The Effect of Caring on Post-bereavement Outcome: Research Gaps and Practice

Priorities

Lauren J. Breen

School of Psychology and Speech Pathology, Curtin Health Innovation Research Institute,

Curtin University

Contact details for correspondence:

Dr Lauren J. Breen

School of Psychology and Speech Pathology

Curtin University

GPO Box U1987

Perth Western Australia 6845

Australia

Tel:   +61 8 9266 7943

Fax:   +61 8 9266 2464

Email: Lauren.breen@curtin.edu.au
Abstract

Family caregivers are the primary caregivers of family members over the course of illness. Some caregivers exhibit elevated levels of distress following the death of the person for whom they were caring. Despite the practical relevance for providing supports and services to caregivers and families, pre- and post-bereavement, the effect of caregiving on bereavement is obscured. In examining the research literature on caregiving and bereavement, three methodological limitations were identified – caregivers’ perspectives on preparing for the death of the person for whom they are caring is typically not assessed; the effect of caring on post-death adjustment tends to be assessed qualitatively, cross-sectionally, and retrospectively; and there is a lack of adequate comparison groups. This paper highlights the need to address two important gaps in understanding the effects of caregiving and bereavement: (1) caregivers’ understandings and experiences of the anticipating and preparing for the death of the person for whom they are caring, and (2) the relationship between caregivers’ pre-death grief and distress and post-death adjustment. Caregivers relieve significant costs from the health system, and improved support, pre- and post-bereavement, will continue to benefit them as well as society. Without significant research investment, palliative care services will continue to operate without a suitable evidence base to support their bereavement care efforts.

Keywords

Family Caregivers, Bereavement, Palliative Care, Research Priorities, Evidence-based Practice
The Effect of Caring on Post-bereavement Outcome: Research Gaps and Practice Priorities

According to the World Health Organization, chronic diseases, including cardiovascular diseases, cancers, diabetes and chronic lung diseases account for 63% of deaths worldwide; this proportion is greater in high income nations. In economically-developed countries, a typical death involves a lengthy period of time whereby the care of patients with chronic and disabling conditions occurs in the home and by one or more family member, usually a spouse or adult child and typically women. Recent years have seen the provision of formal home-based end-of-life services, resulting in family caregivers providing the interface between the person living with chronic disease and the professionals. Family caregivers continue to provide care when (or if) the patient is admitted to a palliative care unit or hospice near the end-of-life. Thus, family caregivers are the primary caregivers over the course of the illness.

The experiences and needs of family caregivers during this time are relatively well-documented. Notwithstanding potential benefits attained from caregiving such as the strengthening their relationship with the patient, the development of new skills, and spiritual growth, and an increased appreciation for life, family caregivers engage in care that may be financially costly, time consuming, physically demanding, and stigma inducing, and that usually impacts negatively on their ability to engage in social and recreational activities. Needs include practical information, emotional support, economic assistance and housing support, improved coordination of formal care and allied services, and bereavement support, while outcomes when engaging in care may include symptoms of psychiatric morbidity and psychological distress; these needs remain largely unmet by services.

Despite the practical relevance for providing supports and services to family caregivers, pre- and post-bereavement, the effect of caregiving on bereavement is less clear.
This paper summarises what is known about the effects of family caregiving on bereavement outcome, and demonstrates that this knowledge is hampered by three serious methodological limitations. The implications for future research in addressing these limitations and developing an evidence-base for bereavement support in palliative care are outlined.

**Limitations to Current Understandings of Caring and Bereavement**

A recent review of the caregiving and bereavement literature\(^\text{21}\) demonstrated that the three theories explaining the effect of family caregiving on bereavement are conflicting. The cumulative stress theory proposes that the ‘wear and tear’ of caring precipitates significant distress following bereavement. On the other hand, the stress reduction theory suggests that family caregivers experience a reduction in their stressors following bereavement, yielding a more favorable post-bereavement adjustment. The third theory concerns the notion of anticipatory grief\(^\text{22,23}\) and suggests that family caregivers engage in much ‘grief work’ before bereavement. The notion of anticipatory grief is accepted by many end-of-life practitioners, despite its theoretical and empirical challenges.\(^\text{24,25}\)

Currently, empirical evidence is equivocal. A pioneering review of the literature on bereavement and caregiving indicated that family caregivers adjusted relatively well to the death of the person for whom they were caring.\(^\text{26}\) However, the ability to draw sound conclusions from the research was encumbered by the studies’ use of cross-sectional and retrospective research designs. A more recent review of the caregiving and bereavement literature concluded that, on the whole, family caregiving was not associated with increased distress following bereavement, and in many cases, bereaved caregivers show improvements in their adjustment over time.\(^\text{21}\) While not all bereaved people experience a significant and long-term grief reaction following the death of a loved one,\(^\text{27}\) it is clear that some bereaved family caregivers do exhibit elevated levels of distress following the death of the person for whom they were caring.\(^\text{28,29}\)
There are three distinct methodological limitations in existing caring and bereavement literature. First, family caregivers’ perspectives on preparing for the death of the person for whom they are caring are typically assumed and not assessed. However, research shows that, despite engaging in high-intensity care of months and years, approximately a quarter of caregivers are not prepared for the death of their loved one; this means that researchers might assume that family caregivers are preparing for the impending death when they are not. Second, the effect of family caregiving on post-death adjustment tends to be assessed qualitatively, cross-sectionally and/or retrospectively or over a very short period of time, or with just two data collection points. Third, there are several longitudinal studies without adequate comparison groups whereby participants are compared to a non-caregiving sample matched to key demographics such as age, sex, domestic arrangements, and household income. These limitations exist across studies of caregivers of patients with a variety of chronic illnesses. Such limitations may exist due to the complexity in conducting research on family caregivers. Issues affecting research include the difficulties in recruiting and retaining participants and the challenges in gaining ethical approval. The studies on caring and post-bereavement distress have tended to overlook that, as a consequence of caring for a dying loved one, family caregivers may be highly distressed upon bereavement. Thus, even if a former caregiver’s distress decreases over time, it cannot necessarily be concluded that this is a return to ‘normal.’

**Implications for Palliative Care Research and Practice**

Clearly then, there is a need for research that addresses two important gaps in the literature on the effects of caregiving and bereavement: (1) family caregivers’ understandings and experiences of the anticipating and preparing for the death of the person for whom they are caring, and (2) the relationship between family caregivers’ pre-death grief and distress and post-death adjustment. In terms of the latter, a longitudinal, prospective approach is
necessary to assess changes in the grief response over time and the use of comparison groups would allow the caregivers’ distress in relation to non-caregivers (a normative group) to be assessed. Such research would be innovative and unique because it would overcome the three methodological flaws identified above and would therefore provide a significant contribution to our understanding of the effects of caring on bereavement.

In addition to these theoretical outcomes, the investigation of the effect of family caregiving on bereavement outcome will inform services and supports offered to caregivers, pre- and post-bereavement. Despite approximately 10 to 20% of bereaved individuals demonstrating persistent psychiatric difficulties, formal services and supports available to family caregivers pre- and post-bereavement in Australia, the United Kingdom, and the United States struggle with how to use their limited resources to deliver best-practice bereavement support. For instance, a survey of Australian palliative care services determined that, although 95% (of 236 services) offered some form of bereavement support, the variability between services resulted from a “lack of clear evidence to guide development and allocation of bereavement programs in palliative care” (p. 230).

Furthermore, such research would complement the current call for evidence-based approaches to bereavement support in palliative care, as evidenced in the palliative care strategies of Australia, the United States, and the United Kingdom. Authors of a recent systematic review of interventions for family caregivers of palliative care concluded that without significant research investment, health professionals would continue to operate without a suitable evidence base to support them. Indeed, Australian palliative care services rate bereavement care as the area of highest priority for improvement. Thus, the results have the potential to inform palliative care policy and practice in the provision of supports and services for family caregivers following bereavement.

**Conclusion**
There is a clear need for research to address the critical theoretical and methodological gaps identified above. While health sectors faces huge financial strains in caring for people in their last year of life,\textsuperscript{50,51} family caregivers absorb most of the cost.\textsuperscript{52} It is apparent that, if caregivers of people with chronic and life-limiting or terminal illnesses ceased caring, the cost to government, health services, and taxpayers would increase tremendously. Thus, there is a clear need for research to make a significant contribution to the theoretical conceptualisation of death and dying and enhance the capacity to provide appropriate supports and services to family caregivers pre- and post-bereavement, which will promote the wellbeing of the large number of caregivers in our communities and support their return to full participation in social and economic life, post-bereavement. An additional benefit of such research is that it may call attention to cost-effectiveness of supporting the needs of these family caregivers while they care and while they grieve.
Acknowledgements

This paper was funded by the Australian Research Council (DE120101640). I would like to thank the anonymous reviewers for their feedback on an earlier version of the manuscript.
References


spouses, bereaved parents, and bereaved gay men. J Personality Soc Psychol 2005; 88:
827-843.

30. Hebert R, Dang Q, Schulz R. Preparedness for the death of a loved one and mental health
in bereaved caregivers of patients with dementia: findings from the REACH study. J

caregivers who have experienced the loss of a terminal-phase cancer patient. Qualitative

32. Grande GE, Farquhar MC, Barclay SIG, Todd CJ. Caregiver bereavement outcome:
relationship with hospice at home, satisfaction with care, and home death. J Palliat Care

33. Koop PM, Strang VR. The bereavement experience following home-based family

34. Gilliland G, Fleming S. A comparison of spousal anticipatory grief and conventional


36. Ferrario SR, Cardillo V, Vacario F, Balzarini E, Zotti AM. Advanced cancer at home:

learned from conducting palliative care research. J Pain Symptom Manage 2009; 37:
387-394.

38. Lobb EA, Kristjanson L, Aoun S, Monterosso L, Halkett GKB, Davies A. Predictors of


Author 2004. Accessed 25th January 2011 from:
http://guidance.nice.org.uk/CSGSP/Guidance/pdf/English


