

Developing an end-of-life care pathway to improve nurses' bereavement care

This article describes the development of a pathway to improve nursing care of dying patients and their families

AUTHOR Dawn Chaplin, MSc, DipC, RGN, is head of bereavement services, Heart of England NHS Foundation Trust.

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This article explores the 'bereavement journey' and the importance of providing the right information and support at the right time by the right people. It outlines a project to develop a bereavement care pathway and bridge the gap between the acute hospital sector and voluntary/community services.

INTRODUCTION

End-of-life and bereavement care delivery remains etched on the memories of bereaved relatives. The importance of delivering this final care appropriately cannot be overemphasised – indeed the Department of Health (2005) said that experiences around the time of death and afterwards can influence grieving and the longer-term health of bereaved people.

Healthcare Commission (2007) findings indicate that nurses need to improve end-of-life care for some and that suboptimal care impacts negatively on people's bereavement experiences. DH (2005) advice and its end-of-life care strategy (DH, 2008) highlight the importance of end-of-life and bereavement care and the impact on relatives' experiences. Nurses must focus on patients' and families' individual experiences.

CULTURAL CONTEXT

Although death is inevitable, as a society we are, in general, death-denying, behaving as if death is something that happens to others. This denial should be addressed through open and honest discussions with all age groups about the processes of dying, death and bereavement, exploring feelings and different ways of coping when a loved one dies. People also need to understand the importance of planning ahead to avoid reacting in crisis. For example, how many have written wills, created advance directives or signed up to the organ and tissue donation register?

There also appears to be an associated belief that, with the 'right' treatment we can live, if not forever, well into our 80s or 90s, and that we will remain mobile, pain free and symptom free. This may contribute to a blame culture in which death, especially death in hospital, is often viewed as failure. It is also noteworthy that our increasingly secular society means roles and rituals around death – once a source of comfort and significant in the process of mourning – may be alien to many people today.

However, it is important to acknowledge our increasingly diverse multicultural society and that, for some people, end-of-life care rituals will have huge significance not only for the dying person but also for relatives and friends. Inability to perform these rituals may have a significant negative effect on people's bereavement experience.

The wide range of religious and cultural

perspectives may at times lead to myth and misunderstanding around end-of-life, death and bereavement care. Consequently hospital staff may require training, education and support to provide appropriate, culturally sensitive care (Chaplin, 2003).

There also needs to be open, two-way communication with religious and community groups to explain procedures and processes when someone dies, especially in hospital. This is essential to ensure understanding and agreement on processes for all those affected by a death.

END-OF-LIFE CARE

Approximately 530,000 deaths occur in the UK each year and currently just under 60% occur in acute hospital settings. Following the launch of the end-of-life care strategy (DH, 2008), there has been much discussion on preferred place of care and place of death. However, the number of deaths in hospital will not decrease immediately or drastically. People are – and will continue to be – admitted to hospital for treatment and cure, although the outcome for some is death. For some patients, hospital will be the most appropriate place to die.

It is also important to note the UK has an ageing population, and recent predictions suggest one-third of people over the age of 65 will be living alone by 2020. Therefore, while the majority may wish to die at home, the practicalities and implications of this need further exploration. It should also be noted that while people may state home is their preferred place of care when they are well, this may change when they are approaching the end of life.

BEREAVEMENT CARE

At the trust where I work, an end-of-life, palliative and bereavement care strategy group was created to look at ways of implementing the end-of-life care strategy. There are approximately 4,300 deaths each year within the trust, involving all age ranges, and patients/families have different cultural and religious requirements.

IMPLICATIONS FOR PRACTICE

- All trusts should have a bereavement policy and clear guidelines on the care that should be provided to dying/deceased patients and relatives.
- Information booklets should also be made available to all bereaved relatives explaining the next steps that must be

taken following a patient's death, such as registration and funeral arrangements.

- Nurses should take time to familiarise themselves with their hospital's policies and procedures for end-of-life and bereavement care, and the training and education currently provided in this area.



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Bereaved relatives are given booklets explaining the next steps when someone has died. Bereavement officers offer further information, such as on the registration process and funeral arrangements when relatives visit to collect the medical certificate of cause of death. The officers also give relatives a condolence card, which has three functions:

- To acknowledge relatives' individual loss;
- To highlight the opportunity for relatives to talk to the relevant doctor if they have any questions about their family member's care;
- To list agencies that provide bereavement support and counselling, which people may find useful at a later date.

Leaflets are also available providing both practical information and emotional support. The bereavement office has an open-door policy, whereby people can make contact if they have any questions at a later date.

BEREAVEMENT PATHWAYS PROJECT

Although most people will move through their bereavement experience with support from family and friends, a small minority may benefit from extra support and/or counselling. At present, acute hospitals do not always have the means to identify or refer these people on to specialist agencies.

The Bereavement Pathways Project, funded by the DH, aims to address this issue by mapping the journey bereaved relatives follow when a person dies in an acute hospital, and identifying ways of bridging the gap between the acute and voluntary bereavement sectors. It is a joint project between the Bereavement Services Association and Cruse Bereavement Care.

The Bereavement Services Association (www.bsauk.org) provides a national network for bereavement support services and a forum for discussion and training. Cruse (www.crusebereavementcare.org.uk) is a national voluntary organisation providing a range of bereavement support and counselling services.

The project's key aims involve partnership working between the NHS and voluntary sector, mapping existing service provision, and establishing clear pathways for bereaved relatives. As part of an initial scoping project, we looked at the end-of-life and bereavement journey and mapped when, where and by whom care was provided along the bereavement pathway, from hospital to community (see Appendix 1 at nursingtimes.net).

A survey of NHS bereavement services was undertaken to identify current provision. The provisional results (see www.bsauk.org) demonstrate that currently there is poor assessment of bereavement need and little follow-up for bereaved relatives:

- 165 hospitals were included in the survey – 56 responded (32%);
- 81% have a designated bereavement service;
- 64% have a designated bereavement manager;
- 40% audit bereavement care;
- 81% provide information on community services;
- 8% carry out bereavement assessment;
- 28% provide a follow-up service for bereaved relatives.

PILOT SITES

Birmingham will be one of the project's first pilot sites. Bereavement volunteers will be recruited to provide an 'at' and 'after' service:

At: To explore whether bereaved relatives have appropriate information and support in the immediate aftermath of a death and are aware of the next steps;

After: To provide a follow-up service and, if necessary and with relatives' agreement, to refer on to an appropriate bereavement support agency for ongoing support.

The trust's bereavement and palliative care team, along with Birmingham Cruse Bereavement Care and Solihull Bereavement Care Service, will provide training and supervision for the volunteers.

To understand how to bridge the gap in service provision, it is also necessary to talk to people who have used voluntary bereavement support, to establish:

- How they heard of the service, such as through the hospital bereavement service, via GP services, internet or word of mouth;
- Why they felt they needed additional support. Was any element of their bereavement experiences a reason for

BACKGROUND

- The Healthcare Commission (2007) highlighted the fact that 54% of complaints it received were bereavement related.
- Poor communication and care were identified as key areas of concern, particularly in acute trusts.
- The commission advocated the DH's (2005) advice as best practice for healthcare professionals.

accessing counselling? This is a key question as such information needs to be fed back to those delivering care so that end-of-life and bereavement care can be tailored to individuals' needs and continue to be improved;

- Whether it has been of benefit. This again is a key question, as services need to ensure the support provided is appropriate and beneficial.

As with any project involving bereaved people, we need to be mindful of their loss and potentially vulnerable state. Care needs to be taken to ensure the project does not foster dependence, disempower people or medicalise bereavement. However, the project should help hospital staff to identify the small number of people who may benefit from appropriate and timely counselling and support to help them through the bereavement process. ■

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