Manuscript Details

Manuscript number	JNEO_2018_48
Title	Systematic review of tube-fed preterm infants in the home supported within a family-centered program
Article type	Review article

Abstract

There is a growing need and demand to redesign neonatal services to place a focus on family-centered care provided locally. Early discharge training programs that prepare parents to tube-feed and care for their preterm infant at home may offer a viable option, but these are understudied. A narrative review of relevant literature was undertaken. The key findings highlighted that within the discharge programs there was no increase in readmission rates caused through home tube-feeding, infant weight gain was adequate and parental satisfaction was reported as high when 24-hour access to staff was available. Further, an increased duration of breastfeeding was associated with a reduced risk of readmission. The review highlights the potential of this service as an alternative to in-patient care for infants requiring short-term tube-feeding during their transition to full oral-feeding.

Keywords	Keywords: early discharge; family-centered care; home care; literature review; low birth weight; neonatal; premature; tube-feeding.
Corresponding Author	Sonya MacVicar
Corresponding Author's Institution	Edinburgh Napier University

 Order of Authors
 Lesley Menczykowski, Sonya MacVicar, Anne Moylan, Caroline Hollins Martin

 Submission Files Included in this PDF

File Name [File Type]

Editor letter.docx [Cover Letter] title page.docx

[Title Page (with Author Details)]

Copy-of-Journal of neonatal nursing.docx [Manuscript (without Author Details)]

Copy-of-Tables.docx [Figure] figures.docx [Figure]

To view all the submission files, including those not included in the PDF, click on the manuscript title on your EVISE Homepage, then click 'Download zip file'.

Research Data Related to this Submission

There are no linked research data sets for this submission. The following reason is given: No data was used for the research described in the article

Systematic review of tube-fed preterm infants in the home supported within a family-centered program

Lesley MENCZYKOWSKI. MSc BSc RGN/RM Advanced Neonatal Nurse Practitioner, NHS Tayside.

Dr Sonya MACVICAR. PhD, MSc, RGN/RM Lecturer in Advanced Neonatal Practice, Edinburgh Napier University.

Anne MOYLAN. MSc BSc RGN/RM Lecturer in Neonatal Nursing Studies, Edinburgh Napier University.

Professor Carolyn J. HOLLINS MARTIN. PhD MPhil RGN/RM Professor in Maternal Health, Edinburgh Napier University.

Corresponding Author

Dr Sonya MacVicar School of Health and Social Care Edinburgh Napier University Sighthill Campus Edinburgh EH11 4BN <u>s.macvicar@napier.ac.uk</u> s macvicar@smacvicar1

Conflict of Interest: None.

Ethical Approval was not required.

Acknowledgement: No acknowledgements

Funding: No funding was attached to project

Word count: 3481 words

Systematic review of tube-fed preterm infants in the home supported within a family-centered program

INTRODUCTION

Recent government initiatives recommend a redesign of neonatal services to focus on family-centered care delivered at home as an alternative to inpatient special care for stable infants with ongoing support needs (Scottish Government 2017). One group of infants considered potential beneficiaries of this service is the preterm infant transitioning from enteral to full oral feeding. Feedback from families who have delivered home enteral feeding is generally positive (Bissell & Miall, 2009), with Dixon et al. (2011) citing benefits in terms of improved family attachments, normalization of the family unit, increased breastfeeding success, reduced infection risk, and significant healthcare cost savings.

Survival rates and outcomes of the smallest and most vulnerable infants continue to improve (Younge et al., 2016), with their clinical care requiring expensive high-level technology and prolonged hospitalization (Petrou et al., 2009). Neonatal services must be geared towards providing intensive care, but this level of care is required for only a tiny proportion of infants. Many more will require only high dependency and special care provision. It is the moderate and late preterm infants who account for the highest occupancy of neonatal cots (Royal College Paediatrics and Child Health, 2016). Additionally, the majority of extreme preterm infants requiring neonatal intensive care initially will only

require this high level for part of their neonatal stay before progressing to less acute cots.

With the need for intensive care usually short-term, the remainder of the infant's hospital stay is categorized as special care. This stage ordinarily involves transitioning to full oral-feeding (Rose et al., 2008) when neuro-developmental maturity can co-ordinate the physiological triad of suck, swallow, and respiration (da Costa et al., 2008). This developmental maturity is critical for successful transition to full oral-feeding, with 98% of infants born at 34 weeks gestation requiring nasogastric tube-feeding. Full oral-feeding has in the past been one prerequisite for preterm discharge home (Swift & Scholten, 2010), with readiness requiring the infant to have physiological stability in terms of respiratory status, nutritional balance and weight gain (Jeffries, 2014). However, the transition process is multifactorial and influenced by neonatal characteristics, co-morbidities and location of care (Jackson et al., 2016). This may take several weeks, is an ongoing burden on healthcare resources and is often found to be frustrating for parents (Rose et al., 2008).

Family-centered care is a collaborative partnership between the multidisciplinary team, patient and family, and involves care-planning and evaluation (Institute of Family-Centred Care, 2017). The key principles of family centered care involve open and honest communication to facilitate informed choice and joint decision-making, with parents as the main caregivers (Bissell & Miall, 2009). Parent satisfaction is also important (Bradley, 2013), where improved communication with staff is key (Weiss et al., 2009). Ortenstrand et al. (1999, 2001) studied infant outcomes from an early preterm infant discharge program that involved

home tube-feeding and concluded that it was a viable alternative to in-patient care, with benefits including improvements in breast-milk supply, increased infant weight gain, reduced hospital stay and improved parent-infant attachment (McGregor & Casey 2012).

With the needs and expectations of women and their families changing, neonatal services should be designed to respond across the spectrum of unique and individualized family requirements. Several models of transitional care and service delivery exist currently. One such model of transitional care has been established which is used as a 'step down' from special care where parenting skills and confidence are supported and grown in preparation for discharge home (BAPM, 2017). In this transitional care model, the mother stays in hospital with her baby and provides care, supported by maternity and neonatal staff. However, it may be unsuitable for some women to remain in hospital for an extended period of time given other family commitments. Home neonatal care may be an alternative for families to a prolonged period of hospitalization for stable infants transitioning to full oral feeding (Bissell and Miall, 2009). Smooth transition to home care, however, requires development of a robust, evidence based and multi-disciplinary approach.

AIM

Our aim was to conduct a systematic review and narrative synthesis of the literature documenting the outcomes of preterm infants and their parents discharged home short-term tube-feeding facilitated by a family-centered care early discharge program. Outcomes of interest included measures of feeding

success and parental satisfaction. Furthermore, the review aimed to enable greater understanding of early discharge programs through consideration of the program elements. This has the potential to inform the redesign of current services to actively involve and empower parents in the care of their infant.

METHODS

To conduct this systematic review, we followed the guidelines in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement for reporting systematic reviews (Moher et al., 2009). Scoping was undertaken to identify terms for the development of the PICOT (Populations, Intervention, Comparators, Outcomes, Time) element of the search strategy (Fineout-Overholt & Johnston, 2005). (see *Table 1*).

TABLE 1: PICOT framework

Search strategy

Assistance was provided by the university librarian to construct a search strategy. Databases MEDLINE, Cochrane Database of Systematic Reviews, DARE and the Cumulative Index of Nursing and Allied Health Literature were searched for articles using the Medical Subject Headings: infant premature, infant low birth weight, infant very low birth weight, premature, neonat*, early discharge, patient discharge, home care, and family-centered care, tube feed*,

enteral feed*, enteral nutrition or breastfeed*. The literature required the full text to be published in English, as translation service was not available. The search was confined to Jan 2006 until July 2017 as a scoping exercise suggested that earlier literature was no longer representational of contemporary neonatal practices related to early discharge programs. No restrictions on study design were imposed. Abstracts identified using the search strategy were included if they met the following criteria: they were research studies reporting quantitative and/or qualitative outcomes on home care of preterm infants requiring short term tube-feeding facilitated by a family-centered care early discharge program and measured one or more of outcomes related to (1) parental satisfaction, (2) neonatal health and (3) infant feeding outcomes including weight gain, transition time to full oral feeding and duration of breastfeeding. Disparities about eligibility was resolved through discussion with research supervisors.

Assessment of study quality

Dependent upon study method, the appraisal of quality of the study was conducted using 6 critical appraisal instruments. These included, Evans (2003), Joanna Briggs Institute (JBI, 2016abc), Daly et al. (2007), and Long's (2005) critical appraisal tools.

Data extraction, synthesis and analysis

A data-extraction form was used to summarize data for evidence synthesis (Holland and Rees 2010). From the review objectives 6 outcome areas were categorized: (1) components of an early discharge program, (2) readmission

rates, (3) time of transition to full oral-feeding, (4) infant weight gain, (5) breastfeeding data, (6) parental satisfaction. Studies included did not report data for all outcomes. Due to the variation of methods used and insufficient incompatible data meta-analysis was not considered possible.

RESULTS

Figure 1 shows the flow of the studies through the selection process (Moher et al., 2009)

FIGURE 1: A PRISMA flow chart for the selection of eligible studies.

The search strategy yielded 249 articles and following abstract screening 42 were shortlisted for full text scrutiny. This excluded a further 38 papers as these were either paediatric studies, unrelated to home care, unconnected with tube-feeding, unrelated systematic reviews or study protocols. This resulted in 4 studies meeting the inclusion criteria. Processes of forward citation yielded 4 additional studies which accumulated to 8 being selected for critical appraisal. The 8 scrutinized papers included 2 qualitative, 5 quantitative, and 1 mixed method study (Ahnfeldt et al., 2015; Brodsgaard et al., 2015; Dellenmark-Blom & Wigert, 2014; Garne et al., 2016; Gund et al., 2013; Lundberg et al., 2016; Meerlo-Habing et al., 2009; Robinson et al., 2016). A brief description, study characteristics and quality of evidence grading of the individual studies are presented in Table 2.

TABLE 2 Study characteristics and data extraction of included studies

All the studies evaluated the impact of family-centered care early discharge programs for the preterm infant home tube-feeding with differing components included in the early discharge home packages and a variety of assessed outcomes. Seven of the included studies were from Scandinavian countries, except Meerlo-Habing et al. (2009) which was based in the Netherlands. A variety of critical appraisal tools were used to appropriately assess the study according to its methodology and 6 studies were graded as good (Brodsgaard et al., 2015; Dellenmark-Blom & Wigert, 2014; Garne et al., 2016; Lundberg et al., 2016; Meerlo-Habing et al., 2009; Robinson et al., 2016). Ahnfeldt et al., (2015) was graded as fair as groups were mismatched and there were no adjustments made for confounders such as parental smoking and education level. The study by Gund et al., (2013) was graded quality fair to poor and considered not to be an RCT despite being described as such (JBI 2016a). This paper was included in the review as it laid the foundation for the follow-on study conducted by the same team (Robinson et al., 2016). The criteria for early discharge and inclusion in the research study was similar in each study. The infants had to be postmenstrual age of 34 weeks gestation, were physiologically stable but still required tube-feeding to maintain optimal nutrition. The study by Ahnfeldt et al. (2015) excluded infants when it was thought their need for tube feeding was less than a week.

Components of an early discharge program

All studies stated criteria for a neonate to be included in an early discharge program, but only Brodsgaard et al. (2015) identified set discharge criteria which was illustrated in a flowchart. All programs included a training and education package to prepare parents for discharge. The pattern of home visits was between 1-3 times a week and one program (Lundberg et al., 2016) had the flexibility for nurses to visit daily whilst another required the infant to return to the hospital for review (Robinson et al., 2016). All cohorts had 24-hour access to advice via telephone, with Gund et al. (2013), Garne et al. (2016), and Robinson et al. (2016) employing additional support technology (e.g., Skype). Parents in the video conference groups reported that the number of home visits could be reduced when consultations were available online.

Readmission rates

Readmission rates were a primary outcome in 5 studies, with no readmission recorded as directly attributable to tube-feeding. (Ahnfeldt et al., 2015; Brodsgaard et al., 2015; Dellenmark-Blom & Wigert, 2014; Lundberg et al., 2016; Robinson et al., 2016). Rates varied significantly across studies from 5.2% to 17%, additionally confounding factors such as gestational age, comorbidities and weight may have impacted on these findings. Robinson et al., (2016) found that 17% of emergency department visits ended in readmission in the telemedicine group although the frequency of the number of unscheduled care episodes were significantly lower in the study group. In comparison

Brodsgaard et al., (2015) reported a readmission rate of 6% with almost half of the parents making additional telephone contact with staff. This extra contact was often in regard to an aspect of parental anxiety or a query which could be answered in a telephone call. The telephone lifeline was the main theme which emerged from the focus group interviews. Ahnfeldt et al., (2015) readmission rate was 10.4% which may have been influenced by the initial mismatching of infant characteristics in each group with infants in the study group being younger and weighed less than those in the control group. Infants who were within a week of achieving full suck feeds were excluded from the study which may also have influenced the study group characteristics favouring a less mature cohort. Lundberg et al. (2016) had a readmission rate of 5.2% with a comparable cohort to that reported by Ahnfeldt et al. (2015) in terms of infants of a lower gestation at birth being more likely to be readmitted. Lundberg et al. (2016) reported a correlation between readmission rates and infant feeding method with breastfed infants less likely to be readmitted compared to the control group.

Time of transition to full oral feeding

Only Brodsgaard et al., (2015) reported data on gestational age and weight at time of feed-tube removal giving a mean of 37+5 weeks but within a range of 34+3 to 43+1 weeks. None of the studies give any information about feeding plans for progression towards full oral feeding although Lundberg et al (2016) and Brodsgaard et al (2015) included teaching parents about behavioural and feeding cues as part of their education program. Three studies gave a corrected

gestational age at final discharge of 39+2 – 39+4 but did not include data on specific time to transition to full oral feeding (Ahnfeldt et al., 2015; Brodsgaard et al., 2015; Robinson et al., 2016).

Infant weight gain

Infant weight data was collected in 4 studies with 3 studies having comparable data sets in terms of gestational age and weight at birth, on entry into the early discharge program and at discharge from the program (Ahnfeldt et al., 2015; Brodsgaard et al., 2015; Lundberg et al., 2016; Robinson et al., 2016). Lundberg et al. (2016) did not include discharge data. There were similarities between the data and the general trend in weight gain, gestational age on entry and at discharge from the program within each of the 4 studies. The weight gain over the time in the neonatal home care program average around 30g per day. Brodsgaard et al. (2015) found that 12% of the infants had difficulty thriving with no further details given regarding this group of infants such as breastfeeding, oxygen requirement or other comorbidities which can impact on growth. The infants in the study group reported by Ahnfeldt et al. (2015) had a greater weight gain than those not in an early discharge program with a difference of 400g between the 2 groups. However, the infants in the study group were over 2 weeks older at just over 39 weeks corrected age compared to just under 37 weeks in the comparison group, this was found not to be statistically significant when analysed as weight for age at discharge.

Breastfeeding data

Two studies focused on breastfeeding as a primary outcome using the World Health Organization/ UNICEF (2015) definition of breastfeeding. Ahnfeldt et al. (2015) reported an 8% (88% vs 80%) higher breastfeeding rate in mothers engaged in early discharge home care programs. This data is supported by Merlo-Habing et al. (2009) who demonstrated an increase in duration of breastfeeding at 6 months, with 22% of study group infants breastfeeding compared to 18% of the control group.

Parental satisfaction

Three studies measured parent satisfaction through interview and questionnaires conducted up to 12 months post-discharge (Brodsgaard et al., 2015; Dellenmark-Blom & Wigert, 2014; Robinson et al., 2016). Parents reported high levels of satisfaction with all parents stating that they would recommend being in such a program to other parents. Robinson et al. (2016) linked parental satisfaction to the freedom which neonatal home care gave families and the control it affords particularly when older siblings are involved.

DISCUSSION

This review synthesized findings from 8 selected papers that studied outcomes for preterm infants, and their parents, when discharged home tube-feeding. Neonatal home care appears to be a viable delivery option for infants during the

transitional phase towards full oral feeding. There were no reports of hospital admission as a result of home tube-feeding and the readmission rates were comparable with previous research for the preterm infant population (Underwood et al., 2007; Lacobellil et al., 2017). Infants within the early discharge program experienced adequate weight gain, averaging around 30g per day which is in keeping with Cole et al. (2014) and Fenton et al. (2013) suggested 16-18g/kg/day as being an adequate weight gain for a preterm infant. There was also an increase in duration of breastfeeding of infants in the study groups with a tentative link between readmission rates and possible protective factor of breastfeeding. Brodsgaard et al. (2015) identified the gestation at which the feeding tube was removed to be 37+5 weeks, which is much later than studies based in hospital on transition time to oral feeding. Parental satisfaction was high with positive feedback particularly where additional support was employed in the form of 24-hour telephone access to nurses on the neonatal unit and video conferencing. Parents thought of these measures as 'a lifeline' which provided security although few parents actually used them.

The report has highlighted a number of implication for practice and recommendations for future management of this neonatal population. Reports surrounding transition to full oral-feeding in hospital have found infants successfully feeding at gestations as early as 34+1 weeks (Jackson et al., 2016) and 35.8 weeks (Pickler et al., 2015), which is much earlier than the 37+5 weeks quoted in the Brodsgaard et al. (2015) study. It may be difficult to

attribute the delay in transition solely on location of care delivery however this has been cited as a factor by Jackson et al. (2016) and there may be suggestion that the organizational push towards discharge due to pressure on neonatal cots may force staff to accelerate the transitioning process to full oral feeding. None of the studies provided feeding plans for progression towards full oral-feeding, with Lundberg et al. (2016) and Brodsgaard et al. (2015) recommending that families be taught behavioural and feeding cues that influence transition to full oral-feeding (Maastrup et al., 2014). Clearly, a knowledge gap exists about transition to full oral-feeding in home care settings. Feeding plans are employed extensively and successfully in neonatal units and integrating these into the home care setting should be considered (Greene et al., 2013).

All study cohorts had 24-hour access to advice via telephone, with Gund et al. (2013), Garne et al. (2016), and Robinson et al. (2016) employing additional support technology in the form of web-based applications and video conferencing. Parents in the video conference groups reported that the number of home visits could be reduced when consultations were available online. Robinson et al. (2016) identified that frequency of ED visits was significantly lower in the video conference group, supporting the worth of developing 24-hour face-to-face technology. A shared information site, with 24hour Skype, email & phone line may offer parents additional support options and widen access to rural areas.

Neonatal home care has the potential to fulfil current services needs and the new knowledge produced in the review has the potential to contribute and influence this model of care (Scottish Government, 2017). This literature review has identified aspects for inclusion in a family-centered home care program and recommendations include education and training package for parents and supporting clinicians, flexible family-centered home/hospital visit schedule, explicit discharge criteria flowchart for infant inclusion in a home care program and community outreach support from video technology, email and telephone. Further recommendations for alternative ways of working towards expanded and enhanced home care delivery could include neonatal reviews held in satellite clinics attached to breastfeeding clinics, thus providing the opportunity for additional feeding support for parents. This systematic literature review has synthesized existing evidence on which to build a comparable service in the UK with transferability of the Scandinavian research particularly applicable in terms of the similar widespread catchment area and diverse mix of urban/rural settings.

Strengths and Limitations

Direct comparison was not possible between the studies due to variations of data collection and presentation. Given the small numbers of articles and heterogeneity of outcomes and definitions it was not appropriate to pool the results to determine the overall effect of a neonatal home care program. However, the range of study objectives has given an overview to the topic of neonatal home care with similarities identified within the criteria for infants

entering an early discharge program. This baseline criteria have been validated in that neonatal home care has been in place for many years in Sweden and Denmark.

CONCLUSION

Given the lack of robust evidence, a conclusion cannot be drawn with confidence. The main inference drawn is that neonatal home care appears to be a viable option for infants requiring short-term tube-feeding, is family-centered with high rates of parental satisfaction. The results reported are a starting point from which diverse countries can begin to build similar services. Implications for clinical practice have the potential to be far reaching not only for the families involved in a neonatal home care program but also in terms of systems of working, service cost and freeing up much needed neonatal cots for the higher acuity infant. Nationally, the increased availability of cots has the potential to reduce pressure on neonatal services enabling staff to be available to care for infants in the most appropriate setting for their care need. For a large majority of infants, this care setting can safely be in the home. Further research is recommended on systems of implementing short term tube-feeding in the home care setting and to determine a core outcome set for neonatal early discharge programs to enable audit of practice and advance knowledge.

REFERENCES

Ahnfeldt, A., Stanchev, H., Jørgensen, H., Greisen, G. (2015). Age and weight at final discharge from an early discharge programme for stable but tube-fed preterm infants. *Acta Paediatrica.* 104(4):377-383. DOI: 10.1111/apa.12917

Bissell, G., Miall, M. (2009). Changing practice by the earlier introduction of tube feeding at home. *Infant.* 5(5):150-154.

Bradley, A. (2013). How creation of a parent satisfaction questionnaire improved multidisciplinary service delivery in a paediatric day surgery unit. *British Medical Journal Quality Improvement Reports.* 2(1):1-4.

British Association of Perinatal Medicine (2017). *A framework for neonatal transitional care*. Retrieved from <u>https://www.bapm.org/sites/default/files/files/TC%20Framework-20.10.17.pdf</u>

Brødsgaard, A., Zimmermann, R., Petersen, M. (2015). A preterm lifeline: Early discharge programme based on family-centred care. *Journal for Specialists in Pediatric Nursing.* 20(4):232-243. DOI: 10.1111/jspn.12120

Cole, T.J., Statnikov, Y., Santhakumaran, S., Huiqi, P., Modi, N. (2014). Birth weight and longitudinal growth in infants born below 32 weeks gestation: a UK population study. *Archives of Disease in Childhood.* 99(1):34-40.

da Costa, S.P., van den Engel-Hoek, L., Bos A.F. (2008). Sucking and swallowing in infants and diagnostic tools. *Journal of Perinatology.* 28(4):247257. DOI: 10.1038/sj.jp.7211924

Daly, J., Willis, K., Small, R., Green, J., Welch, N., Kealy, M., Hughes, E. (2007). A hierarchy of evidence for assessing qualitative health research. *Journal of Clinical Epidemiology.* 60(1):43-9. DOI: https://doi.org/10.1016/j.jclinepi.2006.03.014

Dellenmark-Blom, M., Wigert, H. (2014). Parents' experiences with neonatal home care following initial care in the neonatal intensive care unit: a phenomenological hermeneutical interview study. *Journal of Advanced Nursing*. 70(3):575-586. DOI: 10.1111/jan.12218

Dixon, V., Venkatesh, V., May, J., D'Amore, A., Curley, A. (2011). Improving neonatal resource use through early discharge: experience of a tertiary neonatal unit with a dedicated neonatal community team. *Journal of Neonatal Nursing.* 17(3):111-115. DOI: <u>10.1016/j.jnn.2010.07.017</u>

Evans, D. (2003), Hierarchy of evidence: a framework for ranking evidence evaluating healthcare interventions. *Journal of Clinical Nursing*.12 (1):77-84. DOI: 10.1046/j.1365-2702.2003.00662

Fenton, T., Nasser, R., Eliasziw, M., Kim, J., Bilan, D., Sauve, R. (2013). Validating the weight gain of preterm infants between the reference growth curve of the fetus and the term infant. *BioMedical Central Pediatrics.* 13(92):1-10. DOI: 10.1186/1471-2431-13-92

Fineout-Overholt, E., & Johnston, L. (2005). Teaching EBP: Asking searchable, answerable clinical questions. Worldviews on Evidence-Based Nursing, 2(3), 157-160. DOI: 10.1111/j.1741-6787.2005.00032

Garne, K., Brødsgaard, A., Zachariassen, G., Clemensen, J. (2016). Telemedicine in neonatal home care: Identifying parental needs through participatory design. *Journal of Medical Internet Research Protocols.* 5(3):1-8. DOI: 10.2196/resprot.5467

Greene, Z., O'Donnell, C.P.F., Walshe, M. (2013). Oral stimulation techniques in preterm infants – International research challenges. *Journal of Neonatal Nursing.* 19(4):168-174. DOI: 10.1016/j.jnn.2013.03.005

Gund, A., Sjöqvist, B., Wigert, H., Hentz, E., Lindecrantz, K., Bry, K. (2013). A randomized controlled study about the use of eHealth in the home health care of premature infants. *Biomedical Central Medical Informatics and Decision Making.* 13(22):1-11. DOI: 10.1186/1472-6947-13-22

Lacobelli, S., Combier, E., Roussot, A., Cottenet, J., Gouyon, J., Quantin, C. (2017). Gestational age and 1-year hospital admission or mortality: A nationwide population based study. *Bio Medical Central Pediatrics.* 17(28):1-9. DOI:

10.1186/s12887-017-0787-y

Holland, K., & Rees, C. (2010). Nursing: Evidence-based practice skills (Prepare for practice). Oxford: Oxford University Press

Institute of Family-Centered Care (2017). Advancing the practice of patient and family centered care in hospital. Retrieved from: http://www.ipfcc.org/resources/getting_started.pdf

Jackson, B.N., Kelly, B.N., McCann, C.M., Purdy, S.C. (2016). Predictors of the time to attain full oral feeding in late preterm infants. *Acta Paediatrica*. 105(1):1–6. DOI: 10.1111/apa.13227

Jeffries, A.L. (2014). Going home: facilitating discharge of the preterm infant. *Paediatrics & Child Health*.19 (1):31-42. Advanced online publication. Retrieved from: <u>https://www.ncbi.nlm.nih.gov/pmc/journals/530/</u>

Joanna Briggs Institute (2016a). *JBI Critical Appraisal Checklist for Randomized Controlled Trials*. Retrieved from:

http://joannabriggs.org/assets/docs/criticalappraisaltools/JBI_Critical_Appraisal Checklist_for_Randomized_Controlled_Tri als.docx Joanna Briggs Institute. (2016b). *JBI Critical Appraisal Checklist for Case Control Studies.* Retrieved from: http://joannabriggs.org/assets/docs/criticalappraisal-tools/ JBI_Critical_Appraisal-Checklist_for_Case_Control_Studies.pdf

Joanna Briggs Institute. (2016c). *JBI Critical Appraisal Checklist for Qualitative Research*. Retrieved from: <u>http://joannabriggs.org/assets/docs/critical-appraisaltools/JBI_Critical_Appraisal-Checklist_for_Qualitative_Research.pdf</u>

Long, A. (2005). Evaluative Tool for Mixed Method Studies Prof Andrew Long (2005), School of Healthcare, University of Leeds. Retrieved from: <u>https://usir.salford.ac.uk/13070/1/Evaluative_Tool_for_Mixed_Method_Studies.pdf</u>

Lundberg, B., Lindgren, C., Palme-Kilander, C., Örtenstrand, A., Bonamy, A., Sarman, I. (2016). Hospital-assisted home care after early discharge from a Swedish neonatal intensive care unit was safe and readmissions were rare. *Acta Paediatrica.* 105(8):895-901. DOI: 10.1111/apa.13393

Maastrup, R., Hansen, B.O., Kronborg, H., Bojesen, S.N., Hallum, K., Frandsen, A., Hallström, I. (2014). Breastfeeding progression in preterm infants is influenced by factors in infants, mothers and clinical practice: the results of a national cohort study with high breastfeeding initiation rates. *PLoS ONE.* 9(9):108208. DOI: 10.1371/journal.pone.0108208

McGregor, J., Casey, J. (2012) Enhancing parent-infant bonding using kangaroo care: a structured review. *Evidence Based Midwifery.* 10(2):50-56.

Meerlo-Habing, Z., Kosters-Boes, E., Klip, H., Brand, P. (2009). Early discharge with tube feeding at home for preterm infants is associated with longer duration of breast feeding. *Archives of Disease in Childhood-Fetal and Neonatal Edition.* 94(4):294-297. DOI: 10.1136/adc.2008.146100

Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G., The PRISMA Group (2009). Preferred reporting items for systematic reviews and meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal. pmed1000097

Örtenstrand, A., Waldenström, U., Winbladh, B. (1999). Early discharge of preterm infants needing limited special care, followed by domiciliary nursing care. *Acta Pædiatrica*. 88(9):1024-1030. DOI: 10.1111/j.1651-2227. 1999.tb00201.

Örtenstrand, A., Winbladh, B., Nordström, G., Waldenström, U. (2001). Early discharge of preterm infants followed by domiciliary nursing care: Parents'

anxiety, assessment of infant health and breastfeeding. *Acta Pædiatrica*. 90(10):1190-1195. DOI: 10.1111/j.1651-2227. 2001.tb03253.

Petrou, S., Abangma, G., Johnson, S., Wolke, D., Marlow, N. (2009). Costs and health utilities associated with extremely preterm birth: evidence from the EPICure study. *Values in Health.* 12(8):1124-1134. DOI: 10.1111/j.15244733.2009. 00580.x

Pickler, R., Reyna, B., Wetzel, P., Lewis, M. (2015). Effect of Four Approaches to Oral Feeding Progression on Clinical Outcomes in Preterm Infants. *Nursing Research and Practice*. 1-7. DOI: 10.1155/2015/716828

Robinson, C., Gund, A., Sjöqvist, B., Bry, K. (2016). Using telemedicine in the care of newborn infants after discharge from a neonatal intensive care unit reduced the need of hospital visits. *Acta Paediatrica.* 105(8):902-909. DOI: 10.1111/apa.13407

Rose, C., Ramsay, L., Leaf, A. (2008). Strategies for getting preterm infants home earlier *Archives of Disease in Childhood*. 93(4):271-273. DOI: <u>http://dx.doi.org/10.1136/adc.2005.093039</u>

Royal College of Paediatrics and Child Health. (2016). National Neonatal Audit Programme 2016 Annual Report on 2015 data. Retrieved from: http://www.rcpch.ac.uk/ system/files/protected/page/ NNAP%202016%20Annual%20Report%20on%202015%20data%20%20For%2 0NNAP%20website.pdf

Scottish Government (2017). *The best start: a five-year forward plan for maternity and neonatal care in Scotland*. Retrieved from: http://www.gov.scot/Resource/0051/00513175.pdf

Swift, M., Scholten, I. (2010). Not feeding, not coming home: parental experiences of infant feeding difficulties and family relationships in a neonatal unit. *Journal of Clinical Nursing.* 19(1-2):249-258. DOI: 10.1111/j.13652702.2009.02822.

Underwood, M.A., Danielsen, B., Gilbert, W.M. (2007). Cost, causes and rates of rehospitalization of preterm infants. *Journal of Perinatology.* 27(10):614-619. DOI:10.1038/sj.jp.7211801

Weiss, S., Goldlust, E., Vaucher, Y.E. (2009). Improving parent satisfaction: an intervention to increase neonatal parent–provider communication. *Journal of Perinatology.* 30(6):425-430. DOI:10.1038/jp.2009.163

World Health Organisation and United Nations Children's Fund. (2015). Breastfeeding Advocacy Initiative: For the best start in life. Retrieved from: <u>http://apps.who.int/iris/</u>

bitstream/10665/152891/1/WHO_NMH_NHD_15.1_eng.pdf? ua=1

Wong, G., Greenhalgh, T., Westhorp, G., Buckingham, J., & Pawson, R. (2013). RAMESES publication standards: realist syntheses. BMC medicine, 11(1), 21. https://doi.org/10.1186/1741-7015-11-20

Younge, N., Smith, P.B., Gustafson, K.E., Malcolm, W., Ashley, P., Cotten, C.M., Goldberg, R.N., Goldstein, R.F. (2016). Improved survival and neurodevelopmental outcomes among extremely premature infants born near the limit of viability. *Early Human Development.* 95:5-8. DOI: 10.1016/j.earlhumdev.2016.01.015

Population	Physiologically stable preterm infant
Intervention	Supplementary short-term nasogastric tube feeding at home as part of early discharge program
Comparison	No tube feeding at home
Outcome	Readmission rates Parent satisfaction Weight gain Transition time to full oral feeding Duration of breastfeeding

Time	Readmission rates during early discharge program and up to 1 year of
	age
	Weight gain during early discharge program
	Transition time to full oral feeding during early discharge program
	Duration of breastfeeding up to 6 months of age

Systematic review of tube-fed preterm infants in the home supported within a family-centered program

Table 1: PICOT system used to formulate search strategy for review of tube-fed

 preterm infants in the home supported within a family-centered program, UK 2017

Preterm infant at home tube feeding Preterm infant at home tube feeding **Table 2**: Characteristics of included studies of tube-fed preterm infants in the home supported within a family-centered program, UK,2017.

Author Year Country	Level of Evidence	Subjects	Design/ Method	Intervention/ Objectives	Outcomes	Relevance to Clinical Practice
Ahnfeldt et al. (2015) Denmark	Hierarchy of evidence IV Good quality (Using Evans (2003) rated as IV, and quality as fair with JBI, 2016b).	500 infants in home care 400 (control) in hospital care	Quantitative Retrospective case control study Record analysis	Early Discharge Programme To evaluate the home care programme for infant wellbeing, weight gain, breastfeeding rates and length of hospitalisation	Weight for age at final discharge was similar Hospitalization was 3 days shorter in study group and were 8 days younger on entry to the programme Study group had longer overall neonatal care input (significantly) 10.4% readmission rate Higher breastfeeding success in study group	Safe in terms of readmission rates Increases breastfeeding rates in preterm population Discharge criteria from programme required to maximise cost efficiency and effectiveness of neonatal nurse support

Author Year	Level of Evidence	Subjects	Design/ Method	Intervention/ Objectives	Outcomes	Relevance to Clinical Practice
Country						

Brodsgaard et al. (2015) Denmark	Hierarchy of evidence IV Good quality (using Evans (2003) critical appraisal tool and quality good using Long's (2005)	218 infants 15 parents	Retrospective longitudinal mixed method Focus group interviews x2 qualitative synthesis Record analysis	Present Early Discharge Programme based on Family centred care principles describing impact on families Assess longitudinal growth up to 6 weeks post EDP discharge	MAIN THEME – Parents in control with lifeline to NICU Parents have the primary care giver role in the home Stressful having to choose between hospital or home Family was fragmented when in hospital. Being at home was more relaxing. At home with EDP they felt like a proper family Mean gestation gavage feeds discontinued 37+5 6% readmission rate	EDP is safe - 6% readmission rate Within Denmark 7 out of 18 NICUs offer an EDP
--	--	---------------------------	---	---	--	--

Author Year Country	Level of Evidence	Subjects	Design/ Method	Intervention/ Objectives	Outcomes	Relevance to Clinical Practice

Dellenmark- Blom- & Wigert (2014) Sweden	Hierarchy of evidence III Good quality Evidence rated as III using the Daly et al. (2007) and using JBI 2016c rated as good.	16 families 22 parents	Qualitative Phenomenological hermeneutic open- ended interviews	To determine parent's experiences with Neonatal Home Care following initial care in NICU	94.4% infants received NG feeding as part of NHC 72% infants received NG and breast feeds 0% readmissions NHC helped to establish independent parents mature: - strengthening bonds, trust in their ability to parent, seeing their infant with new eyes NHC nurses helped parents to process experiences of NICU NHC assists the inner emotional journey from having a child to becoming a parent	NG tube feeding within NHC is safe - 0% readmissions (based on 16 families)
--	--	---------------------------	--	---	--	--

Author Year Country	Level of Evidence	Subjects	Design/ Method	Intervention/ Objectives	Outcomes	Relevance to Clinical Practice
· · · · · · ,						

Garne et al. (2016) Denmark	Hierarchy of evidence II Good quality Evidence rated as II using the Daly et al. (2007) and using JBI 2016c rated as good. One criticism is that the sampling process was not stated.	9 in NHC 10 in NNU eligible for NHC	Qualitative Participatory Design Observational studies Individual interviews Focus group interviews	To identify parental needs when providing neonatal homecare (NHC) for their infant supported by telemedicine	Being a family - admission to NNU negatively affected family life, staying in NNU with healthy infant tube feeding NHC allowed them to be a normal family Parent self-efficacy - nurses presence could negatively affect their decision making Self-efficacy increased at home and bonding was strengthened Nurses gave a feeling of security that things were normal Telemed allows staff to see the baby	Being a family is important to parents. NHC supports this and parental self efficacy VC, email and online knowledge base is possible in most settings at minimal cost providing IT/internet access already is in place
-----------------------------------	--	---	---	--	---	---

Author Year	Level of Evidence	Subjects	Design/ Method	Intervention/ Objectives	Outcomes	Relevance to Clinical Practice
Country						

Gund et al. (2013) Sweden	Hierarchy of evidence N/A Fair/poor quality Using the JBI 2016a, quality fair to poor.	34 families (Questionnaire) 16 families (Interviewed) 6 nurses (Questionnaire)	Stated in title- Randomised control study, actually mixed method study questionnaires and semi structured interviews	To investigate whether the use of a web-based application or video conferencing improves parents' satisfaction in taking care of a premature infant at home and decreases the need for home visits by nurse Nurses attitudes to ICT (VC + web-based application)	Families found web-based application and VC easy to use 88% thought VC was better than phone call Parents thought the number of nurse visits could be reduced Parents thought ICT had helped them to feel confident in caring for their infant at home 5 out of 6 nurses were motivated to use ICT Recruitment numbers was variable between nurses	Neonatal Home Care allows progression of normal family life within a supportive network but in the home instead of hospital. Puts parents in charge
---------------------------------	--	---	---	---	---	---

Author Year	Level of Evidence	Subjects	Design/ Method	Intervention/ Objectives	Outcomes	Relevance to Clinical Practice
Country						

Lundberg et al. (2016) Sweden Hierarchy of evidence IV 1410 infants Retrospective nested case control study To determine safety of hospital-assisted neon home care programme (HANHC) Using Evans (2003) rated at IV (good), with one criticism of unevenly matched groups. Note review Note review	natal Median readmission time
--	-------------------------------

Author Year Country	Level of Evidence	Subjects	Design/ Method	Intervention/ Objectives	Outcomes	Relevance to Clinical Practice
· · · · · · ,						

Habing et al. (2009) Netherlands	Hierarchy of evidence IV Fair quality Using Evans (2003) rated as IV (fair), with one criticism of unevenly matched groups	128 infants 50 (study) 78 (control)	Case-control study Case note review Telephone interview	Evaluation of the effect of early discharge home tube feeding of preterm infants under close supervision by paediatric nurse specialist on the duration of breastfeeding	Results suggest home support by a paediatric nurse increase the duration of breastfeeding at the age of 6 month Infants in the study group were more likely to be breastfed at 6 months of age 34% v 21% with greatest difference seen at 4 months 62% v 38% Infants who were fully formula fed at 6 months of age 62% v 79% with greatest difference at 4 months 36% v 63% Relative risk of discontinuing breastfeeding in SG (after adjustment for gestational age, birth weight and parental smoking) was 0.67 (CI 0.43-1.05, p= 0.06) Readmissions not stated	Nurse support in the home setting may increase the duration of breastfeeding in the preterm population but the safety of this service provision would be paramount over breastfeeding rates
--	---	---	---	---	--	--

Author Year Country	Level of Evidence	Subjects	Design/ Method	Intervention/ Objectives	Outcomes	Relevance to Clinical Practice
Robinson et al. (2016) Sweden	Hierarchy of evidence II Good quality Using Evans (2003) rated as II and using JBIa rated good.	47 families - study group 42 families - control group	Randomised mixed method Intervention Questionnaire	To examine the use of telemedicine as a means of follow up of infants discharged from Swedish Neonatal Intensive Care to home based neonatal care Control group received standard follow up care Study group followed this same pattern plus a web- based application. Instead of phone calls the nurses used video calls. VC was scheduled in advance Families could phone in or visit hospital as for control group	telemed group	VC is a useful tool, appreciated by parents and staff VC unlikely to be more time-consuming than a phone call A 7-day service is needed to offer a degree of flexibility Need nursing staff 'buy in' for service to work

Systematic review of tube-fed preterm infants in the home supported within a family-centered program

Figure 1: Flow chart for the selection of eligible studies on tube-fed preterm infants in the home supported within a family-centered program, UK, 2017.

