance helped us in the reporting of this meta-ethnography; thus, it made us aware of the importance of reporting all pertinent aspects for a meta-ethnography, especially regarding translating studies.

6. Conclusion

From this meta-ethnography based on 12 primary studies, we conclude that for the parents of a VLBW infant, discharge from the NICU and the return home with the infant is like wielding a double-edged sword. It is a critical and often disordering transition that encompasses both managing joys and challenges. On the one side, discharge is longed for, and the return home is welcomed. On the other, discharge creates uncertainty about one's own ability and competence, and the return home presents a handful of medical, caring, and relational worries and challenges. Parents, then, are filled with ambiguity of what is right and wrong to do, oscillating between the joy of being a parent and the worries and challenges that their new parental role is causing. Therefore, when VLBW infants are at home after a prolonged NICU stay, their parents still need personalised support and much understanding and encouragement from knowledgeable healthcare providers.

Ethical approval

Ethical approval was not required.

Declaration of competing interest

The authors declare that they have no competing interests.

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