

Planning for Two: A Literature Review on Caregiver Stress near the End-of-Life

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Abstract

Advances in end-of-life research have highlighted the risks associated with informal caregiving before and during bereavement. However, there are diverse conclusions on how to predict negative mental health outcomes and how to treat caregivers upon the development of psychological distress. In order to address this deficit in consensus, we searched PubMed and PsychInfo for relevant articles that identified predictors of negative health, assessed differences based on caregiver type, analyzed the development of complicated grief and depression, and discussed implications for interventions. Results emphasized the need for further research into specific interventions, on behalf of the caregiver, which can be implemented during end-of-life care planning.

Keywords: *caregiver, end-of-life, palliative, grief, hospice, bereavement*

With 78 million baby boomers reaching the age of 65 or over by 2030, the United States will undergo a drastic demographic change.¹ An aging population also indicates an increase in informal caregivers such as family or spouses. At the end of a person's life, those who are most likely to surround and care for them are the ones with whom they were the closest, such as their spouse, their partner, their children, their relatives, or their friends. Doctors and care providers, tasked with supporting the comfort and health of the patient, focus the majority of their energy on the person who is facing the end of life, thus often neglecting the caregiver beside them. Ultimately, if the person who is being cared for dies their caregivers are left particularly vulnerable.

Given that bereavement can be preceded by an intense caregiving period, the opportunity to reduce maladjustment and the development of psychological disorders seems to be during the caregiving period. After the death of a loved one, caregivers can be susceptible to psychological distress, which may include the development of depression, anxiety or complicated grief. Caregivers are susceptible to medical illness as well, but that research is beyond the scope of this review. Complicated grief is a psychological syndrome characterized by intense yearning for the person who is deceased, severe grief symptoms, and impairment of daily life; these symptoms are experienced for more than 6 months after the death.² Around 7.6% and 12.1% of caregivers experience complicated grief or depression, respectively, subsequent to the loss of a loved one.³ This poor adjustment to life without their loved one during the bereavement period can be traced back to distress during caregiving in some cases. Studies have shown a link between several aspects of the caregiving experience as predictors of negative mental health outcomes in caregivers including 1) perceived quality of care⁴, 2) preparedness for the death⁵, and 3) caregiver burden.⁶

With this literature review, we examined studies in which researchers have found a link between caring for a loved one during end-of-life care or palliative care, with the development of complicated grief and depressive symptoms after their loved one dies. The review aims to 1) identify the main elements of the caregiving period that are predictors for the negative mental health outcomes, 2) examine how bereavement outcomes differ by caregiver type, 3) understand the difference between the development of complicated grief versus depression, and 4) explore the implications of these studies on how to address the needs of the caregivers in treatment models.

Method

PubMed and PsychInfo databases were searched for publications between 1997 and the present (June, 2017). We sought to identify articles that contained the keywords caregiver, spouse, or family as well as end of life care, palliative care, terminal illness, complicated grief, depression, or bereavement within the title or abstract, using the following search string in PubMed: (((caregiver[Title] OR spouse[Title] OR family[Title])) AND (end of life[Title] OR palliative[Title] OR terminal[Title])) AND (complicated grief[Title] OR grief[Title] OR depression[Title] OR bereavement[Title]). An identical search was completed in PsychInfo.

Altogether the search yielded 52 relevant articles. Articles were included in the review if they were 1) peer reviewed empirical publications, and 2) addressed caregiver mental health outcomes post death of a loved one. We excluded review articles and non-peer reviewed studies (for example, dissertations or magazine/news articles).

Predictors

Significant research has been conducted recently investigating the main elements of the caregiving period that may serve as predictors of negative mental health outcomes during bereavement. Evaluated in this portion of the literature review are studies which investigate these predictors; specifically, they analyze 1) perceived quality of end-of-life care, 2) caregiver preparedness for their loved one's death, and 3) the burden of care on the caregiver.

The quality of end-of-life care is the factor most often implicated as a predictor of negative health outcomes in caregivers. Miyajima et al.⁴ examine the impact that the quality of end-of life care has on complicated grief amongst bereaved family members within a Japanese population. Regression analysis results revealed that complicated grief symptoms were measured in 24.5% of participants; associated with this development of complicated grief was the individuals' dissatisfaction with expected outcome explanations, cost of care, and completion of life goals, all components of end-of-life care. Other studies have investigated other aspects of end of life care such as the lack of availability of psychological support, for the patient and/or the caregiver, as a predictor for complicated grief and depression.⁷ The level of communication about death and the patient's prognosis with the caregiver has been linked with negative health outcomes as well.³ Caregiver guilt, even if not related to the actual quality of end-of-life care, has also been implicated in the development of complicated grief. Studies like Harrop et al.⁸ have shown that the guilt as to whether or not they made the right decisions during their loved one's end-of-life care is correlated with the development of complicated grief. Understanding how perceived quality of end-of-life care can predict complicated grief and depressive outcomes is an important link to investigate when seeking to understand the relationship between caregiving and grief as a whole.

Studies looking at the etiology of complicated grief during bereavement have implicated the level of preparedness for a loved one's death. In one of these studies, researchers used a prospective design to assess preparedness at six, nine, and 18 months following a dementia diagnosis in their loved one; caregivers largely reported to be as "not prepared" for death at 18 months as they were at the 6-month mark, suggesting that time alone is not an effective method to prepare caregivers.⁵ Recognizing now the importance of preparedness for death when it comes to bereavement, other studies have begun to assess what caregivers and care providers think are important factors in being prepared for these situations.⁹ These studies have found that, above all, communication between caregiver and care provider was most important in making caregivers feel prepared for their loved one's death.¹⁰ As one of the first studies to acknowledge the link between preparedness for death and the development of complicated grief, Barry, Kasl, and Prigerson¹¹ also acknowledge the difficulty in developing an intervention for complicated grief as it is linked to bereavement and death. Since research has only recently begun to assess the risk factors for the development of complicated grief, interventions preventing the disorder are limited.

The final predictor of negative mental health outcomes during bereavement is the caregivers' burden of care. Caregiver burden can be loosely defined as the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning.⁶ This burden has largely been overlooked as a predictor even though its costs to the caregiver are profound. According to Rowland et al.¹², roughly 82% of British caregivers spend up to 20 hours a week providing specific emotional and physical support to their loved ones and 76% reported a large increase in expenditures for their loved one's during end-of-life care. Not only is the caregiver's burden challenging during the pre-loss period, but it is particularly menacing because it has been implicated as a risk factor for the development of complicated grief and depression post-loss¹³; one explanation for this could be the caregiver's neglect of self-care during the caregiving period¹, suggesting that practicing self-care may be integral to a caregiver's mental health.

Above all, these studies help to fulfill a gap in grief research that focuses on the risks of negative health outcomes on the caregiver after the loss of their loved ones. Some of these studies like Miyajima et al.⁴ and Harrop et al.⁸ focus on how well the caregiver perceived the quality of care provided to their loved one. Other studies focus on how prepared the caregivers felt for the death of their loved one¹¹ and how it affected their mental health⁹ Finally, the remaining studies investigate the phenomenon of caregiver burden⁶ and examine how end-of-life care requires the

caregiver to sacrifice an immense amount of their own self-care for their loved one¹. Although they tackle different aspects, each of these studies examine how caring for a loved one at the end of their life can be a significant risk factor for developing debilitating disorders like complicated grief or depression. While these studies have examined this issue from several vantage points, there are very few reviews that analyze the implications of each of these studies. With an aging population, caring for a loved one at the end of their life will become more standard. Therefore, it is important to evaluate the studies on risk factors of caregiving, to understand what these studies have found, and to create new ways to intervene on the caregiver's behalf in order to curb the risk of negative health consequences.

Caregiver Type

The majority of caregivers tend to fall into two relational categories: spouse and adult child (studies did not indicate data on same-sex spouses). While the caregiving experience is difficult on anyone, within these categories there are marked differences between how these groups handle the caregiving experience and in their prevalence of negative health outcomes during bereavement. According to Tang¹⁴, caregivers who have the hardest time coping with the death of a loved one, and subsequently needed the most support, are those who have lost a spouse. Often these spouses don't receive the support needed, which leaves them at risk for psychological distress. Studies have shown that upwards of 20.3%¹⁵ of spousal caregivers develop complicated grief symptoms during bereavement and as high as 45.41% of them exhibit depressive symptoms.¹⁴ These high percentages could be explained by the spouse's close relationships with their loved one making the loss all the more distressing.

The next group vulnerable to psychological distress during bereavement is adult children who lose a parent. Alongside spouses, children of the deceased usually share some caregiving responsibility. However, analyses of the populations of caregiver's show fewer children providing this care than spouses. Regardless, according to Chentsova-Dutton et al.¹⁶ the difference in spousal caregivers and child caregivers appears to be insignificant as they both develop psychopathologies (depression and complicated grief) following the death of a loved one. Knowing who is affected most by the caregiving process may prove integral in developing successful interventions.

Complicated Grief versus Depression

The two most common consequences of psychological distress within the context of the caregiver is the development of disorders such as complicated grief and/or depression during bereavement. Depression is one of the most prevalent disorders to which caregivers are vulnerable, thus making its development important to understand. One of the most obvious ways in which depression affects caregivers is through the level of stress they experience. Tang et al.¹⁷ found that self-efficacy mediates the effect that stress has on caregivers, suggesting that impaired self-efficacy further increases depressive symptoms. Other studies have found that the level of social support available to caregivers during the caregiving period seems to mediate the development of depression symptoms.¹⁸

It is apparent that caregivers are at risk for the development of complicated grief, but the reason behind this is less straightforward. An important way to ascertain why a disorder occurs is to understand how it is mediated in a certain group. According to Coelho, Delalibera, and Barbosa¹⁹ the reason complicated grief is developed in some caregivers is in large part due to the attachment style of their relationship with the deceased. They found that caregivers with insecure attachment style relationships (i.e., anxious for approval in their relationship) were the most likely to develop complicated grief, along with dependent attachment styles (e.g., relying excessively on the spouse). Many studies have also linked coping styles with the development of grief. Chapman²⁰ found a link between using more emotion-based coping strategies with the development of grief in caregivers. Alas, more research is needed in order to understand clearly what mediates complicated grief within the caregiving populations, but understanding its development could be the key to prevention.

Implications

It appears that there is a broad consensus in the published literature that caregivers are susceptible to psychological distress after experiencing an intense caregiving period followed by the death of a loved one. Although this vulnerability is clear, what is less clear is how to prevent or decrease these negative outcomes. When mentioned, studies that suggest interventions propose to treat the caregiver as an additional patient; to acknowledge what was previously an afterthought in medicine. According to Neilsen³, health professionals identifying the key predictors of

negative bereavement outcomes (e.g., perceived low quality of end of life care, low caregiver preparedness, and high caregiver burden) and providing targeted support is pertinent to offsetting the development of complicated grief or depression in the caregivers. In order to account for the caregiver during end-of-life care, it is important that the health provider know if a person is experiencing complicated grief or depression or at risk for its development. For this purpose, Meichsner, Schinkothe, and Wilz²¹, developed the Caregiver Grief Scale (CGS), a brief scale that measures grief symptoms in caregivers, the implications of which are to provide caregivers with the awareness of whether they are susceptible to experiencing extreme grief and to be used by healthcare providers to assess the severity of a caregiver's grief quickly. Asking caregivers to agree or disagree with statements such as "I long for what was, what we had and shared in the past" and "I try to avoid thinking about the fact that I will lose her/him", the CGS can be used in both research and clinical settings to specifically assess caregiver grief effectively²¹. This could provide practitioners with a better understanding of the caregivers' grief experiences, and it also could validate the caregiver's feelings by normalizing their experiences. It is important to assess the level of support the caregiver may need early during end-of-life treatment, and throughout their caregiving experience. Post-loss caregivers should be provided with targeted education and practical support for several months following their loved one's death.²² Caring for the caregiver ultimately consists of three parts: screening for elevated grief risk at the beginning of care, reassessing for this risk during care and providing support as needed, and following up with bereaved caregivers following the death of their loved one in order to continue providing support.

Conclusion

In sum, the loss of a loved one is something that most everyone will have to face at some point in his or her life. With an aging population, and the rising costs of formal healthcare (i.e., in-home care), more and more people will be providing supplemental, informal, end-of-life care to their loved ones. Therefore, it is important to understand that caregiving can leave a person susceptible to psychological distress, or at risk for developing complicated grief or depression. These negative mental health outcomes make bereavement even more daunting and crippling to those at risk. While the literature concedes that there must be interventions to stop the development of these disorders during the caregiving process, so far there is a lack of specific and reasonable ways in which health professionals or caregivers themselves can intervene. These studies cite everything from grief support groups to pre-loss screenings to post-loss counseling as potential interventions, but there is simply a lack of research done showcasing interventions that would work for this population, which is growing more common every day. Hospice care, which focuses on the caregiver and specifically on several of the risk factors named in this review, is an obvious recommendation. The outcomes for caregivers suggest that good hospice care affects their mental health outcome, although there are few good studies in this area. One study showed that caregivers of patients enrolled with hospice for three or fewer days were significantly more likely to have depression during bereavement than caregivers of those with longer hospice enrollment.²³

Overall, as shown in this review, research into the predictors, mediators, and implications of the development of disorders such as complicated grief and depression has grown exponentially in the past 20 years. However, in order to fully support caregivers as they potentially sacrifice their health to care for another, it is paramount that caregivers are included in health care plans of the patient and that further research is done to find interventions that would work to prevent and treat caregiver outcomes.

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