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Bereavement after Caregiving

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Abstract

Approximately 20% of bereaved caregivers will experience a variety of psychiatric symptoms including depression and/or complicated grief, a disorder characterized by persistently high levels of distress that impair functioning in important life domains. We identify prebereavement risk factors for poor adjustment after the death of a loved one along with preventive strategies that can be implemented prior to death as well as diagnostic procedures and therapeutic strategies that can be used to identify and treat individuals who develop complicated grief disorder after death.

Of the approximately 2.4 million deaths that occur in the United States each year, nearly 70% are the result of chronic conditions such as heart disease, cancer, stroke, and respiratory diseases. The large majority of decedents are older persons suffering from one or more disabling conditions which compromised their ability to function independently prior to death. As a result, a typical death is preceded by an extended period of time during which one or more family members provide unpaid care in the form of health and support services to their disabled relative.[1] A recent survey estimates the out-of-pocket cost of caring for an aging parent or spouse averages about $5500 a year.[2]

Our understanding of bereavement is undergoing fundamental changes as a result of recent prospective studies of bereavement that focus on circumstances surrounding the death of a loved one. One important finding to emerge in recent years concerns the impact of family caregiving on caregiver response to death of a loved one.[3,4] Family members involved in care provision before death show remarkable resilience in adapting to the death of their relatives. Symptoms of depression and grief decline rapidly after the death and return to near normal levels within a year of the death.[5] This may be due to multiple reasons, including having time to prepare for the impending death and life afterward, relief from the burdens of caregiving, an end to the suffering of their loved one, and the absence of guilt over having done the "work of caregiving" (see the editorial, "The patient-caregiver dyad" This issue).

Despite the generally positive prognosis for most bereaved caregivers, a sizable minority continues to experience high levels of stress and psychiatric problems after death. Approximately 10% to 15% of people experience chronic depression.[6] In our own work with caregivers of patients with dementia, we found that 30% of caregivers were at risk for clinical

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depression 1 year post-death, and 20% experience complicated grief.[4,5] As described below, complicated grief is distinct from both depression and normal grief reactions.

Understanding the variability in response to death and the role of caregiving factors as predictors of bereavement outcomes is critical to developing effective interventions for this group. To address this issue, we distinguish among 2 types of predictors of pathologic depression and grief outcomes among caregivers: Factors associated with the caregiving experience prior to death, and factors associated with depression and grief assessed postbereavement. The rationale for making this distinction is that each factor provides a different opportunity for intervention. Identifying which caregiving factors contribute to poor bereavement outcomes provides us with important leads about interventions that could be delivered during caregiving. Likewise, postbereavement factors linked to poor bereavement response may help identify intervention options that can be delivered after death.

Caregivers at risk for poor bereavement outcomes

The most common finding across multiple studies is that prebereavement levels of mental distress such as depression and anxiety are predictive of postbereavement adjustment. A related finding is that high levels of burden, feeling exhausted and overloaded, lack of support, and having competing responsibilities such as work or caring for younger children are all associated with negative postbereavement outcomes.[3,7,8] The fact that increased burden is a risk factor for poor bereavement outcomes may explain in part the higher mortality rate observed among caregivers of terminal patients who do not use hospice services when compared to those who do.[9] Demographic factors also play a role. Individuals with lower income, lower education, and those who are African Americans are also more likely to exhibit greater depression and complicated grief after the death.

A recent randomized trial of dementia in caregivers showed that psychosocial-behavioral interventions designed to decrease caregiver burden and distress had the added benefit of preventing complicated grief after the death of their loved one.[4] This suggests that adverse effects of bereavement can be addressed through preventive treatments delivered to family caregivers prior to the death of their loved one. Individuals at risk for negative post-bereavement outcomes can be identified by asking a few questions to determine how stressful caregiving is, the availability of support from family and friends, how depressed and anxious they feel, and whether or not they feel prepared for the death of their loved one (see Table 1). Treatment options for caregivers thus identified include interventions to reduce caregiver burden, such as hospice care, behavioral and pharmacologic treatment of depression and anxiety, and referral to religious counselors.

Diagnosis and treatment of complicated grief

One of the hallmarks of poor response to death is persistent (ie, 6 months or longer) complicated grief. This disorder is distinct from normal grief reactions or depression. It is characterized by an intense longing and yearning for the person who died and by recurrent intrusive and distressing thoughts about the absence of the deceased, making it difficult to concentrate, move beyond an acute state of mourning, form other interpersonal relationships, and engage in potentially rewarding activities. Complicated grief is a source of significant distress and impairment and is associated with a range of negative psychiatric and physical health consequences.[10]

Formal diagnostic criteria for complicated grief disorder have been proposed for inclusion in the *Diagnostic and Statistical Manual of Mental Disorders, FifthEdition (DSM-V).*[11] A diagnosis of complicated grief disorder requires that the bereaved person must have persistent and disruptive yearning, pining, and longing for the deceased. The individual must experience

4 of the 8 symptoms at least several times a day and/or to a severely distressing disruptive degree (see Table 2). Symptoms of distress must endure for at least 6 months and significantly impair functioning in important life domains.

Complicated grief often occurs along with other disorders such as major depression and post-traumatic stress disorder (PTSD) and is associated with suicidality and self-destructive behaviors,[12] but it is a distinct disorder requiring treatment strategies different from those used with major depression and PTSD. A recent randomized trial found higher and faster rates of improvement among persons with complicated grief using loss-focused, cognitive behavioral therapy techniques when compared to rates obtained with a standard interpersonal therapy approach used to treat depression.[13] Components of effective treatment included repeated retelling of the story of the death, having an imaginary conversation with the deceased, and work on confronting avoided situations. In general, although traditional treatments for depression after bereavement such as referral to a psychiatrist or psychologist for medications and/or psychotherapy can be effective in treating depression and to some extent, complicated grief, there is added benefit to treatments that are specifically tailored to address symptoms of complicated grief.[6]

Hundreds of studies carried out in the past 2 decades have documented the negative health effects of caregiving, showing that caregivers are at increased risk of psychiatric and physical morbidity.[14] The challenges of caregiving become even more extreme as the care-recipient nears death. When the death does occur, the caregiver enters bereavement already compromised with high levels of depression and anxiety and sometimes physical exhaustion brought about by the caregiving experience. Even with these vulnerabilities, caregivers, for the most part, adapt well to the death of their loved one. Psychiatric symptomatology typically improves and caregivers are able to effectively reengage in activities that may have lapsed while caregiving.

Opportunities for intervention

Despite this generally positive picture of caregiver adaptation to bereavement, a minority of caregivers exhibit adverse bereavement outcomes in the form of high levels of depression and/or complicated grief. High levels of burden, physical exhaustion, lack of social support, along with traditional predictors, such as prebereavement anxiety and depression, are all associated with negative post-bereavement outcomes. Although empirical support for the efficacy of bereavement interventions to enhance adaptation to bereavement is mixed at best,[13,15] researchers have generally not tested preventive approaches in which interventions are delivered prior to death. In addition, new treatment strategies described above specifically designed to treat complicated grief hold promise for helping individuals who are not able to effectively cope with the death of a loved one.

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Table 1

Questions to identify caregivers at risk for negative postbereavement outcomes

Do you feel overwhelmed by the responsibilities of providing care to your relative?
Do you feel isolated from family and friends?
Do you feel prepared for the death of your loved one?
In the past month have you felt depressed sad or anxious much of the time?

Table 2

Symptoms of complicated grief

Trouble accepting the death
Inability to trust others since the death
Excessive bitterness related to the death
Feeling uneasy about moving on
Detachment from formerly close others
Feeling life is meaningless without the deceased
Feeling that the future holds no prospect for fulfillment without the deceased
Feeling agitated since the death