Hospices and Rituals after Death

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Abstract

The article reports the findings of a survey of UK hospice chaplains concerning hospice involvement in post-mortem, funeral and memorial rituals. Many hospices provide rites for the family both immediately after death and in the year to come, though there was disagreement as to how much other patients should be invited to join in such rites. Getting involved in the funeral itself, however, was confined largely to AIDS and children's hospices; this may be related to the longer time over which a patient can build up relationships with other patients and staff. In some other hospices, funeral and memorial services were perceived by managers as morbid, fitting uncomfortably with the hospice emphasis on life. The article suggests that hospices should choose whether or not this is an area they wish to be involved in.

Hospices and Rituals after Death

In the UK, hospices have pioneered palliative and bereavement care, but historically have shown little interest in the period in between, dominated by the funeral and associated rituals. A small telephone survey of senior nurses in seventeen British hospices (Carline 2000) found that nurses performed a number of post-death rites, and had often thought carefully about what they did and why, but this was not reflected in hospice policy, still less in the nursing press. This article takes a small step further in identifying current practices and attitudes, complementing Carline's study by using chaplains rather than nurses as the source of information.

When in the late 1980s I researched a book on British funerals (Walter 1990), I wondered if hospices had promoted better funeral practice. The critique of funerals current then – that they were impersonal, production-line affairs – was similar to the critique of the depersonalised hospital dying to which the hospice movement was a response. Given hospices' concern for seamless, holistic care, and given their pro-active involvement in bereavement care, it was not unreasonable to ask if they had got involved in funeral and other post-death rites. The answer was clearly not. The subject was rarely, if ever, mentioned in hospice literature (both popular and scholarly), and the London Lighthouse – a centre for people with AIDS - was the only palliative care unit I found that had instructed its architects to include a room that could, among other things, be used for funerals. It seemed that the principles of palliative care applied to dying and grieving, but not to what happened in between.

Since 1990, there has been considerable publicity in the British media concerning woodland burial, do-it-yourself funerals, personalised funerals, and the entry into the UK funeral market of the Texan-based Service Corporation International (SCI) - renamed Dignity in 2002 after a management buy-out. Pressure groups such as the Natural Death Centre and the National Funerals College have promoted more personal funerals, price and ownership transparency in funeral firms, and other reforms. Do the families of those who die in hospice get adequate and impartial advice about this rapidly changing scene and in particular about local funeral directors and clergy? Or is this not seen as part of hospices' role? How do the commemorative rites provided by hospices fit with the formal funeral? Are hospices pioneering commemorations in the way they have pioneered other aspects of care for the dying and bereaved?

Method

As a guest speaker at the 1999 annual conference of the UK Association of Hospice Chaplains, I took the opportunity to distribute a short questionnaire in order to gain some information on the extent to which British hospices in the late 1990s facilitate public commemoration of their dead, or offer advice about such commemoration. The questionnaire invited written answers, in the respondent's own words, about his or her hospice's practices; there were four questions about immediate post-mortem rituals in the hospice, nine about the funeral, and one about later memorials.

Of the 75 chaplains at the conference, 51 filled in the questionnaire. The respondents were half male, half female. The geographical spread was: 20 from the South of England, 10 from the Midlands, 10 from the North of England, 8 from Scotland and 1 from Wales (2 gave

no location). None were from Ireland, north or south. Seven were from religious hospices, with another five noting that – though their hospice had been founded on religious principles - it was now to all intents and purposes secular (cf. Bradshaw 1996). Of the 51 institutions, all were fairly typical British hospices, dealing mainly with adult cancer patients, except for one that was for AIDS patients, two that were for children (a further two were for adults, but included a children's unit), and one that was a hospital palliative care unit. My sample is therefore broadly representative of British hospices.

Findings

The survey can indicate only the chaplain's view of things; many chaplains are part-time, and a fuller study would have to involve nursing and other staff. Some responses clearly report the chaplain's own activities; others report, second hand, the activities of others. Chaplains are likely to be more aware of issues around the funeral, nurses more aware of immediate post-mortem rites (Carline 2000).

The findings are not summarised statistically because a) the data are qualitative, without pre-set categories provided by the researcher, b) my purpose is simply to describe what post-mortem ritual practices are currently provided and/or discussed by hospices. I hope this will encourage readers to consider this under-discussed area, and to judge for themselves which of the practices and attitudes described are ones which they might wish their organisation to subscribe to and which to avoid. To this end, it does not matter whether any particular practice is be found in 80 per cent or 8 per cent of my sample.

1. Immediate post-mortem rites

Many hospices have thought carefully about the period between death and when the body leaves the hospice. Relatives may gather around the bed in the ward. Almost all have a viewing room in which the patient lies on a bed; often a flower is placed on the pillow. A number reported that this room was too warm, or too cold, or in need of refurbishment.

An almost universally mentioned ritual is not using the bed for a new patient for at least 24 hours, though some busy hospices are finding it hard to keep to this intention, while one has a 48 hour policy. In multi-bedded rooms, it seems likely that this gives a strong message to other patients in the room that the deceased, and by implication themselves, are not instantly replaceable.

The extent to which other patients were involved in post-death rituals varied considerably. At one extreme, a chaplain wrote, 'Not at all. Our Director of Nursing is averse to this.' And another: 'They are not involved. A conspiracy of silence operates: if patients enquire, they are told the truth.' At the other extreme, patients are 'Always told of what is happening. Offered comfort, support and are often grateful to have a prayer said for the deceased.' 'All are individually told and stayed with for a few minutes to talk over feelings. They may see the body if they want to - but rarely do.' 'I usually go and speak with the patients in a bay (four beds) as soon as possible after a death. They sometimes like to speak about the person who has died and their own feelings.' In one of the children's hospices, 'Some children may want to write a poem or draw a picture to give to the child who has died.

Or they may watch a favourite video or read a favourite story.' In the other children's hospice, there was no such involvement reported.

Whereas in the wards patient involvement tended to be a matter of one-to-one discussion, in day care there are often more public markings of the death. 'There is opportunity to opt in to a brief candle-lighting ceremony, with stories, reminiscences, music, silence, appropriate to the dead person.' Others are less systematic: 'Occasionally there are brief remembrance periods observed in the day care centre.'

The locker is usually cleared by staff and its contents put into a bag for relatives to collect - 'very rarely taken at the time' wrote one respondent. There was one exception: 'The bed and locker are left undisturbed as long as possible. If possible, the clearing of the locker is done by relatives.' In one hospice there is 'opportunity for family to light a candle when collecting documentation and belongings.'

2. The funeral

It was striking that the only hospice that routinely and as a matter of policy discussed the funeral with patient and family before the death was the one AIDS hospice. All care staff are involved in this, and wishes are recorded in patient notes. For the other hospices, the question of the funeral was raised, if at all, by patients.

It was the policy of many hospices not to recommend particular funeral firms, though some staff would do this off the record if they had had particularly good or bad experiences with a particular firm or if asked - following the bad press received by SCI in Spring 1998, some families wanted to know which local firms did not belong to SCI. Hospices typically just provided names of local firms if asked. I presume that the official policy of non-recommendation derives from a fear that hospices could be open to backhanders or other gifts from funeral firms. Whether the no-advice policy is in fact carried out by the staff that families are most likely to meet immediately after the death, i.e. nurses, is, of course, something this survey cannot tell us.

The only respondents who said they did advise on costs were from the two children's hospices; they informed parents which local firms provided free children's funerals. Why such financial information should be restricted to children is unclear.

Chaplains, especially in Scotland and the north of England, said that requests for information about non-Christian or secular funerals were rare. Some chaplains had led one secular funeral, rarely more. The following is unusual: 'I am experienced in conducting non-religious funerals, and am happy to explore all options with patients and family. My Bishop and Archbishop have forbidden me doing any more - but I will advise and help people construct what they feel they want.'

Only the AIDS hospice regularly holds funerals, or some part of a series of funeral rites, on the premises. The involvement of AIDS patients and staff with one another are often longer and deeper than in other hospices. 'Usually patients can get to the funeral, possibly in hospice transport if funeral not in the hospice. If residents can't get to the funeral, they can request a memorial service in the hospice.... Often people are using the hospice for many years - for some it is a vital social network, so often they feel a real need to be included in

funerals, etc.' The two children's hospices have also held funerals. Very few of the other hospices had, and when they had it had often not proved ideal.

Chaplains did not take the funerals of patients as a matter of course - usually only when they had established a close relationship with the patient and there was no church connection. Several chaplains said they would consult with the parish clergy, and perhaps do the service together. Many part-time chaplains simply did not have time to take funerals. But there were more extreme views. At one end of the spectrum, one chaplain directs requests to the local priest: 'The local church is the place where ongoing spiritual care of the bereaved can take place most effectively and I want to encourage this.' Even if one grants this to be admirable in theory, what if the local church does not see pastoral care of the bereaved as a priority? At the other end of the spectrum, one chaplain said he took funerals 'Wherever possible, always if requested - part of the continuing care.' Another reported: 'What seems to be important to the unchurched is that the person leading the funeral service had met and had conversation with the patient.'

3. Memorials

Most, but not all, hospices provide a range of memorial services and rituals, both religious and secular. By far the most common is the 'Light up a Light' ceremony before Christmas, when memorial lights are placed around a Christmas tree; the previous year, one hospice held this at the railway station and 4,000 people attended. Though primarily a fund-raising event, some respondents felt this provided a meaningful memorial, and in some places large numbers attend.

Many hospices have an annual, or more frequent, day of remembrance (see Heslop 2001 for an example). Not unusual is one hospice where there is a 'monthly remembrance service of poems, reading, quiet, prayer, music and lighting a candle as names are read out. Relatives are invited to attend six months after the death. Also an annual service in a local church. Services are held in the day hospice quarterly for day patients.' A number of hospices have books of remembrance. Many send a card on the first anniversary; in one hospice this is signed by all the staff. Others have weekly rituals, remembering in silence at the weekly multi-professional staff meeting those who have died. One lights candles in the quiet room every Friday from 3.30 - 4 pm. One chaplain said 'I write to each bereaved spouse/family re every patient I have ever met. Good response to this.'

Discussion

In the past decade, the emphasis of many British funerals - especially in the South of England – has shifted from mourning the deceased's death to celebrating his or her life. But there has been considerably more innovation, and more grass-roots innovation, in less formal rites of remembrance (Haney et al 1997). Leaving flowers at the site of accidents, signing books of condolence, one-minute silences, sending condolences through the internet, virtual cemeteries on the World Wide Web, memorial services, etc. The responses of mourners after the death of Princess Diana and after 9/11 indicate a popular culture (at least in Britain and the USA) that is highly creative in the way it mourns public deaths, even though funerals themselves remain largely in the hands of funeral directors who have traditionally been reactive, rather than pro-

active, to change. Berridge (2001: 220) astutely notes that we now have low-key funerals but elaborate public rituals of remembrance, often for people we've never met. It seems that hospices have, to an extent, followed this trend, by creating innovative memorial services, while leaving the funeral itself well alone. (Hospices abroad have copied much of the British hospice model, but whether they have also copied this hands-off approach to the funeral I do not know.)

In the discussion that follows, I will consider some of the implications of my study for the funeral, since this remains the one part of the process that seems untouched by 'the healing hand' of hospice. Why is it that British hospices do not offer funerals and advice about funerals?

One possible reason is that the funeral entails working relationships that are unfamiliar to hospice staff. It is not always easy for a hospice, or indeed any care institution, to co-ordinate with doctors, nurses and social workers in the community, but at least these are fellow care professionals with whom, for example, case notes can be shared and who may be treated as colleagues. They are de facto members of the care team. Funeral directors, however, unlike doctors, nurses and social workers, are commercial operators who are paid by families for their services. Nurses and other hospice staff may feel on alien territory if asked to provide a consumer's guide to local funeral directors.

Local clergy are different again, being responsible for a parish or congregation, not - as are doctors, nurses and social workers - for specific named clients. There is no guarantee that a referral to local clergy will be followed up; nor indeed is there any redress if it is not followed up. Only in some parts of Norway have I heard of local parish clergy being formally incorporated into the palliative care team. So, organisationally speaking, handing a British funeral over to local clergy entails a loss of accountability. (This problem affects every aspect of spiritual care in hospice work in the UK: the community end of the team does not in fact belong to the team.)

So do hospices steer clear of the funeral because they do not want to tread on the toes of local clergy and funeral directors whose business they perceive this to be? But if this is so, why do so many hospices set up bereavement services? One large city in the north of England has over 35 bereavement organisations, many duplicating each other. Hospices themselves can be founded without clear regional planning, thus duplicating services. So British hospices that gaily step onto other people's patches when it comes to palliative and bereavement care can hardly use this as a reason for not providing ritual commemoration.

Funerals are typically 'men's business' and hospices are largely run by women, and this may be one reason why hospices do not think much about the funeral – and why immediate post-mortem rites are carried out by nurses with little or no formal discussion, because this is what female carers of the dying have always done (Adams 1993). But there is no evidence in my survey either for or against this 'gender hypothesis'.

A number of respondents reported that funerals and memorials were seen by other hospice staff as militating against the 'add life to years' hospice philosophy. 'We're not into funerals' is the policy of one hospice director. Another respondent reported, 'Management do not like them - they are death denying - want to create impression that our hospice is a happy and wonderful place to be. Do not like chaplain's suggestions to light a candle in chapel when a patient dies, or have a weekly service to pray for the recently died - they say it's morbid.' The dilemma is well put by a third respondent: 'It is difficult to strike the balance between the

hospice as a place to live and a place where persons die. Rituals therefore tend to be conducted at home, in church and in the crematorium.'

Rituals and advice about funerals were most developed in the handful of AIDS and children's hospices. This may be because of longer stays, and hence greater involvement between patients and between patients and staff; it may be because younger people are more open to innovative ritual; or it may be that staff are concerned that such deaths have been insensitively handled by some parish clergy or funeral directors, so the hospice is more pro-active in ensuring the funeral goes to plan. There are a few exceptions in other hospices. One chaplain provides training in this area for student clergy, doctors and nurses. Another reported that 'We are beginning to look at our 'no advice' policy, especially in the light of the Charter for the Bereaved adopted (without too much understanding of the implications) by the local authority.'

Since most people do not think about the funeral until the death actually occurs, staff at the place where people die are in a key position to offer information and support as families make their funeral choice - the first choice being which funeral director to choose. If funeral standards are to be raised, it is crucial that those who nurse the dying be at least minimally trained about funeral options and provide unbiased information, just as they provide basic information about bereavement.

To this end, the National Funerals College recently conducted a pilot project in a small number of hospices and old people's homes, training staff as funeral advisers (Heatley 2002; National Funerals College 2002). Help the Hospices (34-44 Britannia Street, London WC1X 9JG) ran a number of 'funeral information' workshops in 2001 and 2002. The Office of Fair Trading (2001) provides information about choosing a funeral director that can be downloaded from the web by organisations such as hospices and integrated into their own leaflets for families. Hospices and other places where people die could easily do their own price survey of local funeral directors, so that they can offer families unbiased, accurate, local information. No-one else can offer families such information in the few hours after death that the funeral director is typically selected.

Without duplicating services already provided by funeral directors, clergy and other officiants, there is much that hospices can do to prepare families for a funeral experience that embraces the hospice principles of autonomy and holism. Hospices may choose not to do this, but this should be a thought-out choice, rather than simply the default option.

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