

Bereavement round up

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Many palliative care and bereavement journals contain personal reflective accounts of bereavement by a health professional. Sometimes it is their personal bereavement, sometimes it is a reflection on their care of memorable patients and their families. Below are some recent articles concerning the day of death and reflections on bereavement – from the death of a young child to that of grandparents. Each writer has clearly articulated their situation with depth of clarity and feeling. These articles can provide resources for some bereaved people, for the education of health professionals and possibly for staff support. ■

From professional to bereaved relative

Rousseau P (2014). *Deathbed memories. Journal of Palliative Care* 30(2) 125-126.

Dr Rousseau works in palliative medicine in the US and has written many papers on the subject. He has also written about the dying and death of his wife in various journals (referenced in the article). The time surrounding her death is etched forever on his mind. As with the experience of Fulton and Yasuf below, the boundaries between being the provider and receiver of health care are explored.

As soon as his wife died, the chaplain and the social worker said she was in a 'better place'. You can hear the anger in Rousseau's tone as he writes this. How can this be when he still loved and needed her, just as his two daughters also did? In seven years the moment of death is still with him as is a hollow future without her. He describes his grief as 'a wound that heals but leaves a persistent pain'.

He refers to his own denial of what was happening. The difficulty of being a patient/relative in the institution where one works is alluded to. He reflects on the importance of staff 'being present' with the patient and family and of the fact that it is especially vital when there are no solutions and death is inevitable. He strongly believes that the way a death occurs in a health care setting can dramatically affect the grief and bereavement of that person's surviving family members. ■

Family conflict over resuscitation

Resnikoff M (2014). *A hard goodbye. Journal of Palliative Medicine* 17 (7) 859-860.

This vignette describes a tense family situation at the moment of death in a New York hospital. An elderly man is in the last days of life and his wife is exhausted. He has had to be resuscitated a number of times already and the staff explain that it is futile.

His wife understands but she indicates some of her family think differently and she also needs to consider them.

The patient has a grandson who is like him in appearance and personality. When it is explained to the family that resuscitation is futile the grandson finds it impossible to agree. He cannot believe his grandfather is dying. 'We are strong fighters,' he says. Then the situation is again explained to the family – that this man is brain damaged, that he will never walk again, that his ribs will be broken during resuscitation. The family take in this enormously blunt message. They do not want the doctors to carry on. The grandson again is the sole person against the DNR. In desperation he says 'Don't kill him!' He wanted another day to see if there was any improvement. So the doctors prepare once again for the futile intervention.

Then his wife realises, as she stands at the door of the resuscitation room, that she does want not want resuscitation to proceed. The doctors stop. The bed rails are lowered. The family gather around. Even the grandson stands beside his grandfather, talking to him softly. His anger has faded, he seems accepting of the situation. There is complete quiet.

The whole family have been in turmoil but the hope is that the grandson, who loved his grandfather so much, has an acceptance that would not otherwise have occurred, had his anger not been heard. ■

Setting aside professional roles

Fulton AE (2014). *Reflections. Personal grief: on losing my grandfather. Journal of Social Work and End of Life Care* 10(1) 3.

A Canadian woman sees much of her identity tied up in her role as a social worker. She has a long journey to be at the bedside of her grandfather and finds herself dreading the moment of his death. She is alone with him as she was when she was a child. Her 'social work hat' has been discarded. This is a rather frightening situation for her and when the hospital social worker introduces herself, she could not say she was a social worker herself. ... 'Like a hat, perspective can be lost but the hope lies in knowing it can be found anew'. She is both a competent social worker and a bereaved grandchild – both roles will remain with her, throughout her life. ■

A doctor's expectations

Yasuf MA (2014). *Stepping back. Journal of Palliative Medicine* (2014) 17(4) 492.

A doctor working in the UK recalls the expectations placed on him

by his family as his grandfather was dying. He had to be careful about what to tell/not tell to each of his extended family. They had originally come from another country and his grandfather could not even speak English. His sons could communicate reasonably well in English but the writer felt it was best to stand back, rather than rushing in to facilitate communication between the health professionals and the rest of the family. This, he felt, would have led to family friction between the family and medical team. He felt it was best to trust this medical team to provide the best care possible for his grandfather and the family just as he himself did for families and patients.

As with Fulton above, he took off his 'doctor's cap' when visiting his grandfather. In retrospect he thinks this was also the right decision. He was simply a grandson on the day his grandfather died. That was more than enough to cope with. ■

A chance for a child to express grief for his twin

Kobler K (2013). *Matching strides. Illness Crisis and Loss* 22 (1) 73-76.

A nine year old dies from a rare and difficult illness. She had insight to her approaching death, but no one expected it to be so sudden and quick. Staff and family spent many hours in her hospital room, packing up her belongings after a long time spent in the unit.

She had a twin and he was given great support by all around him but the staff gradually drifted off as their shifts ended. He sighed and sat beside the nurse outside the office (the author). His parents were still busy in his sister's bedroom. She said 'Waiting is hard work' and he raised an eyebrow simply saying 'Can we walk somewhere?' Where did he want to go? To the 14th floor in the lift. So off they went.

He said he knew the view would be stupendous but he had not known his sister would die that day. Long pause. It was night time and another decision had to be made about where to go. The nurse knew of a lounge on one ward where one could see the bright lights of Chicago. A member of staff ushered them into the ward and understood there must be a special reason for this. She directed them towards the lounge. 'Wait' he said 'I need to tell you – my sister died today. She's my twin. She'll always be my twin'. In the dark lounge, there was a silence and the nurse had gauged the darkness might be a safe place for him to cry. 'I really don't like that she died'. The nurse nodded in agreement. Then after experiencing this 'gracious holding place for tears' he said, 'It is time I should go back to my parents'.

There followed a game played by the two of them in which the young boy was already practised but he had never yet had a companion with which to play it. It concerned strides between the different floor hospital tiles – shared for once with this nurse. They returned to his sister's room. She walked with him and his parents to the car where he became almost invisible beneath his sister's things. She felt small shared steps of healing had

taken place – and she hoped other people would take up the 'privileged' task of walking alongside this special family.

Persistent complex bereavement-related disorder

Boelen PA, Prigerson HG (2012). *Commentary on the inclusion of persistent complex bereavement-related disorder in DSM-5. Death Studies* 36(9) 771-794

Colin Murray Parkes writes: In this article Boelen and Prigerson welcome the recognition that disabling grief is being addressed in the DSM but observe that there is a lack of clear research evidence validating this category of Adjustment Disorder and that fears of over-diagnosis may be justified.

Much more rigorous is the diagnosis 'Persistent Complex Bereavement-Related Disorder' (PCBRD) yet this has been confined to a special category 'for further research'. At first glance PCBRD sounds like the Prolonged Grief Disorder (PGD) that has emerged from Prigerson's own exhaustive research. She has developed a research questionnaire, the Inventory of Complicated Grief, and a sophisticated scoring process that has put PGD on a firm footing and enabled numerous studies to be carried out in many part of the world. Unfortunately the DSM committee, perhaps in an attempt to please too many 'experts', have included a larger battery of 'symptoms' including four that belong more appropriately in bereavement-related depression, despite clear evidence that Major Depressive Disorder and PGD are separate categories that respond to quite different methods of treatment. The symptoms of PCBRD and PGD are compared in detail in this article (alongside a third version that is an expanded version of PGD used by Shear, *et al* in their successful evaluation of a treatment for what they call 'Complicated Grief' (Shear, *et al* (2005)).

Boelen and Prigerson conclude that PCBRD '...is a hastily conceived and extremely heterogeneous construct that endangers major advances in our understanding of what constitutes dysfunctional grief. It thereby sets the bereavement research clinical clock backwards, and ignores current strides in current understanding... some of the proposed criteria overlap with uncomplicated or "normal" grief... complicating clinicians' efforts to integrate this research into their clinical work'. (pp789-790)

Their arguments are too numerous to be given in detail here but they are well-informed and cannot be ignored. This said, if the inclusion of PCBRD meets its objective of stimulating further research in this contentious field it will have achieved something useful. It is clear that no single diagnostic category can be expected to cover all of the forms complicated grief takes. Prigerson and her colleagues have done us a great service by identifying the most frequent of these forms which overlaps so well with the rather over-inclusive version used by Shear, *et al* that it is possible to use the Inventory of Complicated Grief to measure both for research purposes. The same cannot be said for PCBRD. ■