The bereavement experiences and support needs of bereaved family caregivers in the context of palliative care

Jane Mowll
Lecturer in Social Work,
University of New South Wales,
and Bereavement Counsellor
(Accredited mental health social worker)

Palliative care services around the world are often mandated to provide support to bereaved family caregivers in the wake of a death in palliative care. At the same time there is increasing debate on the parameters and models of such support and about how and when to provide professional support. Research has focussed important attention on the minority of bereaved caregivers who experience a pathological reaction, most commonly equated with Complicated Grief (CG) or Prolonged Grief Disorder (PGD) (Hall, 2014). However, such a focus privileges a medical or psychiatric understanding of grief and does not always take into account the breadth and varied bereavement experiences and concomitant support needs of caregivers.

The three articles discussed take a rigorous qualitative and interpretive research approach to provide further insights. The research contributes a deepened understanding of the experiences of bereaved caregivers in context of end of life (EOL) or palliative care and invites us to consider the multiple layers and complexities of bereavement support needs.

Holtslander, L., Baxter, S., Mills, K., Bocking, S., Dadgostari, T., Duggleby, W., Duncan, V., Hudson, P., Ogunkorode, A. & Peacock, S. (2017). Honoring the voices of bereaved caregivers: a metasummary of qualitative research. *BMC Palliative Care*, *16*(48).

Hotslander et al's comprehensive literature review systematically examines qualitative findings of studies reporting on the experiences of bereavement for caregivers in palliative care. The study employs a Sandelowski & Barroso's qualitative 'metasummary' approach to examine the frequency of findings across qualitative studies and to integrate and interpret qualitative findings from the selected studies.

Studies included in the review are qualitative or mixed methods research published between 1990 and 2014, which examined experiences of bereaved family caregivers of adult patients who were receiving palliative care services. A total of 1287 articles were identified, and 47 studies, which fit the criteria noted above, were included for analysis. The studies were first assessed by at least two independent raters using a Critical Appraisal Skills Program to determine quality of the studies including reliability, bias, and significance, and studies were given a quality score. A table helpfully summarises the key characteristics of each study, including the assessed study quality, and including the study country. Studies were all from developed countries including the USA, Canada, Australia, New Zealand, some in Europe, and a few from Hong Kong, Japan, and Korea.

The data analysis process for the metasummary was adapted from Sandelowski, Barrosso, and Voils (2007) and each step is described in detail in the paper. Data analysis software was used to organise extracted qualitative findings reporting the experiences of caregivers based on the studies' data as well as direct extracts of study participants' quotes. The research team undertook a rigorous analysis, which

included extracting, coding, and grouping the findings. They employed an iterative coding process so that codes and themes were systematically examined and discussed within the research team to form themes and subthemes. A review to refine emerging themes was also elicited from bereaved caregivers and helping professionals in a research forum, adding to the rigour of the study. A frequency score was calculated to indicate the most prevalent themes. Of the 15 themes identified, seven focussed on the emotional experiences or 'journeys' and included a broad spectrum of reactions. The positive emotions encompassed by 'serenity' was the most frequent, noted in 35 studies, followed by sadness (34), guilt and regret (25), uncertainty (25), trauma (19), escape (numbness or avoiding painful feelings) (17), and anger (15). The other eight themes included: post-loss experiences that helped the caregiver; post-loss experiences that hindered; practical life changes; caregiver role identity; pre-loss experiences that helped; pre-loss experiences that hindered; caregiver context; and a need for different kinds of supports. A summary is also provided of the characteristics and demographic data of participants across the 47 studies.

One of the key facets arising from the themes is that both informal and formal support from others was noted as the most helpful experience after the death. Participants across the studies noted the importance of consistency of support, and support to talk about their loss with others, including with people experiencing similar losses. Information about and availability of formal support was also helpful, and in some studies, this included a continuity of support from caregiving through to bereavement. Factors that made support less helpful included, underestimating the significance of the loss, pressure to either 'move on' or conversely, talk about the loss when they didn't want to, and sometimes that supporters lacked a personal experience of death.

The themes were considered together by the research team and overarching meta-themes pointed to: the impact of caregivers' experiences during caregiving on bereavement; the unique experiences of loss between participants; and the need for different sorts of supports for caregivers. One of the many important take home messages from this research is the importance of not generalising about caregivers' grief so that instead we hold a sense of the varied experiences of loss and thus offer a broad range of services and support options in the wake of the death.

Harrop, E., Morgan, F., Byrne, A. & Nelson, A. (2016). "It still haunts me whether we did the right thing": a qualitative analysis of free text survey data on the bereavement experiences and support needs of family caregivers. *BMC Palliative Care, 15*(92).

This UK based study also examines the qualitative experiences of bereavement on data taken from a

large public survey of 1403 people, including patients, caregivers, professionals and interested members of the public, designed to generate research priorities. A thematic analysis of qualitative and free text data from the survey responses was undertaken of a subset of 154 respondents. These were primarily bereaved carers (family member or friend) or a professional working in EOL/palliative care, as well as current carers and volunteers. Qualitative coding software was used to organise the data, and two researchers independently compared and coded the data and generated themes. Three main themes were described, and verbatim quotes from the surveys were used to illustrate themes: death and end of life experiences and impacts on bereavement; improved communication during the dying stages and post death; and living in a void: the need for continuity of care.

Death and end of life experiences and impacts on bereavement: this theme described the impact of the death for participants and the ways that traumatic death experiences stayed with them, leaving lasting feelings of regret, guilt and unanswered questions. Respondents described being 'haunted' by vivid images of physical suffering, particularly referencing the (now withdrawn) Liverpool Care Pathway (LCP). Further facets of the death described by participants as impacting on their bereavement included 'nagging doubts' concerning the decisions made, such as the place of death, and whether they could have done more for their loved ones. Some respondents also gave examples of more positive experiences of end of life care, including the value of multi-professional support during care and death and follow-up contact and support in bereavement. Interestingly, the authors note that this support seemed to underline perceptions of good care as well as relating for respondents to their own recovery and adjustment.

Improved communication during the dying stages and post death: both caregivers and professional respondents suggested ways of improving communication and support during the dying process, including what to expect at the end of life and the signs of impending death. Needing guidance and preparation for the death was emphasised, importantly including in circumstances of chronic/long term conditions such as MS and Alzheimer's disease. Also noted was the need for effective communication and support to explain interventions and help carers understand the shift to prioritising EOL/palliative care. Some respondents suggested that a meeting after the death with the professional carer/team could facilitate an understanding of what happened for bereaved caregivers.

Living in a void: the need for continuity of care: here the emphasis is on the need for a continuity of care from services for bereaved carers after the death but also from the professional care team with whom they had built relationships. Carers described the 'void' left after the

death associated with the withdrawal of support from professional carers after the death. This was also linked to the loss of identity and role of long term caring for some caregivers. Professional carers also reflected this theme, recognising this emptiness for some caregivers and a need to provide on-going support to caregivers after the death.

Discussion and conclusions

The impact of the death in particular is discussed alongside research extrapolating the perhaps more hidden aspects of traumatic stress experiences after an expected death (e.g. Sanderson, Lobb, Mowll, Butow & McGowan 2013). Respondents in Harrop et al's study, however, also emphasised critical feelings of guilt and regret, alongside feelings of confusion, exclusion, and powerlessness.

The authors acknowledge the limitations of the study, including a reliance on survey/text data (rather than, for example, in-depth interviews). Further, the survey aim, which was to generate research priorities, may have encouraged the more extreme experiences of difficult EOL experiences to be shared. Nevertheless, the study provides a broad range of perspectives and highlights two important aspects of bereavement in the context of palliative care that have not perhaps had sufficient attention. First, the impact and effects on bereaved caregivers of traumatic deathbed experiences and second, what they describe as the 'void' effect of withdrawal of professional support immediately after the death.

Taken alongside Hotslander et al's (2017) more recent and comprehensive metasummary of qualitative studies reviewed here, there is a clear need to understand more about the difficult experiences of witnessing and caring for a loved one's expected death, and the reverberations of those experiences into bereavement. Along with this, there is the need to encompass a more holistic view of the support needs of caregivers through the caring, the death, and post the loss.

Kirby, E., Kenny, K., Broom, A., MacArtney, J., & Good, P. (2017). *The meaning and experience of bereavement support: A qualitative interview study of bereaved family caregivers.* Palliative and Supportive Care, pp. 1-10. Cambridge: Cambridge University Press.

On a different scale from the previous two studies reviewed, this is a small qualitative study of 15 bereaved caregivers' experiences taken from a larger study exploring a range of caregiving experiences. Thematic analysis of transcribed semi-structured interviews was used to draw out key themes regarding participants' experiences of bereavement and support. Identified themes included: the sociocultural constructions of bereavement support;

perceptions of bereavement support services as narrow in scope; the unique character of bereavement and incompatibility with formalised support, and issues around the timing and style of offered support. Social constructions of support included equating the need for support with those who are not coping and importantly that support is synonymous to counselling.

Indeed, one of the contributions that this study adds is attention to a sociocultural understanding and the needs for support that are outside a pathological experience of grief. For example, participants discussed the financial and practical stressors and the need for support and guidance with navigating the funeral, legal and other issues. The combined practical and emotional support therefore, such as provided by social workers and others, may be invaluable in the aftermath of a death.

Similarly to the review discussed in Hotslander et al (2017), this study also emphasised the unique experiences of grief. In particular, the researchers noted the lack of consistency in experiences across participants such as coping with the strains of managing the deceased's affairs. The authors note the need for research to discover more about how best and when to approach or avoid with offers of support.

In conclusion

The research studies discussed here elaborate and distil some of the nuances and complexities across the caregiving bereavement experience. We are aware from quantitative and mixed method research that intense or prolonged symptoms of distress may need particular psychological support. However, as the research discussed here suggests this focus, while important, perhaps deemphasises the range of support needs after bereavement. As indicated by these studies, the community, family and friends, while vital, may not for everyone provide the breadth and depth of emotional and practical support that is sometimes required. Further, simply equating professional support with counselling may obscure the need for various types of support needed from professional carers and bereavement practitioners. This includes, for example, support: to understand and emotionally integrate the death event; with the management of the funeral and deceased's affairs; to understand the process of death and and care decisions. Other facets recognised in practice, but with less research attention, also crucially involve a family focus of support, particular in circumstances of deprivation or conflict. It is clear that we need further research to explore and understand the nuances of these support needs and develop innovative ways of researching their effectiveness in the broad contexts of practice. Here we should also emphasise the need to include bereaved participants with the range of diversities including (to note just a few) socioeconomic,

gender, sexuality, culture, ethnicity, and languages, on which there remains little sustained research attention. ∎

References

Hall, C. (2014). Bereavement theory: recent developments in our understanding of grief and bereavement. *Bereavement Care*, *33*(1), 7–12.

Sandelowski, M., Barroso, J., & Voils, C. I. (2007). Using qualitative metasummary to synthesise qualitative and quantitative descriptive findings. *Res Nurs Health*, *30*(1), 99–111.

Sanderson, C., Lobb, E., Mowll, J., Butow, P., & McGowan, N. (2013). Signs of post-traumatic stress disorder in caregivers following an expected death: a qualitative study. *Palliative Medicine*, *27*(7), 625–631.