A bereavement care service to address multicultural user needs

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A bereavement care service was set up in a large, acute NHS trust to understand and address the multicultural and multifaith needs of all its users. The service has not only facilitated support and guidance for friends and relatives at a time of great need and vulnerability, it has also made professionals throughout the trust aware of the importance of death with dignity.

Bereavement, whether it is sudden or expected, can be a bewildering and distressing experience. In the immediacy of a bereavement, relatives may experience numbness and disbelief, combined with an overwhelming sense of isolation and vulnerability. These feelings may be intensified in members of an ethnic minority group. Issues such as lack of effective communication, if the bereaved relatives’ first language is not English, and lack of awareness and sensitivity of funeral rites among health care professionals may create further distress. These barriers may increase existing feelings of vulnerability and isolation.

Identifying the need for a care service

The University Hospital Birmingham NHS Trust is a large teaching trust, affiliated to Birmingham University, and comprises two hospitals, the Queen Elizabeth and the Selly Oak. It is a centre of excellence and one of the main tertiary referral centres, accepting patients from all over the UK and beyond. It has over 5,000 staff and during 2000–2001 a total of 502,354 patients were treated.

In addition to its large medical and surgical services, the trust houses many supra-regional specialties including neuroscience, oncology, a major trauma centre, cardiac services and the largest transplantation centre in Europe.

Before the bereavement care service was created there was no coordinated holistic approach to the needs of bereaved relatives at this distressing time. The lack of a formalised system often meant that relatives might have to visit up to three separate locations within the hospital and wait for long periods of time to receive their deceased relative’s documentation and personal effects.

There were no measures in place to identify and address the cultural and religious needs of ethnic minority groups at and around the time of death. There was also perceived to be a lack of privacy and personalisation of the deceased relative’s documentation and personal effects.

Developing the service

In 1997 the bereavement care service was created as part of a Department of Health-funded initiative to create culturally sensitive services for black and ethnic minority communities. The aim was to provide a trust-wide service that catered for the individual needs of bereaved relatives and friends. From 2000–2001 the service dealt with about 2,500 deaths, of which approximately 15 per cent were from faiths other than Christianity.

A questionnaire was distributed to every ward in an attempt to ascertain the need for bereavement services across the trust. Forty-six of the 51 questionnaires (90 per cent) were completed and returned. The comments received fell into three main categories:

- Staff training and support;
- Information and support for bereaved relatives;
- The need for a centralised service.

Staff training and support

Comments highlighting the need for more staff training and support on bereavement care issues included:

- ‘Staff need training on how to deal with relatives and paperwork post death’;
- ‘Many feel inadequate when dealing with grieving relatives’;
- ‘[W]e need study days on death and dying in different faiths’;
- ‘Someone who could offer a few words of comfort and support, to give care to the carer.’

Information and support for relatives

Comments regarding relatives identified the need to support relatives (and patients) during their last journey through the hospital, and to provide written, in addition to verbal, information:

- ‘I believe there should be a service provided for the relatives’;
- ‘We are awaiting a new booklet providing advice following a death to help reinforce the information given verbally at this time’;
- ‘Care for the patient should also include care for the family.’

The need for a centralised service

Staff stressed that relatives should only have to visit one place to complete necessary administration:

- ‘Relatives have to go to three or four places to collect the death certificate, property, their valuables. There should be one collecting point’;
- ‘We would benefit from a trust-wide policy on bereavement care.’
Care manager to determine what service they provided and what they required from the hospital. The coroner and the coroner’s officers were also contacted to clarify their role and requirements associated with the death of a patient. Issues such as ownership and possession rights regarding the deceased, removal of the body to another country and sudden or suspicious death were all discussed and procedures and policies agreed.

In an attempt to acknowledge and understand cultural and religious requirements of dying and deceased patients and their relatives, the bereavement care manager visited and had discussions with the following local community and religious groups, and religious leaders:

- University Hospital Birmingham Chaplaincy Department;
- Hindu elders;
- Council of Sikh Gudwaras;
- Kashmiri and Pakistani Professionals Association;
- Bangladesh Women’s Forum;
- Birmingham Hebrew Congregation;
- Humanist Society.

Following these discussions, the manager created policies and guidelines to assist staff in attempting to provide culturally sensitive care for dying and deceased patients and their relatives.

**The bereavement care service**

The bereavement care service deals with every death that occurs within the trust. An appointment system ensures that everything can be made ready for when the relatives arrive.

Arrangements can be made for them to discuss any incidents leading up to their relative’s death with nursing staff and/or doctors. This is particularly important if they could not or did not wish to be present at the time of death. The service also coordinates requests from relatives to view the deceased person if this is required. Guidelines to facilitate viewing outside office hours have been created and this is coordinated by the senior nurse and the porter’s team leader.

The opportunity to view a relative (if this is desired) is acknowledged as an important part of the grieving process to help relatives accept the finality of the situation (Wright, 1991). Wright suggests that it is vital to facilitate viewing if the death was sudden, unexpected or caused by trauma. The process of formal registration of the death is discussed in detail with relatives, to prepare them for what will be required later on. This information is also provided in written form and booklets have been published in six languages other than English (Arabic, Bengali, Chinese, Gujarati, Punjabi and Urdu).

The bereavement care service operates an ‘open door’ policy so that relatives can visit or telephone the manager or officers after their initial appointment for further information, guidance or support.

Approximately six weeks after the death, the service sends out a remembrance card to relatives. This is in acknowledgement that it may be around this time (after the funeral when support from family or friends may have declined) that relatives may wish to obtain further information or support.

**Staffing the service**

The bereavement care service currently has a staff of three – two bereavement care officers and a bereavement care manager, who is a nurse and a counsellor. In acknowledgement of the demands and expectations placed upon the service it is anticipated that staffing levels will increase.

The service aims to facilitate the closure of the hospital episode for bereaved relatives by ensuring that their immediate needs have been met and their questions answered. The service utilises other support agencies, both within the hospital and externally, for longer-term support where necessary. By playing a coordinating role the bereavement care service staff can gently inform

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**BOX 1. EXTERNAL SUPPORT SYSTEMS FOR BEREAVED RELATIVES**

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cruse Bereavement Care</td>
<td>Offers free bereavement counselling for relatives and friends as well as group support, coffee mornings and social events. Recently, Cruse has been actively recruiting counsellors from ethnic minority backgrounds.</td>
</tr>
<tr>
<td>Sunrise</td>
<td>A Birmingham-based charity, originally linked to Birmingham Children’s Hospital, which provides bereavement support for parents who have lost a child of any age. It also provides bereavement support for children who have lost a significant carer.</td>
</tr>
<tr>
<td>Compassionate Friends</td>
<td>A nationwide organisation offering support for those relatives and friends who have lost someone through suicide. Suicide is regarded as a taboo subject in many cultures and a stigma is often still attached to those who take their own life. This organisation provides a safe environment for relatives and friends to explore these and other issues.</td>
</tr>
<tr>
<td>Survivors of Death by Suicide</td>
<td>Another national organisation that offers support for those relatives and friends who have lost someone through suicide.</td>
</tr>
<tr>
<td>The Samaritans</td>
<td>A nationwide charity providing confidential, emotional support to people in crisis. They provide a 24-hour, seven-day-a-week telephone counselling service, drop-in service and e-mail and internet sites.</td>
</tr>
<tr>
<td>The Lesbian and Gay Bereavement Project</td>
<td>Provides counselling and support for bereaved partners in a same gender relationship.</td>
</tr>
<tr>
<td>Many GPs</td>
<td>Many GPs have counsellors attached to their surgeries who can provide ongoing support for bereaved relatives. There is also a growing number of accredited private counsellors who can provide ongoing support for bereaved relatives.</td>
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bereaved relatives of further support that is available to them should they feel it may help them – whether immediately or in the future. The service provides leaflets, information and contact details for these internal and external support agencies. Sometimes, a contact number to have ‘just in case’ can help people find the strength to cope on a day-to-day basis.

Support systems

The bereavement care service works closely with other services within the trust to provide support and guidance for relatives. The trust employs a number of specialist nurses, such as Macmillan, motor neurone, head and neck, and lung cancer nurses, and these are available to provide information and support for patients and families, from diagnosis to terminal care and beyond.

The hospital chaplaincy department has experienced staff from different religious faiths (Buddhist, Christian, Hindu, Jewish, Muslim and Sikh). They provide psychological and spiritual support for patients, relatives and staff. The remit of the chaplaincy service is to be available to all, and it is acknowledged that many patients, relatives and staff appreciate seeing people from their own faith in times of crisis.

An interpreting service is to be implemented within the trust to assist with communication issues. This will be extremely valuable for the bereavement care service, as it will ensure that relatives whose first language is not English will have an equal opportunity to have their questions answered and concerns addressed. It is hoped that it will provide an independent voice for those who, until now, have remained silent.

Relatives are also given information about several different external support agencies (Box 1, p27).

The bereavement care policy provides information on the care of dying and deceased patients from differing cultural and religious backgrounds. It includes the following guidelines:

● Care of the deceased patient (‘last offices’);
● Fast-track release of a deceased patient;
● Religious requirements;
● Postmortem consent;
● Last will and testament;
● Retention of limbs or tissue (Human Tissue Act, 1961; DoH, 2003);
● Viewings;
● Organ donation;
● Care of deceased patients with no next of kin.

The coroner’s office

By law, certain deaths must be reported to the coroner (Box 2) – an independent judicial officer whose role is to inquire into deaths that may be violent, unnatural, sudden or of unknown cause. Although the majority of coroners are lawyers they can also be doctors.

Through investigations – either an inquest or postmortem examination – the coroner will seek to establish the

### BOX 2. DEATHS THAT MUST BE REPORTED TO THE CORONER

A death should be reported to the coroner if:

- The death cannot readily be certified as being due to natural causes;
- The deceased was not seen by a doctor within 14 days prior to death;
- There is any element of suspicious circumstances;
- There is any history of violence;
- The death may be linked to an accident (whenever it occurred);
- There is any question of self-neglect or of neglect by others;
- The death has occurred or the illness has arisen during or shortly after detention in police or in prison custody (including voluntary attendance at a police station);
- The deceased was being detained under the Mental Health Act;
- The death is linked to an abortion;
- The death might have been contributed to by the actions of the deceased himself/herself (such as by a history of drug or solvent abuse, or through self-injury or overdose);
- The deceased was receiving any form of war pension or industrial disability pension, unless the death can be shown to be wholly unconnected;
- The death could be due to industrial disease or related in any way to the deceased’s employment;
- The death occurred during an operation or before full recovery from the effects of the anaesthetic, or was in any way related to the anaesthetic (in any event a death that occurs within 24 hours of theatre should be reported);
- The death may be related to a medical procedure or treatment, whether invasive or not;
- The death may be due to lack of medical care;
- There are any other unusual or disturbing features to the case;
- The death occurs within 24 hours of admission (unless the admission was purely for terminal care);
- It may also be wise to report any death where there is an allegation of medical mismanagement.

over any deceased person leaving or returning to the country.

The bereavement care office is fortunate to be able to work closely with the coroner’s office. The two offices are
able to provide guidance and advice to all medical and nursing staff. In recent months two important documents have been published: *The Fundamental Review of Death Certification and the Coroner Services in England, Wales and Northern Ireland* (Coroner Reform Team, 2003) and the third Shipman report (The Shipman Inquiry, 2003).

**Coronial service and death certification**

These reports have made recommendations for a radical review of the coronial service and death certification in England, Wales and Northern Island.

The reports differ on which profession best suits the role of coroner. The Shipman Inquiry recommends a medically qualified coroner, whereas the Coroner Reform Team stresses that the role should be undertaken by someone who is legally qualified. They do, however, agree that a marriage of the two professions is required within the new system.

Both reports acknowledge the need for open and honest communication with bereaved relatives and stress the importance of sensitivity and understanding. They also both suggest mandatory training for coroners and their officers. The need for a change of practice to facilitate the close scrutiny of the completion of medical certificates is recommended.

These moves could be seen as an attempt to provide both support for medical staff in a difficult area of their work and a means of advocacy for the deceased patient and bereaved relatives. The importance of such training and the recommendations of the Coroner Reform Team in general is acknowledged by Parkes (2003) who states that ‘this [The Fundamental Review] has made a number of recommendations which, if implemented by the government, may well reduce the psychological impact of these bereavements’.

**Change of practice and implementation of bereavement care policy**

In order to effectively change practice, the following avenues were explored: teaching and training, link nurses and sharing good practice.

**Teaching and training**

Training is provided for nurses, nursing students and nursing staff. This training covers:
- The bereavement care service;
- The practical arrangements required after a death;
- Last offices;
- The grieving process;
- Bereavement support;
- Sudden death;
- Cultural and religious requirements.

The bereavement care manager also provides ongoing teaching and training for medical students and doctors in death certification. This includes completing the cause of death on medical certificates, completing cremation papers and postmortem consents, making appropriate referrals to the coroner and attending to cultural and religious needs.

On-call managers are also given training covering release of deceased patients out of hours, viewing out of hours and coroner referrals. Porter and domestic staff receive training and support in recognition of the important contact they have with patients and relatives.

**Link nurses**

To ensure that all staff are aware of policies and guidelines pertaining to the care of dying and deceased patients, link nurses have been identified on all wards and departments. They are responsible for cascading information to their ward or department. Bimonthly meetings are organised for link nurses to address any issues that may have arisen in their area and for updates on any new information. Bereavement care folders containing policies and guidelines are also available on all wards and departments.

**Sharing good practice**

The bereavement care manager has been involved in newspaper and radio presentations on the service and cultural sensitivity at times of bereavement. Other trusts, both locally and nationally, have contacted the bereavement care manager and guidelines created by the manager have been freely circulated to all interested parties.

**Impact of the service**

The creation of the bereavement care service has enabled the trust to standardise its practices in bereavement care. This has facilitated individualised, culturally sensitive care for dying and deceased patients and their relatives. These standards have been sanctioned by community ethnic groups and their leaders, and since their inception have enabled compliance (within legal boundaries) with cultural and religious requirements.

Complaints pertaining to the death of a patient have decreased. It is acknowledged that a chance for relatives to voice any concerns and receive an immediate response may have contributed to this change.

It is hoped that the bereavement care service, working in collaboration with other support agencies, will continue to empower staff to deal with the death of a patient effectively and appropriately. The service has facilitated support and guidance for friends and relatives at a time of great need and vulnerability, and highlighted the importance throughout the trust of death with dignity.

**Future developments**

We hope eventually to develop a seamless service based on the understanding of individual needs and religious and cultural requirements. Investment in the appropriate management of the acute stages of grief will undoubtedly benefit relatives, staff and also the NHS. Further research by the bereavement care manager will explore the phenomenon of bereavement through the experiences of relatives of patients from the Christian, Jewish and Muslim faiths and professional accounts from nurses and doctors. The pain of acute bereavement will never be erased but with thoughtful and sensitive intervention it can be made more manageable.