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Reaction to Caregiving by Hospice Caregivers Upon Enrollment

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Abstract

Significant research exists demonstrating the challenges faced by informal family caregivers as they care for their loved ones. How caregivers react to this experience, especially in the case of a terminal illness, is less understood. This study explores the reactions of hospice caregivers to their caregiving experience prior to enrollment in hospice and identifies potential stressors associated with those reactions. Results found anxiety to be a significant predictor in the reaction of caregivers to their caregiving experience upon hospice enrollment.

Keywords

hospice; caregiving; caregiver reaction assessment

A significant body of research has found that caregiving precipitates adverse health effects for the caregiver and negatively impacts morbidity and mortality.^{1–5} Negative impacts include anxiety, depression, challenges in social relationships, and physical symptoms.^{6–10} For those caregiving for hospice patients, with a life expectancy of less than 6 months, the burdens can be even greater. Among older informal caregivers (ICGs), the emotional distress of the expected loss of a loved one, the physical demands of caregiving, and the biological vulnerability of older age combine to increase the risk of health problems and early death.^{5,11} The emotional needs of individuals caring for dying persons in their home receive too little attention¹² and very few tested interventions offer support to ICGs.¹³

This research team's current work has revealed significantly high levels of anxiety in hospice ICGs in 3 separate projects. In a combined analysis of 445 ICGs from US hospices in the Northwest, Midwest, and East, we found that 31% had moderate to severe anxiety.¹⁴

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Likewise, data on 288 ICGs in the Midwest and East show that 22% had moderate or severe depression. This is consistent with a systematic literature review concluding that depression is common among hospice ICGs.¹⁵ Given these caregiving challenges, translational research for developing and evaluating interventions for ICGs is greatly needed.¹⁶

Despite the burdens and challenges associated with caregiving, there are also studies showing that caregivers receive satisfaction in assisting their loved ones. Not only can these challenging experiences lead to caregiver satisfaction, but they can also increase confidence and provide opportunities to find and share meaning through loss.^{17,18} Although these reactions to caregiving have been explored for individual disease conditions (dementia, cancer, stroke, etc)^{19,20} and specific relationship experiences (daughter, wife, and son), few studies have looked specifically at the hospice caregiving experience, across diseases and relationship status. A better understanding of the challenges and needs of caregivers when they and their loved ones are being admitted to hospice can better inform the delivery of supportive services to address their situation earlier on. A systematic investigation of biobehavioral and emotional responses to caregiving at or shortly after admission can direct the type and frequency of support services that a caregiver may need during the hospice experience.

Conceptual Model

This study is guided by a conceptual model called Assessing Caregivers for Team intervention (ACT).²¹ This model, modified the original by Pearlin et al,^{22,23} holds that interventions can mediate the impact of primary and secondary stressors on the caregiving experience. The mediation of these stressors can improve outcomes. The model is conceptual and does not suggest causal relationships between the constructs but provides direction in the selection and grouping of factors that have been associated with the hospice caregiving experience.

The *Background context* was conceptualized as those factors that precede or help explain the hospice caregiving experience. It was operationalized in the present study as the caregivers' sex, age, ethnicity, race, marital status, relationship to patient, employment status, and whether or not they reside with the patient. Stress is the process by which we respond to challenges to the body or mind. *Stressors* were conceptualized as the response factors to this stress. They were operationalized as caregivers' anxiety level and changes social, emotional, financial, and physical quality of life, respectively. *Caregiving experience* was conceptualized as how caregivers respond to these stressors. It was operationalized as caregivers' reactions to caregiving.

The purpose of this study was to examine the caregiving reaction of family caregivers of hospice patients when they enroll in hospice and identify potential stressors associated with those reactions. It is also important to note the study does not look at caregiver outcomes at the end of the caregiving experience but rather during the experience as measures are taken upon hospice admission, not at the conclusion of hospice care. The study seeks to answer the following research questions: (1) What background factors are associated with the reaction of caregivers toward the caregiving experience as they enter into hospice care? (2) What

stressors are associated with hospice caregivers' reactions to caregiving? (3) How are background factors and stressors associated with the reaction to hospice caregiving?

Method

Study Design and Sample

This study is a part of an ongoing randomized clinical trial in 2 large hospice programs in a city in the Northwest of the United States. The clinical trial focuses on improving the quality of life for hospice caregivers (R01NR012213). The intervention trial encourages caregivers to identify challenges in caring for their loved one and teaches them a structured problem-solving approach to overcome these problems. Caregivers are randomized into either an attention control group, receiving friendly visits, or 1 of 2 intervention groups taught the problem-solving intervention (face-to-face or via video). The current study examined baseline data collected shortly after hospice enrollment from individuals in all groups.

The study examined 9 possible variables to predict reactions to the caregiving experience. Tabachnick and Fidell²⁴ suggest applying $N > 50 + 8m$, where m is the number of predictor variables, to estimate sample size for multiple regression. This equated to needed sample size of 122 cases.

Study Variables

Demographic characteristics—The following demographic characteristics were considered as background context: sex (0 = *female*, 1 = *male*), age (in years), ethnicity (0 = *non-Hispanic*, 1 = *Hispanic*), race (0 = *white*, 1 = *not white*), marital status (0 = *married*, 1 = *not married*), relationship to patient (adult child, spouse), employment status (0 = *no*, 1 = *yes*), and location of patient (0 = *not with caregiver*, 1 = *with caregiver*).

Caregiver anxiety—Caregivers' anxiety was measured shortly after hospice enrollment using the Generalized Anxiety Disorder 7-Item (GAD-7) scale. The GAD-7 is a 7-item self-report instrument that is scaled from 0 = *not at all sure* to 3 = *nearly every day* with total scores ranging from 0 to 21; higher scores indicate higher levels of anxiety.²⁵ Previous studies²⁵ of the psychometric properties of the instrument have shown excellent internal reliability ($\alpha = .92$). The overall internal reliability of the GAD-7 in the current study was very good ($\alpha = .88$).

Caregivers' quality of life—Caregivers' quality of life was measured shortly after hospice enrollment with the Caregiver Quality of Life Index-Revised (CQLI-R). The CQLI-R is a 4-item self-report instrument that measures social, emotional, financial, and physical quality of life. The caregivers' responses are scaled from 0 = *lowest quality of life* to 10 = *highest quality of life*. Previous studies of the psychometric properties of the instrument have shown acceptable internal reliability ($\alpha = .72$).²⁶ In the current study, the overall reliability of the CQLI-R was acceptable ($\alpha = .78$).

Caregivers' reactions—Caregivers' reaction to caregiving was measured shortly following hospice enrollment with the Caregiver Reaction Assessment (CRA) questionnaire. The CRA is a 24-item self-report instrument with 5 subscales: caregiver self-esteem (7

items), lack of family support (5 items), impact of finances (3 items), impact on schedule (5 items), and impact on health (4 items). The caregiver's responses are scaled from 1 = *strongly disagree* to 5 = *strongly agree*. Each subscale's composite score is the mean of ratings for those items (range from 1–5).²⁷

The original CRA did not include a total score²⁸; however, Grov et al²⁹ created a method for total score, and we replicated this by recoding the self-esteem subscale so that it has the same valence as the other subscales; the higher the total score, the higher the caregiver burden. Previous studies²⁷ of the psychometric properties of the instrument have shown good internal reliability for each subscale ($\alpha = .80-.90$). The overall internal reliability of the CRA in the current study was also good ($\alpha = .80$).

Data Analysis

Descriptive statistics—Frequencies and percentages were calculated for sex, ethnicity, race, marital status, relationship to patient, employment status, and location of patient. Mean and standard deviation [SD] were calculated for age, anxiety, quality of life, and caregiver reactions. Histograms and boxplots were also reviewed to determine the distributions of the study variables.

Missing data—We had complete data for the sex, age, marital status, relationship to patient, employment status, location of patient, and quality-of-life variables. We had missing data for the caregiver reactions (9%), ethnicity (5%), race (<1%), and anxiety (<1%) variables. Multiple imputations through the Markov chain Monte Carlo method³⁰ were used for missing data.

Regression diagnostics—All assumptions for regression were checked including univariate/multivariate normality, homoscedasticity of the residuals, and diagnostic testing for multicollinearity and independence of errors. We detected no multicollinearity problems across the independent variables with the mean level of the variance inflation factor ranging between 1.58 and 1.61 for the different regression models.³¹ We used a clustered sandwich estimator for all analyses.³²

Multiple regression—The first analysis used regression to model the associations between the background and the stressor variables. The second analysis used regression to model the associations between significant background and stressor variables and caregivers' reactions to caregiving. All statistical analyses were performed with Stata 13 for Windows.³³

Results

The sample from 2 hospices in the Northwest was comprised of 204 caregivers from the first 2 years of the study. The caregivers (75% female) were mostly married (77%), white (90%), older (mean = 61, SD = 12.2), and either the adult children (55%) or spouse (31%) of the patients. Approximately half (51%) resided with their patients. Table 1 presents complete caregiver characteristics.

Factors Associated With Anxiety

Age was significantly associated with a decrease of anxiety in caregivers. Caregivers' sex, ethnicity, race, marital status, relationship to the patient, employment status, and whether or not he or she lives with the patient were not associated with caregiver anxiety.

Factors Associated With Quality of Life

Male caregivers were significantly associated with a lower social quality of life. Older caregivers were significantly associated with having higher emotional, financial, and physical quality of lives. Nonmarried caregivers were significantly associated with a lower financial quality of life. Caregivers who were spouses to the patient were significantly associated with lower emotional, financial, and physical quality of lives. Table 2 presents complete information on the associations between background factors and quality of life.

Factors Associated With Reactions to Caregiving

Caregivers with a higher level of anxiety were significantly associated with more negative reactions to caregiving. Male caregivers with a higher social quality of life were significantly associated with less negative reactions to caregiving. Older caregivers with higher emotional, financial, and physical quality of lives, respectively, were significantly associated with less negative reactions to caregiving. Table 3 presents complete information on the associations between background and stressor factors and quality of life.

Discussion

The purpose of this study was to examine the caregiving reaction of family caregivers of hospice patients at the time of enrollment and identify potential stressors associated with those reactions. Our results suggest that older caregivers are less likely to experience anxiety in response to caregiving; that those caregivers with higher levels of anxiety are more likely to experience more negative caregiving experiences; and that older age seems to be a protective factor for retaining a higher quality of life when caregiving.

National data and demographics are not readily available for hospice caregivers; however, the National Hospice and Palliative Care Organization (NHPCO) does report annually on demographics of hospice patients. This limitation in national benchmarks for caregivers makes comparison of our sample to the overall population of hospice caregivers impossible. It is noteworthy, however, that the lack of racial diversity in our sample is also reflected in the overall hospice patient population. The NHPCO reported that 83% of hospice patients were white/caucasian in 2012. Likewise, 90% of this sample of hospice caregivers were white. Although this sample is not representative of minority populations at large, it is comparable to the minority makeup of the population receiving hospice care.

Although the mean age of caregivers in this study is 61, there was a large variance as the range was from 25 to 96 years old. As expected, the experiences gained in aging seem to be reflected in the association found with anxiety, as age appears protective against anxiety in these caregivers.¹⁴

Nearly half (45%) of the caregivers were employed, thus the lack of a significant association between employment and anxiety is surprising. Although it is unknown whether or not the employed caregivers were on family leave, it remains interesting that employment may be a protective factor against anxiety. Further research with hospice caregivers is needed.

The mean anxiety score for all caregivers was 6.7 (SD 4.9), which is considered mild. Total scores of 5, 10, and 15 represent thresholds for mild, moderate, and severe anxiety, respectively, with the GAD-7. Total scores of 10 or higher are generally considered clinically significant, signaling a need for additional evaluation and possible intervention.²⁵ On average, anxiety was not a major problem for these caregivers and thus may not have been an effective variable to represent stressors indicated in the ACT model.

These results indicate that the components of overall quality of life (social, physical, emotional nor financial quality of life) were not predictive factors for caregiver reaction. Anxiety was a predictive factor but in an unusual direction. Our theory would suggest that lower anxiety would correlate with a more positive caregiving experience and this indeed was what we found (at least to the point of hospice enrollment).

Conclusion

This study is a unique exploration of the reaction of caregivers upon enrollment in hospice. The results suggest that practitioners assess caregiver anxiety upon enrollment to hospice as an indication of how caregivers perceive their experience. Age, gender, and quality of life are additional variables that may influence the reaction to the caregiving experience and thus are worthy of attention. Additional research to understand minority perceptions and the influence of employment on caregiving reaction are needed. Finally, additional research to explore how the hospice experience influences the initial caregiving experience is also warranted.

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Table 1

Characteristics of Caregivers.

Characteristics	# of caregivers (n = 204)	%
Sex (male)	52	25
Ethnicity (Hispanic)	14	7
Race (not white)	20	10
Marital status (not married)	47	23
Relationship to patient		
Adult child	112	55
Spouse or partner	63	31
Other	29	14
Employed (full or part time)	92	45
Lives with patient	103	51
Age, in years, mean (SD)	61 (12.2)	
Anxiety, mean (SD) ^a	6.7 (4.9)	
Quality of life, mean (SD) ^b		
Physical	7.2 (2.1)	
Social	7.8 (2.2)	
Emotional	7.3 (2.1)	
Financial	6.9 (2.7)	
Caregiver reactions, mean (SD) ^c	12.45 (2.42)	

Abbreviation: SD, standard deviation.

^aHigher scores indicate higher levels of anxiety.

^bHigher scores indicate better quality of life.

^cHigher scores indicate higher levels of caregiver burden.

Table 2

Background Variables Associated With Stressor Variables.

Stressor variables	Background variables	B (SE) ^a	95% CI for B	P value
Anxiety, n = 204	Male	-1.22 (.87)	-2.95 to 0.5	.16
	Age, years	-0.07 (.03)	-0.13 to -0.01	.03
	Hispanic	-2.78 (2.53)	-7.79 to 2.23	.27
	Not white	-0.7 (1.06)	-2.79 to 1.39	.51
	Not married	0.03 (.97)	-1.88 to 1.95	.51
	Adult child	1.49 (1.01)	-0.49 to 3.48	.97
	Spouse	1.21 (1.21)	-1.17 to 3.6	.32
	Employed	0.12 (.75)	-1.35 to 1.59	.87
	Not living with patient	0.41 (.76)	-1.09 to 1.92	.59
Model statistics	Adjusted $R^2 = .02^b$, $F_{9, 191.4} = 1.53$, $P = .14$			
Social QOL, n = 204	Male	-.87 (.39)	-1.65 to -0.1	.03
	Age, years	.02 (.02)	-0.014 to 0.05	.31
	Hispanic	.41 (.81)	-1.21 to 2.03	.62
	Not white	.13 (.54)	-0.94 to 1.2	.82
	Not married	-.75 (.44)	-1.62 to 0.12	.09
	Adult child	-.21 (.39)	-0.98 to 0.56	.59
	Spouse	-.37 (.53)	-1.42 to 0.67	.48
	Employed	.15 (.32)	-0.48 to 0.77	.64
	Not living with patient	.63 (.37)	-0.1 to 1.36	.09
Model statistics	Adjusted $R^2 = .05^b$, $F_{9, 190.7} = 1.77$, $P = .08$			
Emotional QOL, n = 204	Male	-.45 (.36)	-1.17 to 0.26	.21
	Age, years	.04 (.01)	0.01 to 0.06	.01
	Hispanic	.2 (.78)	-1.35 to 1.75	.8
	Not white	.63 (.59)	-0.54 to 1.79	.29
	Not married	-.76 (.43)	-1.6 to 0.08	.08
	Adult child	-.4 (.44)	-1.23 to 0.46	.36
	Spouse	-1.09 (.53)	-2.13 to -0.05	.04
	Employed	-.29 (.31)	-0.89 to 0.32	.35
	Not living with patient	-.27 (.93)	4.34 to 8	.45
Model statistics	Adjusted $R^2 = .03^b$, $F_{9, 191.7} = 1.79$, $P = .07$			
Financial QOL, n = 204	Male	-.5 (.46)	-1.41 to 0.41	.28
	Age, years	.04 (.02)	0.01 to 0.07	.01
	Hispanic	.71 (1.19)	-1.88 to 3.31	.56
	Not white	-.63 (.79)	-2.18 to 0.92	.42
	Not married	-1.14 (.53)	-2.18 to -0.09	.03
	Adult child	-.2 (.53)	-1.24 to 0.84	.71
	Spouse	-1.45 (.67)	-2.77 to -0.12	.03
	Employed	-.12 (.4)	-0.91 to 0.67	.76

Stressor variables	Background variables	B (SE) ^a	95% CI for B	P value
Model statistics	Not living with patient	-.46 (1.1)	-1.4 to 0.49	.34
	Adjusted $R^2 = .04^b$, $F_{9, 172.1} = 2.01$, $P = .04$			
Physical QOL, n = 204	Male	-.43 (.36)	-1.15 to 0.29	.24
	Age, years	.02 (.01)	0.01 to 0.05	.03
	Hispanic	-.22 (1.42)	-3.03 to 2.59	.88
	Not white	-.49 (.58)	-1.63 to 0.65	.4
	Not married	-.49 (.43)	-1.33 to 0.36	.26
	Adult child	-.23 (.31)	-1.01 to 0.54	.55
	Spouse	-1.61 (.53)	-2.65 to -.57	.003
	Employed	-.23 (.31)	-.83 to 0.38	.45
	Not living with patient	-.23 (.84)	5.09 to 8.42	.55
	Adjusted $R^2 = .04^b$, $F_{9, 192} = 2.29$, $P = .02$			

Abbreviations: CI, confidence interval; QOL, quality of life; SE, standard error.

^aSE robust standard errors.

^bBased on Fisher z transformation.

Table 3

Background and Stressor Variables Associated With Caregiver Reactions (CRA).

Caregiver reactions	Independent variables	B (SE) ^a	95% CI for B	P value
Model 1, n = 204	Anxiety	.18 (.04)	0.09 to 0.26	.01
	Age, years	-.02 (.01)	10.89 to 14.42	.08
Model statistics	Adjusted $R^2 = .14^b$, $F_{2, 56.9} = 14.53$, $P = .01$			
Model 2, n = 204	Social QOL	-.59 (.08)	-0.75 to -0.43	.01
	Male	-1.68 (.37)	-2.42 to -0.94	.01
Model statistics	Adjusted $R^2 = .29^b$, $F_{2, 48.1} = 30.97$, $P = .01$			
Model 3, n = 204	Emotional QOL	-.51 (.09)	-0.7 to -0.33	.01
	Age, years	-.03 (.01)	-0.05 to 0.0004	.05
	Spouse	.32 (.9)	-0.39 to 1.03	.38
Model statistics	Adjusted $R^2 = .2^b$, $F_{3, 146.1} = 16.17$, $P = .01$			
Model 4, n = 204	Financial QOL	-.31 (.07)	-0.45 to -0.17	.01
	Age, years	-.03 (.01)	-0.06 to -0.004	.03
	Not married	.04 (.48)	-0.92 to 1.01	.93
	Spouse	.34 (.36)	-0.38 to 1.06	.35
Model statistics	Adjusted $R^2 = .14^b$, $F_{4, 148.1} = 7.53$, $P = .01$			
Model 5, n = 204	Physical QOL	-.51 (.09)	-0.7 to -0.33	.01
	Age, years	-.03 (.01)	-0.06 to -0.003	.03
	Spouse	-.03 (.36)	-0.73 to 0.68	.94
Model statistics	Adjusted $R^2 = .2^b$, $F_{3, 164.6} = 13.17$, $P = .01$			

Abbreviations: CI, confidence interval; QOL, quality of life; SE, standard error.

^aSE robust standard errors.^bBased on Fisher z transformation.