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Bereavement among Hospice Caregivers of Cancer Patients One Year following Loss: Predictors of Grief, Complicated Grief, and Symptoms of Depression

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Abstract

Background: Informal caregivers are an integral part of end-of-life care for hospice patients with cancer. Although adjustment following loss is highly individual, many caregivers have significant psychological distress after the death of a loved one. This study investigated risk factors that may predict psychological distress, which could aid hospice bereavement departments in targeting bereavement services.
Method: Demographic characteristics, patient impairment, caregiver baseline symptoms of depression, and caregiver resources were assessed among 188 cancer patient–caregiver dyads. Regression analyses identified predictors of symptoms of depression, grief, and complicated grief one year following loss.
Results: Over 50% of bereaved caregivers had clinically significant depressive symptoms one year after death of their relative. Caregivers with fewer years of education and more baseline symptoms of depression had significantly worse grief, complicated grief, and depression. Younger patient age was a significant predictor of poorer outcomes for grief and complicated grief; and less patient impairment was a significant predictor of more post-loss symptoms of depression. Lower social support satisfaction was correlated with worse grief and complicated grief but was not a significant multivariate predictor of poorer outcomes.
Conclusion: Despite having access to hospice bereavement services, many former caregivers had high psychological distress one year following loss. Bereavement departments could consider utilizing readily available risk factors to target services to former caregivers who may benefit from bereavement services. Bereavement departments might also consider including brief, standardized screenings of caregiver depression in initial risk assessments. Future studies should investigate evidence-based approaches for assessment and interventions among highly distressed former hospice caregivers.

Introduction

A CENTRAL PART OF HOSPICE CARE is to provide emotional support to family members and caregivers after patients have died.[1] Medicare requires that certified hospice programs offer bereavement services for one year following patient death.[2] Although a majority of individuals are resilient following loss,[3] many caregivers may benefit from bereavement support, as 12% to 40% experience poor psychological well-being, including depression and complicated grief, six months to one year following loss.[4–7] Bereavement services may be particularly beneficial to caregivers who have been engaged in highly stressful caregiving. Despite the availability of bereavement support, only 30% of all bereaved caregivers and less than half of caregivers with major depressive disorder utilize hospice bereavement services during the year following loss.[8]

Targeting services to caregivers at risk for poor psychological well-being following loss may facilitate efficient use of hospice bereavement services. However, costs for bereavement services are included in a Medicare benefit bundled per diem rate and cannot be reimbursed separately by hospice providers.[2,9] Therefore, many hospice programs may have limited ability to provide comprehensive resources to all

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bereaved individuals. While Medicare Conditions of Participation require hospice programs to conduct an initial bereavement risk assessment shortly after patient admission,[10] the utility of these assessments has been criticized, as they are often based on clinical opinion, lack consistent completion, and have poor psychometric properties.[11] Research that identifies readily available, empirically based, pre-loss risk factors could aid in addressing these limitations.

Demographic characteristics and indicators of patient impairment can be quickly assessed by bereavement staff and are frequently part of hospice medical records. Although some studies have found female gender, lower caregiver education, younger caregiver age, and a spousal relationship are associated with poorer bereavement outcomes, others report no significant gender or relationship differences.[12–15] A recent review found several studies in which poor patient health was associated with poorer caregiver pre-loss mental health outcomes;[14] however, less research has considered the effects of patient health on caregiver bereavement outcomes. Little research has included measures completed at hospice admission, e.g., the Palliative Performance Scale (PPS).[16]

Medicare guidelines encourage that risk assessments include indicators of caregivers' social support networks,[17] and some studies suggest social support plays an important role in well-being following loss. For example, Burton and colleagues[18] found less caregiver social support at hospice admission was associated with more symptoms of depression during bereavement. However, less social support has not always been found to increase risk for difficult bereavement.[19]

Finally, pre-loss psychological distress can have important effects on post-loss well-being.[15,20,21] Kapari and colleagues[23] found poorer mental health prior to loss was a significant predictor of poorer bereavement outcomes three and six months following loss among hospice caregivers. However, a national study of hospice bereavement programs in the United States revealed that only slightly more than half of hospice programs screened caregivers for major depression at time of admission, during patient stay, and following patient death.[22] Baseline symptoms of caregiver depression also deserve attention as a predictor of bereavement outcomes in hospice.

This study investigated possible predictors of bereavement outcomes among former caregivers of hospice patients with cancer. Specifically, we investigated potential risk factors that could be quickly assessed by hospice bereavement staff, including a number of patient and caregiver demographic characteristics, indicators of patient impairment, caregiver pre-loss depression and caregiver resources (i.e., social support). We also explored whether predictors differed for symptoms of depression, grief, and complicated grief, given that these outcomes have been identified as related but distinct constructs.[23–29] We hypothesized that greater patient impairment, lower social support satisfaction, and more baseline symptoms of depression would be associated with poorer bereavement outcomes.

Methods

Sample and setting

The current study is derived from a larger, randomized trial collected from 2005 to 2008. The study investigated the efficacy of a systematic patient and caregiver assessment, with feedback to staff, in improving well-being among hospice patients and caregivers. The feedback intervention group showed significantly greater improvements in patients' symptoms of depression than in participants who did not receive the intervention, but no effects on improving caregivers' well-being.[30] Caregiver bereavement outcomes were assessed to explore possible long-term benefits of the assessment and feedback intervention.

The original sample included patients and family caregivers admitted to hospice homecare in one of two large, not-for-profit hospice programs in west central Florida. Eligible patients were (1) diagnosed with cancer, (2) 18 years of age or older, (3) able to read and write English, (4) made ≤2 errors on the Short Portable Mental Status Questionnaire (SPMSQ),[31] and (5) scored ≥40 on the PPS.[16] Family caregivers that were identified as patients' primary caregivers (i.e., provided an average of four or more hours of daily care) were eligible for the study. Caregivers were excluded if they were actively receiving cancer treatment and patients were excluded if they were confused, comatose, excessively debilitated, or actively dying. These eligibility criteria were used to identify patient-caregiver dyads likely to survive long enough in hospice to benefit from the assessment intervention.

Caregivers were assessed at baseline (24–72 hours after patient enrollment into hospice care) and one year following patient death. Of the initial sample of 717 dyads, 201 caregivers completed the bereavement outcomes measures one year following loss. Preliminary analyses indicated that caregivers in treatment and control conditions did not differ significantly on the three bereavement outcomes, so results were pooled for further analyses. Participants who had missing or insufficient data on any of the variables of interest for the present study were excluded from analyses, resulting in a sample of 188 participants.

Measures

Demographics. Demographic and sample characteristics including patient and caregiver age, gender, race/ethnicity, education in years, caregiver employment status, and type of caregiver-patient relationship were collected via self-report and medical chart review at study baseline.

Patient impairment. The PPS[16] was completed by hospice admission staff and assessed patient ambulation, activity performance ability, extent of disease, self-care ability, intake of food and fluids, and level of consciousness. Possible scores range from 0–100 with 100 indicating full capacity in all domains and 0 indicating death. Acceptable test-retest reliability and content validity of the PPS have been reported.[32] The revised 25-item version of the Memorial Symptom Assessment Scale (MSAS)[30,33,34] was completed by interviewing patients at study baseline to assess number of cancer symptoms. For each symptom item reported, patients provided distress ratings on four-point Likert-type scales. Possible symptom distress scores range from 0–100 with higher scores reflecting greater distress. Prior research has provided evidence for construct validity of the revised MSAS and reliability of distress scores within a sample of hospice cancer patients.[30,34]

Caregiver psychological well-being. Caregiver depressive symptoms were assessed at both study baseline and

12 months following loss using the short form 10-item version of the Center for Epidemiological Studies Depression Scale (CES-D 10),[35] also called the Boston Short Form.[36] Higher scores indicate more symptoms of depression[35] and a cutpoint ≥4 has been identified as an indicator of clinically significant depression.[37] Acceptable construct, concurrent, and discriminant validity of the full CES-D have been reported in clinical and general populations[36] and high reliability of the short form has been reported.[37] To assess bereavement outcomes one year following loss we utilized the Present Feelings subscale of the Texas Revised Inventory of Grief (TRIG).[38] Responses are rated from one to five and scores on 13 items were summed. For the present study, responses were reverse coded so that high scores indicated high grief by subtracting the participants' score from a possible score of 65. Previously reported alpha coefficients range from 0.69 to 0.93.[39] Finally, the 19-item Inventory of Complicated Grief (ICG) [40] evaluated presence of symptoms of complicated grief one year following loss. Possible scores range from 0–76, with higher scores indicating greater complicated grief. Scores >25 have been identified as high risk of being clinical cases.[40,41] Prigerson and colleagues[40] reported high reliability and evidence for concurrent validity of the ICG.

Caregiver resources. Three items from the Satisfaction with Social Support subscale from the social support measure by Krause and Borawski-Clark[42] assessed caregivers' perceived tangible, emotional, and informational social support satisfaction. Possible scores ranged from one ("not at all") to four ("very"). Krause and Borawski-Clark[42] reported acceptable reliability for the three item summary score. We also investigated the availability of other caregivers by using a single item that asked caregivers to provide a "yes" or "no" response to the question, "Are there other caregivers who routinely help you to provide care?"

Analyses

All analyses were conducted utilizing SPSS 20.0 (SPSS Inc., Chicago, IL) software. Basic descriptive analyses assessed demographic characteristics of the sample and the study measures; and independent samples t-tests were conducted to examine group differences on baseline symptoms of depression among caregivers who completed the 12-month follow-up interviews and caregivers who only completed baseline interviews. Next, bivariate analyses were conducted to examine correlations between demographic characteristics, patient impairment, caregiver depression at study baseline, caregiver resources, and the bereavement outcome measures to identify necessary covariates for regression analyses. In consideration of statistical power and the small sample size, only independent variables significantly correlated with the bereavement outcome variables were selected for the regression analyses. We then created separate hierarchical multiple regression models (one for post-loss depression, one for grief, and one for complicated grief) to test the hypotheses concerning patient impairment, caregiver well-being prior to loss, and caregiver resources in relation to bereavement outcomes, after controlling for other factors. Four blocks were entered into the regression models and the order of entry was (1) demographic characteristics, (2) patient physical impairment factors, (3) caregiver baseline symptoms of depression, and (4) caregiver resources.

Results

Descriptive and demographic information

Table 1 describes the study sample. Patients were predominately white (99%) males (60%); and caregivers were predominately female (74%), white (99%), and not employed full- or part-time at study baseline (79%). Thirty percent of caregivers scored ≥4 on the CES-D at study baseline, 55% had a CES-D score of ≥4 one year following loss, and 18.5% had complicated grief scores >25, indicating high levels of clinically relevant depression and grief. Caregivers who did not complete the follow-up interviews had significantly higher baseline symptoms of depression ($M=3.06$, $SD=1.94$) than caregivers who completed bereavement interviews. Forty-one percent of caregivers who completed baseline interviews but did not complete the 12-month follow-up interviews had a CES-D score ≥4.

Risk factors identified by correlational analyses

As shown in Table 1, fewer years of caregiver education, less patient impairment as indicated by the PPS, and more caregiver symptoms of depression at study baseline were significantly associated with more symptoms of depression one year following loss. Younger patient age, fewer years of caregiver education, greater number of baseline symptoms of depression, and less social support satisfaction at baseline were significantly associated with greater (i.e., higher) present feelings of grief. Finally, younger patient age, fewer years of caregiver education, greater number of symptoms of depression at baseline, lack of other caregivers, and less satisfaction with social support were significantly associated with higher (i.e., greater) complicated grief at 12-month follow-up. None of the gender, race/ethnicity, employment status, relationship type, or MSAS indicators of patient impairment and distress variables were significantly correlated with any of the outcome measures and were excluded from regression analyses.

Regression analyses investigating predictors of caregiver bereavement outcomes

Regression analyses predicting depression, grief, and complicated grief are shown in Table 2. For depression, lower caregiver education, higher PPS (i.e., less patient impairment), and higher baseline symptoms of depression were associated with greater symptoms of depression one year following loss, after controlling for other factors. The regression model predicting present feelings of grief showed that younger patient age, fewer years of caregiver education, and more baseline symptoms of depression were associated with worse grief. Patient impairment and caregiver resource variables were not significant.

Finally, the model predicting complicated grief showed that younger patient age, fewer years of caregiver education, and more symptoms of depression were associated with more symptoms of (i.e., worse) complicated grief one year after patient death. Although caregiver resource variables as a group explained significant additional variance in the regression predicting complicated grief, none of the variables

Table 1. Means, Standard Deviations, Ranges, and Correlations of Descriptive Independent Variables and Main Outcome Measures of Depression, Grief, and Complicated Grief ($N=188$)

			Correlations		
Variable	*M*	*SD*	*Depression*	*Grief*	*Complicated grief*
Demographics					
CG age	66.41	11.66	−0.08	0.01	0.07
PT age	73.63	10.44	−0.05	−0.16*	−0.17*
CG education	13.41	2.38	−0.18*	−0.25**	−0.15*
PT education	12.55	3.22	−0.08	−0.05	0.01
Relationship (% spousal)	0.33 (66%)	0.47	0.04	−0.06	−0.14
Patient impairment					
PPS	57.66	10.59	0.19**	0.05	0.04
MSAS symptoms	10.07	4.48	−0.01	0.02	−0.00
MSAS distress	21.13	14.62	0.01	0.06	0.03
Caregiver baseline depression					
CES-D	2.64	1.94	0.36***	0.37***	0.45***
Caregiver resources					
Social support	11.08	1.37	−0.06	−0.18*	−0.22**
Other CG (% yes)	0.32 (32%)	0.47	−0.04	−0.06	−0.16*
Caregiver bereavement outcomes					
Depression	4.38	2.09	–	0.53***	0.50***
Grief	40.91	9.38		–	0.79***
Complicated grief	16.54	11.14			–

*$p<0.05$.
**$p<0.01$.
***$p<0.001$.
CES-D, Center for Epidemiological Studies Depression Scale; CG, caregiver; M, mean; MSAS, Memorial Symptom Assessment Scale; PPS, Palliative Performance Scale; PT, patient; SD, standard deviation.

reached significance. Similar to the analyses predicting grief, patient impairment was not a significant predictor of complicated grief.

Discussion

The purpose of this study was to investigate potential risk factors for poor bereavement outcomes among family caregivers of hospice patients with cancer one year following loss. More than half of bereaved caregivers had scores above the cutoff for depression, and approximately 19% were above the cutoff for complicated grief at follow-up, suggesting high levels of distress one year following loss, despite access to bereavement support services over the last year.

Overall, demographic characteristics were not consistent predictors of bereavement outcomes, although younger

Table 2. Hierarchical Regression Analysis Summary for Predicting Depression, Grief, and Complicated Grief One Year Following Loss ($N=188$)

	Depression			*Grief*			*Complicated grief*		
Variables	β	R^2	ΔR^2	β	R^2	ΔR^2	β	R^2	ΔR^2
Block 1: *Demographics*		0.04*	0.04*		0.09***	0.09***		0.05**	0.05**
PT age	−0.05			−0.17*			−0.18*		
CG education	−0.18*			−0.25***			−0.15*		
Block 2: *Patient impairment*		0.08**	0.04**		0.09***	0.00		0.06*	0.00
PPS	0.21**			0.07			0.05		
Block 3: *Caregiver baseline depression*		0.20***	0.12***		0.22***	0.13***		0.25***	0.20***
CES-D	0.35***			0.36***			0.45***		
Block 4: *Caregiver resources*		0.20***	0.08		0.23***	0.01		0.28***	0.03*
Social support	0.02			−0.10			−0.11		
Other CGs	0.02			−0.01			−0.12		

*$p<0.05$.
**$p<0.01$.
***$p<0.001$.
CG, caregiver; MSAS, Memorial Symptom Assessment Scale; PPS, Palliative Performance Scale; PT, patient; β, standardized regression coefficient; R^2, variance explained; ΔR^2, change in variance explained.

patient age was a significant predictor of worse grief and complicated grief, and fewer years of caregiver education was a consistent, significant predictor of poorer bereavement outcomes. Low education may be a marker for low socioeconomic status and resources, which are known risk factors for psychological distress.[43] In contrast to the hypothesis that greater patient impairment would be associated with poorer bereavement outcomes, we found a higher PPS score at baseline (i.e., better health and functioning) was a significant predictor of more symptoms of depression but not grief or complicated grief during bereavement. In addition, our results add to the mixed findings on social support and bereavement outcomes among caregivers. Less social support satisfaction was associated with greater grief and complicated grief following loss, and a lack of other caregivers was associated with higher complicated grief. However, these factors did not remain significant after controlling for other factors. While caregiver resources were not significant predictors of psychological well-being one year following loss, social support may change significantly over the course of bereavement and merits further study.

As hypothesized, more symptoms of caregiver depression during the first week of hospice admission was a significant predictor of more depression, present feelings of grief, and higher complicated grief one year following loss. Baseline caregiver depression predicted 12% to 20% of variance in these bereavement variables and was by far the strongest and most consistent predictor. We did not have data on participation in bereavement services, but Bergman and colleagues[44] reported less than half of spousal hospice caregivers participated in professional bereavement services such as support groups, bereavement counseling, or seeing a mental health professional, and noted that many individuals who could benefit from hospice bereavement support did not seek or utilize services.

This study had a number of limitations, including a focus solely on cancer patients and caregivers within hospice. The sample was also not ideal in terms of diversity and there was a high rate of attrition. It is noteworthy that family members who were not available for bereavement assessment had even higher baseline levels of depression than those included in the current analyses, suggesting our results may underestimate levels of distress during bereavement. However, results could be useful in providing information to improve bereavement risk assessments among caregivers of hospice patients with cancer. Many hospice programs may not have the resources to provide comprehensive services to all bereaved individuals. Although our results should be replicated in other settings, pre-loss symptoms of depression were strong and consistent predictors of long-term psychological distress during bereavement. Hospice programs should consider conducting standardized assessments of caregivers' symptoms of depression while caregivers are still providing care to patients (e.g., during initial bereavement risk assessments required by Medicare Conditions of Participation.)[10] Including standardized assessments of depression in risk assessments will likely lead to treatment at the beginning stages of hospice care of caregivers with high levels of depression, which may affect bereavement outcomes. Further, given the high rates of psychological distress we found following loss, and that most hospice programs provide follow-up telephone calls to bereaved family members,[22] bereavement departments should consider completing standardized measures of depression and grief during follow-up calls and conducting these phone calls at regular intervals during the first year of bereavement.

In addition to caregiver baseline depression, better patient health (i.e., higher PPS), younger patient age, and lower caregiver education predicted poorer bereavement outcomes in the regression analyses. These factors can be quickly assessed by hospice staff, and could be considered for inclusion in bereavement risk assessments, although they are less potent predictors of bereavement outcome than caregiver depression.

In the focus within hospice and palliative care on managing patient pain and other symptoms at the end of life, it is important to also recognize that caregivers may experience significant suffering in terms of their own health and well-being, both while caregiving and after the death of a loved one.[45–48] Since evidence-based interventions are available to help bereaved former caregivers who have depression and complicated grief,[49,50] it is vital that hospice programs identify at-risk caregivers and target services to them.

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