

Original Article

Risk Factors for Developing Prolonged Grief During Bereavement in Family Carers of Cancer Patients in Palliative Care: A Longitudinal Study

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Abstract

Context. Family carers of palliative care patients report high levels of psychological distress throughout the caregiving phase and during bereavement. Palliative care providers are required to provide psychosocial support to family carers; however, determining which carers are more likely to develop prolonged grief (PG) is currently unclear.

Objectives. To ascertain whether family carers reporting high levels of PG symptoms and those who develop PG disorder (PGD) by six and 13 months postdeath can be predicted from predeath information.

Methods. A longitudinal study of 301 carers of patients receiving palliative care was conducted across three palliative care services. Data were collected on entry to palliative care (T1) on a variety of sociodemographic variables, carer-related factors, and psychological distress measures. The measures of psychological distress were then readministered at six (T2; $n = 167$) and 13 months postdeath (T3; $n = 143$).

Results. The PG symptoms at T1 were a strong predictor of both PG symptoms and PGD at T2 and T3. Greater bereavement dependency, a spousal relationship to the patient, greater impact of caring on schedule, poor family functioning, and low levels of optimism also were risk factors for PG symptoms.

Conclusion. Screening family carers on entry to palliative care seems to be the most effective way of identifying who has a higher risk of developing PG. We recommend screening carers six months after the death of their relative to

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Key Words

Family carer, family caregiver, family support, prolonged grief, grief, bereavement, distress, palliative care, terminal illness, death, dying, end-of-life care

Introduction

Specialist palliative care services involve consultative and ongoing care for patients and family carers during the patient's illness and in bereavement. International and Australian standards explicitly acknowledge that the needs of primary caregivers and family members should be considered as an integral component in the provision of specialist palliative care services.^{1–3} Furthermore, it is deemed best practice for this care to extend into the phases of postdeath of the patient and bereavement.^{2–4}

Family carers within the context of palliative care have been defined as a relative, friend, or partner who has a significant relationship and provides assistance (physical, social, and/or psychological) to a person with a life-threatening, incurable illness. Family carers of palliative care patients shoulder many responsibilities including personal hygiene, medical care, emotional support, financial and legal tasks, household duties, patient advocacy, and consultation with health professionals.⁵ Several studies show that caring for terminally ill patients is associated with depression, anxiety, burnout, fatigue, and sleeping problems.^{6–9}

Despite demonstrated psychological burden among family carers, limited information exists on the prevalence of mental health problems.¹⁰ A study of 153 family carers of patients with advanced cancer showed that more than 50% of the carers had depression scores at or near the cutoff for clinical depression.¹¹ In an Australian study of family carers who were providing informal care to a person receiving palliative care, 44% of the carers were found to experience probable caseness for depression and/or anxiety.¹² Additionally, family carers also report high levels of mental health problems during bereavement. Bonanno et al.¹³ report that 10%–15% of the bereaved individuals suffer chronic distress and

depression for years after the loss, whereas others experience acute distress and depression from which they recover in approximately one or two years. Furthermore, although there is consensus that grief is a normal experience after major loss, in a minority of bereaved persons (10%–20%), a normal grief adjustment does not occur and debilitating grief is experienced for an extended period.¹⁴

Prolonged grief (PG) disorder (PGD), previously called complicated grief, is the most recent term used to describe grief that continues in intensity beyond a time frame in which some form of adjustment is expected and to an extent that is significantly disruptive to a person's life.^{15,16} It has been shown that people who suffer from PGD have increased risk for adverse health effects.¹⁵ Further development of conceptualizing this disorder has resulted in a proposed set of diagnostic criteria for PGD.¹⁷

In the last decade, there has been much effort to identify the risk factors for bereavement outcome, and more specifically, for PGD. Age and gender have been found to be associated with bereavement outcome, with female carers having significantly greater psychological distress than male carers,^{18,19} and a greater mortality risk to younger bereaved people who have lost a spouse.²⁰ Generally, the loss of a close relationship, such as that of a spouse, parent, or child is associated with greater risks to health.^{15,21} Insufficient economic resources are also a significant risk factor for poor bereavement outcomes among carers.²² Personality traits such as trait anxiety, neuroticism, and a pessimistic outlook also have been found to be associated with emotional burden in bereavement,²³ and having a history of mental health problems also has been found to be related to PG symptoms before the death.¹⁵ However, research by Bonanno et al.²⁴ has highlighted individual resilience as a common reaction to bereavement that protects against PG.

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