

Preparing for Home: a before-and-after study to investigate the effects of a neonatal discharge package aimed at increasing parental knowledge, understanding and confidence in caring for their preterm infant before and after discharge from hospital

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Scientific summary

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Scientific summary

Introduction and research objectives

The survival of preterm infants has improved over recent years; lengths of hospital stay for survivors have decreased, but parents commonly feel unprepared for taking their baby home. Delays in discharge lead to delays in transferring other babies from intensive care and difficulties in making optimal use of neonatal intensive care cots. Despite recognition of the importance of parent-centred care in neonatal units, few units have structured family-orientated discharge pathways in place.

The aim of the study was to assess whether the introduction of the parent-centred neonatal discharge package (Train-to-Home) could increase parental confidence in caring for their infant, reduce infants' lengths of stay (LOS) in neonatal care and reduce health-care resource use after discharge from hospital.

The primary objective was to compare maternal and paternal confidence when caring for a premature baby just after birth, around the time of discharge from hospital, and at home 8 weeks after discharge. Parents in four local neonatal units (LNUs) in South West England were compared before and after the introduction of the Train-to-Home package over two 11-month periods.

The secondary objectives were to:

- measure the LOS of infants born in the two periods and assess whether or not this intervention was associated with any reduction in overall hospital LOS
- estimate the potential cost savings associated with implementation of the Train-to-Home intervention in terms of UK NHS and other health-care resources consumed by parents and infants in the 8-week periods after discharge home before and after implementation
- explore parents' and staff's views of the intervention and its delivery in greater detail using qualitative interviews.

Background

The improvements in survival of preterm infants over the past 20 years mean that > 90% of all infants born at ≥ 27 weeks' gestation will survive to go home. For most infants, a relatively short period in intensive care will be followed by a longer period in high-dependency care and then special care before discharge home.

Parents of these infants need to learn how best to look after their infants after discharge, and prepare themselves and their home environment to care for their baby. There is increasing evidence that ex-preterm infants make a disproportionate demand on emergency and 'out-of-hours' health services. Parents have expressed concern and uncertainty about how best to respond to minor illness or changes in routine in these very vulnerable infants.

In a preliminary survey of neonatal units in the UK we found that in most neonatal units the process of preparing families for discharge home with their preterm infant is relatively unstructured and is commonly left until relatively late in the hospital stay. The emphasis is on informing the parents about issues the nursing and medical staff feel are important rather than a two-way process in which the parents' needs and anxieties are identified and appropriate support provided.

In other areas of medicine it has been shown that a structured approach to discharge planning, with the use of a care pathway and predictable timing for discharge, improves the quality of care before and after discharge, and reduces the need for unexpected readmission after discharge, as well as improving patient satisfaction.

Many parents of preterm infants are routinely informed by medical and nursing staff that their baby will be discharged home at, or around, the time the baby was due to be born: that is, the estimated date of delivery (EDD). This is despite increasing evidence in recent years that improvements in neonatal care were leading to progressively shorter stays in hospital and earlier discharge to home. Using EDD as the expected discharge date means that in many neonatal units the process of preparing parents to take their baby home is often left until shortly before the baby is to be discharged, commonly leaving parents feeling unprepared and lacking in confidence in caring for their baby.

In an audit of the LOS of preterm infants in LNUs in South West England from 2011 to 2013 we found that almost all infants born at 27–33 weeks' gestation were discharged home well before their original EDD, and almost 50% were discharged home around 4 weeks before this date.

Building on a similar approach developed at McMaster University in Canada, we have developed a UK parent pack (Train-to-Home) for improving parents' preparedness to take their baby home. Parents are encouraged to become involved in the care of their baby from an early stage and develop their understanding of their baby's needs. Soon after the baby is admitted to hospital, an accurate estimate of when the baby is likely to be discharged from hospital is also provided. The pack is parent centred, and provides a means of improving communication between staff and parents throughout the baby's hospital stay.

The aim of this approach was to improve parents' self-confidence and knowledge about how to care for their baby after discharge, with the potential aim of facilitating earlier discharge to home and reducing the use of emergency or 'out-of-hours' services after discharge.

Development and implementation of the intervention

The Train-to-Home package was developed using a multistage Delphi process involving parents, and medical and nursing staff. The laminated image of a train has five carriages, with the headings: Breathing, Feeding, Growth, Temperature and Sleeping. It is attached to the cot side and, with the assistance of the medical and nursing staff, using agreed criteria, parents insert a red, yellow or green sticker in each window, indicating the stage of preparedness for discharge home.

Charts were constructed using data from the previous 2 years from the four LNUs, to show the 50th and 75th centiles for LOS at each gestation. A few days after the baby's admission to the LNU, the range of estimated dates for discharge (corresponding to the 50th and 75th centiles from the locally developed charts) were entered onto the train, and these dates, together with the coloured stickers, were reviewed regularly by medical and nursing staff with the parents, who then made changes to the train.

Pathways, including information on likely changes in the five areas of care (breathing, feeding, growth, temperature and sleeping), and questions likely to arise at each stage from admission to discharge were also developed using the Delphi procedure, with separate pathways for infants of 27–30 weeks' and 31–33 weeks' gestation. These were given to parents soon after admission, and parents were encouraged to use them to record their baby's progress and as a basis for asking questions to help them understand their baby's progress and needs.

The intervention was introduced to each LNU after an intensive period of staff training in its use, with continued assistance from the research team during the 11-month study period after implementation.

The Parent Advisory Group, composed of parents of ex-preterm infants, had a major role in the development and implementation of the intervention.

Research methods and outcome measures

Parents of infants born between 27 weeks 0 days and 33 weeks 6 days were recruited in four LNUs in South West England (Exeter, Taunton, Bath and Swindon). They were recruited during two 11-month periods (phase 1, October 2012 to August 2013; phase 2, October 2013 to August 2014) before and after the introduction in the LNUs of the Train-to-Home package (with parent pathways). Infants with major congenital anomalies or those whose mothers were aged < 16 years were excluded. Parental consent was sought by a study researcher. Demographic and clinical information were collected for all participating infants. Both parents were asked to complete the Perceived Maternal Parenting Self-Efficacy (PMPS-E) tool soon after their baby's admission to the LNU, shortly before discharge home and 8 weeks after discharge, to measure perceived parental self-confidence when caring for their infant.

Information on all health-care contacts for the baby, recorded on diary sheets by parents, was collected at telephone follow-up at 4 and 8 weeks after discharge. The final PMPS-E questionnaire was also completed at the 8-week telephone call. Thirty-seven parents completed a subsequent semistructured telephone interview about their experiences and perceptions. All data were anonymised before analysis. Focus groups were held to collect the views of nursing staff, and telephone interviews were held with senior medical staff from all LNUs.

Statistical analysis was performed using Statistical Statistical Package for Social Sciences (SPSS) version 21 (IBM Corporation, Armonk, NY, USA) and Stata v13 (StataCorp LP, College Station, TX, USA). For proportional data, chi-squared tests were used to $n - 1$ degrees of freedom. Test of normality on continuous data was conducted using the Shapiro–Wilk test and observing the Q–Q plots. The Mann–Whitney *U*-test was used for non-parametric data, which were described using medians and interquartile ranges (IQRs).

Parent interviews and nursing staff focus groups were audio-recorded, transcribed verbatim and analysed using thematic methods facilitated by the qualitative package NVivo version 9 (QSR International, Warrington, UK).

Results

In phases 1 and 2, respectively, 128 infants and 117 infants were recruited and included in the study. There were no significant demographic differences between the two phases, which were well matched for infant sex, gestation, birthweight, month of birth, family size, socioeconomic status, maternal conditions and type of infant feeding, although at discharge fewer babies in phase 2 were exclusively bottle-feeding. There was no difference in overall severity of illness or prevalence of cardiorespiratory or infective conditions between the groups but metabolic, endocrine gastroenterological and neurological problems were more common in infants in phase 1.

More parents (89.3%) reported being given a probable discharge date soon after admission in phase 2 than in phase 1 (71.1%) ($p < 0.001$), whereas more parents in phase 1 than in phase 2 reported the proposed discharge date having been brought forward (62.1% vs. 24%, respectively; $p < 0.0001$).

The length of hospital stay in phase 1 (median 28 days, IQR 19.5–43.5 days) was not significantly different from phase 2 (median 32 days, IQR 20–46 days). Almost 75% of infants were discharged home on or before the initially estimated discharge dates.

The overall median maternal PMPS-E scores in phase 1 and phase 2 at baseline [60 (IQR 54–69.5) and 59 (IQR 54–67), respectively], at discharge [70 (IQR 61.5–76.5) and 69 (IQR 64–74.75), respectively] and

8 weeks after discharge [74 (IQR 66–79) and 74 (70.25–78), respectively] were not significantly different. The median improvement in individual mothers' scores between baseline and discharge home was slightly higher in phase 2 than in phase 1 (+14 vs. +11) but this was not statistically significant. Similar findings were seen in the paternal PMPS-E scores. There was some suggestion that maternal PMPS-E scores improved more from baseline to 8 weeks post discharge in LNUs in which staff engaged with the intervention, but there was insufficient power to test whether or not this was truly significant.

Parents were overwhelmingly positive about the 'Train to Home' package and reported being better prepared for home in phase 2 than phase 1. Most found the Train-to-Home package helpful in showing them in a visual way that their baby was progressing, and they described feelings of being given hope and feeling in control. Mothers, fathers and siblings enjoyed using it.

Medical and nursing staff generally agreed that the intervention materials were helpful in explaining a baby's progress to parents, but some nursing staff had concerns that the estimated discharge dates were too optimistic. Staff in one unit were particularly positive about the Train-to-Home intervention and were keen for it to continue.

There was no difference between phases 1 and 2 in the number of hospital readmissions, or hospital outpatient appointments attended by the infants after discharge, and no difference in primary care attendances. There were, however, significantly more attendances at emergency departments (EDs) by infants in phase 1 than in phase 2 (31 vs. 20, respectively; $p = 0.03$), with an associated significantly higher estimated cost in phase 1 than in phase 2 (£3400 vs. £2200, respectively; $p = 0.03$).

Discussion and conclusions

The predicted discharge dates helped parents prepare for home and the ways in which staff engaged with the materials when communicating with them helped them feel more confident, as well as having something visual to show their baby's progress.

Medical and nursing staff felt that the 'Train-to-Home' package fitted well with the NHS discharge planning initiative, but some nursing staff were reluctant to engage fully, expressing concern that the estimated discharge dates were too optimistic. These findings may reflect the limited time available within the study for effective implementation and cascade training of nursing staff.

There was similar improvement in the PMPS-E scores in both study phases, which, although not statistically significant, was slightly greater in phase 2. Parents reported feeling more confident in phase 2, with a small but significant reduction in out-of-hours ED visits. This was particularly notable in view of an increase in ED attendances nationally over this period, which coincided with the introduction of the 111 'out-of-hours' service.

There was no significant change in LOS, although more than half the infants went home at > 3 weeks before the EDD in both phases. During phase 2, all of the LNUs were working towards gaining full World Health Organization/United Nations Children's Fund Baby Friendly Initiative accreditation and were encouraging and supporting mothers to go home breastfeeding, as reflected by the increased proportion of infants breastfeeding at discharge in phase 2. Breastfeeding is more difficult for these preterm babies and is often a reason for a longer stay while mothers learn how to breastfeed their babies.

Few studies have investigated parent-centred approaches to improving parental involvement in the care of their babies while in neonatal care. We are not aware of any studies that have systematically attempted to assess the impact of such an intervention on parental self-efficacy or babies' LOS.

Some of the implementation difficulties were recognised by parents who reported nursing staff ambivalence about the intervention. Parents found the intervention helpful, informative and reassuring as they became more engaged and involved in understanding their baby's progress through the LNU.

Although our initial primary outcome measure did not show any significant differences, the improvement in preparedness for discharge home reported by the parents, and the measured reduction in ED attendances, suggest that the intervention had significant benefits.

This approach to educating and involving parents in the care and needs of their preterm baby in hospital has potential value and warrants further study and more widespread adoption.

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