

# Abstracts

## Denise Brady

Librarian

St Christopher's Hospice, London

Denise Brady presents a round-up of recent research literature and other publications relating to bereavement. This issue, she discusses some articles which were published last year concerning groups of elderly people, where grief could be disenfranchised.

### Helping those with dementia to understand death and cope with bereavement

Gruetzner H, Ellor JW, Back N (2012). Identifiable grief responses in persons with Alzheimer's disease. *Journal of Social Work in End of Life and Palliative Care* 8 (2) 151-64.

This piece of research involved two focus groups. One was composed of 12 family members, each of whom had a relative with dementia, four of them with advanced dementia. The second was with six health professionals from different disciplines who had experience of geriatrics. Both groups were asked what they observed about the grief reactions of people with Alzheimer's Disease, how they responded to this, and what the participants observed about the long-term reactions to the grief of people with dementia. (The terms 'dementia' and 'Alzheimer's Disease' were used interchangeably).

Although the results of each group were analysed separately, the themes were similar. Three main ways that people with dementia reacted to grief were categorised as a) 'self-threat' – they did not grieve so much as worry about who was going to care for them in the future; b) substitution – they may forget who has died and substitute with a family member who died many years ago; and c) metaphone where they substitute an object or unrelated item for the loss of a love one. Examples are provided of each of these phenomena.

The authors suggest that, in general, people should be told their relative has died, although they may forget this, and a judgement has to be made about whether this is too upsetting for them and for those in contact with them. Relatives need to be aware that people with dementia may not react to a bereavement in expected ways.

Two interesting approaches to assisting bereaved people with dementia are mentioned. One is 'spaced retrieval' where health professionals help the person to remember their loved one to understand the impact of the death on them. The second is using 'group peers' where a person with dementia but with a higher level of functioning assists their peer to appreciate what has happened to them. This seems like an imaginative approach to care as it involved the accompanying person in having a role in caring not easily available to many older people, especially those with dementia. Such innovations would obviously have to

be managed carefully but the quoted article (Lewis & Trzinski) is worth reading by anyone interested in helping bereaved people with memory difficulties.

The authors discuss ethical, compassionate care for people with dementia and suggest that there is a need for more information, both for relatives and health professionals on the subject. They suggest observational research is also needed. This article goes some way towards providing a guide on how to deal with issues related to the bereavement of people with dementia. It is certainly useful as a basis for developing such guidelines. ■

### Impact on residents of frequent deaths in a care home

O'Connor M, Tan H, O'Connor D, Workman B (2013). Is the frequent death of residents in aged care facilities a significant cause of grief for residents with mild dementia? *Progress in Palliative Care* 21 (1) 7-12

The article begins with a brief literature review of the many losses an elderly person may have experienced before they became a resident in a care home. This sets the scene for a piece of research asking if fellow residents' deaths in four 'aged care facilities' are a significant source of grief. 23 residents (screened for mild dementia so that they were capable of responding to the questions) were asked about their fear of death, the impact of the death of a fellow resident and whether the death impacted on the community life of the care home. 70% indicated they were not afraid of death. 25% indicated they missed a friend in the home – however, most of these said that even if they missed a friend, they knew the person was ready to die and were glad they did not suffer any more. However, most felt that 'they passed like ships in the night' and fellow residents were no more than acquaintances. 60% of residents thought there was no sense of community in the home. All the residents had been in the home more than a year – and six had been there for more than three years.

26 health professionals (the majority being nurses) were also interviewed and answered similar questions. They had rather different views and thought that 65% of the residents feared death. They thought the impact of the death was felt most by people who sat at the same table each day. A third of the staff thought there was no sense of community in the home.

Both residents and staff felt that the impact of the death of a fellow resident was far less significant than other losses they had experienced in the recent past. In relation to this, the following are discussed as reasons for this lack of connectedness: 1) the existence of single rooms; 2) apathy; 3) isolation by choice.

Perhaps most significant was the fact that 65% of the staff thought that most residents feared death and 70% of residents said they did not. Yet this is not commented upon. It is a rather bleak piece of research that offers only reasons as to why residents do not build close relationships and offers no positive suggestions about how to help people in nursing homes deal with death and in so doing, possibly develop a greater sense of community. While the results are thoughtful, I found myself wanting to direct staff to other articles (Lewis & Trzinski, 2006; Mathie et al, 2012) as well as others discussed in this issue. ■

### Coming to terms with death: a case study

Temple-Jones J (2012). 'I want to find my life again': dementia and grief. *Journal of Pastoral Care and Counseling* 66 (2) 5:1-76. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/23045906> [Accessed 16 September 2013].

This case study describes how a spiritual care professional communicated with a recently bereaved resident in a care home to help her come to terms with the death of her husband. It offers a model of how to communicate with a person with mild to moderate dementia when they have been bereaved.

The author records a conversation soon after the death of a resident's (Maureen) husband (Bert). They had been in the same home together for some time. Maureen had dementia. They had cared for each other for over 60 years.

It is usually helpful to have access to a verbatim conversation within an article and the author does this, responding to Maureen's emotional statement: '...When Bert was here I knew where I was. Now I don't know where I am...'. For the reader of the article, it enables a deeper empathy with the situation. A second, shorter verbatim conversation focuses on how to relate to Bert, now that he has died. The author suggested that they could write about Bert, but she sensed that Maureen recognised not just that he had died but a significant social role had ended in her life. In addition she was coming to terms with the fact that she had dementia and the author points out that while her phraseology was confused, her *feelings* of pain and loss were very clear. The author considers there are psychosocial layers of 'self', that become problematical when someone with dementia is bereaved. She describes these layers in some detail.

This is the kind of work that could be conducted by a bereavement counsellor. The article might also be helpful to care workers in a care home to help them understand the nature of dementia and to help them relate to the losses of their residents. With mild dementia, residents can often talk about their previous lives, including their losses. The author suggests that carers can encourage this and relay it back to the resident so that there is someone to talk with, who has a connection with their former life.

The author also describes other ways to help residents to find some meaning in their lives. If a resident does not even have photographs, then discussions of the seasons can take place, especially through enabling residents to touch objects eg fallen leaves, or fresh garden produce. The articles clearly shows how the losses of loved ones as well as of one's physical and mental faculties can merge – and how this can be eased, by thinking

holistically of the lives of those people who have dementia and are also recently bereaved. ■

### Loss of an adult child by elderly parents

Van Humbeeck L, Piers RD, Van Camp S, et al (2013). Aged parents' experiences during a critical illness trajectory and after the death of an adult child: a review of the literature. *Palliative Medicine* 27 (7) 583-95

There is a dearth of literature on the experience of elderly people whose adult child has died, especially when one compares it with bereaved parents of young children. The search strategy for the systematic review presented in this article is clearly outlined and just 19 articles were considered as relevant. Even this small number were not easy to locate.

Analysis was divided into the parents' experience: a) prior to the death of their adult child with a life-threatening illness; and b) their experience after the death of their child. Issues of loss and grief often continued from one phase to the other eg. the fact that parents – if their child had married or had children of their own – were often sidelined in a way that would not have happened had the child been young.

Issues highlighted before the death of their child included:

1. A multitude of intense feelings eg. feeling a sense of injustice if their child had cancer, because they had provided their children with the genes whereas they themselves had been spared.
2. The transformation of the parent role eg. often just 'being there for their children' rather than actively caring for them.
3. Mutual protection, both parents and adult children trying to protect each other from their different perspectives.

After the death of the adult child other factors were identified a) reduced functioning – with many parents being more prone to illness; b) survivor guilt; c) lack of perspective – parents became more concerned about who would take care of them, in the future; and d) further transformation of the parent's identity and the parent role. These are thoughtfully discussed and many are similar to the experience of parents whose young children have died – eg. 'being a parent without a child to parent'. The authors speak of the intensity of the need for an unbreakable bond with these children – very similar to the concept of continuing bonds. The authors also provide an extensive list of the particular grief issues that affect older bereaved parents, one being the fact they have fewer distractions, such as work, to find some relief from their emotional pain. ■

This is an article worth suggesting to anyone who may not understand how an extended family can be affected by a life-threatening illness of a family member or to anyone working with elderly people who wants to understand the myriad of issues that affect them after the death of an adult child.

Lewis MM, Trzinski A (2006). Counselling older adults with dementia who are dealing with death: innovative interventions for practitioners. *Death Studies* 30 (8) 777-787

Mathie E, Goodman C, Crang C et al, (2012). An uncertain future; the unchanging views of care home residents about living and dying. *Palliative Medicine* 26 (5) 734-743