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Long term prevalence and predictors of prolonged grief disorder amongst bereaved cancer caregivers: a cohort study

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INTRODUCTION

With advances in cancer treatments and outcomes there are increasing numbers of people living with advanced cancer requiring palliative care services particularly over the final stages of life. Coinciding with this are an increasing number of family caregivers who, alongside health professionals, provide much of the essential informal daily care and assist with decision-making. They are a major source of support to the patient with advanced cancer and are an integral component of health care services. While more recently the significant contribution of caregivers has been recognised, less attention has

been given to the considerable physical and psychological costs shouldered by caregivers who experience bereavement.

Grief is a normal reaction to loss and refers to the distress resulting from bereavement. While there are individual differences in the intensity and duration of grief and expressions of grief (Christ, Bonanno, Malkinson, & Rubin, 2003), most bereaved people show similar patterns of intense distress, anxiety, yearning, sadness and pre-occupation, and these symptoms gradually settle over time without adverse health-related effects (Allumbaugh & Hoyt, 1999; Bonanno, Wortman, & Nesse, 2004). However, for some, grief does not settle over time with between 4% to 10% of people experiencing abnormal grief, specifically called complicated grief (CG) or prolonged grief disorder (PGD) (Kersting, Brähler, Glaesmer, & Wagner, 2011; Lundorff, Holmgren, Zachariae, Farver-Vestergaard, & O'Connor, 2017; Newson, Boelen, Hek, Hofman, & Tiemeier, 2011; Prigerson et al., 1996; Stroebe, Hansson, Schut, & Stroebe, 2008). Cancer caregivers are vulnerable to PGD, with Guldin et al (2011) reporting rates of 40% at 6 months, 28% at 13 months, and 27% at 18 months post bereavement. There has been considerable debate in the literature associated with PGD, CG and persistent complex bereavement disorder terminology (American Psychiatric Association, 2013; Crunk, Burke, & Robinson, 2017; Maciejewski, Maercker, Boelen, & Prigerson, 2016). This manuscript will use PGD to reflect all three terms.

People with PGD report experiencing persistent and disturbing disbelief regarding the death of their relative or friend and resistance in accepting the reality. Symptoms include intense yearning, and longing for the deceased, preoccupying thoughts of the loved one and continued distressing intrusive thoughts related to the death. Situations and activities that serve as a reminder of the loss are avoided and interest and engagement in life is limited or absent (Shear & Shair, 2005). In these circumstances, a normal grief adjustment does not occur and debilitating grief is experienced for an extended period.

The short-term impact of PGD following bereavement is well documented (Shear et al., 2011), however the longer-term sequelae are poorly documented, possibly unrecognised

and may be incorrectly attributed to other mental health disorders, and hence undertreated (Maciejewski et al., 2016; Maercker & Lalor, 2012; Shear et al., 2011). It is clear that if left untreated, PGD can become entrenched. The work of van de Houwen and colleagues (2010) has highlighted the importance of identifying risk factors for PGD, particularly as evidence suggests that interventions for all bereaved are ineffective, and in some cases, potentially damaging. Certainly, proponents of a public health model of bereavement support would endorse targeted interventions for only those considered at risk (Aoun et al., 2015; Lundorff et al., 2017).

Unfortunately, there are conflicting findings as to what may be considered risk factors for the development of PGD, making early identification and intervention for those at risk imprecise. While the evidence now suggests that the circumstances of the death is not a risk factor, a lack of preparedness may be (Barry, Kasl, & Prigerson, 2002). Barry et al (2002) found prior psychiatric history was not predictive of CG at 9 months, yet Kapari et al (2010), found that caregiver mental health was a significant predictor of PGD at 6 months post-bereavement. It is possible that retrospective data may be contributing to the conflicting findings.

Therefore, the aims of the current study were to prospectively evaluate the prevalence of PGD three years post bereavement and to examine the predictors of long term PGD in a population-based cohort of bereaved cancer caregivers.

METHOD

This article reports on the longer-term follow-up of a cohort of cancer caregivers recruited before the patients' death into a study examining the well-being, mental health, and bereavement of the caregivers of patients receiving palliative care (Time 1, T1) (Hudson, Thomas, Trauer, Remedios, & Clarke, 2011). In this cohort study, caregivers were followed up at six months (Time 2, T2) (Thomas, Hudson, Trauer, Remedios, & Clarke, 2014), 13 months (Time 3, T3) (Thomas et al., 2014), and then, building on the existing study, at 37 months (Time 4, T4) post-bereavement.

The relevant human research ethics committees approved the study.

Sample and setting

Primary family caregivers of patients admitted to one of three palliative care services in Melbourne, Australia were invited to participate in the study. All services were delivered by multidisciplinary palliative care specialists with the aim of providing comprehensive support to patients with advanced, life threatening, non-curable disease and their families. Primary caregivers were identified by patients as the person (friend or relative) who had prime responsibility for their day-to-day care.

The inclusion criteria for caregivers were: identified as a primary caregiver by a patient; over 18 years of age, and able to speak, read and understand English (in order to participate in the interview at T1 and subsequent data collection). Caregivers were excluded if they had cognitive impairment that would influence their ability to understand the consent process.

Procedure

Upon the patient's entry into palliative care services, all eligible caregivers were invited by telephone by an independent research assistant to participate in the project. Those who gave verbal consent were given the option of having the research assistant meet with them at either in their home or at the palliative care service to administer the T1 survey. The T1 survey took between 45-60 minutes to complete. At T1, data were collected by the research assistant, and subsequently by self-report questionnaires.

All participants were re-contacted by telephone at six, 13 months and 37 months post bereavement. Verbal consent to continue participating in this study was sought ahead of being mailed the time specific questionnaire. If the questionnaire was not returned to the research group within two weeks the participant was contacted to encourage them to complete and return the questionnaire and to offer assistance if required. See Figure 1, the recruitment diagram for data on participants at each time point.

INSERT FIGURE 1 HERE

Measures

Validated and purpose-designed self-report measures were administered at each time point and relevant to the current study are listed in Table 1. Relevant sociodemographic data was collected from both carers and patients at T1. A complete list of all measures administered to participants (cohort profile) has been reported (Hudson et al., 2011).

INSERT TABLE 1 HERE

Prolonged grief disorder scale

PGD was measured using the Prolonged Grief Disorder Scale (PG-13) (Prigerson et al., 2009; Prigerson & Maciejewski, 2006) a 13-item self-report questionnaire, including PGD symptoms – feelings, thoughts, actions. Each item was scored on a 5-point Likert scale from 1 (not at all) to 5 (very much). Respondents were categorised as non-cases, sub-threshold cases, or cases, based on an algorithm developed by the scale authors. In brief, PGD cases met the following four criteria: (1) at least daily separation distress (score of 4+ on item 1 or 2); (2) at least five cognitive, emotional, or behavioural symptoms (score of 4+ on at least five of 9 items from 3-11); (3) Symptoms for 6+ months (item 12); and (4) significantly impaired social, occupational, or other important areas of functioning (score of 4+ on item 13) (Prigerson et al., 2009). The nine symptoms of PGD include: feeling stunned / dazed, intense emotional pain / pangs of grief, bitterness, numbness, and confusion / a loss of self, trouble accepting the reality of the loss, a mistrust of others, difficulty moving on, and that life is meaningless. PGD sub-threshold cases met three of the four PGD criteria. Non-cases included all others.

A total prolonged grief symptom score was also calculated by summing the scores of the symptom items 1-11. Possible scores range between 11 and 55, with higher scores reflecting greater symptoms of PGD (Prigerson et al., 2009).

Pre-loss prolonged grief score

As there was not a specific measure available to assess pre-loss prolonged grief, items 1-11 of the PG-13 were adapted for this purpose. For example “In the past month, how often have you tried to avoid reminders that the person is gone” was replaced with “In the past month, how often do you try to avoid reminders of your relative’s diagnosis or prognosis” to reflect the grief experienced related to the illness rather than the death of the person being cared for. A total pre-loss prolonged grief scores was calculated by summing the scores of items 1-11.

Mental health risk factors

Fourteen mental health lifetime risk factors were identified from key literature (Andershed, 2006; Docherty et al., 2008; Eagar et al., 2007; Kristjanson, Lobb, Aoun, & Monterosso, 2006; Smith, Kalus, Russell, & Skinner, 2009). These were then reviewed by experts in psychiatry, psychology, and bereavement, and through an iterative approach, the final 14 risk factors were agreed upon. These were: i) sleeplessness, ii) serious financial problems, iii) drug or alcohol dependency, iv) cumulative multiple losses, v) multiple stressful situations, seen a vi) counsellor, vii) general practitioner, viii) psychologist, ix) psychiatrist for mental health problems, x) taken medication for mental health problems, xi) family history of mental illness, xii) death of a parent during childhood, xiii) overly controlling parents, and xiv) childhood abuse or neglect. Participants were asked whether they had ever in their lifetime experienced each of these factors and were asked to respond in a Yes/No format. Data was also collected on the participants mental health service use in the previous six months which allowed for an understanding of mental health concerns developed in the caregiving role versus a lifetime risk factor.

Circumstances surrounding death

Information regarding the circumstances surrounding the patient’s death were collected at Time 2. These included: i) the opportunity to say goodbye (yes/no) and ii) discuss death with the patient (yes/no), iii) present at the time of death (yes/no), iv) attendance at the

funeral (yes/no); and v) a three-part question about the location of the patient's death (home, hospital, aged care facility, palliative care unit, other) and congruence between the carer's ideal location and patient's ideal location of death (answered yes/no). Participants were also asked to rate the dying experience on a Likert scale from 1 to 10, with 10 indicating the best experience possible.

Self-report measure of coping

Finally, participants were asked to rate how well they thought they were coping in relation to their relative's death with a response format of "not well at all", "quite well" and "very well".

STATISTICAL METHODS

All models were pre-specified to guard against spurious findings (Harrell, Lee, & Mark, 1996). The primary outcome was the total score for prolonged grief at T4, and was modelled with linear regression. The first set of models focused on the traditional risk factors, as identified in the literature, for prolonged grief: serious financial problems, drug or alcohol dependency, cumulative losses, multiple stressful situations, seen mental health professional, medication for mental health problem, family history of mental illness, experienced the death of a parent in childhood, overly controlling parents, experienced childhood abuse or neglect. These risk factors were considered univariately and in a multiple linear regression with all risk factors.

The second set of models aimed to explore predictors from T1 and T2 of prolonged grief at T4. Family functioning, social support, bereavement dependency, death circumstances (as a total score from 5 items), and pre-loss grief were used in a multiple linear regression.

Since there was a substantial amount of missing data at T4, and because restricting analysis to those who had complete data is inefficient and can seriously bias results, we used multiple imputation for the primary analysis (Bell & Fairclough, 2014). Multiple

imputation is a method of “filling in” missing data from a plausible distribution which validly accounts for the uncertainty associated with both sampling and imputation, and yields unbiased estimates for data which are missing completely at random and at random (Little & Rubin, 1987). As recommended we used an “inclusive” strategy for the imputation model, including all outcome and predictor variables which would then be used in the analysis models (Collins, Schafer, & Kam, 2001). Fifty datasets were multiply imputed, and results of the various analyses combined by using SAS Proc MI and MIANALYZE.

Sensitivity analyses

We undertook sensitivity analyses by comparing the primary results, which used multiple imputation, to results from a complete case analysis and results obtained with different multiple imputation models. All analyses were performed in SAS v9.2, tests were two-sided, and statistical significance was set at 0.05.

RESULTS

Of the 992 caregivers who were eligible for the study, 381 agreed to participate. Of these, 301 caregivers completed the questionnaire, corresponding to a response rate of 30%. Figure 1 shows the sample size, response rates, and reasons for refusal at T2, T3, and T4. For more information about T1, T2, and T3 reasons for refusal please refer to the associated publications (Hudson et al., 2011; Thomas et al., 2014).

Participant demographic data is presented in Table 2 and divided by those who made criteria for Pre-loss PGD or PGD at any time point (T1, T2, T3 or T4) and those who did not.

INSERT TABLE 2 HERE

PG and Sub-threshold PG

The prevalence of PGD and sub-threshold PGD post-bereavement were determined using the PG-13 as a binary measure, and presented in Table 3.

INSERT TABLE 3 HERE

In a regression model for PGD at T4 with traditional risk factors (serious financial problems, drug or alcohol dependency, cumulative losses, multiple stressful situations, seen mental health professional, medication for mental health problem, family history of mental illness, experienced the death of a parent in childhood, overly controlling parents, experienced childhood abuse or neglect), none were found to be significant, either in a multiple regression model (Table 4) or univariately (results not shown). The explained variance of the model was $R^2 = 0.04$.

INSERT TABLE 4 HERE

The second model included the circumstances surrounding the death, the carer's rating of the death experience, and a self-report measure of coping. The explained variance of the model was $R^2 = 0.33$, and the self-report measure of coping was a highly statistically significant predictor in this model ($p < .0001$) (see Table 5).

A final model including family functioning, social support, bereavement dependency, death circumstances, and pre-loss anticipatory grief found that pre-loss anticipatory grief measured at T1 was a highly statistically significant predictor of PGD at T4 ($p < .0001$), (see Table 5). The explained variance was $R^2 = 0.33$.

INSERT TABLE 5 HERE

All results from sensitivity analyses were similar to the primary analysis.

DISCUSSION

To our knowledge, this is the first prospective study examining a cohort of primary caregivers of cancer patients in the final stages of life, enabling the collection of pre-bereavement mental health data with systematic follow-up of the cohort up to three year post-bereavement. Unlike other longitudinal studies of this population, where participants are self-selected via internet notices (van der Houwen, Stroebe, Stroebe, et al., 2010), this

cohort of caregivers was a predefined homogenous group of primary caregivers of patients with cancer in need of palliative care services where patient deaths were anticipated. This provides a scenario where the focus of examination is on the mental health factors of caregivers in predicting outcomes, removing the variability in the data that is associated with unanticipated deaths, and sudden deaths through natural causes, accident/homicide, and suicide in the same group (van der Houwen, Stroebe, Stroebe, et al., 2010). The true strength of this study design is the comprehensive pre-loss caregiver data, missing in most studies of this kind which rely on patient data as a proxy for caregiver data.

The number of caregivers experiencing PGD decreased with time and at 37 months post-loss, four caregivers met the criteria for PGD. A recent meta-analysis of prevalence data for PGD suggests approximately 5% of the bereaved population will be affected, (Lundorff et al., 2017) which is what was found in this study. However, the number of caregivers with sub-threshold PGD at 37 months was high (n=12; 14%) and worthy of attention. For almost 20% of caregivers the symptoms of PGD appear to persist at least three years post-bereavement. It is possible that these numbers underestimate the number of bereaved caregivers affected by PGD. One of the distinguishing features of PGD is avoidance of any reminders of the loss, and it is highly probable that those experiencing PGD would avoid participating in T4 of the study. Certainly, there is anecdotal evidence to support this.

Caregiver pre-loss PG at T1 (patient admission to palliative care) was highly predictive of PGD in the longer-term, building on existing findings in this area (Kapari et al., 2010). In the second set of models there were two highly statistically significant predictors, pre-loss grief and “how have you been coping in the past month?” which was asked at T2.

These results suggest value in screening caregivers upon the patient’s admission to palliative care which is in keeping with international guidelines (World Health Organisation, 2002). Included in this model were social support, family functioning, bereavement dependency, and circumstances surrounding the death which were not

predictive of PGD in the longer-term. These findings support the work of other researchers in this area (Barry et al., 2002; Kapari et al., 2010). Contrary to expectation, social support did not predict PGD. This is supported by the findings of van der Houwen et al (2010) who also found that social support did not have the protective effect against PGD. The authors conclude the reasoning for this finding is unclear. One possibility may be that the caregiver has lost their major source of support through the death of the person they are grieving for. Additionally, it is possible that social support received upon entry to palliative care may decrease over time, particularly in individuals who have symptoms of PGD, including social isolation or withdrawal.

The caregiver's experience of the death was not predictive of PGD, indicating that, in this study, the quality of the patient's death is not a contributing factor in the development of PGD in caregivers. As palliative care services were involved, aspects of the death experience which could lead to caregiver distress, like poor symptom management, should have been minimised. As participants were recruited upon the patient's admission to palliative care, all deaths were anticipated and (we expect) the caregivers were supported by palliative care staff both pre, during, and post-death. This supports the finding of van der Houwen et al (2010), who also found that bereavement-related factors, except the expectedness of the death (which was not a factor in our study), did not contribute to CG.

Caregiver self-assessment of coping six months post-bereavement was highly predictive of PGD in the long-term. It appears that simply asking caregivers how they are coping at six months post-bereavement may be effective in identifying those at high risk of PGD in the longer-term. Far from being a complicated questionnaire, this self-report measure was a simple question with a choice of answers on a 3-point Likert scale ranging from "not well at all" to "very well". In hospitals where there are few resources available to provide bereavement services and staff are unable or ill-equipped to administer standardised questionnaires assessing mental health, this may be a useful screening instrument to identify those likely to benefit from early intervention.

Bereaved caregivers may realise that they are not coping well, but may not be aware that this is reflecting symptoms of a mental health disorder that can benefit from bereavement care, and that such care is available, either through the palliative care services or through community based services. Indeed of the four participants who made criteria for PGD at T4, only one patient reported receiving psychological treatment in the form of antidepressant medication. Palliative care bereavement services are potentially well placed to conduct such screening pre-loss and 6 months post-bereavement, and when required, institute early intervention including referral to specialist mental health professionals.

None of the traditional risk factors for PGD analysed in this study were statistically or clinically significant. This supports previous findings that a prior psychiatric history in caregivers is not predictive of PGD (Barry et al., 2002). However, it is important to note that psychiatric history may predict other bereavement related mental health outcomes, such as major depressive disorder.

This further supports the importance of screening caregivers upon the patient's admission to palliative care and at six months post bereavement to ascertain their current mental health, as it appears this may be more relevant to their on-going mental health than past history. This also lends support for a less invasive approach to the screening of caregivers.

There are a number of strengths and limitations associated with this study. This study is limited by the usual challenges associated with recruitment and retention of participants to bereavement studies. Many caregivers declined participation at Time 1 and we are unable to comment on their experience. Additionally, caregivers did not complete all surveys. However, the statistical analysis conducted aimed to directly address this missing data. This study was extremely comprehensive including sociodemographic, mental health, circumstances related to the death, and relationship factors in the design. It did not investigate all the factors which may contribute to the development of PGD, for

example, family conflict and attachment style. It is possible these factors may contribute to PGD in this population.

Future research should aim to develop and evaluate a screening process for prolonged grief in palliative care and bereavement settings. Based on the findings of the current study, caregivers should be screened for prolonged grief symptoms pre-loss and at 6 months post-bereavement. The evidence presented here indicates that this screening does not need to be arduous or overburden already struggling palliative care services.

Additionally, research should follow the work of van de Houwen and colleagues (2010) who have moved beyond merely identifying risk factors for PGD and towards an understanding of mediating factors, including rumination and threatening grief interpretations. Others have found those with PGD have impaired cognitive functioning (autobiographical memory) and aberrant future-related thinking (Maccallum & Bryant, 2010, 2011). This provides an understanding of the aetiology and maintenance of PGD in specific populations. In this way, we can move beyond just identifying those and ideally prevent PGD before it is established.

DISCLOSURE

The authors have no conflicts of interest.

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Table 1. Summary of measures administered at each time point

Variable	Instrument	No. of items	Response format	Total score range	Administered *
Bereavement dependency	Bereavement Dependency Scale	6	0-4	0-24	Time 1
Social support	Multidimensional Scale of Perceived Support	12	1-7	12-84	Time 1
Family functioning	Family Environment Scale	12	1-2 (T/F)	12-24	Time 1
Perceived preparedness for the caregiver role	Preparedness for Caregiving Scale	8	0-4	0-32	Time 1
Pre-loss grief - Criteria for diagnosis - Pre-loss grief behavioural & emotional symptoms	Prolonged Grief Disorder Scale (PG-13) - Pre-loss Caregiver Version	13 11	1-5 1-5	NA 11-55	Time 1
Lifetime mental health risk factors	Purpose-designed	14	Y/N	0-14	Time 1
Post-loss grief - Criteria for diagnosis - Pre-loss grief behavioural & emotional symptoms	Prolonged Grief Disorder Scale (PG-13)	13 11	1-5 1-5	NA 11-55	Time 2, 3, 4
Circumstance surrounding patients death	Purpose-designed	6	Y/N	0-6	Time 2
Death experience	Purpose-designed	1	1-10 1=worst experience	1-10	Time 2
Coping in relation to the death	Purpose-designed	1	1-3 1=not well at all	1-3	Time 2

*Time 1 = before the patient's death; Time 2 = six months post-bereavement; Time 3 = 13 months post-bereavement; Time 4 = 37 months post-bereavement.

Table 2. Descriptive data for Caregiver socio-demographic variables by presence of Pre-loss Prolonged Grief Disorder/Prolonged Grief Disorder at T1, T2, T3 or T4 versus no Prolonged Grief Disorder

Caregiver Characteristics	PGD not present (n=246)		PGD present (n=55)	
	<i>Mean (SD)</i>	<i>Range</i>	<i>Mean (SD)</i>	<i>Range</i>
Age (in years)	56.4 (13.93)	21-87	57.8 (12.40)	24-85
Current health (1=very poor, 5=very good)	3.8 (0.92)	1-5	3.5 (0.95)	1-5
Length of time caring for patient (in months)	18.4 (41.16)	1-360	20.4 (38.16)	1-216
	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>
Gender				
Female	175	59	45	15
Male	70	23	10	3
Country of birth				
Australia	162	55	29	10
Other	79	26	26	9
Marital status				
Married/De facto	183	61	37	12
Single/Divorced/Widowed	63	21	18	6
Education Level				
Professional/university degree	60	20	11	4
Technical/apprenticeship	50	17	8	3
High school completed	20	7	7	2
Did not complete high school	109	37	29	10
Employment status				
Full-time employment	67	23	13	4
Part-time employment	39	13	5	2
Not in the workforce	136	46	37	12
Stopped work to be a carer	55	19	19	6
Reduced work to be a carer	73	25	18	6
Seen a mental health professional past 6 months	64	22	20	7
Counsellor	18	6	5	2
GP	36	12	9	3
Psychologist	13	4	3	1
Psychiatrist	5	2	2	<1
Other	12	4	3	1
Taken medication for a mental health problem during the past 6 months	40	13	11	4

Table 3. Prevalence and CI95% of PGD and sub-threshold PGD

	PGD			Sub-threshold PGD	
	N	n	% (CI _{95%})	n	% (CI _{95%})
T2	163	10	7 (3,11)	42	29(22,36)
T3	142	13	11 (6,16)	24	20 (17,31)
T4	85	4	5 (0.4,10)	12	14 (5,10)

PGD, prolonged grief disorder; T2, time 2; T3, time 3; T4, time 4.

Table 4. Regression analyses of predictor variables on PGD at T4 using traditional risk factors (n = 85)

Predictor variable	Parameter Estimate	P	CI (95%)
Model 1, R ² = 0.04			
Serious financial problems	1.36	0.42	-2.00
Drug or alcohol dependency	3.32	0.33	-3.39
Cumulative multiple losses	2.55	0.11	-0.54
Seen health professional for MHP	0.73	0.66	-2.49
Taken medication for MHP	-0.76	0.76	-5.62
Family history of mental illness	-0.31	0.89	-4.60
Death of parent in childhood	-0.001	0.99	-4.98
Overly controlling parents	-1.49	0.41	-5.03

MHP, mental health problem; PGD, prolonged grief disorder.

Table 5. Regression analyses of predictor variables on PGD at T4

Predictor variable	Parameter		95% CI	
	Estimate	p-value		
Model 2, R ² = 0.33				
Opportunity to say goodbye	0.28	0.93	-5.91	6.46
Opportunity to discuss death	-0.84	0.70	-5.11	3.43
Congruence between carers ideal place of death and actual place of death	1.74	0.45	-2.86	6.34
Congruence between patients ideal place of death and actual place of death	2.93	0.15	-1.03	6.89
Death experience (1-10, 1=worst experience)	-0.30	0.18	-0.75	0.14
Present at time of death	-2.20	0.28	-6.22	1.83
How well carer feels they have been coping (1=not well at all, 2=quite well, 3=very well)	-6.29	<.0001	-8.79	-3.80
Model 3, R ² = 0.33				
Bereavement dependency	0.20	0.30	-0.18	0.58
Social support	0.03	0.57	-0.08	0.14
Family functioning	0.32	0.36	-0.37	1.02
Pre-loss grief	0.51	<.0001	0.37	0.64
Circumstances of the death (total)	0.73	0.27	-0.56	2.01