

The Prevalence and Risks for Depression and Anxiety in Hospice Caregivers

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Abstract

Background: Depression and anxiety are common concerns for hospice caregivers.

Objective: This study looked at the prevalence and variables associated with hospice caregiver depression and anxiety, as well as the relationship between the two conditions.

Subjects: We did a secondary analysis of preexisting data.

Measurements: Measures included the PHQ-9 and GAD-7.

Results: Nearly one-quarter of caregivers were moderately to severely depressed, and nearly one-third reported moderate to severe symptoms of anxiety. Risk factors for both depression and anxiety included younger age and poorer self-rated global health. Depression-specific risk factors included being married and caring for a patient with a diagnosis other than cancer. The sole anxiety-specific risk factor identified was geographic location, as caregivers living in the Southeast were found to have greater anxiety than those in the Midwest.

Conclusion: Hospice providers' recognition of family caregivers as both coproviders and corecipients of care underscores the need to more fully assess and respond to depression and anxiety among caregivers.

Keywords: anxiety; caregivers; depression; hospice

Introduction

MANY HOSPICE PATIENTS are primarily cared for in their home by a family caregiver. Family caregivers also play a key role in managing and coordinating the care provided by trained staff in skilled nursing facilities and other settings. While recent studies have found emotional benefits to caregiving for hospice patients,¹ there are more studies that have identified negative emotional outcomes from this experience. The National Institute of Nursing Research has identified the need for tested interventions for those caring for patients at the end of life.² Despite the hospice philosophy, which explicitly includes family members as coproviders and corecipients of care, the focus of hospice staff on caregivers has been found to be limited.³ Few comprehensive assessments are done of caregivers, and even fewer evidence-based interventions have been tested for those caregivers whose assessments indicate that further intervention is warranted.⁴⁻⁶

Depression among family caregivers of hospice patients is a commonly noted problem. Systematic reviews of the peer-

reviewed literature found the prevalence of depression in hospice caregivers to range from 26% to 57%.^{5,7} One of the reviews found that, of 16 studies of hospice caregiver depression, the mean sample size was 146, but the samples ranged from 6 to 702. In addition, numerous instruments were used to assess depression, and some of the studies were of bereaved individuals who were no longer caregiving.⁷ These methodological issues point to the need for a larger scale study with consistent instrumentation.

In addition to depression, numerous studies have found caregiving to result in significant anxiety.⁸ Compared to research on depression, however, fewer studies have focused specifically on the impact that caring for a family member or friend receiving hospice services has on anxiety. One study established that the prevalence of anxiety is higher in hospice caregivers than in nonhospice caregivers.⁹ One of the few studies¹⁰ reporting prevalence in a geographically diverse population found that nearly one-third of hospice caregivers were moderately to severely anxious and that geographic location, employment, physical health, age, and gender were associated with levels of anxiety.

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The importance of assessment of caregiver anxiety and depression by the hospice team is evident in numerous theoretical frameworks. In particular, the Assessing Caregivers for Team intervention (ACT) model indicates that caregiver anxiety and depression are outcomes of the caregiving experience and are potentially affected by the caregiver's background and primary, secondary, and intrapsychic stressors. This model holds that assessment and intervention can mediate the relationship between stressors and potentially harmful outcomes such as anxiety and depression.¹⁰⁻¹⁵ The aim of this study is to explore potential variables affecting depression and anxiety, which can then lead to development of interventions to address these conditions.

Using preexisting data, this secondary analysis investigated the following questions: (1) What is the prevalence of depression among hospice family caregivers?, (2) What are the variables associated with depression in hospice family caregivers?, (3) What is the prevalence of anxiety among hospice family caregivers?, (4) What are the variables associated with anxiety among hospice family caregivers?, and (5) What is the relationship between depression and anxiety among hospice caregivers?

Methods

Data

Researchers conducted a secondary analysis using data from two geographically distinct studies ($N=395$): a randomized controlled trial of a psychosocial intervention for informal hospice caregivers conducted in the Midwestern United States from 2008 to 2014¹⁶; and an observational study of family hospice caregivers' stress and coping experiences conducted in the Southeastern United States between 2011 and 2013.^{11,17,18} Only baseline (preintervention) data were utilized from the randomized controlled trial. All studies used similar protocols and instruments to capture a range of patient and caregiver characteristics. The original studies were approved by the individual university institutional review boards. This combined database study was approved by the University of Missouri Institutional Review Board.

Measures

Demographics

Patient characteristics included age, gender, residence (private residence vs. other), and diagnosis (cancer, dementia, and/or other). The following caregiver characteristics were examined: age, gender, race, residence (coresides with patient or not), marital status (married vs. other), study site (Midwest or Southeast), employment status (employed vs. unemployed), and relationship to patient (spouse/partner, adult child, and other). In addition, caregivers were asked to describe their health, with response options ranging from 1 (poor) to 5 (excellent).

Depression

Hospice family caregivers participating in the original studies completed the Patient Health Questionnaire 9-item (PHQ-9) scale,¹⁹ a multipurpose instrument used to measure, screen, provisionally diagnose, and grade the severity of

depression. Caregivers were asked to rate how often (over the past two weeks) they had been bothered by problems such as having little interest in doing things, feeling hopeless, having a poor appetite, having difficulty concentrating, and experiencing thoughts of hurting themselves or thinking that they would be better off dead. Response options ranged from 0 (not at all) to 3 (nearly every day), with total scores ranging from 0 to 27. PHQ-9 scores of 10 or more indicate moderate to severe levels of depression.

Anxiety

The Generalized Anxiety Disorder 7-item (GAD-7) scale²⁰ was used to measure caregiver anxiety. Caregivers were asked to rate how often (over the past two weeks) they had been bothered by problems such as feeling nervous or anxious, feeling afraid, experiencing restlessness, having difficulty relaxing, and being unable to control worrying. Response options range from 0 (not at all) to 3 (nearly every day), with total scores ranging from 0 to 21. Total scores of 5, 10, and 15 represent thresholds for mild, moderate, and severe anxiety, respectively. Total scores of 10 or higher are generally considered clinically significant, signaling a need for additional evaluation and possible intervention.²⁰ Spitzer et al.²⁰ have shown that the GAD-7 has good internal consistency (Cronbach's $\alpha=0.92$) and test-retest reliability (ICC=0.83).

Analysis

Descriptive statistics was examined for all patient and caregiver characteristics and outcomes (i.e., caregiver depression and anxiety) for the full study population and within each study site. To examine differences between the two study populations, chi-square analyses (or t tests for continuous variables) were utilized. In addition, separate multivariable logistic regressions were used to model the associations between specific patient characteristics (age, gender, residence, and diagnosis) and caregiver characteristics (age, gender, relationship to patient, residence, marital status, employment, and global health) with caregiver-reported levels of depression and anxiety. Odds ratios (OR) and 95% confidence intervals (CI) were calculated, and model discrimination was assessed with the c-statistic (1.0 indicates perfect fit and 0.5 is no better than a coin toss). The Hosmer-Lemeshow goodness-of-fit X^2 test was used to determine model fit ($p>0.05$ indicates adequate fit). All analyses were performed in SAS version 9.4 (SAS Institute, Cary, NC).

Results

Patient and caregiver characteristics

The study sample size was 395 caregiver/patients: 171 (43%) from the Midwestern site and 224 (57%) from the Southeastern site. Table 1 provides a summary of patient and caregiver characteristics. A majority of patients in the study were women (62.3%), and most lived in a private residence (67%). Patients had a mean age of 79.4 years, and 37% had a cancer diagnosis. Thirty percent of the patients in the study had dementia, with the Southeastern site having a significantly higher rate ($p<0.0001$) than those in the Midwestern site (44% with dementia vs. 11%, respectively). Caregivers

TABLE 1. CHARACTERISTICS OF INFORMAL HOSPICE PATIENTS AND CAREGIVERS

	<i>Total</i>		<i>Study site</i>				<i>p</i>
	<i>N</i>	<i>%</i>	<i>Midwestern</i>		<i>Southeastern</i>		
			<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	
Overall	395	—	171	43.3	224	56.7	—
Patient characteristics							
Age, mean (SD)	392	79.4 (12.8)	171	79.2 (13.8)	221	79.5 (13.9)	0.84
Female	246	62.28	114	66.67	132	58.93	0.11
Has cancer	147	37.22	55	32.16	92	41.07	0.06
Has dementia	119	30.13	19	11.11	100	44.64	<0.0001
Lives in home (private) residence	263	66.58	102	59.65	161	71.88	0.005
Caregiver characteristics							
Age, mean (SD)	395	60.6 (12.6)	171	59.6 (12.4)	224	61.4 (12.7)	0.16
Female	322	81.52	142	83.04	180	80.36	0.55
White/caucasian	362	91.65	155	90.64	207	92.41	0.52
Lives with patient	207	52.41	66	38.60	141	62.95	<0.0001
Employed	135	34.18	71	41.52	64	28.57	0.005
Married	295	74.68	124	72.51	171	76.34	0.34
Relationship to patient							0.05
Spouse/partner	120	30.38	44	25.73	76	33.93	
Adult child	194	49.11	96	56.14	98	43.75	
Other	80	20.25	31	18.13	49	21.88	
Global health rating	395	3.3 (0.9)	171	3.2 (0.9)	224	3.4 (1.0)	0.08
Poor	15	3.80	4	2.34	11	4.91	
Fair	55	13.92	30	17.54	25	11.16	
Good	158	40.00	74	43.27	84	37.50	
Very good	120	30.38	49	28.65	71	31.70	
Excellent	47	11.90	14	8.19	33	14.73	

SD, standard deviation.

had a mean age of 61 years. Most were female (81%) and Caucasian (92%). Slightly more than half (52%) of caregivers reported to be coresiding with the patient, with a higher percentage of these in the Southeastern site (63% vs. 39%, respectively). Caregivers were mostly either adult children (49.1%) or spouses (30.4%); married (75%); and 35% was employed either full or part-time.

Depression among family hospice caregivers

PHQ-9 total scores ranged from 0 to 27 with a mean score of 6.4 (median score = 5, interquartile range = 0–27). Twenty-three percent of caregivers reported moderate to severe levels of depression (i.e., PHQ-9 total scores ≥ 10). No significant differences in depression levels were found between the Southeastern and Midwestern sites ($p=0.65$). Additional detail regarding caregiver depression is provided in Table 2.

To examine the association of patient and caregiver characteristics with depression (PHQ-9 total scores ≥ 10), a multivariate logistic regression model was conducted (Table 3). After adjusting for patient and caregiver characteristics, caregivers were more likely to be depressed when they were younger (OR = 0.96, 95% CI = 0.94–0.99; mean age of caregivers with depression was 57.4 years vs. 61.6 without, $p < 0.01$), married (OR = 2.24, 95% CI = 1.11–4.54), or caring for noncancer patients (OR = 0.48, 95% CI = 0.26–0.89). In addition, the probability of caregivers being moderately or severely depressed increased when their general health was worse (OR = 0.48, 95% CI = 0.36–0.65). Model discrimina-

tion was good with a c-statistic of 0.77, and model fit was adequate ($\chi^2 = 10.23$, $p = 0.24$).

Anxiety among family hospice caregivers

GAD-7 anxiety scores ranged from 0 to 21 with a mean score of 7.3 (median score = 6, interquartile range = 0–21), and 33% of caregivers reported moderate to severe levels of anxiety. Caregivers from the Southeastern site (40%) reported significantly higher levels of anxiety than caregivers from the Midwest (24%) [$\chi^2 (2, N = 391) = 11.77$, $p < 0.001$].

The association of patient and caregiver characteristics with anxiety (GAD-7 anxiety scores ≥ 10) was examined using a multivariate logistic regression model (Table 3). After adjusting for patient and caregiver characteristics, caregivers were more likely to have high anxiety if they were younger (OR = 0.97, 95% CI = 0.94–0.99; mean age of caregivers with anxiety was 58.4 years vs. 61.6 without, $p = 0.01$) or from the Southeast (OR = 1.73, 95% CI = 1.31–2.28). The probability of caregivers being moderately or severely anxious increased when their general health was worse (OR = 0.60, 95% CI = 0.46–0.78). Model fit was adequate ($\chi^2 = 9.10$, $p = 0.33$), as was model discrimination (c-statistic = 0.71).

Relationship between depression and anxiety among informal hospice caregivers

As noted previously, 23% of caregivers reported moderate to severe levels of depression, while 33% reported severe

TABLE 2. INFORMAL HOSPICE CAREGIVER LEVELS OF ANXIETY (GAD-7) AND DEPRESSION (PHQ-9)

	<i>Total</i>		<i>Study site</i>				<i>p</i>
	<i>n</i>	<i>%</i>	<i>Midwestern</i>		<i>Southeastern</i>		
			<i>N</i>	<i>%</i>	<i>n</i>	<i>%</i>	
PHQ-9 depression score							
Mean (SD)	395	6.4 (5.3)	171	6.2 (4.9)	224	6.5 (5.6)	0.65
Median (IRQ)	395	5.0 (0–27)	171	5.0 (0–21)	224	5.0 (0–27)	0.92
Severity, %							
Minimal (0–4)	172	43.54	74	43.27	98	43.75	
Mild (5–9)	131	33.17	57	33.33	74	33.04	
Moderate (10–14)	57	14.43	27	15.79	30	13.39	
Severe (>= 15)	35	8.86	13	7.61	22	9.82	
% PHQ Score >= 10	92	23.29	40	23.39	52	23.21	0.96
GAD-7 anxiety score							
Mean (SD)	391	7.3 (5.6)	171	6.2 (4.9)	220	8.2 (6.0)	<0.001
Median (IRQ)	391	6.0 (0–21)	171	5.0 (0–21)	220	7.0 (0–21)	<0.001
Severity, %							
Minimal (0–4)	150	38.37	78	45.61	72	32.72	
Mild (5–9)	111	28.38	52	30.41	59	26.81	
Moderate (10–14)	80	20.47	29	16.96	51	23.18	
Severe (>= 15)	50	12.78	12	7.02	38	17.29	
% GAD Score >= 10	130	33.24	41	23.98	89	40.45	<0.001

IRQ, interquartile range; GAD-7, generalized anxiety disorder 7-item.

TABLE 3. MULTIVARIABLE LOGISTIC REGRESSIONS PREDICTING DEPRESSION AND ANXIETY AMONG INFORMAL HOSPICE CAREGIVERS

	<i>Depression (PHQ-9)</i>			<i>Anxiety (GAD-7)</i>		
	<i>OR</i>	<i>(95% CI)</i>	<i>p</i>	<i>OR</i>	<i>(95% CI)</i>	<i>P</i>
Southeastern Site	1.14	(0.84–1.54)	0.41	1.73	(1.31–2.28)	<0.0001
Patient characteristics						
Age ^a	0.98	(0.95–1.00)	0.05	0.99	(0.97–1.01)	0.40
Female	0.93	(0.47–1.84)	0.82	1.00	(0.54–1.84)	0.99
Residence (home/private)	1.94	(0.85–4.41)	0.11	1.13	(0.54–2.36)	0.75
Cancer	0.48	(0.26–0.89)	0.02	0.88	(0.51–1.52)	0.64
Dementia	0.74	(0.37–1.49)	0.39	0.70	(0.38–1.28)	0.24
Caregiver characteristics						
Age ^a	0.96	(0.94–0.99)	0.007	0.97	(0.94–0.99)	0.008
Female	1.01	(0.47–2.16)	0.98	1.70	(0.83–3.47)	0.14
Relationship to patient ^b						
Adult child	1.46	(0.57–3.75)	0.43	0.72	(0.31–1.69)	0.45
Other	0.69	(0.24–2.02)	0.50	0.43	(0.17–1.11)	0.07
Lives with parent	0.69	(0.30–1.58)	0.37	0.79	(0.37–1.67)	0.53
Married	2.24	(1.11–4.54)	0.02	1.61	(0.87–2.97)	0.12
Employed	0.77	(0.41–1.43)	0.40	0.93	(0.54–1.63)	0.80
Global health ^c	0.48	(0.36–0.65)	<0.0001	0.60	(0.46–0.78)	<0.0001
Model fit statistics						
<i>N</i>		375			371	
Hosmer-Lemeshow, <i>p</i>		$X^2 = 10.23, p = 0.24$			$X^2 = 9.10, p = 0.33$	
C-statistic		0.77			0.71	

^aCaregiver age was centered at the mean.

^bReference = spouse or partner.

^cGlobal health item, higher values equate to better health.

OR, odds ratios; CI, confidence intervals.

levels of anxiety. Eighteen percent of caregivers had reported severe levels of both depression and anxiety, and PHQ-9 and GAD-7 scores were found to be highly correlated after performing a Pearson product-moment correlation coefficient ($r=0.74$, $p<0.0001$, $n=391$).

Discussion

As essential members of the hospice team, family caregivers encounter numerous stressors that may give rise to negative caregiving outcomes such as depression and anxiety. Risk factors for both depression and anxiety included younger age and poorer self-rated global health. Depression-specific risk factors included being married and caring for a patient with a diagnosis other than cancer. The sole anxiety-specific risk factor identified was geographic location, as caregivers living in the Southeast were found to have greater anxiety than those in the Midwest. These results support other research reporting a noteworthy prevalence of depression and anxiety among hospice family caregivers.^{7,9,21} In addition, existing research has identified younger age and poorer health as risk factors for depression and anxiety among family caregivers^{22–26} and a well-established correlation between depression and anxiety.²⁷ Results of this study, as it relates to patient diagnosis, differ from at least one other published study.²⁴ Haley et al. found no statistically significant differences in caregiver depression by patient diagnosis (cancer vs. dementia), suggesting the need for additional research on this topic.²⁴ Furthermore, additional research is recommended to better interpret the finding related to marriage and depression. Many studies have found that marriage may, in fact, be a protective factor against depression; however, fully understanding this linkage requires investigating factors such as marital distress and whether or not the current marriage is a second or subsequent marriage,²⁸ variables unavailable in the dataset analyzed in this study. Similarly, while research has identified considerable geographic variation in rates of anxiety,²⁹ additional factors such as regional economic conditions may explain these differences³⁰ to a greater degree than differential caregiving experiences alone.

These results identify background variables, primary stressors, and secondary stressors, which impact the caregiver outcomes of depression and anxiety. As suggested in the ACT model, interventions to change the caregiving experience and reduce anxiety and depression must address the variables impacting them. Thus any intervention to improve these outcomes must also consider caregiver age, health, marital status, geographic location, and patient diagnosis.

Despite their notable prevalence, formal assessment of caregiver depression and anxiety remains uncommon in hospice.^{31,32} Another foundation of the ACT model is the necessity of assessment of the stressors and caregiver outcomes. Lack of assessment ensures that caregiver distress is underidentified and, thus, suboptimally managed, calling into question the ability of hospice teams to fully realize their goal of meaningful holistic support for both patients and their families. While some sadness and worry are expected components of caring for a dying family member or friend, clinically significant depression and anxiety need not be. Neither depression nor anxiety has been shown to be intractable among hospice family caregivers; several evidence-based interventions have been shown to significantly reduce

distress among family members and friends caring for patients at end of life.³³ Assessment tools for depression and anxiety are also widely available and affordable, and existing instruments such as the ones used to generate the data analyzed in this study are decidedly brief, alleviating many common barriers to adoption into clinical practice and creating the potential for improved clinical outcomes for family caregivers in need of additional support.

Despite the broad nature of these two sets of data, generalization of this data to all hospice caregivers is not feasible. It is unknown how comparable subjects are to the larger population of hospice caregivers. In addition, as is the case with any secondary analysis of data, some questions, such as the reason for geographic variance, are not able to be answered.

Conclusion

Many hospice family caregivers experience concerning levels of depression and anxiety, yet research suggests that existing clinical processes are often inadequate in terms of identification and treatment of these conditions. Hospice providers' recognition of family caregivers as both coproviders and corecipients of care underscores the need to more fully assess and respond to depression and anxiety among caregivers. Several well-established tools and interventions are available to aid in these efforts. Further research of general hospice caregiver anxiety and depression is needed to allow greater generalization into the larger hospice population.

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