


Caregiving and bereavement research: Bridges over the gap

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Type of death and the focus of bereavement research: missing links?

Investigation of phenomena associated with bereavement following sudden or untimely deaths figures prominently in the scientific literature. This is hardly surprising: Not only has losing a loved one under traumatic conditions been established as a main risk factor for poor mental and physical health outcomes,¹ but one type of complication following such deaths, namely, Post Traumatic Stress Disorder, has long been included as a mental disorder in the *Diagnostic and Statistical Manual of Mental Disorders* system (while Persistent Complex Bereavement Disorder is currently a condition for further study in *Diagnostic and Statistical Manual of Mental Disorders–Fifth Edition* (DSM-5); American Psychological Association (APA), 2013). Yet, there are features of bereavement following a period of illness in general and caregiving in particular which suggest the need for scientific attention to the consequences of this type of loss too. Research – much of which has been conducted under the leadership of Richard Schulz – has established specific difficulties in bereavement adaptation among people in the latter group.^{2,3} Indeed, one can expect to find large numbers affected: Worldwide, the majority of deaths currently result from chronic conditions such as heart disease, cancer, strokes, or respiratory diseases. A large proportion of these deaths occur in old (and increasingly older) age, from disabling conditions, prominently dementia and frailty. Adjustment problems among caregivers are likely to reflect depletion of reserves and age-related vulnerabilities.^{4,5} Compounding the burden, limited capacities of formal health care systems result in high demand for intense family caregiving until the time of death.

So has investigation of the situation of bereaved persons following caregiving during the end-of-life phase received too little attention in scientific inquiry? Two significant contributions in this issue of *Palliative Medicine* illustrate that this may be the case; each identifies major gaps in knowledge, pinpointing crucial issues. Sealey et al.⁶ review risk assessment measures for the pre-death caregiving or post-death bereavement phase; they show a paucity of suitable ones and highlight concerns about their implementation. Endo et al.⁷ demonstrate the lack of evidence about the efficacy of intervention for bereaved parents and siblings following a child's death. As examination

of their overview shows, the empirical studies concentrate on intervention *after* loss of the child. Thus, both articles point to the lack of evidence which could guide pre-death risk identification and interventions that could (if proven efficacious in further research) benefit caregivers before and after the death of their loved one.

We know of only one study that has investigated whether intervention for caregiving itself (e.g. aimed at reducing burden and distress) impacts on adaptation to bereavement; Schulz et al.⁸ found that caregivers who were enrolled in a psychosocial caregiver intervention reported lower levels of complicated grief. The authors concluded that reducing the burden of caregiving and treating depressive symptoms prior to the death of the care recipient can prevent post-death psychiatric morbidity. While this evidence points towards a potentially helpful role of pre-bereavement support in caregiving, the impression from the review papers in this issue still holds, namely, that deeper insight into pre-death at-risk assessments and interventions would be valuable: What kind of bereavement risk assessment in the pre-bereavement, caregiving period may contribute to improvement of bereavement outcomes? Should it be implemented as a routine practice? Is it a neglected '... window of opportunity to assess grief and bereavement needs in the lead up to the patient's expected death' (p. 9) that Sealey et al. propose? Does it enable better targeting of bereaved in need? Despite advancements, we still lack knowledge to answer such questions. However, on a more general level, and from the perspective of bereavement researchers, there is also reason for optimism. Importantly, there is evidence that the fields of caregiving and bereavement are coming closer and that researchers are spanning the pre- to post-bereavement phases.

How far have we come towards integration of caregiving and bereavement research?

Across many decades of the last century, collaboration between researchers in the areas of caregiving and bereavement remained quite rare, reflecting what seemed to be independent disciplines with separate issues and different theoretical approaches. There was lack of continuity of research from pre- to post-loss, a lack of understanding, for

example, of how events in the period prior to death could impact on subsequent reactions. Today, we see increasing evidence of continuity in investigation and integration across the two areas. There are various indications. Bereavement support practices during the caregiving period have undergone significant advancements in many countries in recent decades, as reviewed by Breen et al.⁹ They also identify ongoing challenges within this sphere, but the trend is towards implementation of research-guided strategies and professionally developed policies. Furthermore, a wide range of concerns has been investigated, including the nature of bereavement in caregiving context, the course of bereavement after caregiving, predictors of bereavement outcome among caregivers, and the impact of such factors as preparedness for death on adjustment to bereavement (reviewed by Schulz et al.).⁵ The results have implications both for research and care provision. To illustrate, finding benefit in caregiving is actually associated with poorer bereavement outcomes (perhaps due to caregiver-role loss or reflecting a very close relationship – that is a topic for follow-up investigation; intervention protocols should be built on scientific results). Likewise, not feeling prepared for the death is associated with poor bereavement outcome.³ In this context, teasing apart the components and meanings of ‘anticipatory grief’ and how these may affect bereavement adaptation is a topic for future study.⁵ Findings are likely to have implications for professionals supporting relatives during the pre-bereavement phase too: Can strategies be developed to assist caregivers in feeling more prepared for the death and their bereavement? As a final example, pre-bereavement levels of psychological distress (e.g. anxiety, depression) are predictive of post-bereavement maladjustment, as are high levels of caregiving burden. So high-risk groups are being identified; further subgroup patterns of resilience versus risk need to be established. High risk groups can subsequently be better identified and professional help targeted towards those who most need it.

The advancements illustrated above owe much to the collection of longitudinal, large-scale data sets, with investigation commencing during the caregiving period and following through various durations of bereavement. Two caregiver studies, the Caregiver Health Effects Study, an ancillary of the Cardiovascular Health Study, and the Resources for Enhancing Alzheimer’s Caregiver Health Study (REACH), a multi-site controlled trial testing psychosocial and skills training interventions for dementia caregivers, have increased understanding about the burden of caregiving in relationship to bereavement outcome.^{10,11} Findings based on REACH data have also contributed insights about predictors of complicated grief. Another source of information is the Changing Lives of Older Couples (CLOC) Study, a multi-wave, prospective study of spousal bereavement.¹² Of benefit to this field, the CLOC and REACH data sets have been made accessible to researchers in general. One study using the CLOC data-set showed that high-stress caregiving led to

bereavement problems such as social isolation.¹³ Again, such findings suggest future directions: In research, for example, to exploration of the nature, mediators/moderators and consequences of social isolation, which could usefully extend to examination of social and emotional loneliness¹⁴ among subgroups of bereaved (caregivers vs non-caregivers). On an applied level, such results speak for alerting health care professionals to assess social isolation and potentially work towards reintegration of high-stress carers who have become bereaved.

Bridges under construction

We have illustrated the coming closer of caregiving and bereavement research. In our view (and without wanting to deny the usefulness of collaborations of other types), a significant further extension would be to include intra- and interpersonal levels of analysis in the before–after (caregiving–bereavement) designs outlined above. What we have in mind is further integration of family level perspectives with the largely intrapersonal approaches to coping. For example, much research fuelled by Bowlby’s attachment theory¹⁵ or Lazarus and Folkman’s cognitive stress theory¹⁶ is basically individual-oriented, with family-oriented care for the bereaved being neglected until recently.¹⁷ Yet the latter, in turn, has continued to focus mainly on the family unit. Our plaidoyer is for an integrative perspective, one which goes so far as to recognize the ‘interactive’ nature of intra- and interpersonal processes. To elaborate, those caring for and subsequently bereaved of a family member have to cope with their own grief and that of others. These interactions affect both individuals and families. Furthermore, there are not only individual but also family issues at stake (e.g. the course of personal grief versus family conflict over inheritance). So we need to conduct research examining the impact of family dynamics on individuals and vice versa, in the arduous caregiving phase, as well as how these evolve during bereavement.

Added to the individual and family levels, exploring different types of caregiving and bereavement, also in broader societal context, seems imperative. There are considerable cultural variations in bereavement reactions and health outcomes.⁴ Furthermore, there are differences in caregiving not only in terms of the cause of the terminal illness or disability but also in terms of the type of relationship (parent, spouse, child, etc.). Conclusions have frequently been based on middle-aged children caring for parents or older spouses caring for their partners. Each caregiving situation at the end-of-life is, of course, unique; generalizing from one type to another is questionable.

Closing remarks

As attachment theorists have suggested, grief is the price we have to pay for our ability to form nurturing, rewarding

relationships with others. Thus, grief following bereavement is a normal, emotional reaction to the loss of a loved person, not a psychiatric disorder, even though in some cases, it is associated with higher risk of intense symptomatology, which can lead to complications among a minority of persons. Most caregivers adapt well to the death of their loved one. Symptomatology typically declines, while reintegration in the social network and reengagement in activities, dropped due to caregiving, are revived.⁵ However, some may enter bereavement already exhausted following intensive, long-drawn-out caregiving, so although not all bereaved (or caregivers for that matter) need professional help, knowing where to turn for practical and emotional support in case difficulties arise is of paramount importance.

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