

A national survey of neonatal palliative care in the UK

Currently the majority of neonatal deaths occur in hospital, but some of these babies could be transferred either to their family's home or a local hospice for end-of-life care. Bereavement support is a vital aspect of the service offered to parents who lose a baby. A survey was undertaken to explore the palliative care support provided by tertiary neonatal units in the UK and inform future practice.

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'Palliative care is an active and total approach to care embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite, and care following death and bereavement.' Association for Children's Palliative Care (ACT) 2009.

A present 98% of neonatal deaths occur in hospital settings, with few families spending the last few days of their baby's life at home or at a children's hospice¹. Due to the advances in antenatal diagnosis, obstetric care and neonatal care, there is an increasing need to make critical end-of-life decisions in neonates and to support the families through the bereavement process. This survey was carried out to examine the quality of palliative care support provided by tertiary neonatal units in the UK.

The survey

A link to a survey website was sent out with the British Association of Perinatal Medicine (BAPM) electronic newsletter in October 2009. The survey targeted tertiary neonatal units, although no units were excluded from submitting a response. The survey consisted of 20 online multiple choice questions with opportunities to add free text.

The questions included details about:

- Access to a local guideline or care plan
- Members of the palliative care team
- Whether babies were transferred to a local hospice or discharged home
- Provisions for follow-up after discharge
- Staff involved in follow-up care
- Literature and bereavement support offered to families
- Staff debriefing after handling difficult situations.

Results

Thirty-five responses were obtained from

29 tertiary neonatal units. The locality of the units was fairly evenly distributed within the UK (**FIGURE 1**). Participants were all consultant neonatologists.

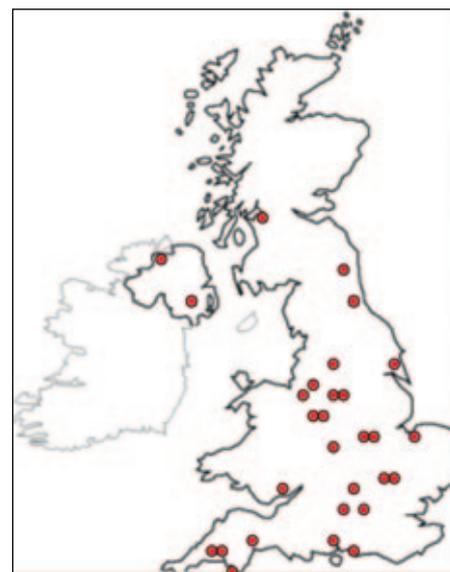


FIGURE 1 Locality of responding units.

All respondents worked in units that offered palliative care to some babies with more than half of the units offering it to 1-10 babies per year and 17% to more than 20 babies. Twenty-four per cent of units had an existing guideline. All of these included emergency contact details for parents, medications for distress or pain and resuscitation instructions, but 30% did not have a feeding guideline. Only two of the responding units had a neonatal palliative care team. This constituted a consultant neonatologist, paediatrician and

Keywords

infant; newborn; hospice care; bereavement; palliative care; guideline

Key points

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1. Most neonatal units (76%) did not have a structured palliative care plan.
2. Only two of 29 units had an organised palliative care team.
3. Few babies were offered palliative care at a hospice or at home.
4. Only 30% of units had a trained counsellor or psychologist for bereavement support, follow-up and staff debriefing.

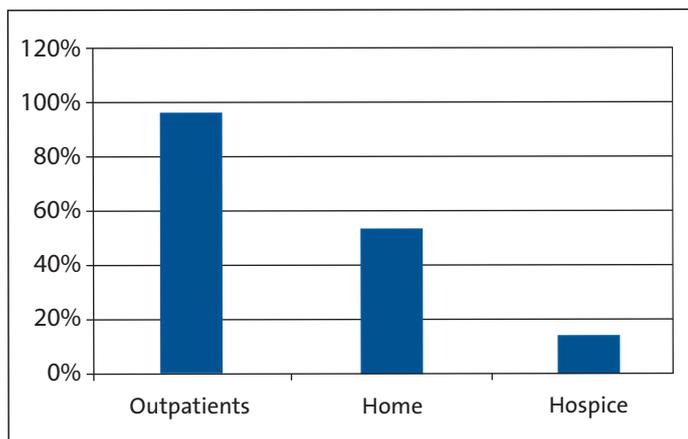


FIGURE 2 Place of follow-up after discharge home.

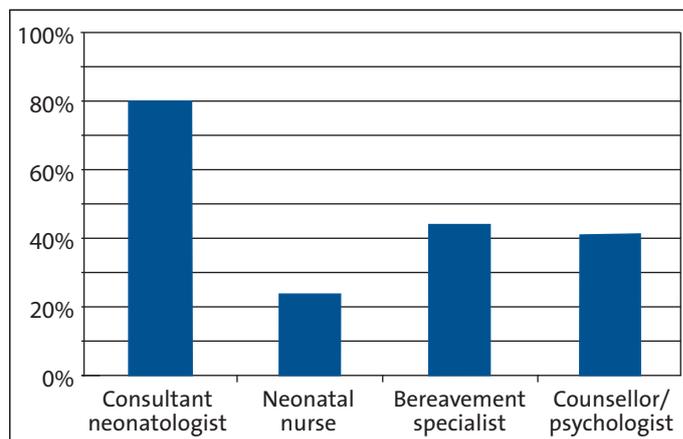


FIGURE 3 Professionals involved in providing bereavement support.

outreach/community nurse in both cases. A counsellor/psychologist was part of the team in one unit.

A local children's hospice was available to 93% units but only 63% referred babies for palliation. One third of the units did not discharge any babies home for end-of-life care. Only 30% units had any literature for parents and just 20% had literature for the siblings. Most units (83%) offered follow-up for babies once discharged home on palliative care. The majority of these were seen in outpatients and a few were seen at home and in hospice (FIGURE 2).

All units except one offered bereavement support to parents. This was mostly provided by consultants (FIGURE 3). Only 40% units had a trained psychologist or counsellor.

All units invited the parents back for a follow-up appointment after the baby's death and in all cases were seen by a consultant neonatologist. A nurse, psychiatrist/counsellor or a multidisciplinary team were available in less than 20% units. All units except one offered support/debriefing to staff following deaths in difficult situations. This was provided by consultant neonatologists in all units. Nurses and psychiatrists/counsellors were involved in 30-40% of units. There was a strong need expressed by most respondents for the development of specific bereavement support staff. The development of local neonatal palliative care teams, a national guideline and literature for parents and siblings were other popular suggestions.

Discussion

The main objective of the survey was to explore the availability of guidance to professionals regarding palliative care

services and the level of support offered to bereaved families in neonatal units across the country. There are around 40 tertiary neonatal units in the country. A response was obtained from 29 units which is a good representation of neonatal practice in the country.

The survey found the majority (76%) of neonatal units offering palliative care have to do so in the absence of clear palliative care guidelines. There are few available national guidelines on neonatal palliative care and local guidelines vary. In this survey few babies were being transferred home or to a hospice.

The recent publication of the BAPM framework, 'Palliative Care (supportive and end-of-life care) A Framework for Clinical Practice in Perinatal Medicine'², will provide units with a useful guide on which to base local guidelines. The document identifies five candidate conditions for palliative care and covers most aspects of end-of-life management including planning with the family, support for the family and staff, resolving conflict and management of common symptoms.

The ACT care pathway 'A Neonatal Pathway for Babies with Palliative Care Needs'¹ states that parents should be offered a choice in where palliative care is delivered. The pathway aims to ensure that the baby and family are central to care planning. It is guided by six sentinel standards. The ACT also provides a basic symptom management manual which has a chapter on neonates and includes the management of feeding, pain, seizures, reflux etc.

It is acknowledged that bereaved families need to be better supported by multidisciplinary bereavement support teams. Creation of individualised care

plans where appropriate would be beneficial for the family as well as health professionals. The availability of appropriate literature for families and offering them a choice of place of care and follow-up will allow them to feel better supported and more involved with their baby.

There is an increasing need for awareness among neonatal health professionals about the role of palliative care and bereavement support. Bliss, the special care baby charity has been organising nationwide workshops and study days to facilitate this. Neonatal palliative care should be included in the core curriculum while training neonatal professionals. In addition there needs to be identified support systems for debriefing neonatal staff following difficult deaths.

Conclusions

Neonatal palliative care is emerging as an essential part of neonatal intensive care. This survey highlights the fact that palliative care in neonates is provided by most units but has identified the need for a well structured palliative care pathway. Multidisciplinary teams with interest in providing palliative care and bereavement support need to be developed to offer support to all such units. The ACT Neonatal Pathway and the BAPM Framework provide a structured means of developing palliative care teams in individual units and networks.

References

1. ACT. *A Neonatal Pathway for Babies with Palliative Care Needs*. ACT:2009.
1. BAPM. *Palliative Care (supportive and end-of-life care) A Framework for Clinical Practice in Perinatal Medicine*. BAPM: August 2010.