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Factors of complicated grief pre-death in caregivers of cancer patients

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Abstract

Purpose—Over the past decade, Prigerson and her colleagues have shown that symptoms of ‘complicated grief’—intense yearning, difficulty accepting the death, excessive bitterness, numbness, emptiness, and feeling uneasy moving on and that the future is bleak—are distinct from depression and anxiety and are independently associated with substantial morbidity. Little is known about complicated grief experienced by family caregivers prior to the death. This study sought to examine differences in caregiver age groups and potential risk factors for complicated grief pre-death.

Method—Two hundred and forty eight caregivers from multiple sites nationwide (20–86 years of age) identified themselves as primary caregivers to a terminally ill cancer patient. Each caregiver was interviewed using the following measures: the Pre-Death Inventory of Complicated Grief-Caregiver Version; the Brief Interpersonal Support Evaluation List; the Structured Clinical Interview for the DSM-IV Axis I; the Life Orientation Test-Revised; the SEPRATE Measure of Stressful Life Events; the Covinsky Family Impact Survey; and mental health access questions.

Results—The study found that those under 60 years old had higher levels of complicated grief pre-death than caregivers 60 and older ($t(246) = 2.30, p < 0.05$). Significant correlations were also found between levels of complicated grief pre-loss and the following psychosocial factors: perceived social support ($r = -0.415, p < 0.001$); history of depression ($r = -0.169, p < 0.05$); current depression ($r = -0.158, p < 0.05$); current annual income (Spearman rho = $-0.210, p < 0.01$); annual income at time of patient's diagnosis (Spearman rho = $-0.155, p = 0.05$); pessimistic thinking ($r = 0.320, p < 0.001$); and number of moderate to severe stressful life events (Spearman rho = $0.218, p = 0.001$). In a multi-variate analysis ($R^2 = 0.368$), pessimistic thinking (Beta = $0.208, p < 0.05$) and severity of stressful life events (Beta = $0.222, p < 0.05$) remained as important factors to developing complicated grief pre-death.

Conclusions—These results suggest that mental health professionals who work with caregivers should pay particular attention to pessimistic thinking and stressful life events, beyond the stress of the loved one's illness, that caretakers experience. Additionally, although not reaching significance, mental health professionals should also consider younger caregivers at greater risk for complicated grief pre-loss.

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Keywords

cancer; oncology; caregivers; complicated grief; pre-death

Introduction

Although the loss of a loved one affects everyone, some people are affected more severely than others. In Freud's [1] seminal paper, 'mourning and melancholia', he acknowledged that all grief was not the same and that some particular grief was actually pathological (what he called melancholia) regarding a person's inability to interact with and manage the external world. Since Freud's contribution to distinguishing normal from abnormal grief, grief experiences to a loss of a loved one have been divided into non-pathological and pathological reactions.

Prigerson and her colleagues [2,3] have operationalized this distinction as uncomplicated and complicated grief. Prigerson *et al.* [2,3] define complicated grief as a cluster of experiences that include: separation distress; post-traumatic stress; and an inability to cope with the loss of a loved one. Complicated grief has been further divided into anticipatory grief reactions and bereavement reactions. Research has demonstrated that these two experiences, pre- and post-death grief, are unique phenomena from each other and other psychiatric diagnoses. Despite this, very little research has studied complicated grief pre-loss. Additionally, these few studies have not focused on the factors that predict complicated grief (e.g. [4,5]), and even fewer have examined these factors in relation to the pre-grief experience. Of the studies that have examined complicated grief pre- and post-loss, the limited research has focused on primarily middle- to older-aged samples. Very little research has examined the experience of complicated grief in the younger adult population (younger than 50 years old).

Beery *et al.* [4] examined complicated grief pre-loss in 70 elderly participants. These subjects were, on average, 50 years old and older. Beery *et al.* [4] examined the effects of changes in role function, caregiver tasks, caregiver burden, and gratification on complicated grief symptoms. They found that caregiver burden and depression significantly affected levels of complicated grief. This study did not examine age as an independent variable. Van Doorn *et al.* [5] examined the effects of marital quality and attachment styles on complicated grief pre-loss in 59 participants who were on average 50 years old and older. Their findings suggest spousal caregivers of terminally ill patients who have a secure, supportive spouse and an insecure attachment style contribute independently to the severity of complicated grief symptoms. They found that younger age was related to complicated grief pre-death. However, the age ranged from 40 to 87 years; therefore, few younger caregivers were included in the sample.

Kelly *et al.* [6] examined the effects of adverse life events, coping responses, past bereavement and separation experiences, relationship with the patient, and the severity of the patient's illness on pathological grief pre- and post-loss in 178 caregivers of terminal cancer patients ranging in age from 22 to 87 years old. Their research did not use pathological grief measures, which they acknowledged to be a limitation of their design. Instead, general measures of social functioning, adjustment and coping were used. Additionally, the average age for participants was approximately 69 years old and age was not included in their empirical model.

Ball [7] examined whether age and mode of death predicted the intensity of anticipatory grief reactions (before the term complicated grief pre-loss had been coined) in a sample of 200 widows whose spouses died of illness or accident 6–9 months prior to the study. Age was found to be a more significant predictor of grief intensity than mode of death. Regardless of the mode of death, the young widow (18–46) suffered a more intense grief than middle (47–59) or older

widows (60–73). This is the only study to include young participants in the examination of anticipatory grief, but the sample size for the young widows, ($N = 10$), makes the reliability of this finding questionable.

The limited research on this construct thus far has not specifically operationalized complicated grief, have had a relatively small sample, lacked a cohort of younger subjects, and have not yet established predictive variables associated with complicated pre-grief. Perhaps with the inclusion of both younger and older caregivers that reflect an adequate range of ages, elevations for complicated grief would appear in both of these groups.

Since the development of the ICG by Prigerson and her colleagues [8], few studies have looked at factors that relate to complicated grief [9]. Vanderwerker and Prigerson [9] examined the role of social support and technological connectedness as protective factors in bereavement. Ellifritt, Nelson, and Walsh [10] used a different bereavement risk questionnaire to diagnose complicated grief, but they also found that lack of social support is a significant risk for complicated bereavement. Maddison and Walker [11] showed that widows at greater risk for unresolved grief perceive themselves to have more unmet needs in interpersonal relationships than did those with resolved grief outcomes. Bereavement is a social process that involves numerous relationships. Therefore the interaction with others is a necessary component of bereavement, allowing the caregiver to come to an acceptable understanding as to why the death occurred [12]. Despite this knowledge of the interaction between social support and bereavement, no studies have used social support as a factor in understanding the pre-death grief experience.

Individual differences in optimism also play an important role in the adjustment to stressful life events [13]. Previous research has demonstrated that optimists use different strategies to cope with stress than do pessimists and that these coping strategies contribute to a better adjustment to a stressful life event [14,15]. In a study by Robinson-Whelen, Kim, MacCallum, and Kiecolt-Glaser [16], caregivers and noncaregivers were examined for the effects of recent negative life events on their levels of optimism, pessimism and psychological distress. This study found that caregivers expressed less optimism than noncaregivers, and caregivers showed a trend toward more pessimism. Additionally, pessimism predicted subsequent psychological health problems. To date, no studies have been conducted examining the relationship between pessimism and the experience of complicated grief pre-loss. In light of the research that has demonstrated relationship between pessimism and psychological health, it is important to examine if a pessimistic view puts caregivers at more risk for a pathological grieving reaction.

This study attempts to fill the gaps in the current pre-grief literature by studying caregivers of terminally ill cancer patients, ranging in age from early twenties to late eighties. Few studies have examined complicated grief pre-loss and no studies have examined the role of social support, pessimism, depression, stressful life events and access to mental health services in the experience of complicated grief before the loss of a loved one. This study hypothesizes that there will be elevations in complicated grief pre-loss for younger and older groups as compared to middle-aged adults, and that variables such as social support, pessimism, depression, stressful life events, and access to mental health services relate to higher levels of complicated grief pre-loss.

Method

This study examined data collected from a larger NIH multi-site study investigating complicated grief in caregivers of terminally ill cancer patients. This study was reviewed by and passed all Institutional Review Board requirements. Researchers interviewed 248 (98%) caregivers of terminally ill cancer patients face to face and interviewed four (0.02%) caregivers

over the telephone using a battery of clinician administered questionnaires regarding their level of complicated grief pre-death and other pre-grief experiences. The telephone interviews were a small minority and there was no difference in complicated grief levels for mode of interview. Caregivers were identified as family members or friends of a patient who provided a majority of the patient's care. Caregivers were recruited from five hospitals throughout the Northeast and two hospitals in the state of Texas. Medical teams referred caregivers to the study if they met the following inclusion criteria: caregiving of a patient with advanced stage cancer; caregiving of a patient with distant metastasis and failure of first and/or second line of cancer therapy; living within a 60 mile radius of the hospital site; English speaking; able to give informed consent; and at least 18 years old.

Measures

Researchers administered the following measures

1. Pre-Death Inventory of Complicated Grief-Caregiver Version (Pre-ICG): The pre-loss version of the Inventory of Complicated Grief (ICG) assesses grief over the expected loss of a loved one. The pre-death ICG has demonstrated high levels of internal consistency among caregivers (Cronbach's alpha = 0.90) [4,5,17]. Due to continued measurement development, refined versions of the ICG were administered during the course of the study. As a result of these revisions, four questions from the Inventory of Complicated Grief Pre-Death were consistently used at all sites to measure complicated grief pre-loss. The Cronbach's alpha for these questions was 0.76. In assessing complicated grief pre-loss symptoms, the mean value for these four questions in the Pre-Death Inventory of Complicated Grief-Caregiver Version was used (see Table 1 for listing of questions).

2. Structured Clinical Interview for the DSM-IV (SCID) Axis I modules: The SCID is a semi-structured interview for making Axis I DSM-IV diagnoses. Using a decision tree approach, the SCID guides the clinician in testing diagnostic hypotheses as the interview is conducted [18]. This widely used rater-administered instrument has been tested in numerous studies for inter-rater and test-retest reliability. Using an earlier version of the Axis I SCID (DSM-III-R), data were collected on 506 pairs of interviews at six sites in a test-retest reliability study, and test-retest reliability for current and lifetime diagnoses was all over 0.60. For the nonpatient samples, the test-retest reliability for current diagnoses was 0.37 and 0.51 for lifetime diagnoses [19]. Recently, a number of newer studies have tested the SCID, focusing on particular diagnostic groups and using joint or videotaped interviews. These studies found higher Kappa levels, ranging from 0.70 to 1.00 [20–22].

3. Brief Interpersonal Support Evaluation List (ISEL): This Brief ISEL lists 16 statements about four domains of social support: material aid; someone to talk to about one's problems; comparison of self with others; and people with whom to share activities. This measure has been shown to have good internal consistency with alpha levels ranging in the general population from 0.88 to 0.90 [23]. Robinson-Whelen *et al.* [24] used a shortened version of this measure with caregivers and reported an alpha level of 0.79. The ISEL has also been used in several caregiver studies (e.g. [9,25,26]).

4. Life Orientation Test-Revised (LOT-R): The Life Orientation Test (LOT) was developed to assess individual differences in generalized optimism versus pessimism. This measure has been used in numerous behavioral, affective, and health studies. Six items from the 10-item instrument were used to assess individual differences in generalized optimism versus pessimism. Psychometric properties of the LOT-R include alpha reliability of 0.87 and test-retest reliability of 0.74 in a sample of breast cancer patients [27] and alpha reliability ranged from 0.80 to 0.74 for caregivers [16].

5. Mental Health Service Use: Participants were asked whether or not they have discussed psychosocial problems and mental health issues with a health-care professional (e.g. their primary physician or a mental health professional).

6. Structured Event Probe (SEPRATE) measure of stressful life events: Dohrenwend's Structured Event Probe is a checklist measure of recent (within the last 6 months) stressful life events that assesses the undesirability and disruptiveness of each reported event. The measure has been used extensively in prior research and is psychometrically sound [28].

Results

Participants

Two hundred and forty-eight caregivers, 68 males (27%) and 180 females (73%) were included in the analyses. Ages for caregivers ranged from 20 to 86 years of age. The mean age of the caregivers enrolled in this study was 52 years old ($SD = \pm 13.67$). There were 179 white (72%), 35 African American (14%), 25 Hispanic (10%), and 6 Asian American/Pacific Islander/Indian (2%) caregivers enrolled in this study (see Table 2). Forty caregivers were 20–39 years old (16%), 131 were 40–59 years old (53%), and 77 were 60 years old and older (31%) (see Table 3).

The mean education level was at least 1 year of college, ($SD = \pm 3.31$). A majority of caregivers were spouses or partners of the terminal patient (68%). The other caregiver relationships were: dependent child (18%); dependent adult (6%); other relative (3%); friend (3%); and other (2%). No significant statistical relationship was found between caregiver relationship and complicated grief experiences pre-loss. The median annual income level per household was \$51 000 or above and 78% of the sample reported having health insurance at the time of the study interview. The average length of time for taking care of a patient was approximately two and a half years (30 months).

The frequencies of complicated mean levels are reported in Table 4. A One-way Analysis of Variance (ANOVA) was performed to measure the difference among the three age groups (young = 20–39 years old, middle = 40–59 years old, and older = 60 years and above) on levels of pre-loss complicated grief. The mean levels of complicated grief were 2.34 ($SD = 1.01$) for young adults, 2.42 ($SD = 0.98$) for middle aged adults and 2.09 ($SD = 0.95$) for older adults and an F-test revealed marginally significant differences ($F(2, 245) = 2.736, p = 0.06$). Because the ANOVA did not yield significant results, age was dichotomized to determine if there was a relationship between younger (59 years and below) and older (60 years and above) caregivers (as opposed to young, middle and older categorization) and levels of complicated grief pre-loss. This difference was significant for caregivers fifty-nine years old and younger (2.40) versus sixty years old and older (2.09); $t(246) = 2.30, p = 0.02, d = 0.32$.

Correlations were performed on all the independent variables (age, social support, pessimism, current diagnosis of depression, and psychosocial discussion prior to patient's illness and use of mental health services after patient's diagnosis) and the dependent variable (levels of complicated grief pre-loss). Social support ($r = -0.42$), pessimism ($r = 0.32$), current depression ($r = 0.16$), depression history ($r = 0.17$), and moderate to severe stressful life events ($r = 0.22$) were all significantly correlated with complicated grief pre-loss. Mental health discussion pre-diagnosis and mental health use post-diagnosis were not significantly correlated with complicated grief pre-loss (see Table 4). To further understand our findings, additional demographic variables were included in a correlational matrix (current income, income at diagnosis, loss of income, gender, race, relationship to the patient, and education). Current income and diagnosis income were significantly correlated with complicated grief pre-loss (see Table 5).

Age (dichotomized), demographic, and psychosocial variables that were significantly correlated with complicated grief pre-loss (as well as loss of major source of income which was close to significance with p -value = 0.05) were tested in a multivariate analysis. The results for the multiple regression model that predicted complicated grief pre-loss appear in Table 6. This analysis produced a significant model ($F(9, 100) = 6.459, p < 0.01, R^2 = 0.37$). Pessimism (Beta = $-0.21, p < 0.05$) and the number of moderate to severe stressors (Beta = $0.22, p < 0.001$), excluding the diagnosis of cancer, remained as predictors to developing complicated grief pre-loss.

Discussion

Few studies have examined factors of complicated grief pre-death. In the last decade, much of the research on complicated or pathological grief reactions has focused on the post-death experience. The minimal research completed on pre-death experiences has also been limited in its methodology and age range. This study was able to include a wide age range of caregivers (20–86 years old) with a sample size large enough to examine age-group differences. The original hypothesis that younger and older caregivers would experience higher levels of complicated grief than middle-aged caregivers was not supported in this analysis. When the three age groups were examined, although not statistically significant ($p = 0.07$), the middle-aged group had higher levels of complicated grief diagnoses than the older caregivers. It is possible that the ‘younger middle-aged’ caregivers is a cohort more vulnerable to complicated grief pre-death experiences. When age was dichotomized into younger and older cohorts, greater mean levels of complicated grief were observed for younger caregivers. This may be related to the greater number of stressors (e.g. child rearing, employment, financial position) that the caregivers in that cohort experience compared to other age groups. Future research may want to examine the experiences of this age group in more depth and also provide an anticipatory grief treatment approach focused on this group's age-specific risk factors.

In the multivariate analysis, caregivers' income, perceived social support, age, and depression did not remain as significant predictors of complicated grief pre-loss. A caregiver's pessimistic view of the world is one of the strongest predictors to developing complicated grief pre-death. According to Scheier *et al.* [27], the pessimism measure used in this study (LOT-R) measures dispositional optimism as opposed to state optimism. This suggests that pathological pre-grief reactions are related to an individual's enduring personality characteristics as opposed to other psychosocial risk factors (e.g. social support, depression, mental health access and use) or demographic factors (e.g. relationship to patient, income level, race, education, gender). Prigerson *et al.* [17] found a similar result in their article on case histories of caregivers with traumatic grief. They found that those within the ‘syndromal’ range of traumatic grief appeared to remain stable pre-to-post-loss, suggesting that pathological grief reactions are related to stable personality traits rather than with the characteristics of the death. This strong relationship between complicated grief pre- and post-death also illuminates the importance of studying pre-loss grief reactions. The more mental health professionals know about the risk factors of complicated grief pre-death, the more they can identify those at risk for post-death bereavement and offer appropriate symptom-focused treatments to aid in the management of pathological grief reactions.

Additionally, previous research has demonstrated that bereaved elderly individuals with higher levels of complicated grief were more at risk for mental and physical health problems than those with lower levels of complicated grief [3,29]. Therefore, the ability of mental health professionals to assess complicated grief prior to the loss of loved one may help to protect bereaved individuals from future mental and physical impairment.

Significant correlations between these variables and the Stressful Life Events Scale may explain this result. A caregiver's number of moderate to severe stressors, outside of a cancer diagnosis (measured by the Stressful Life Events Scale), has the most predictive value in developing complicated grief pre-loss. According to Stroebe and Schut [30], the cognitive stress model of understanding grief is a 'fine-grained analysis' for understanding the process of coping with bereavement. This theory asserts that stress is experienced by an individual when the demands of a certain situation are seen as taxing or exceeding resources, which endangers their well-being and health. Stroebe and Schut [30] point out that not all parts of bereavement are out of one's control; some aspects of bereavement are changeable (e.g. financial situation). This examination of bereavement illuminates the possibility of working with bereaved individuals using a problem-focused approach, in addition to an emotion-focused one, to help alleviate the emotional and cognitive stress.

There are a few important limitations to this study. First, the study was a cross sectional design. The NIH-funded study that originally provided the data is a longitudinal study, examining caregivers and patients before the loss to up to 6 months post loss. Results from this longitudinal study will help to add more of an understanding to complicated grief experiences. Due to an attempt to revise and improve the complicated grief pre-loss measure, four questions from the Inventory of Complicated Grief Pre-Death were consistently asked among the multiple sites. Therefore, only four questions were used to measure complicated grief pre-loss. These four questions were measured to see how well, as a set, they captured the construct of complicated grief pre-death. The Cronbach's alpha = 0.761, which suggests that the four questions used together were a reliable measure of complicated grief pre-death. Nonetheless, the current Complicated Grief Pre-death Inventory includes 34 questions within three subheadings (separation distress, traumatic distress, and course of symptoms), therefore, it is likely that the full measure is a richer examination of the complicated grief experience. This study should be replicated, using a complete measure of complicated grief pre-loss experiences, to determine if a more complete diagnosis yields different results than the ones obtained from the present study.

Another possible limitation for this study lies in the sample characteristics of the caregivers who participated in the study. All of the caregivers experienced a loss to a cancer diagnosis; therefore, these results cannot be generalized to those who lost loved ones to violent deaths. A majority of the sample was Caucasian, female, educated, and in a higher-income bracket. In examining the generalizability of this study's findings, the 2000 Census Bureau information on United States ethnic and education percentages was obtained. Interestingly, the demographic breakdowns for ethnicity and education obtained in this study were quite similar to the breakdowns gathered in the 2000 Census. Therefore, although ethnicity and educational level were not equally weighted in this study, they may not limit the generalizability of the findings. Additionally, no significant differences were detected for complicated grief experiences between genders; therefore, the inclusion of more female caregivers should not affect the results of this study significantly. Despite these insignificant differences for gender, race, and economic status, it is important to note that if this sample was more heterogeneous, different results might have emerged regarding risk factors for complicated grief experiences. Lastly, the NIH-funded study that originally provided the data recently included publicly funded hospitals. This inclusion will be important in examining whether lower-income caregivers differ in complicated grief pre-loss experiences and risk factors than the participants used in this study.

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Table 1
Four questions from the pre-death inventory of complicated grief

I feel myself longing and yearning for (patient) as they used to be prior to becoming so ill
I feel that life is empty and meaningless without (patient) being healthy
I am bitter over (patient's) illness
I think about (patient's) diagnosis/illness so much that it can be hard for me to concentrate on anything else or do the things I normally do

Table 2

Racial demographics of caregivers

Race/ethnicity	Frequency	Percent (%)
White	179	72.1
African-American	35	14.1
Hispanic	25	10.1
Asian-American/Pacific Islander/Indian	6	2.4
Missing information	5	2

Table 3

Sample size by age group

Age group	Sample	Percent (%)
20–39 years old	<i>N</i> = 40	16.1
40–59 years old	<i>N</i> = 131	52.8
60 and older	<i>N</i> = 77	31

Table 4

Correlations between independent variables and pre-complicated grief

	Complicated grief pre-loss
Age	−0.109
Social support	−0.415 *
Pessimism	0.320 *
Current depression	0.158 *
Depression history	0.169 *
Mental health discussion pre-Dx	−0.082
Mental health discussion post-Dx	−0.104
Moderate to severe stressful life events	0.218 *

*
 $p < 0.01$.

Table 5

Correlations between complicated grief pre-loss and additional demographic variables

	Complicated grief pre-loss
Current income	-0.210 ^{**}
Diagnosis income	-0.155 [*]
Loss of income	0.125
Gender	-0.020
Race	0.030
Relationship	-0.095
Education	-0.087

*
 $p \leq 0.05$.**
 $p < 0.01$.

Table 6

Regression coefficients of the risk factors of complicated grief pre-loss for caregivers

Risk factors	Beta	<i>t</i>	Significance
Annual family income at dx	-0.169	-1.251	0.214
Current family income	-0.106	-0.748	0.456
Patient's illness a (Major loss of income)	0.041	0.447	0.656
Age	-0.117	-1.419	0.159
Social support	-0.158	-1.534	0.128
Pessimism	0.208	2.318	0.022 *
History of depression	0.019	0.209	0.835
Current depression	0.092	1.036	0.303
Moderate to severe stressors (Excluding cancer dx)	0.222	2.351	0.021 *

* $p < 0.05$, $F(9, 100) = 6.459$, $p < 0.01$, $R^2 = 0.37$.