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...
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. Furthermore, it is deemed best practice for this care to extend into the phases of postdeath of the patient and bereavement.

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. Several studies show that caring for terminally ill patients is associated with depression, anxiety, burnout, fatigue, and sleeping problems. Despite demonstrated psychological burden among family carers, limited information exists on the prevalence of mental health problems. 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. 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. Additionally, family carers also report high levels of mental health problems during bereavement. Individual resilience as a common reaction to bereavement that protects against PG.
Studies show that situational factors during the delivery of patient care can impact on bereavement outcomes including perceptions of greater problems in caregiving, quality of caregiving and feelings of burden while caring,\textsuperscript{15,18,25,26} and lack of preparation for death.\textsuperscript{27–29} There is also consistent evidence that carer grief is greatly influenced by social context. Most studies indicate that high levels of social and emotional support may buffer bereavement distress.\textsuperscript{27,30,31} Furthermore, family functioning has a significant impact on bereavement adjustment.\textsuperscript{32,33}

The key aim of this study was to ascertain whether family carers who have high levels of PG symptoms and those who develop PGD at six and 13 months postdeath can be predicted from predeath information. This study attempted to include all of the previously identified predeath risk factors for PG in one comprehensive analysis to explore a model of PG at six and 13 months postdeath. A secondary aim of the study was to clarify the prevalence rates of psychological distress (PG, depression, anxiety, demoralization, and post-traumatic stress disorder [PTSD]) for family carers of patients receiving palliative care at six and 13 months postdeath.

**Methods**

**Sample and Setting**

Primary family carers of patients admitted to one of the three palliative care services in Melbourne, Australia, were approached for participation in the project. This research was an extension of a previous study based on Time 1 data regarding a psychosocial profile of family carers on commencement of palliative care provision.\textsuperscript{12} Details about the participating services and Time 1 recruitment procedures and results have been published.\textsuperscript{12} All participants provided informed consent, and the study was approved by the relevant research ethics committees.

**Data Collection**

Time 1 (T1) data included: 1) six validated self-report instruments that measured 11 family carer–related psychosocial factors (Table 1), 2) four validated self-report instruments that measured four carer psychological distress factors (Table 1), and 3) a questionnaire that included a number of items about basic sociodemographic information and about the participant’s caring role.

At Time 2 (T2: six months postdeath of the patient) and Time 3 (T3: 13 months postdeath of the patient), the four psychological distress measures (used at T1) were repeated and a measure of PTSD also was included (all sent via post). All 11 self-report instruments used for this study had good reliability and validity and have been previously used with a similar population. Table 1 lists the self-report instruments; specifies at which time point they were measured; and includes the variable being measured, the instrument name, key references that report the psychometric properties, the number of items, and total score ranges.

The PG (PG-13) Scale,\textsuperscript{34} previously PG-12,\textsuperscript{44} is based on the Inventory of Complicated Grief (ICG), which has been widely used to measure complicated grief. The advantage of the PG-13 is that it is consistent with the suggested Diagnostic and Statistical Manual of Mental Disorders criteria for PGD.\textsuperscript{34} We accessed the PG-13 directly from the authors during its development. The PG-13 was used in two ways. The first was to categorize participants as to whether they met the criteria for PGD, which required meeting all of the following four criteria: 1) a score of four or five on either Items 1 or 2 indicating separation distress (had one of these symptoms at least daily); 2) a score of four or five on at least five of Items 3–11 indicating other symptoms (had at least five of these symptoms daily or quite a bit); 3) a response on Item 12 indicating that they had been experiencing the symptoms for at least six months; and 4) a score of four or five on Item 13 indicating impaired functioning, at least significantly.\textsuperscript{34} The second way the scale was used was to provide a total PG symptoms score by summing the scores on the symptom distress and behavioral and emotional symptoms subscales (Items 1–11). This method has been used previously, although not in a palliative care setting,\textsuperscript{35} and has the benefit of providing a continuous total score that can identify individuals at high levels of distress who may not quite meet the criteria for a diagnosis but still would benefit from being offered psychosocial support or bereavement services.
The PG Scale (preloss version) is just a minor adaptation of the PG-13. The wording has been altered to reflect that the grief experienced relates to the illness rather than the death of the person being cared for. Only Items 1–11 are used to create a continuous PG symptom score. The measures of post-traumatic stress, anxiety, depression, and demoralization also provide either a continuous total score or a cutoff or criteria method of scoring to indicate a probable disorder.

Statistical Analysis

Descriptive and frequency analyses were conducted to establish the prevalence of carer psychological distress at T2 and T3. Pearson’s correlations, t-tests, and Chi-squared analyses were used to determine whether any of the sociodemographic data were related to psychological distress at T2 and T3. Hierarchical regression analyses were conducted to identify risk factors (measured on entry to palliative care) for PG symptoms at T2 and T3. A logistic regression also was conducted to identify the risk factors for meeting the criteria for PGD at T3. Data were analyzed using SPSS v. 11 (SPSS, Inc., Chicago, IL).

Results

Of the 992 carers who were eligible for the study, 301 (30%) agreed to participate and completed the T1 data. Fig. 1 shows the sample size, response rates, and reasons for refusal at T2 and T3. For more information about T1 reasons for refusal, please refer to the study by Hudson et al.12

Descriptive Data

Demographic information was collected for all 301 participants and has been reported in detail in the study by Hudson et al.12 along
with means and standard deviations for all T1 variables. Demographic information about the 163 participants who participated at T2 is shown in Table 2. Means and standard deviations for the psychological distress scales used at each time point are shown in Table 3. A number of variables were significantly skewed, and the median and interquartile ranges also are shown for these variables. Cronbach’s alpha scores for all of the scales and subscales were very good at all three times (0.80 or above). Skewed variables were not transformed as data analyses were conducted with transformed and untransformed variables and results did not significantly differ.

Prevalence of Psychological Distress

Table 4 shows the proportion of the sample at T2 and T3 that reached cutoffs or criteria on each of the measures of psychological distress, indicating a moderate-to-severe level of distress. At T2, 58 (35.6%) participants met the criteria for at least one of the five psychological distress measures. At T3, 41 (28.9%) participants met the criteria for at least one of the five psychological distress measures.

Predictors of PG Symptoms

Sociodemographics and PG. A number of Chi-squared analyses, t-tests, and correlations showed that only a few of the sociodemographic variables (reported at T1) were significantly related to PG symptom scores at T2 (note that the results are the same for T1 variables relating to PG symptom scores at T3).

First, living with the patient was significantly associated with higher PG symptom scores ($t_{[159]} = 4.12; P < 0.001$; and mean = 30.14 and 22.73 if living together and if not living together, respectively). Second, spousal carers reported significantly higher PG symptom scores (mean = 29.93) than carers of parents (mean = 24.62, $t_{[134]} = 2.79$, and $P < 0.01$). This finding also was reflected by patient age being negatively correlated with PG symptom scores (i.e., the younger the patient, the higher the PG symptom score), $r = -0.34$ and $P < 0.05$. Third, carers who had not completed high school had higher PG symptom scores (mean = 29.65) than carers who had finished high school (mean = 25.82; $t_{[161]} = 2.22$; $P < 0.05$).

No differences on PG symptom scores were found for carer gender, carer age, patient level of functioning (Eastern Cooperative Oncology Group performance status), length of time spent caring, or previous caregiving experience.

Carer-Related Factors and Psychological Distress

Factors and PG. A hierarchical regression was used to explore which of the factors measured at T1 (three sociodemographic variables, 11 carer-related factors, and four psychological distress factors) predict high levels of PG symptoms (Criteria 1 and 2) at T2 ($N = 163$). Only demographic variables that were found to have a significant relationship with PG...
symptoms were included in the regression analyses. Patient age was not included because of high levels of missing data and a strong correlation with relationship to the patient. Variables were entered into the equation in the following order: Step 1: T1 measures of psychological distress including preloss PG symptoms, anxiety, depression, and demoralization and Step 2: T1 sociodemographic variables including relationship to patient, education, and living with the patient, and T1 measures of caring-related psychosocial variables including carer esteem, lack of family support, impact on finances, impact on schedule, impact on health, bereavement dependency, social support, family functioning, optimism, preparedness, and competence. This analysis was repeated for PG symptoms at T3 (N=142).

The hierarchical regression of T2 PG symptom scores (Step 1) revealed that the T1 psychological distress factors significantly predicted T2 PG symptom scores, $R^2 = 0.48$ (adjusted $R^2 = 0.47$), $F_{inc}(4, 158) = 36.37$, $P < 0.001$. Furthermore, the addition of T1 sociodemographic and caregiver-related psychosocial factors (Step 2) improved the prediction of T2 PG symptom scores, change in $R^2 = 0.11$, $F_{inc}(14, 144) = 2.78$, $P = 0.001$. The T1 factors accounted for 59% (54% adjusted) of the variance of T2 PG symptom scores.

As shown in Table 5, univariate analyses revealed that there was a unique contribution to T2 PG symptom scores for T1 PG symptom scores, $t = 7.06$, $P < 0.001$ and bereavement dependency, $t = 2.21$, $P < 0.05$. The largest amount of variance in predicting T2 PG symptom scores was by T1 PG symptom scores. Therefore, as expected, higher scores on T1 PG symptom scores were strongly related to higher scores on T2 PG symptoms. In addition, greater bereavement dependency was also weakly (but significantly) related to higher scores on T2 PG symptoms.

For T3 data, the hierarchical regression of T3 PG symptom scores (Step 1) revealed that the T1 psychological distress factors significantly predicted T3 PG symptom scores, $R^2 = 0.52$ (adjusted $R^2 = 0.50$), $F_{inc}(4, 138) = 37.07$, $P < 0.001$. Furthermore, the addition of T1 sociodemographic and caregiver-related psychosocial factors (Step 2) improved the prediction of T3 PG symptom scores, change in $R^2 = 0.16$, $F_{inc}(14, 124) = 3.21$, $P < 0.001$. The T1 factors accounted for 67% (63% adjusted) of the variance of T3 PG symptom scores.

As shown in Table 5, univariate analyses revealed that there was a unique contribution to T3 PG symptom scores for T1 PG symptom scores.
scores, \( t = 6.20, P < 0.001 \), relationship to patient, \( t = -2.69, P < 0.01 \), caregiver reactions assessment impact on schedule, \( t = 2.47, P < 0.05 \), family environment, \( t = -2.12, P < 0.05 \), and optimism \( t = -3.19, P < 0.01 \). The largest amount of variance in predicting T3 PG symptom scores was T1 PG symptom scores. Therefore, as expected, higher scores on T1 PG were strongly related to higher scores on T3 PG symptoms. In addition, caring impact on schedule, being a spouse, poor family environment, and lower scores on optimism, were also weakly (but significantly) related to higher scores on T3 PG symptoms.

**Predictors of PGD Diagnosis**

Because there were only 16 participants who met the PGD criteria at T3, we were unable to include all the variables and factors in one analysis. Exploratory analysis was conducted to determine which of the variables and sociodemographic factors measured at T1 should be included in a logistic regression of meeting the criteria for PGD at T3. The T1 variables that were included in the logistic regression of PGD at T3 were impact on finances, schedule, social support, optimism, and PG symptoms. In addition, the T2 PG symptoms were added to the logistic regression as a second step to examine whether this would improve prediction of meeting the criteria for PGD at T3.

Following Step 1, the T1 variables significantly predicted PGD at T3, \( \chi^2(5) = 31.89, P < 0.001 \). However, only five of the 15 cases with PGD at T3 (33.3%) were correctly classified using this model (and 116 of the 119 cases without PGD were correctly classified). Univariate analyses showed that T1 optimism and PG symptoms significantly contributed to the model.

Following Step 2, the addition of T2 PG symptoms significantly improved the prediction of PGD at T3, \( \chi^2(6) = 57.58, P < 0.001 \). The new model including both steps significantly predicted PGD at T3, \( \chi^2(1) = 25.69, P < 0.001 \). With the addition of T2 PG symptoms, 10 of the 15 cases with PGD at T3 (66.7%) were correctly classified using this model (and 115 of the 119 cases without PGD were correctly classified). Univariate analyses showed that only T2 PG symptoms significantly contributed to the model.

**Discussion**

In the last decade, there has been much effort to identify the risk factors for PGD and greater psychological distress during bereavement. The key aim of this study was to ascertain whether family carers who have high levels of PG symptoms and those who develop PGD at six and 13 months postdeath can be predicted from predeath information.

The results of this study confirm previous findings that caregivers of patients receiving palliative care have a high prevalence of...
psychological distress during bereavement. Six months postdeath, more than one-third (36%) of the carers met the criteria for at least one of the five psychological distress measures. By 13 months postdeath, the proportion of highly distressed carers had only slightly decreased (29%). It has been shown that people who suffer from PGD have the greatest risk for adverse health effects. At 13 months postdeath, 11% of the carers in this study met the criteria for PGD, which is consistent with previous literature that reports 10–15% of the bereaved individuals meet the criteria for PGD.

In relation to the predeath risk factors for PG, the results of this study showed that very few of the previously identified predeath risk factors were accurate predictors of PG. Preloss PG symptoms were a strong predictor of PG symptoms at six and 13 months postdeath. This finding is consistent with the previous findings of the carers of Alzheimer’s patients. Greater dependency on the person who died also significantly (but weakly) predicted PG symptoms at six months. At 13 months, predeath risk factors that significantly (but weakly) predicted PG symptoms included caring for a spouse, greater caring impact on schedule, poor family environment, and lower scores on optimism.

In relation to actually predicting carers who will meet the criteria for PGD (as opposed to those reporting high levels of PG symptoms) at 13 months postdeath, the results consistently showed that the predeath PG symptoms were the strongest predictor. Optimism also had a small additional effect. However, only a third of the carers with PGD were correctly classified using this model. Two-thirds of carers with PGD at 13 months could be identified at six months postloss by screening for PG symptom scores at six months postloss.

The results suggest that the most effective way to screen for those at risk of high levels of PG symptoms or who will meet the criteria for PGD during bereavement is to screen for PG (using the PG-13 preloss version) on entry to palliative care. Many carers are already experiencing high levels of distress at this time and may benefit from some immediate support.

### Table 5

Predictors of Prolonged Grief Symptom Scores at Times 2 and 3

<table>
<thead>
<tr>
<th>Parameters</th>
<th>Time 2 Prolonged Grief Symptoms (N = 163)</th>
<th>95% CI for B</th>
<th>Time 3 Prolonged Grief Symptoms (N = 142)</th>
<th>95% CI for B</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>β</td>
<td>P-Value</td>
<td>B</td>
</tr>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>6.12</td>
<td>4.66</td>
<td></td>
<td>10.27</td>
</tr>
<tr>
<td>Time 1 preloss grief</td>
<td>0.63</td>
<td>0.56</td>
<td>0.000*</td>
<td>0.45, 0.80</td>
</tr>
<tr>
<td>Time 1 anxiety</td>
<td>0.19</td>
<td>0.09</td>
<td>NS</td>
<td>0.24</td>
</tr>
<tr>
<td>Time 1 depression</td>
<td>0.25</td>
<td>0.10</td>
<td>NS</td>
<td>0.24</td>
</tr>
<tr>
<td>Time 1 demoralization</td>
<td>0.02</td>
<td>0.02</td>
<td>NS</td>
<td>0.07</td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>10.27</td>
<td>9.36</td>
<td></td>
<td>10.27</td>
</tr>
<tr>
<td>Live with the patient</td>
<td>−0.72</td>
<td>−0.03</td>
<td>NS</td>
<td>−1.40</td>
</tr>
<tr>
<td>Relationship to patient</td>
<td>−1.90</td>
<td>−0.09</td>
<td>NS</td>
<td>−4.49</td>
</tr>
<tr>
<td>Education level</td>
<td>−1.21</td>
<td>−0.05</td>
<td>NS</td>
<td>−0.61</td>
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<tr>
<td>Time 1 caregiver esteem</td>
<td>0.00</td>
<td>0.00</td>
<td>NS</td>
<td>0.21</td>
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<tr>
<td>Time 1 lack of family support</td>
<td>0.35</td>
<td>0.13</td>
<td>NS</td>
<td>0.21</td>
</tr>
<tr>
<td>Time 1 impact on finances</td>
<td>0.24</td>
<td>0.06</td>
<td>NS</td>
<td>0.50</td>
</tr>
<tr>
<td>Time 1 impact on schedule</td>
<td>0.23</td>
<td>0.08</td>
<td>NS</td>
<td>0.45</td>
</tr>
<tr>
<td>Time 1 impact on health</td>
<td>−0.53</td>
<td>−0.12</td>
<td>NS</td>
<td>−0.35</td>
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<tr>
<td>Time 1 bereavement</td>
<td>0.47</td>
<td>0.16</td>
<td>0.03*</td>
<td>0.05, 0.90</td>
</tr>
</tbody>
</table>

B = unstandardized coefficient; β = standardized coefficient; CI = confidence interval; NS = not significant.

*p < 0.001.

*p < 0.01.

*p < 0.05.
However, it is vital that a second screening for PG (using the PG-13) be conducted at six months after the patient’s death. This will identify about two-thirds of people who would meet the criteria for PGD 13 months post-death. It is important to acknowledge that the remaining third of carers who develop PGD by 13 months would not be identified by a screen at six months postdeath. This suggests that a further screening (or contact) after the anniversary of the death might be warranted to identify these late developers. This is particularly concerning, as many palliative care services are not funded to offer support for this length of time and, therefore, many highly distressed people will be left to seek out their own support. Further research is needed to examine how to identify late developers and encourage them to seek mental health support.

Health professionals who are unable to screen for PG using the PG-13 also should be aware of other risk factors for PG identified by this study. Although not as reliable, they offer some guidance as to carers who may be at greater risk.

**Limitations**

There are several noteworthy limitations with our study. First, the poor participation rate at T1 and high dropout of participants at T2 means that the results should be interpreted with caution. It is possible that the sample of carers reported on in this study are biased, specifically they may actually be higher functioning than those who chose not to participate in the study (who may have felt more overwhelmed with their situation, which prevented them taking part). Although we do not have any data on those who did not participate at T1, we do know that there were no differences between those who participated at T2 and those who dropped out on T1 measures. However, this does not mean that the two groups went on to have similar experiences at T2 and T3. Second, with such a small number of cases of PGD, we had to limit the number of variables examined within the logistic regression. Furthermore, the less than optimal response rate for T2 data meant that the sample size was not as large as planned for the regression analyses. The study should be replicated with a larger sample.

**Conclusion**

Future research is needed to develop and evaluate a screening process for PG in palliative care and bereavement settings. Based on our findings, it should incorporate a screen for PG symptoms preloss, at six months after the death, and again at 13 months (if possible). Future research also should explore what interventions might improve psychological distress for those identified as being at risk. Although this article focused on PG symptoms and PGD, the results of this study show that the prevalence of bereaved carers meeting the criteria for other disorders is very high (particularly, PTSD). Further research is required to explore the relationships between bereavement, PGD, and other mental health disorders.

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2. Palliative Care Australia. Standards for providing quality palliative care for all Australians, 4th


