



Development of a care pathway for babies being discharged from a level 3 neonatal intensive care unit to a community setting for end-of-life care

Amanda Williamson^{a,*}, Charlotte Devereux^b, Julia Shirtliffe^c

^a School of Nursing and Midwifery, Faculty of Health, Edith Cavell Building, University of East Anglia, Norwich, NR4 7TJ, UK

^b Neonatal Intensive Care Unit, Norfolk and Norwich University NHS Foundation Trust, Colney Lane, Norwich, NR4 7UY, UK

^c Palliative Care Services, East Anglia Children's Hospice, Quidenham, Norfolk, NR16 2PH, UK

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Abstract The development of a care pathway for babies being discharged from a level 3 neonatal intensive care unit (NICU) to a community setting for end-of-life care is discussed. The development of the care pathway was a collaborative project between a level 3 NICU, the local children's hospice and the local primary care trust. The development of the care pathway enables parents to decide where they want their babies to be cared for: NICU, hospice or home care. It enables staff to rapidly refer babies and their families to hospice or community care and provides staff with the support they also need during this difficult time.

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Our aim was to facilitate a care pathway for babies and their families that that would establish palliative care that is as meaningful and as clinically and socially acceptable as the provision of continued life extending endeavours (Caitlin and Carter, 2002). The development of a care pathway for babies being discharged from a level 3 neonatal

intensive care unit (NICU) to a community setting for end-of-life care is discussed. The development of the care pathway has been a collaborative project between a level 3 NICU, the local children's hospice and the local primary care trust.

Background

The Health Care and Partnership Analysis (HCPA) report that there have been on average 2109 neonatal deaths each year from causes likely to

* Corresponding author. Tel.: +44 1603 597092; fax: +44 1603 597019.

E-mail address: a.j.williamson@uea.ac.uk (A. Williamson).

require palliative care between 2001 and 2005 (HCPA, 2007). However, palliative care for babies with life limiting conditions is an important aspect of neonatal care that is often largely overlooked in the provision of services. Significantly, the comprehensive review of Palliative Care Services for Children and Young People in England (Craft and Killen 2007) did not include a review of palliative services for neonates within their remit. The HCPA (2007) review found that 98% of neonatal deaths occurred in a hospital setting. Palliative care is currently provided for children over 28 days and for adults but the neonate has generally been cared for within the highly clinical environment of the neonatal unit. Anecdotal evidence from local hospice staff indicated that quality of life for families is improved when babies are transferred to hospice or home with hospice support, and more family members are able to be involved in the final days of the baby's life (Oliver and Oliver, 2006).

Development

The steering group worked collaboratively with the NICU, the local children's hospice and the local PCT to develop a care pathway to ensure that care could be transferred quickly and effectively from the NICU to the hospice team. Existing care pathways for children, devised at Liverpool and Cambridge were considered but needed to be redesigned to suit local needs in relation to neonates. The pathway provides a clear guide to ensure coordinated planning, management and documentation to enable the rapid discharge of babies from NICU to hospice or community for end-of-life care. The use of the pathway is commenced as soon as it is clear that a baby is moving towards imminent end-of-life care or it is recognised that the baby has a life threatening condition. Introduction of the concept of rapid discharge to the family should ideally be undertaken by the babies lead consultant but may also be undertaken by the medical team caring for the baby at the point when end-of-life care is becoming a clear option.

The pathway is designed to be simple to use. Currently it is used only for babies on NICU. Each section of the care pathway focuses on issues surrounding the care needs for the baby at the end-of-life stage. A checklist for rapid discharge is incorporated into the pathway. Most areas are either short answers or a tick list to enable staff to complete the pathway quickly and effectively. Clear guidance is given to nursing staff as to who to inform or what instructions should be if the baby died during transfer. Parent's wishes and understanding of their baby's condition is a major

component of the pathway and family support workers from the hospice visit families on NICU once the care path way is commenced. The hospice allows parents to build up positive memories of their baby and much of the work focuses on this (Table 1). Sharing notes means that the notes that accompany the baby in relation to the care pathway are used by the hospice and community staff. It means that all staff involved in the care are clear what the family and baby's needs are.

One area that took much time was ensuring that the pathway met the requirements of the acute trust, hospice and PCT governance groups. Thanks to a fantastic secretary who gave us much help and advice with formatting and how to match all requirements, the pathway was approved by all three in the summer of 2008, one year after the initial meetings.

Implementation phase

A training package has been implemented to educate staff in the care that can be provided by the hospice, how to manage the transfer and how to use the care pathway effectively. The training of staff to use the care pathway effectively was undertaken as a joint study day with both hospice and NICU staff attending. This collaborative approach has led to staff visiting each other's area of work to gain greater understanding of the differences and common aims of care. Initially training has been given to the senior staff but it is hoped that junior staff will also be able to undertake the training day. The training day enabled staff from the NICU to see the services that the hospice offers and enables them to feel better able to talk about the options to parents. The training day also allowed NICU staff to understand the long-term effects on families of not getting the 'ending' right and the importance of staff being able to let go and let the hospice take over. It also

Table 1 Examples of memory work.

Visits home including being in baby's nursery
Use of items chosen for their baby such as Moses basket, blankets, toys
Family events such as naming ceremonies
Photos, visual and auditory recordings
Memory boxes including locks of hair, hand and foot casts/prints, finger tip pictures, activity folders which may only be small but will include lots of photos prints and captions
Often undertaken as a duplicate activity for separated parents, siblings and/or grandparents

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