Family-centred discharge planning from neonatal care units

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Family-centred care in neonatal units emphasises the need for consistent communication, support in developing readiness for home, and good discharge information. Despite the importance accorded to family-oriented neonatal care by the Department of Health and the National Institute for Health and Care Excellence (NICE), few neonatal units offer structured, family-oriented discharge planning.

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 (the estimated date of delivery, EDD). However recent improvements in neonatal care have led to shorter stays in hospital and earlier discharge home. Using EDD as the expected discharge date often results in parents being unprepared for an earlier discharge date and lacking confidence in caring for their baby at home. Parents have reported being uncertain how to respond to minor illness or changes in routine in these very vulnerable infants once at home.

In other areas of medicine structured approaches to discharge planning, using care pathways and predictable timing for discharge, have improved the quality of care before and after discharge, and reduced the need for unexpected re-admission.

The train-to-home discharge planning package

The 'train-to-home' package, originally used in Canada, was developed for UK parents to improve their preparedness to take their infant home from neonatal care. Early involvement in baby care helps parents develop a better understanding of their baby's needs. The package also encourages improved communication between staff and parents throughout the baby's hospital stay.

FIGURE 1 shows the laminated image of a train with carriages labelled with the five areas of care – breathing, feeding, growth, temperature and sleeping. It is attached to the cot-side and, in collaboration with nursing and medical staff, a red, yellow or green sticker is placed on each carriage, to indicate the baby's condition and their progression towards discharge.

Centile charts giving the average lengths of stay were developed using data from the four local neonatal units (LNUs) in south west England involved in our study (Exeter, Taunton, Bath and Swindon).[1] For all gestations from 27-33 weeks inclusive, the 75th centile for corrected age at discharge was close to 37 weeks' post-menstrual age, while the 50th centile equated to 35 weeks' post-menstrual age for infants born at 27-30 weeks, and close to 36 weeks for infants of 31-33 weeks' gestation.

Within a few days of admission to the neonatal unit, the nursing staff use the centile charts to calculate the range of estimated dates for discharge, and write them onto the laminated train (corresponding to the 50th and 75th centiles). These dates, together with the coloured stickers, are expected to be under constant review by medical and nursing staff in collaboration with the parents. Two separate sheets detailing the 'pathways to discharge' were developed for infants born at 27-30 weeks' and 31-33 weeks' gestation (**FIGURE 2**). They suggest questions likely to arise from the expected changes in the five areas of care from admission to discharge. Parents are given the pathway sheets when the train-to-home is given to the baby. They are encouraged to use them as a basis for asking questions that might help them understand their baby's care and progress.

The research study

The aim of the train-to-home package was to enable parents to be well prepared at the point of discharge by improving their knowledge and confidence about how to care for their infant. Perceived parental confidence in caring for their baby (self-efficacy) was recorded soon after their baby's admission to the LNU, shortly before discharge home, and eight weeks after discharge using a validated measure. Health care usage was documented for eight weeks after going home.

Our study was conducted before and after introducing train-to-home and included infants born at 27-33 weeks' gestation admitted to the participating units, and their parents. The detailed results are reported elsewhere.[1,2]

Thoughts of parents and staff

Parents were overwhelmingly positive about the train-to-home package and reported being better prepared after its introduction. Most found the visual nature of train-to-home helpful in showing their baby's progress and described feelings of being given 'hope' and feeling 'in control'. Mothers, fathers and siblings all enjoyed using it. Parents found the intervention informative and reassuring as they became more engaged and involved in understanding their infant's care.

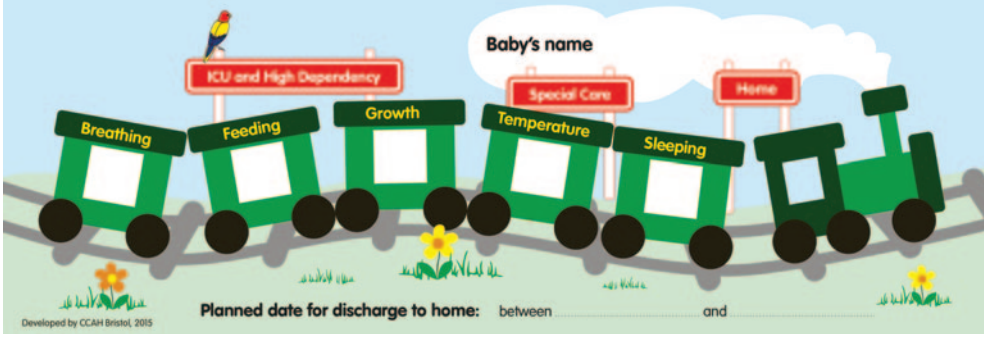

FIGURE 1 The image of the 'train-to-home'. A laminated version is attached to each baby's cot.

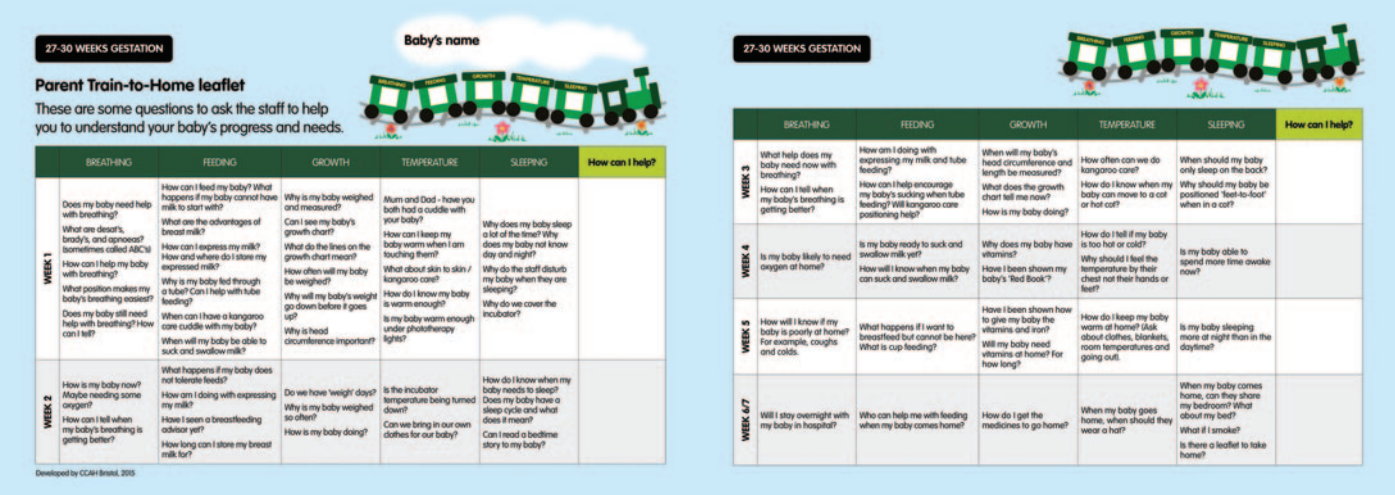

FIGURE 2 The 'pathway to discharge' leaflet for infants born at 27-30 weeks' gestation.

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 EDDs were too optimistic. Staff and parents in one unit were particularly positive about the train-to-home intervention and have continued to use it, as have several new units.

Nursing staff felt that the train-to-home package fitted well with the NHS discharge planning initiative while giving a focus on where infants were in their gestational developmental journey. Optimum delivery of the package was hampered by a lack of cascade training and more time was needed to embed the materials into each LNU. Without this period of normalisation some staff were uncertain about using the package.

Maternal confidence, length of stay and use of emergency departments following discharge

There was similar improvement in the self-efficacy scores in both study phases, but it was slightly greater after introducing the train-to-home package. In LNUs where staff embraced the intervention, maternal self-efficacy scores improved more from baseline to eight weeks post-discharge, but numbers were too small to test whether this was truly significant.

Over half of the infants went home more than three weeks before the EDD in both phases and there was no significant change in length of stay between the time periods studied. During the latter period all LNUs were working towards gaining full Unicef Baby Friendly Initiative accreditation and were encouraging and supporting mothers to go home breastfeeding. As breastfeeding is more difficult for these preterm infants and is often a reason for a longer stay while mothers and babies learn to breastfeed, this might have contributed to the lack of difference found.

There was no difference between the study periods in the number of hospital re-admissions, 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 by infants in the first study period than after introducing train-to-home, with an associated significantly higher estimated cost before introducing the package. This was particularly notable in view of an increase in emergency department attendance nationally during the latter period, which coincided with the introduction of the '111 out of hours' service.

Implications for practice

This study has shown that the use of the infant's EDD as the basis for estimating when a preterm infant is likely to go home from hospital is no longer appropriate – almost all infants go home considerably earlier than this. Using routinely collected data from the Badgernet database, locally derived length of stay centile charts can be produced, for individual networks or even individual units. This means that parents can be given accurate information on the likely date of discharge for their baby.

Staff concerns regarding giving parents an early estimated date for discharge that might be delayed, thereby increasing parental anxieties, were not borne out in the opinions expressed by the parents in this study. Parents reported that they could easily understand and accept that not every baby would go home exactly on the estimated date. Parents were very clear that they welcomed partnership working with the health professionals, and needed to be informed about their baby's likely discharge date. Discussing the problems and questions that might arise at each stage of a baby's pathway through the neonatal unit was a positive and helpful experience for parents.

In conclusion

We feel that the train-to-home approach to educating and involving parents in the care and needs of their preterm baby in hospital has potential value and warrants more widespread adoption.

The train-to-home materials and a self-directed training package for staff are available on the South West Neonatal Network website at: www. swneonatalnetwork.co.uk/train-to-home.

We have recently added a pathway to discharge leaflet for infants born between 34 and 36 weeks' gestation. We hope this will allow individual neonatal units to obtain and use the materials for all infants and facilitate effective implementation of the train-to-home initiative.

References

1. **Ingram J., Blair P.S., Powell J.E. et al.** 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. *Health Serv Deliv Res* 2016;4: DOI: http://dx.doi.org/10.3310/hsdr04100.
2. **Ingram J.C., Powell J.E., Blair P.S. et al.** Does family-centred neonatal discharge planning reduce healthcare usage? A before and after study in South West England. *BMJ Open* 2016; 6:e010752 doi:10.1136/bmjopen-2015-010752.