

Original Article

Associations Between Hospice Care and Scary Family Caregiver Experiences



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Abstract

Context. Hospice deaths in the U.S. are increasing. Dying hospice patients may have rapidly emerging needs the hospice team cannot immediately meet, exposing family caregivers to fright-inducing (i.e., scary) situations.

Objectives. To examine relationships between hospice care and family caregiver exposures and psychological responses to witnessing common and distressing patient symptoms near the end of life.

Methods. Secondary analysis of prospective cohort study of 169 patients with advanced cancer and their family caregivers was analyzed. Multivariable regression analyses modeled associations between hospice use and caregiver exposures and psychological responses (fear and helplessness) to witnessing distressing symptoms common near death, adjusting for potential confounding influences (e.g., home death, patient characteristics, and suffering). Caregiver self-reported exposures and responses to observing patient symptoms during the last month of life were assessed using the validated Stressful Caregiving Response to Experiences of Dying (SCARED) scale.

Results. Hospice care was significantly positively associated with more exposures and negative psychological responses to distressing patient symptoms, adjusting for home death, patient characteristics, and physical and mental suffering. On average, hospice patients' caregivers scored 1.6 points higher on the SCARED exposure scale and 6.2 points higher on the SCARED psychological response scale than caregivers of patients without hospice (exposure: 10.53 vs. 8.96; psychological responses: 29.85 vs. 23.67). Patient pain/discomfort, delirium, and difficulty swallowing/choking were reported by three-fourths of caregivers and associated with the most fear and helplessness among caregivers.

Conclusion. Hospice care is associated with more exposures to and caregiver fear and helplessness in response to scary patient experiences. Research is needed to understand how better to support family caregivers of hospice patients to enable them to cope with common distressing symptoms of dying cancer patients. Hospice clinicians providing additional education and training about these symptoms might enable caregivers to better care for dying loved ones and reduce the stresses of end-of-life caregiving. *J Pain Symptom Manage* 2021;61:909–916. © 2020 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Hospice, caregiver distress, cancer, end-of-life care

Key Message

This article examines hospice, family caregiver distress, and patient experiences in a cohort of patients with advanced cancer and their caregivers. Results suggest hospice is associated with more

caregiver exposure to scary patient experiences compared with other end-of-life care. Witnessing pain/discomfort, delirium, and difficulty swallowing/choking may be particularly frightening for hospice family caregivers.

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Introduction

Hospice enrollment has increased in recent years, characterized by more home deaths and an increasingly heterogeneous patient population.¹ Hospice care in the U.S. focuses on comfort and supportive care, requires foregoing curative treatment, and can be provided in home, nursing home, hospital, or inpatient hospice settings. Hospice can be a helpful source of support for dying persons and their families; it is generally associated with better quality of life for dying individuals and high levels of satisfaction among their family caregivers.^{2,3} However, dying persons, even in hospice, are likely to experience distressing symptoms, such as pain and delirium,^{4–9} which can occur when hospice staff are not present. Almost all (99%) of hospice care is provided outside residential hospice programs,¹ where hospice personnel are not with patients around the clock, leaving family caregivers to provide needed care, particularly when loved ones die at home. As a result, family caregivers with varying degrees of experience and preparedness often must witness and attempt to manage patients' episodic symptom distress, which may contribute to their own distress and burden.⁴

As hospices become more involved at the end of life, it is increasingly important to understand the implications of hospice care and to identify aspects of dying that may prove especially upsetting, or scary to family caregivers. In this study, we examined relationships between hospice care and family caregiver exposures and psychological responses to exposures to common distressing symptoms of dying cancer patients.

Methods

Data

This is a secondary analysis of data from the 2002–2008 Coping with Cancer I study funded by the National Cancer Institute to explore how patient and caregiver experiences associated with end-of-life cancer care affect the well-being of family caregivers.¹⁰ Patients with advance cancer and their informal family caregivers were recruited from seven outpatient oncology clinics across the U.S. Family caregivers were followed for up to one year after patients' deaths and answered questions about patients' end-of-life experiences. Here, we analyzed data for 169 family caregivers who cared for patients who died with or without hospice and completed questions about their witnessing and their psychological responses to witnessing distressing patient symptoms.

Outcome Measures

We measured caregivers' exposures and psychological responses to witnessing distressing patient

symptoms using the Stressful Caregiving Response to Experiences of Dying (SCARED) scale.⁴ The SCARED scale was recorded a median of six months after the patient's death and retrospectively assesses nine items about what the caregiver experienced in the patient's last month of life. Seven items are related to witnessing distressing symptoms in patients: severe pain/discomfort, trouble eating/swallowing/choking, vomiting, dehydration, insomnia, falls/loss of consciousness, and confusion/delirium. The final two items assess whether the caregiver felt the patient had had enough suffering and that there was no obvious value in continuing on in that way or thought the patient had died. Caregivers rated each item on three dimensions: 1) frequency of occurrence of the item in the last month (response options: never, one to two times, five to six times, or daily); and 2) how fearful; and 3) how helpless they felt when the item occurred (response options: not, somewhat, or a great deal). We calculated an SCARED frequency score by summing the frequency exposures rating over the nine experiences (possible range: 0–27). We calculated an SCARED total score by summing the nine exposure ratings weighted by how fearful and helpless the experience made the caregiver feel (possible range: 0–108). Cronbach's alpha was 0.74 for the frequency scale and 0.91 for the response scale for the SCARED assessment focusing on end of life. These alphas are higher than reported in previous studies examining SCARED scores collected at study entry.^{4,7}

Hospice Use

We measured whether the patient received hospice care at home or in a nursing home, hospital, or hospice residence (1 = yes and 0 = no).

Covariates

We controlled for patient demographic and caregiving factors that prior research suggests are linked to hospice involvement and family caregiver burden. Women and adults older than 80 years comprise most hospice patients, and non-Hispanic black and Hispanic persons are less likely to enroll in hospice than non-Hispanic whites.¹ Medicaid and Medicare are the largest payers of hospice care. Being a spousal caregiver is associated with poorer caregiver outcomes such as burden and grief.^{11,12} We controlled for recruitment site by whether the site was a cancer center (yes = 1; 0 = no) and region (New England: Connecticut, New Hampshire, Massachusetts = 1, and Texas = 0). Texas recruitment sites differed from New England in that most Texas participants came from a safety net hospital and were nonwhite (84% vs. 16%) and uninsured (94% vs. 6%). We also controlled for factors that might affect caregiver exposures and response to patient end-of-life experiences,

including caregiver reports of patient physical and mental suffering (0 = none to 10 = great deal).

Analysis

We calculated descriptive statistics for patient baseline characteristics and caregiver assessments of patient's end of life. We report patient characteristics by hospice care and used Chi-squared tests and analysis of variances to identify differences for each. For each outcome—SCARED exposures and psychological responses at end of life—we calculate both bivariate associations using Pearson's correlation. We also use multivariable ordinary least squares regression or linear regression to estimate the association between the key independent variable (hospice use) and two continuous dependent variable outcome measures (caregiver exposure and response to distressing end-of-life experiences, measured by the SCARED frequency and total scores that factored in the fear and helplessness associated with each exposure, respectively). We selected covariates that prior research finds are associated with our dependent variable outcomes (caregiver burden and distress) and the primary independent variable predictor (hospice) and/or that were associated with SCARED frequency of exposures and total scores at $P < 0.05$ (Table 1). We performed postestimation testing to ensure linear regression assumptions were met, including normal distribution of residuals, homoscedasticity, and collinearity. All analyses were conducted using Stata/MP 15.1 software (StataCorp LP, College Station, TX).

Results

Table 2 presents descriptive statistics for the overall sample and by hospice care. Seventy-one percent of patients received hospice care. A slight majority of patients were males (54%), and nearly two-thirds non-Hispanic white (63%). On average, decedents were 59 years old ($SD = 12.2$), had a high school education or less (58%), and were insured (54%). Half of caregivers were married to the patients with cancer (50%). More than half (55%) of patients died in a home setting, and caregivers reported that patients experienced moderately high physical (6.7 of 10) and moderate mental (5.5 of 10) suffering at the end of life. Hospice patients died at home more often than nonhospice patients but otherwise did not differ on key sociodemographic characteristics, physical symptoms, or mental distress at end of life.

Table 3 reports response to individual SCARED items. Caregivers most often reported that patients experienced pain/discomfort (79%), confusion/delirium (75%), and trouble eating/swallowing/choking (73%) in the last month of life. Caregivers also felt fear and helplessness most often with these experiences. Caregivers' weighted mean scores in response to patient pain/discomfort were 2.3 for fear and 3.1 for helplessness. Weighted mean scores for confusion/delirium were 2.34 for fear and 2.69 for helplessness. Caregivers reported thinking the patient had died (41%) and patient vomiting (37%) the least often.

Bivariate associations (Table 1) suggest that hospice care and perceiving patient physical and mental

Table 1
Bivariate Correlations Between SCARED Scale Exposures (Frequency) and Responses (Total Scores), Hospice Care, and Covariates

Sample Characteristics	Exposures (Frequency)		Exposures and Responses (Total)	
	<i>r</i>	<i>P</i>	<i>r</i>	<i>P</i>
Hospice care	0.18	0.02	0.16	0.04
Male	0.03	0.65	0.08	0.29
Non-Hispanic white	−0.06	0.46	−0.07	0.34
Age	−0.10	0.18	−0.15	0.06
Insured	−0.29	<0.001	−0.27	<0.001
Less than high school education	0.08	0.30	0.09	0.23
High school	0.14	0.08	0.13	0.09
Some college	−0.05	0.50	−0.02	0.75
Bachelors or higher	−0.19	0.02	−0.22	0.004
Spousal caregiver	−0.08	0.29	0.03	0.70
Region: NH, MA, and CT (reference = TX)	−0.24	0.002	−0.25	0.001
Cancer center	−0.31	<0.001	−0.30	<0.001
Home death	0.17	0.03	0.12	0.12
Decedent experienced physical suffering (1–10)	0.41	<0.001	0.34	<0.001
Decedent experienced distress/ anxiety/mental suffering (1–10)	0.40	<0.001	0.36	<0.001

SCARED = Stressful Caregiving Response to Experiences of Dying; NH = New Hampshire; MA = Massachusetts; CT = Connecticut.
Bolded text indicates P value <0.05 .

Table 2
Descriptive Statistics of 169 Patients With Advanced Cancer and Informal Caregivers for Total Sample and by Each Key Predictor, Coping With Cancer I

	Sample <i>n</i> = 169	Hospice <i>n</i> = 120	No Hospice <i>n</i> = 49	
Sample Characteristics	Prop/Mean (SD)			<i>P</i> ^a
Outcomes: Stressful end-of-life events				
SCARED frequency (exposures) ^b (<i>r</i> : 0–27)	10.53 (5.68)	11.19 (5.79)	8.92 (5.10)	0.02
SCARED total (exposures and response) ^c (<i>r</i> : 0–105)	29.85 (24.18)	32.29 (25.00)	23.86 (21.10)	0.04
Key predictor				
Hospice care	0.710			
Covariates				
Decedent characteristics				
Male	0.54	0.50	0.63	0.12
Race/ethnicity				0.93
Non-Hispanic white	0.63	0.63	0.63	
Non-Hispanic black, Hispanic, other race/ethnicity	0.37	0.37	0.37	
Age (<i>r</i> : 27–93)	59.37 (12.20)	58.45 (11.48)	61.61 (13.66)	0.13
Insured	0.54	0.52	0.61	0.26
Education				0.61
Less than high school	0.29	0.31	0.24	0.37
High school	0.29	0.27	0.35	0.25
Some college	0.20	0.19	0.22	0.18
Bachelors or higher	0.22	0.23	0.18	0.20
Spousal caregiver	0.50	0.53	0.45	0.37
Region				0.64
TX	0.54	0.55	0.51	
NH, MA, and CT	0.46	0.45	0.49	
Cancer center	0.52	0.49	0.59	0.24
Home death	0.550	0.68	0.24	<0.001
Caregiver perceptions of end of life				
Decedent experienced physical suffering (1–10)	6.69 (3.10)	6.46 (3.19)	7.24 (2.82)	0.13
Decedent experienced distress/anxiety/mental suffering (1–10)	5.51 (3.06)	5.40 (3.19)	5.80 (2.71)	0.45

SCARED = Stressful Caregiving Response to Experiences of Dying; TX = Texas; NH = New Hampshire; MA = Massachusetts; CT = Connecticut.

Bolded text indicates *P* values <0.05.

^a*P* values calculated using Chi-square tests for categorical variables and analysis of variance for continuous variables.

^bSCARED frequency = summed frequency of nine caregiver-reported stressful end-of-life events.

^cSCARED total = summed frequency of nine caregiver-reported stressful end-of-life events, weighted by fearfulness and helplessness the events cause.

suffering were significantly positively related to exposures and responses to stressful experiences at end of life. Being insured or from New England, receiving care in a cancer center, and having a college degree were significantly negatively associated with end-of-life SCARED exposures and stress responses. Home death was significantly positively associated with exposures reported by caregivers but not their stressful responses.

In multivariable linear regression (Table 4), receiving hospice remained significantly associated with higher SCARED exposures ($\beta = 2.21$; 95% CI = 0.51, 3.92) and responses of fear and helplessness ($\beta = 8.69$; 95% CI = 1.06, 16.33). Converting these results to average scores that account for covariates ($Y = \beta_0 + \beta_1 X_1 + \beta_2 X_2 + \dots + \beta_k X_k + \varepsilon$), caregivers of

hospice patients reported an SCARED frequency score of 10.53 compared with 8.96 for caregivers of patients without hospice. Caregivers of hospice patients also reported an average total SCARED score of 29.85 compared with average scores of 23.67 among caregivers of patients without hospice. Having a college degree was associated with fewer SCARED exposures and responses, whereas increased patient physical and mental suffering was associated with more SCARED exposures and responses. Being non-Hispanic white was associated with more SCARED exposures. Receiving care at a cancer center was associated with less SCARED exposure. Adjusted R^2 s indicated that adjusted regression models explained 37% and 31% of the variance in SCARED exposure and response scores, respectively. In sensitivity analyses comparing

Table 3
SCARED Scale Individual Item Responses for 169 Patients With Advanced Cancer

SCARED Item	Exposures					Responses		
	Frequency in Last Month of Life					Fear		Helplessness
	Any Occurrence (%)	Never (0) (%)	One to Two Times (1) (%)	Five to Six Times (2) (%)	Daily (3) (%)	Mean	Weighted Mean ^a	Mean
Pain/discomfort	79	21	13	21	46	0.93	2.30	1.24
Trouble eating/swallowing/choking	73	27	12	21	40	0.96	2.34	1.12
Confusion/delirium	75	25	28	24	23	0.85	1.63	1.05
Thought patient had had enough	68	32	24	14	30	0.85	1.83	1.04
Dehydration	55	45	23	13	19	0.69	1.43	0.73
Insomnia	44	56	9	12	23	0.44	1.11	0.54
Fall/collapsing/passing out	44	56	29	11	4	0.70	1.01	0.66
Thought patient died	41	59	23	11	7	0.69	1.18	0.69
Vomiting	37	63	18	9	9	0.46	0.86	0.56
Total (overall score: 29.85)							13.69	16.16

SCARED = Stressful Caregiving Response to Experiences of Dying.

^aWeighted by frequency of even in the last month of life.

F tests in nested models, including hospice significantly improved model fit for both outcomes. Postestimation suggests that both regression models are well specified. We confirmed normal distribution of residuals in both models using kernel density plots with a normal density curve overlaid and standardized normal probability plots. White's tests for heteroscedasticity and visual plots of residuals against fitted values indicate that heteroscedasticity is not an issue. Collinearity was not present in either model when testing the variance inflation factor.

Discussion

We found hospice was associated with more exposures and heightened negative responses (fear and helplessness) to stressful end-of-life experiences, adjusting for place of death, patient sociodemographic characteristics, and caregiver perceptions of patient physical and mental suffering. On average and accounting for potential confounding factors, caregivers of hospice patients reported 1.6 more exposures to stressful patient experiences and 6.2 more fearful and helpless responses than caregivers of patients who were not in hospice. Increased SCARED exposure and response scores have been linked to increased risk of major depressive disorder in analyses not accounting for hospice care.⁴ Fortunately, in the current analysis, hospice care alone was not associated with a large enough increase in SCARED scores to put caregivers at increased risk for depression. It does, however, contribute to increased caregiver exposure and distress at a time when caregivers are particularly vulnerable. Hospice care relies on the involvement of family caregivers. As the number of persons who die with hospice continues to grow,¹ research is needed to identify why common but potentially distressing end-of-life experiences are potentially scarier for family caregivers of hospice patients and to develop interventions and practice that prevent or address negative caregiver reactions to these experiences.

We found that caregivers report most frequently witnessing patients experiencing pain, delirium, and choking, and that exposures to these patient symptoms result in fear and helplessness, signaling key targets for interventions to reduce caregiver stress. Frequent caregiver reports of patient pain in our analysis are consistent with studies showing pain is common at end of life and among hospice patients.^{13,14} Pain can be difficult to control, even in inpatient hospice settings, where staff experienced in end-of-life pain management are present.^{9,13–16} As the numbers of home and hospice deaths increases, addressing patient pain and negative caregiver reactions to that pain

Table 4
Multivariable Regression Models of Hospice and Exposures and Responses to Stressful End-of-Life Events Using SCARED Scale

Key Predictor	Exposures (Frequency)			Exposures and Responses (Total)		
	<i>B</i>	95% CI	<i>P</i>	β	95% CI	<i>P</i>
Hospice care	2.21	0.51–3.92	0.011	8.69	1.06–16.33	0.03
Covariates						
Decedent characteristics						
Male	0.12	–1.36 to 1.59	0.88	2.31	–4.32 to 8.94	0.49
Non-Hispanic white	2.25	0.48–4.01	0.013	7.81	–0.10 to 15.73	0.053
Age	0.03	–0.03 to 0.09	0.36	0.04	–0.25 to 0.32	0.80
Insured	0.57	–1.88 to 3.02	0.65	2.51	–8.49 to 13.51	0.65
Education						
Less than high school (reference)						
High school	–0.25	–2.21 to 1.70	0.80	–1.31	–10.07 to 7.46	0.77
Some college	–1.28	–3.50 to 0.93	0.25	–4.11	–14.04 to 5.83	0.42
Bachelors or higher	–2.83	–5.02 to –0.64	0.012	–14.92	–24.74 to –5.09	0.003
Spousal caregiver	–0.28	–1.80 to 1.24	0.72	5.00	–1.81 to 11.81	0.15
Region: NH, MA, and CT (reference: TX)	0.81	–2.26 to 3.89	0.60	–1.16	–14.96 to 12.64	0.87
Cancer center	–4.35	–8.06 to –0.65	0.02	–15.33	–31.95 to 1.30	0.07
Home death	1.49	–0.13 to 3.10	0.07	3.28	–3.96 to 10.52	0.37
Caregiver perceptions of end of life						
Decedent experienced physical suffering (1–10)	0.60	0.35 to –0.86	<0.001	1.83	0.69–2.98	0.002
Decedent experienced distress/anxiety /mental suffering (1–10)	0.58	0.33–0.84	<0.001	2.44	1.30–3.58	<0.001
Constant	0.33	–4.55 to 5.22	0.89	–3.06	–24.95 to 18.84	0.78
Adjusted R^2	37.38%			30.60%		

SCARED = Stressful Caregiving Response to Experiences of Dying; NH = New Hampshire; MA = Massachusetts; CT = Connecticut; TX = Texas. Bolded text indicates *P* value <0.05.

will be increasingly important. Although hospice team members report spending substantial amounts of time discussing pain management with family caregivers,¹⁷ we find pain results in fear and helplessness among caregivers. Barriers to pain management include caregiver lack of knowledge about pain assessment, lack of skills for medication administration, and poor communication with the hospice team.^{14,18–20} Educational interventions may improve family caregiver knowledge and decrease concern about pain management,²¹ but providers say they would benefit from additional resources to support caregivers.¹⁸ As pain at end of life can be unavoidable, interventions to improve communication between the hospice team and family caregivers are needed and may ameliorate negative caregiver responses to patient pain.²²

Consistent with other studies, we found caregivers frequently report confusion and delirium in dying patients,^{8,9,23,24} and that caregivers respond with fear and helplessness to patient delirium. Witnessing patient delirium can contribute to caregiver distress^{25–27} and may be more upsetting to caregivers than to patients.²⁸ In patients with cancer, these states may be more common when pain is poorly managed and when pain medications, such as opioids, are administered, and may worsen as death nears.²³ Hospice clinicians can identify and manage delirium with early and repeated assessment.^{29–31} Proactively educating family caregivers about how to identify and address delirium

and revisiting this information regularly could help reduce distress when it occurs.^{31,32}

Consistent with other studies, we found caregivers frequently observe difficulty swallowing and choking in dying patients,³³ resulting in fear and helplessness. More instances of difficulty swallowing and choking may result from ongoing efforts to feed and hydrate dying patients, as hydration has been found to be important to patients and caregivers.³⁴ Speech-language pathologist availability hospice varies widely, underscoring importance of educating nurses in dysphagia care. Hospice nurses often lack knowledge about dysphagia care, which can be improved through training interventions.³⁵ However, dysphagia care best practices of modifying and thickening food can conflict with patient and family member wishes, creating a difficult situation for hospice clinicians³⁵ and underscoring the importance of clear communication-shared decision making between patients, family caregivers, and the hospice team.³⁶ Hospice clinicians may provide caregivers with reassurance and valuable information about safe feeding practices how to address difficulty swallowing and choking when it occurs,^{37,38} as family caregivers often fail to receive relevant information about dysphagia.³⁹ Caregivers may also mistakenly associate choking with the sound that accompanies pooling of secretions in the throat that are common at end of life. Home hospice nurses are well positioned to address this occurrence as

normal and reassure family caregivers that the patient is not suffering, possibly reducing fear or distress that may otherwise accompany observing this common event.

This study has limitations. Caregivers may not accurately recall events that occurred at the end of life. However, there is no reason to expect that recall bias would differ among caregivers based on place of death or hospice receipt. Second, additional research is needed to determine if our findings are generalizable to other caregivers of persons with cancer and caregivers of persons who die of causes other than cancer. The SCARED scale has been successfully used in more general palliative care patient samples⁷ and could be a useful tool in such research. Third, hospice practices may have changed since these data were collected in 2008 to better address the issues we observed. However, multiple studies published that after our data were collected, pain, delirium, and dysphagia are still common at end of life;^{8,9,13,14,23,24,33} family caregiver barriers to symptom management persist;^{14,18–20,35,39} and educational and communication interventions are needed.^{18,22,31,35,37–39} Our analyses uniquely identifies exposures to these symptoms as scary for family caregivers, underscoring the urgency for interventions that target both relieving patient suffering and mitigating negative caregiver responses.

Conclusion

Observing patients with pain/discomfort, confusion/delirium, and difficulty swallowing/choking are common experiences for family caregivers of patients with advanced cancer who receive hospice. Our results suggest that caregivers of hospice patients encounter these experiences more frequently and feel more fear and helplessness when exposed to them compared with caregivers of patients who die without hospice care. Additional research is needed to understand why, in hospice settings, caregivers experience more distress observing common symptoms of dying cancer patients than in nonhospice settings. Hospice providers might offer additional education and training of family caregivers to address hospice patient pain/discomfort, confusion/delirium, and difficulty swallowing/choking, and to inoculate them from the stresses of end-of-life caregiving.

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