Maintaining wellbeing when a service user dies

Abstract

People who work with the homeless are likely to be exposed to the trauma and death of services users. A theory of how workers deal with sudden death was developed through grounded theory analysis of in-depth interviews with people who had worked in the sector. Maintaining well-being involves positively framing the life and death of the service user and homeless sector work. This involves a number of related processes and factors, such as the nature of the encounter with death, responding to death emotionally and procedurally, and being involved in the marking of death and memorials of the person's life. Being able to recognise and respond to the vulnerability of self, peers and service users is also important. Successfully framing death enables workers to stay in the sector while maintaining their own wellbeing, enthusiasm for their work and compassion for users.

Richard Lakeman
Lecturer, Dublin City University

Everyone must confront the inevitability of death at some point in their lives, but most do not need to deal with death as part of their work. Encountering death is to be expected in some occupations (medicine, nursing, fire-fighting and the police, for example) and fields of practice (such as palliative care, care of older people and emergency work). Dealing with death, even for well-prepared professionals can be difficult, and painful.

People who work with 'at risk' groups (such as homeless people or active drug users) are likely to encounter service users who are traumatised and who die. These occupational groups do not tend to enter the workforce with preparation to help them make sense of and deal with such experiences. Thus, they face challenges in trying to maintain their own wellbeing and optimism when confronted by the death of someone they are trying to help. This project explored how people working with homeless people deal with sudden death in the context of their work.

Homeless people in western urban cities experience high levels of deprivation, illness, trauma and risk of death relative compared to securely housed people. While the profile of homeless people varies from city to city, most homeless people have an exceptionally complex constellation of needs. Many people have experienced lengthy periods of incarceration, or institutional care, and repeated trauma before and after homelessness (Buhrich, Hodder and Teeson 2000; Kushel et al, 2003; Shanzer et al, 2007; Taylor and Sharpe, 2008). Alcohol and drug dependence with associated problems are highly prevalent, as are rates of communicable diseases, malnutrition, and mental health problems. Homeless and insecurely housed people have a much shorter life expectancy and are at higher risk of death from a variety of causes causes than their securely-housed counterparts. Rates of homicide, suicide, trauma, drug overdose and other alcohol and drug-related problems are all relatively common (Cheung and Hwang, 2004; Haw, Hawton and Casey, 2006; Hwang et al, 1997; Morrison, 2009; Nordentoft and Wandall-Holm, 2003).

The homeless sector is comprised of people from diverse backgrounds who work for a range of agencies providing various services. Assisting homeless people to access health, treatment and welfare services and then providing appropriate support to enable them to address their problems, and secure and maintain accommodation, are ongoing challenges for local government and other providers. In Dublin there are at least 250 such agencies. Some work exclusively with the 2300 adults (approximately) registered by the city council as homeless (Homeless Agency, 2009) or the 98 to 115 people sleeping in public spaces on a given night (Homeless Agency, 2009).

In addition, various agencies—including correctional services, alcohol and drug treatment services, and community support projects—work with both securely housed and homeless people. People who work in this sector are likely to have encountered the death of service users. In 2007, 53 deaths (41 men and 12 women, aged from 26 to 59) were reported to the Homeless Agency of people who were current or recent users of homeless services (Homeless Agency, 2008). This reflects a conservative rate of death at least three times the general population and many times higher again when the ages of those who died are taken into account.

Methodology

A grounded theory methodology was used to explore how people dealt with the death of service users. Grounded theory (GT) was originally developed by Glaser and Strauss (1967), and there is now some variation in how GT is practised. This project attempted to conform to the methods developed by

Glaser. All GT is concerned with generating theory from the field (rather than testing pre-existing theories) so essentially the researcher begins with a blank sheet and a broad problem area. The researcher seeks informants or data and reviews this data continuously asking questions such as: 'What is this data a study of ?'; 'What category or property of a category, of what part of the emerging theory does this incident indicate?'; and: 'What is actually happening in the data?' (Glaser, 1978). The researcher usually undertakes a painstaking coding of each line of transcribed interviews, and creates memos of any insights or ideas that come to mind, seeking examples of concepts and their properties. As these emerge the researcher seeks more data (theoretical sampling), and revisits the existing codes until categories and concepts are sufficiently elaborated, saturated and verified. The products of a GT study should be a rich description of theoretical concepts.

After obtaining ethical approval from the Dublin City University, homeless sector workers in Dublin who wished to discuss their experiences were recruited through advertisement. Around 40 people made contact and discussed experiences on the telephone; of these 16 were interviewed in depth (for periods ranging from 40 to 120 minutes). These people were aged from their late 20s to mid-50s, and had worked in the sector for periods ranging from 2 to 30 years. They had worked in the full range of homeless services including street outreach work, kitchens, supported housing, residential alcohol and drug treatment facilities, with families, sex workers, and drug users. All had worked with people whom had died and these specific experiences were explored.

Findings

The overarching process that people were engaged in was positively framing death and carrying on after a service user died. These processes are illustrated in *Figure 1*.

When a service user dies this is an extraordinary experience that provokes a deviation from the usual rituals and practices of working life. A response is demanded of both the individual worker and the agency. The processes of responding to death, marking death and recognising and responding to vulnerability (of colleagues, self, and service users) are interlinked, but not necessarily linear processes, which bring people more closely in contact with the deceased. The successful passage through these processes leads to a positive frame of the service user, the restoration of wellbeing and a hopeful attitude being adopted towards work with others.

Expecting the unexpected

Few respondents started working in the homeless sector with an expectation of working with people who might die. Many, indeed, had gained little experience of death in their own lives. Despite this, most workers came to appreciate that the lives of service users are fraught with risks of harm. This realisation can arise in numerous ways. Examples include witnessing risk-taking behaviour, talking about death and loss, or having direct personal encounters with the deaths of service users. Homeless sector workers are some of the few people who engage with the homeless as people, and they are witness to their marginalised lives, trauma, suffering and stories of loss. The homeless sector worker comes to appreciate that some service users are on a trajectory that, if not corrected, will lead to death or harm. While this awareness primes workers to expect death or harm, paradoxically when such harm occurs it is often experienced as unexpected (not the time, place or person perceived to be most at risk) and is greeted with shock as a result.

Encountering death

Death may be encountered directly or indirectly. The worker's emotional response is affected by factors such as being present when a person dies, witnessing the body and the nature of the death. Some people work with people who are diagnosed with a terminal illness and are involved in providing palliative care or organising the person's admission to hospital,

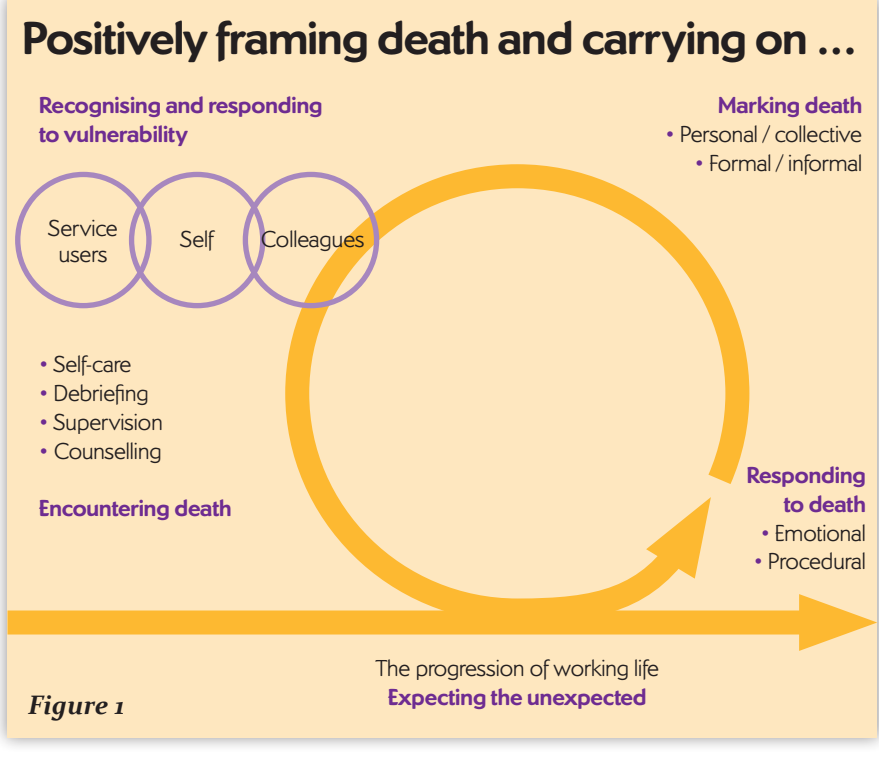

Figure 1

for example. The quality of this encounter with the dying person and their death is different to the sudden, unanticipated death of a service user.

Deaths by suicide, homicide, misadventure or from causes unknown (to the worker) provoke conflicted and intense emotional responses and pose particular challenges as the worker attempts to make sense of the experience. A worker reflecting on several traumatic deaths of young people noted: 'Sometimes there is no dignity in death.' Death by drug overdose can often occur when people otherwise appear to be doing well, after a period of abstinence or reduction in usage. Thus when such deaths occur, they can particularly damage the worker's sense of efficacy as a helper.

The directness of the encounter with death also varies and affects the response. Homeless sector workers, particularly those working in shelters or residential facilities may discover the body, sometimes with signs of trauma. They may have attempted to visit a person previously and eventually a forced entry to a room may be necessary, revealing that the person has died some time ago. Encountering death directly, particularly when trauma is involved, is almost always shocking. In the witness, it provokes an immediate but long-lasting need to process the experience in order to maintain one's equilibrium and to avoid intrusive recollections of the body. More often, however, news of the death of a service user is passed on verbally by other workers or service users formally, such as through staff meetings, or informally, soon after the death or some considerable time later.

Responding to death

Most people report feeling initially shocked, surprised or numb on encountering death. If the death occurred in the workplace or recently, people reported taking solace from following the established procedures, such as securing the scene, or contacting authorities or other workers. This was reported as helpful as it provides the worker with a sense of purpose, a sense of being able to do something if not for the deceased, then for others. The full range of emotions and intensities were reported, but generally strong emotions did not appear until the shock had subsided (sometimes several days or weeks later). The bonds the worker had with service user, the extent to which he or she held hopes for the person's future, or identified in some way with him or her, were important factors. The worker's own vulnerability due to personal experiences of loss and other issues, all affected how he or she responded emotionally and psychologically.

Strong emotional responses were not associated with every encounter with death. Some people attempted to suppress memories and strong emotions; they often used the analogy 'putting them [memories] in boxes. This they acknowledged appeared initially helpful but ultimately dysfunctional as a coping mechanism as memories and emotions would flood back, often unbidden at a later date. Some people presented with the constellation of symptoms characteristic of post traumatic stress disorder.

Others, particularly those who had worked in the field over many years, appeared to have gained mastery over the process of framing death and their work with service users; they experienced some sadness but were not overwhelmed by the experience. However, everyone was able to provide an account of someone for whom they had particular hopes or perceived a special relationship whose passing affected him or her deeply. For example, a worker who had worked for many years providing services to chronic street drinkers recalled being informed that a man who had serious liver damage as a consequence of drinking had died in hospital. His initial response was one of gratitude that the man died in the company of others in a caring environment. His fear (as is often the fear of many homeless people, themselves; see: Song, Bartels, et al, 2007; Song, Ratner, et al, 2007) had been that the man might die anonymously and alone. He subsequently discovered that the man had died in a hospital waiting room without having been seen by a health professional and this provoked sadness and distress.

Commonly people feel personally guilty for failing to prevent a death or blame services for failing to intervene or provide adequate or timely assistance to the person. Workers tend to construct a view of

service users as being responsible for their choices to engage in risk taking behaviour but rarely do workers ascribe blame or express anger towards the deceased. Anger is commonly directed towards services and managers for perceived shortcomings in helping the person and also if the person's death is not perceived to be marked respectfully.

Marking death

The way the death of someone is marked and their life is remembered is important in helping people grieve, express emotions and otherwise deal with death. People reported small, personal gestures they made to mark a person's death, such as lighting a candle, or spending some time alone in quiet reflection. Public and shared ways of marking death such as religious observances, funerals and wakes vary culturally and people's roles in proceedings and permitted behaviour depend on the relationship with the deceased person. This often places homeless sector workers in an ambiguous position. One respondent said it was easier to deal with the death of a family member or friend than a service user because it was clearer how one ought to respond.

Many of the experienced workers chose not to attend funerals of service users. Some said this was because funerals were principally for friends and family, and also that the frequency of encountering death would make this option impractical. For others attendance was deemed essential to help with emotional 'closure', or simply to demonstrate respect for the deceased. In residential facilities attending funerals or convening a memorial service was considered important to show solidarity with the community of residents. Funerals could bring home to people how marginalised a life the homeless person had led on seeing how few people attended. In other instances the relationship the homeless sector worker may have had with the person is not acknowledged or the knowledge that the person had of the person cannot be shared in order to be sensitive to family members' need to grieve. For example, the homeless sector worker may know details about a 'dark side' to the person's behaviour or character that is deemed better not shared with others. Nevertheless the choice to attend a funeral of a service user was valued by many people.

Recognising vulnerability

Many homeless sector workers develop formal and informal networks in which their special relationships with service users and their own vulnerabilities are tacitly known by colleagues. Acknowledging the vulnerability of both service users and workers and responding with sensitivity enables people to work through the experience. People may be vulnerable because of past experiences, such as the suicide of a family member, miscarriage, personal bereavement, the accumulation of stress, or personal identification with a service use. When a person is perceived as vulnerable, gestures such as a kind word, an enquiry as to their wellbeing, permission to leave work early or an invitation to talk are often appreciated.

People were acutely aware of the vulnerability of service users around the death of others, taking particular care in how the news was shared with them. They were aware that the response of some service users to stressful events was often an exacerbation of substance misuse or other potentially dangerous behaviour. Thus, the worker would attempt to contain and channel the distress of service users. This poses a risk that the worker's own needs in relation to dealing with the death are not addressed. Recognising one's own vulnerability and taking care of oneself were considered important for enduring the stresses of homeless sector work at the best of times and essential when confronted by events involving trauma and death. Methods of self care are diverse but can include exercising, humor, engagement in activities with family and friends and otherwise disengaging from work in some way. Those with experience of counselling commended it as an important means to help distinguish between professional and personal issues and effective supervision in the workplace helped to prevent encroachment of work related issues

For some workers, attending funerals helps with emotional 'closure'

> *'A positive frame enables the experience of working with the person and his or her death to be explored. Lessons learned from the experience can then be applied in the future'*

into people's personal lives. Ongoing supervision or even time-limited debriefing (particularly when facilitated by someone outside of the agency) were highly valued as avenues to voice feelings of anger, blame and irrational thoughts without fear of negative sanctions (thus reducing the need to suppress or put these things in 'boxes').

Positively framing the death of a service user

Positively framing death is an outcome of the processes described and this enables people to carry on working in the field with enthusiasm. Those people who appeared to do this well tended to articulate an awareness of and acceptance of the limitations of their role. One, for example, stated: 'You can only do as much as you can', while another person said: 'There is nothing more I can do for that person now but the living still need looking after.' These people come to see death as a professional loss rather than a personal one, and failures as service or system failures or opportunities for professional improvement rather than as personal flaws.

Sometimes the death of a service user arouses feelings of injustice or indignity and appears senseless. In such cases, the death may renew or stimulate a commitment to address injustice or make extra efforts to help others. For example one worker who worked with a person who was shot dead stated:

'It made me question ... is this the job for me? Is this what I want to do? But in a way it has kind of pushed me harder to try even better or to try and stick with people and see how they are doing and things like that.' Others emphasised the importance of maintaining hope for other service users and acknowledging positive elements of the job or people's progress no matter how minor.

Positively framing death encompasses more than a particular cognitive frame or set of explanations. The frame can be thought of as being like a picture frame in which the memory of the deceased person and his or her relationship with the worker is contained, preserved and available for review at the person's leisure. In this way the experience is consolidated, memories preserved, details do not need to be suppressed and neither do they demand constant attention. The worker can continue working with vulnerable people if they choose, having worked through these traumatic events rather than accumulating a burden of stress and suffering. A positive frame enables the experience of working with the person and his or her death to be explored. Lessons learned from the experience can then be applied positively in future work.

Discussion

While the experiences of homeless sector workers in relation to the death of service users does not appear to have been reported in the literature before, the theory generated from their accounts may have resonance with other groups.

The processes of encountering and responding to death, and recognising and responding to vulnerabilities of self, colleagues and service users are not unique to homeless sector workers as an occupational group. The uniqueness of their work and how these processes are resolved stems from the marginalised lives and marginalised deaths of homeless people they serve and to some extent their marginalised position as workers in society.

Homeless sector workers are a heterogeneous group who vary in training, work focus and responsibilities. Unlike health professionals and many others who routinely encounter death and trauma in their work homeless sector workers are often relatively poorly paid, have limited direct power to influence the social trajectories of people into or out of homelessness, and they do not enjoy the status, training or institutional support of professional groups.

Those professionals who do work in outreach capacities with the homeless sometimes find that they are somewhat marginalised from their colleagues in institutional settings.

The concept of grief has been used to make sense of the experience of health professionals and the process they undergo when dealing with the death of patients (Redinbaugh et al, 2003; Papadatou, 2000). Some people's responses were characteristic

of grief. Grief by homeless sector workers might be construed as arising from many losses but particularly the non-realisation of hopes held for service users in relation to their experience of death or a different future. Funerals and other such rituals are one means to work through grief and accept the reality of loss (Worden, 2001). Homeless sector workers cannot engage in these rituals in the same way as family members and others. They therefore may not realise the personal benefits and must avail of other means such as supervision or personal mechanisms for giving voice to and accepting their losses.

There is some support from existing research for the propositions that arise from this theory. For example, the way that death is encountered influences how people respond and subsequently cope. Encountering emotionally shocking or unexpected death has been found to alter the clinical behaviour and career paths of physicians and such encounters were countered pivotal in learning how to cope with dying and deal with dying patients (Jackson et al, 2005). Doctors who had worked for longer with patients reported stronger emotional reactions and were more vulnerable to feelings of loss (Redinbaugh et al, 2003). The impact of death on a small group of nurses was explored by O'Hara et al (1996), who found that sharing feelings about death (not putting things in boxes) and framing one's work as contributing to a 'good death' helped soften the impact of working with dying people.

Conclusion

Positively framing the death of service users contributes to the wellbeing of workers. This process can be supported in various ways. First, clear policy and procedures relating to what to do when death is encountered is vital. Second, the potential for encountering death and trauma among service users ought to be made clear to workers in this sector on appointment and appropriate, ongoing supervision should be offered. Third, competent debriefing ought to be offered to people after traumatic incidents, which should be available for at least two weeks after incidents. Fourth, workers ought to look out for colleagues who are potentially vulnerable and thus need greater support—regardless of their perceived bonds with the deceased service user. Fifth, opportunities should be available to workers to mark death in a personal way and to participate collectively to memorialise death. Finally, individuals and organisations need opportunities to review the event separately from dealing with its emotional impact. Thus, they can learn from the experience and prevent harm to others in future. It is a testimony to the resilience of those in the homeless sector that they generally maintain their wellbeing and continue to promote the health, welfare and wellbeing of others in the face of death and trauma. How homeless sector workers positively frame the deaths of service users may be of use to others who need to preserve hope and optimism so that they can make a difference to those who remain.

BJW

References

Buhrich N, Hodder T, Teesson M (2000) Lifetime prevalence of trauma among homeless people in Sydney. *Aust N Z J Psychiatry* **34**(6): 963–6

Cheung AM, Hwang SW (2004) Risk of death among homeless women: A cohort study and review of the literature. *CMAJ* **170**(8): 1251–1252

Glaser BG (1978) *Advances in the Methodology of Grounded Theory: Theoretical Sensitivity*. Sociology Press, Mill Valley, CA

Glaser BG, Strauss AL (1967) *The discovery of grounded theory: Strategies for qualitative research.* Aldine Transaction, London

Haw C, Hawton K, Casey D (2006) Deliberate self-harm patients of no fixed abode: A study of characteristics and subsequent deaths in patients presenting to a general hospital. *Soc Psychiatry Psychiatr Epidemiol* 41(11), 918–5

Homeless Agency (2008) *Findings from Death Policy Notifications in 2007*. The Homeless Agency, Dublin

Homeless Agency (2009) *Rough Sleeper Count. Update: The Newsletter of the Homeless Agency* **62**: 5

Hwang SW, Orav EJ, O'Connell, JJ, Lebow JM, Brennan TA (1997) Causes of Death in Homeless Adults in Boston. *Ann Intern Med*, **126**(8): 625–8

Jackson VA, Sullivan AM, Gadmer NM et al (2005) 'It was haunting …' : Physicians' Descriptions of Emotionally Powerful Patient Deaths. *Academic Medicine* **80**(7): 648–56

Kushel MB, Evans JL, Perry S et al (2003) No Door to Lock: Victimization Among Homeless and Marginally Housed Persons. *Arch Intern Med* **163**(20): 2492–9

Morrison DS (2009) Homelessness as an independent risk factor for mortality: results from a retrospective cohort study. *Int J Epidemiol* **38**(3), 877–83

Nordentoft M, Wandall-Holm N (2003) 10 year follow up study of mortality among users of hostels for homeless people in Copenhagen. *BMJ* **327**(7406): 81

O'Hara PA, Harper DW, Chartrand LD, Johnston SF (1996) Patient death in a long-term care hospital: A study of the effect on nursing staff. *J Gerontol Nurs* **22**(8): 27–35

Papadatou D (2000) A proposed model of health professionals' grieving process. *Journal of Death & Dying* **41**(1): 59–77

Redinbaugh EM, Sullivan AM, Block SD et al (2003) Doctors' emotional reactions to recent death of a patient: Cross sectional study of hospital doctors. *BMJ* **327**(7408): 185

Schanzer B, Dominguez B, Shrout PE, Caton CLM (2007) Homelessness, Health Status, and Health Care Use. *Am J Public Health* **97**(3): 464–469

Song J, Bartels D, Ratner E, Alderton L, Hudson B, Ahluwalia JS (2007) Dying on the streets: homeless persons' concerns and desires about end of life care. *J Gen Intern Med.* **22**(4): 435–41

Song J, Ratner E, Bartels D, DM, Alderton L, Hudson B, Ahluwalia JS (2007) Experiences with and attitudes toward death and dying among homeless persons. *J Gen Intern Med* **22**(4): 554–5

Taylor KM, Sharpe L (2008) Trauma and post-traumatic stress disorder among homeless adults in Sydney. *Aust N Z J Psychiatry* **42**(3): 206–13

Worden JW (2001) *Grief Counselling and Grief Therapy: A Handbook for the Mental Health Practitioner* (3rd ed) Routledge, New York