



Do we need to change our understanding of anticipatory grief in caregivers? A systematic review of caregiver studies during end-of-life caregiving and bereavement



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HIGHLIGHTS

- The effect of anticipatory grief (AG) on bereavement outcome has been much debated.
- Low preparedness seem to affect caregivers' psychological adjustment.
- AG and low preparedness was found to be associated with poor bereavement adjustment.
- Furthermore, the role of AG is questioned and may be termed pre-loss grief.
- Pre-loss grief support and preparedness initiatives for caregivers are required.

ARTICLE INFO

Article history:

Received 6 November 2014

Received in revised form 31 December 2015

Accepted 7 January 2016

Available online 8 January 2016

Keywords:

Anticipatory grief
Bereavement
Caregivers
Forewarning
Pre-loss grief
Preparedness

ABSTRACT

Objective: Caregivers of terminally ill patients may experience anticipatory grief or low levels of preparedness for the patient's impending death. Both concepts are related to a *forewarning* of the impending loss. Anticipatory grief has been suggested to be *grief work* before the loss, which would improve bereavement outcome, but recent studies indicate a negative impact. Hence, this review systematically investigates key issues relating to anticipatory grief and preparedness for the death; definitions, measurement tools, and potential effects on caregiver outcome.

Methods: We used a systematic approach (PRISMA statement). Databases were searched for publications during 1990–2015. Studies on adult caregivers of terminally ill adult patients were included if anticipatory grief or preparedness was assessed by a measurement tool.

Results: Anticipatory grief was captured in the definition "pre-loss grief." High levels of grief and low levels of preparedness during caregiving were associated with poor bereavement outcome such as complicated grief.

Conclusions: The assumptions that *grief work* before the loss would alleviate bereavement outcome was not confirmed. Thus, the concept of anticipatory grief is questioned. High preparedness was associated with improved caregiver outcome. Additional support should be given to caregivers with pre-loss grief and low preparedness.

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1. Introduction

1.1. Caregivers to terminally ill patients

Becoming a family caregiver of a terminally ill patient is a challenge faced by many people in modern society. Approximately 70% of all deaths involve chronic, potentially life-threatening conditions, such as cancer, dementia, or organ failure (Schulz, Boerner, & Hebert 2008). A serious illness causes changes for the patient and caregiver and inflicts diverse losses. The caregiver may be confronted with patient's deterioration, loss of future plans, and uncertainties of the near future (Moon, 2015; Evans 1994). Losses occurring during the illness trajectory are most likely to cause grief, and caregivers in this vulnerable position are highly exposed to psychological distress during caregiving and after the death of the patient (Fasse et al. 2014; Kim, Lucette, & Loscalzo 2013; Schulz et al. 2008). Psychological distress during the bereavement period may include depression, anxiety, and complicated grief (Hudson et al. 2008). Complicated grief is a syndrome characterized by intense yearning for the deceased, grief symptoms, and impairment of daily life, which persists for more than 6 months after the death (Guldin, Vedsted, Zachariae, Olesen, & Jensen 2012; Prigerson & Maciejewski 2013; Shear 2015).

Among other things, poor adjustment during bereavement is influenced by psychological distress during caregiving (Stroebe, Hansson, Schut, & Stroebe 2008). Since a caregiving period antecedes the majority of deaths, caregiving seems to entail an opportunity to adjust to the impending death. In the Handbook of Bereavement Research, this has been termed "forewarning" (Schulz et al. 2008). Forewarning has been reported as a temporal assessment of forewarning for the death or awareness of the impending death (Carr, House, Wortman, Nesse, & Kessler 2001; Valdimarsdottir, Helgason, Furst, Adolfsson, & Steineck

2004), and it has been operationalized as "anticipatory grief" (AG) or "preparedness for death."

However, the effect of forewarning of death on caregivers' psychological adjustment remains unclear (Schulz et al. 2008). This uncertainty has prompted the present systematic review on effects, definitions, and measurements of AG and preparedness.

1.2. Risk factors for psychological distress during bereavement

The development of psychological distress during bereavement is found to be related to a broad range of factors such as socio-demographic factors, predisposing vulnerabilities, the relation to the deceased, social support, and caregiving strain (Stroebe, Schut, & Stroebe 2007). One of the most consistently found risk factors is depressive symptoms in caregivers during caregiving (Kim et al. 2013; Parker Oliver et al. 2013; M. Stroebe et al. 2007). Pre-loss depressive symptoms have also been associated with low preparedness during caregiving (Schulz, Boerner, Klinger, & Rosen 2015) and pre-loss grief symptoms (Kiely, Prigerson, & Mitchell 2008), which underline the complexity of factors.

To provide an overview and stimulate research of multiple influential factors, Stroebe et al. presented the "Integrative risk factor framework for the prediction of bereavement outcome" (the integrative risk factor framework) (Stroebe, Folkman, Hansson, & Schut 2006). It comprises categories of predictive factors for bereavement outcome, which constitute (A) the *nature of the stressor* (e.g., type of death; sudden, expected, unprepared, untimely, type of loss: spouse, child), (B) *intrapersonal* factors in caregiver (e.g., previous depression, socio-economic factors), (C) *interpersonal* factors in caregiver (e.g., family dynamics, social support), and (D) *appraisal and coping strategies* (cognitive processes and emotion regulation). The latter category comprises

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