Exploring the Collective Hospice Caregiving Experience

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Abstract

Background: Collective caregiving, performed by caregivers working in pairs (informal primary and secondary caregivers working together), is common in the hospice setting. Research suggests that caregiving pairs may experience different caregiver outcomes. However, little is known about how caregiving pairs differ from solo caregivers (informal primary caregivers) on outcome measures.

Objective: The goal of this study was to determine whether being in a caregiver pair affected caregiver anxiety and depression and how outcomes changed over time.

Design: A mixed model analysis was used.

Setting/subjects: Hospice caregivers (260 solo caregivers and 44 caregivers in 22 pairs) who participated in a larger, randomized controlled trial completed caregiver measures upon hospice admission and periodically until the death of the patient or hospice decertification.

Measurements: Measured were caregiver quality of life, social support, anxiety, and depression.

Results: Caregiver pairs had higher anxiety and depression scores than solo caregivers. Emotional, financial, and physical quality of life were associated with decreased depression, whereas only emotional and financial quality of life were correlated with lower levels of anxiety. Social support was associated with lower levels of depression and anxiety.

Conclusions: Despite assumptions that social support is positively facilitated vis-a-vis collective caregiving, caregiving pairs may be at higher risk for anxiety and depression. Future research is needed to address why individuals become anxious and/or depressed when working as part of a caregiving pair.

Introduction

ALTHOUGH LITERATURE on the impact of hospice caregiving is extensive, there has been little attention paid to caregiving pairs (informal primary and secondary caregivers working together). Caregiver pairs are often necessary to meet the multitude of caregiving demands, especially for elderly patient population.¹ Among some families, cultural background and beliefs discourage the use of outside professional services to assist with caregiving, resulting in a collective caregiving approach to care.² In rural settings in particular, a primary caregiver's poor physical health is associated with having a secondary caregiver.¹ While collective caregiving is evident in the hospice setting,³ little is known about outcomes associated with this shared experience. Preliminary research on primary and secondary caregivers suggests there is disagreement between caregivers and variation in the collec-

tive caregiving experience that may yield different caregiver outcomes.^{4,5}

Although receiving more help from other family members can ease caregiver stress,⁶ and caregiver closeness positively impacts the collective caregiving experience,² the literature, although scant, reveals contradictory experiences for caregiving pairs. In collective caregiving, disagreement about family members' attitude and actions towards the primary caregiver can create greater conflict and greater risk for depression and anger.⁴ With no differences in reported caregiver efficacy, primary caregivers who had secondary caregivers reported more depression and more caregiver burden.^{4,7} Still, some caregivers report positive relationships with other family members as a result of caregiving,⁸ and siblings report that parental caregiving brought them closer together.⁹ While secondary caregivers experience less caregiver burden than primary caregivers,⁷ they perceive the caregiving situation as more stressful than primary caregivers.⁴

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Within a caregiver's social support network, family dynamics can negatively impact the caregiving experience for both caregiving pairs and solo caregivers (primary informal caregivers). For primary and secondary caregivers, changing roles during caregiving are common and expectations for each person are not always met.¹⁰ Disappointment and frustration can result from role ambiguity and conflict, leading to role strain and stress.^{10,11} When caring for a dying family member, caregivers report that fatigue and tension can manifest in anger toward other family members.¹² The primary caregiver's dissatisfaction with the secondary caregiver can stem from confusion over support given and received.¹⁰ Likewise, solo caregivers report that family members can be unwilling or unable to help with care.¹¹ In these cases, caregiver burden is exacerbated by limited assistance and leads to poor health for the solo caregiver.¹¹

The ACT theoretical framework (Assessing Caregivers for Team interventions)^{13,14} proposes that caregivers experience a variety of stressors that impact caregiving outcomes. The degree of anxiety that occurs as a consequence of caregiving can be counterbalanced by positive experiences gained through support and information. Assuming that more social support leads to better outcomes, collective caregiving could be an external mediator in the caregiving process and thus positively impact caregiver outcomes. The purpose of this study is to compare how caregivers in pairs (informal collective caregivers) experience anxiety and stress during caregiving compared to solo caregivers. Specifically, after controlling for social support and quality of life, does being in a caregiver pair affect anxiety or depression?

Methods

The health sciences institutional review board at the supporting university approved this study. Detailed methods for the ongoing intervention are published elsewhere.¹⁵ Briefly, informal caregivers of patients at two hospices were informed of the study and asked to participate. Multiple caregivers per patient could be enrolled provided each was importantly involved in caring for the patient. Caregivers were not cognitively screened for this study, yet staff deemed caregivers eligible to participate in patient care. Staff assessed patients using the Palliative Performance Scale and excluded those with a life expectancy of less than 14 days from the larger intervention study.¹⁶ After giving informed consent, caregivers for each patient were randomized into usual care or intervention groups (ClinicalTrials.gov registration number NCT01211340). For patients with multiple caregivers, both caregivers were randomized to the same group. Caregivers in the intervention group were invited to attend biweekly interdisciplinary team meetings through a web-conferencing website, www.vifamilies.com. Data were collected from caregivers in both groups at specific times: baseline, two weeks, monthly through month six, and every 45 days thereafter. We included caregivers who were enrolled as of January 31, 2013, using all follow-up assessments collected through March 15, 2013.

Measures

The two outcome measures are anxiety and depression, measured with the Generalized Anxiety Disorder instrument

(GAD-7) and the Patient Health Questionnaire (PHQ-9), respectively.^{17,18} The GAD-7 scale is a sum of seven items scored 0 to 3, where 0 indicates that an anxiety symptom occurred "not at all" during the past week and 3 indicates that the symptom occurred "nearly every day." Total scores range from 0 to 21, where higher values indicate greater anxiety. Psychometric properties demonstrate internal consistency at 0.89. The PHQ-9 is a sum of nine items regarding symptoms of depression scored on the same 0 to 3 scale. Total scores range from 0 to 27, with higher values indicating greater depression. The PHQ-9 has demonstrated strong internal reliability (0.86 and 0.89) with caregivers.^{19,20}

Other follow-up data include the Lubben Social Network Scale (LSNS)²¹ and the Caregiver Quality of Life Index-Revised (CQLI-R).²² The LSNS has two social support subscales, one for family and one for friends. Each subscale is comprised of three items scored 0 to 5; subscale scores vary from 0 to 15, with higher numbers indicating greater social support. The internal consistency for the LSNS is 0.83. The CQLI-R consists of four items evaluating different domains of quality of life: emotional, social, financial, and physical. Each item is scored from 1 to 10, with 1 indicating the lowest quality of life and 10 the highest. Reliability has been measured at 0.94 and internal consistency at 0.77.

Statistical analysis

Statistical software SAS (SAS version 9.3 for Windows; SAS Institute Inc., Cary, NC) was used for all analyses. To avoid deleting observations due to missing variables, categorical variables were imputed to the mode and age was imputed to the mean. We dichotomized caregiver education (high school or less versus greater than high school) and household income (less than \$40,000 annually versus \$40,000 or more) because of nonlinear relationships with the outcome variables.

We compared the demographic characteristics of solo caregivers with those in pairs using the chi-square statistic. The latest available GAD-7 and PHQ-9 scores were compared between these two groups of caregivers using t-tests. We used mixed models (PROC MIXED) to determine whether being in a caregiver pair affected these measures and how they change through time, including all available measures for each caregiver. PROC MIXED can model many types of repeated measures data, accommodate correlated data, and allow specification of different covariance structures. Because we started collecting the GAD-7 and PHQ-9 as of September 15, 2011, the repeated measures models include caregivers enrolled as of this date through the end of January 2013. Repeated measures of anxiety or depression were nested within caregivers. Covariates included the caregiver's age, sex, race, education, employment, income, relationship to the patient (spouse, adult child, or other), whether the caregiver lives with the patient, the family and friends subscales of the LSNS, and all four items from the CQLI-R. All available measures of social support and quality of life were included as time-varying covariates. Caregiver pair status was included as both a main effect (being in a caregiver pair is associated with a difference in score at time 0) and as an interaction with time (being in a caregiver pair affects the rate of change in a score through time).

Results

There were 260 solo caregivers and 44 caregivers in 22 pairs. Caregiver characteristics are shown in Table 1. The

TABLE 1. SUMMARY OF CAREGIVER CHARACTERISTICS, BY CAREGIVER PAIR STATUS [N (PERCENT)]

Characteristic	Caregivers in pairs (N = 44)	Solo caregivers (N = 260)
Sex		
Female	31 (70.4)	200 (76.9)
Male	13 (29.6)	60 (23.1)
Age (years)		
21–40	4 (9.1)	20 (7.7)
41–60	26 (59.1)	117 (45.0)
61 or more	14 (31.8)	123 (47.3)
Race		
Caucasian	38 (86.4)	240 (92.3)
African-American	4 (9.1)	15 (5.8)
Other	2 (4.5)	5 (1.9)
Education^a		
Less than high school	2 (4.6)	27 (10.4)
High school/GED	17 (38.6)	52 (20.0)
Some college/trade school	13 (29.6)	62 (23.8)
Undergraduate degree	7 (15.9)	62 (23.8)
Graduate/professional degree	5 (11.4)	45 (17.3)
Other/unknown	0 (0.0)	12 (4.6)
Marital status		
Never married	3 (6.8)	28 (10.8)
Married	27 (61.4)	179 (68.8)
Separated or divorced	12 (27.3)	36 (13.8)
Widowed	2 (4.6)	15 (5.8)
Other/unknown	0 (0.0)	2 (0.8)
Relationship to patient^a		
Spouse	4 (9.1)	69 (26.5)
Adult child	24 (54.6)	136 (52.3)
Other	16 (36.4)	55 (21.2)
Household annual income		
Less than \$20,000	12 (27.3)	55 (21.2)
\$20,000–\$40,000	17 (38.6)	71 (27.3)
Greater than \$40,000	12 (27.3)	109 (41.9)
Unknown	3 (6.8)	25 (9.6)
Employment		
Full-time	16 (36.4)	76 (29.2)
Part-time	6 (13.6)	28 (10.7)
Retired	8 (18.2)	97 (37.3)
Not employed	8 (18.2)	23 (8.8)
Other/unknown	6 (13.6)	36 (13.8)
Caregiver resides with patient		
Yes	13 (29.6)	114 (43.8)
No	31 (70.4)	146 (56.2)

^aDistribution between groups differs, $p < 0.05$.

majority of caregivers were women, Caucasian, married, or did not live with the patient. Over half of the caregivers in both groups were adult children of the hospice patient. The distribution of relationship to the patient differed between the caregiver groups, with caregiver pairs having fewer spouses and more other relationships than solo caregivers ($p = 0.014$). Almost half of caregivers in pairs had a high school education, while having some college or a college degree was more common among solo caregivers ($p = 0.04$). The means for the latest available measures for anxiety and depression did not differ by caregiver-pair status ($p = 0.22$ and 0.12 , respectively).

The number of follow-up assessments varied from 1 to 16, with 78% of caregivers having two or more. Results of anal-

ysis of repeated measures of anxiety and depression are shown in Table 2. After controlling for caregiver characteristics, social support, and quality of life, being in a caregiver pair was associated with higher anxiety and depression (both $p < 0.02$). Neither time nor the interaction of time with caregiver pair status was statistically significant, indicating that anxiety and depression scores did not change over time and that caregiver pair status was not associated with change in scores over time. Male caregivers scored approximately 2.1 points lower on the anxiety scale ($p = 0.006$) and 2.3 points lower on the depression scale ($p = 0.002$) than women. Being the patient's spouse was associated with greater anxiety, almost 2.9 points higher than other relationships ($p = 0.01$). Similarly, spouses also had mean depression scores that were 2.7 points higher than other relationships ($p = 0.012$). Being the patient's adult child, caregiver age, education beyond high school, higher income, full-time employment, and living with the patient were not statistically significantly associated with anxiety and depression.

In the multivariate model (see Table 2), the family subscale of the LSNS was not associated with either anxiety or depression. The friends subscale, however, was associated with slightly lower anxiety (0.25 points, $p < 0.001$) and depression (0.16 points, $p = 0.02$) scores. Better emotional and financial quality of life were associated with less anxiety (0.68 and 0.04 points respectively, both $p < 0.001$); while social and physical quality of life were not associated with anxiety. Better emotional quality of life was similarly related to lower depression (0.67 points, $p < 0.001$). Better financial and physical quality of life were also both associated with lower depression scores, although to a lesser degree (0.19 and 0.26 points, respectively; both $p \leq 0.02$). Social quality of life was not associated with depression in our analysis.

Discussion

To determine if collective caregiving mediates the caregiving experience by improving caregiver outcomes, we explored whether being in a caregiving pair affected anxiety and depression and how outcomes changed through time. The ACT framework is based on a stress and coping model, wherein the provision of social support facilitated by collective caregiving would presumably aid in coping and thus improved outcomes; however, this study found that caregiving pairs may be at higher risk for anxiety and depression. Prior research has also found that caregiver perception of social support does not decrease psychological symptoms²³ and social support has not been found to be a significant predictor of caregiver quality of life.²⁴ Our own research on hospice caregiving has found that caregivers experience social support burden, defined as the burden associated with accessing and receiving support from others, which often stems from family dynamics.²⁵

Interestingly, we found that caregiver pairs were less likely to be spouses. This contradicts preliminary research on collective caregiving that has suggested that older spouses require assistance and thus utilize secondary caregivers.¹ Given that the preponderance of hospice primary caregivers often emerge from a deep sense of family solidarity and obligation to perform caregiving duties,²⁶ it is possible that spouses decline offers for collective caregiving. Research on caregiving consistently demonstrates that female spouse caregivers have

TABLE 2. REGRESSION ANALYSIS OF REPEATED MEASURES OF ANXIETY AND DEPRESSION ON CAREGIVER CHARACTERISTICS, SOCIAL SUPPORT, AND QUALITY OF LIFE

	<i>Anxiety (GAD-7)</i>		<i>Depression (PHQ-9)</i>	
	<i>Parameter estimate</i>	<i>p-value</i>	<i>Parameter estimate</i>	<i>p-value</i>
Intercept	18.74	<0.001	16.12	<0.001
Caregivers in pairs	2.14	0.018	2.74	0.002
Time (weeks)	−0.024	0.130	−0.023	0.140
Time x caregiver pair	−0.063	0.420	−0.12	0.110
Caregiver characteristics				
Age	−0.061	0.066	−0.028	0.370
Annual income over \$40,000	−0.13	0.860	−0.54	0.460
Education beyond high school	−0.15	0.830	0.40	0.560
Employed full-time	−0.82	0.330	−0.68	0.400
Lives with patient	−0.68	0.360	−0.21	0.770
Male gender	−2.11	0.006	−2.32	0.002
Relationship to patient				
Spouse	2.88	0.0096	2.67	0.012
Adult child	1.44	0.0840	1.16	0.150
Other relationship	reference		reference	
Repeated measures of social support and quality of life				
Lubben Social Network Scale– friends	−0.25	0.0004	−0.16	0.016
Lubben Social Network Scale– family	−0.00065	0.990	0.035	0.660
Quality of life–emotional	−0.68	<0.001	−0.67	<0.001
Quality of life–social	0.048	0.580	−0.0038	0.960
Quality of life–financial	−0.43	<0.001	−0.19	0.020
Quality of life–physical	−0.0092	0.930	−0.26	0.009

The intercept represents the overall mean score across all assessments, while the other parameter estimates represent the change in mean score associated with each characteristic in the model.

^aReference category is other relationship to patient.

GAD-7, Generalized Anxiety Disorder instrument; PHQ-9, Patient Health Questionnaire.

more negative experiences, lower mental health and physical health, and poorer quality of life compared to male spouse caregivers,²⁷ suggesting that the gender of the spouse may be most influential in determining participation in collective caregiving. Research on collective caregiving is still in its infancy, and little is known about how caregiver pairs emerge and are negotiated among informal caregivers.

A review of family caregiving concluded that caregivers experience anxiety, depression, and strain in marital relationships,²⁸ and this study supports prior work that being a spouse and being female is associated with greater anxiety and depression. These findings are consonant with other research on depression illustrating that caregiver spouses are more depressed than others and that women have higher levels of depression than men.²⁹ Gender is a key factor associated with caregiver distress,⁶ with female caregivers reporting more negative life changes resulting from caregiving than men.⁸ Overall, females report higher levels of depression, exhaustion, and role entrapment associated with caregiving.³⁰ We also found that male caregivers had lower anxiety and lower depression. While secondary caregivers tend to be younger and employed,⁷ findings from this study suggest they may also be more likely to be male.

Prior research has found that educational status, physical health status, spirituality, and social support influence caregiver quality of life.²⁴ Caregivers who are able to satisfy their basic needs and can perform daily activities have higher perceived levels of social support and lower psychological symptoms.²³ Similarly, this study found that better emotional and financial quality of life was associated with less anxiety and lower de-

pression. While age and gender are not related to quality of life,²⁴ primary caregiver characteristics that increase the likelihood of there being a secondary caregiver include age (older caregivers), not employed, and scope of the patient's physical dependency.¹ Given that our study findings indicate that spouses experience greater anxiety and higher depression, future research should examine caregiver outcomes among spouses who are part of a collective caregiving effort, as this may account for higher comorbidity rates among spouse caregivers.³¹

Although this study provides preliminary evidence for outcomes associated with collective caregiving, there are limitations. We did not distinguish between primary and secondary caregivers, only that more than one caregiver was involved in the patient's care. As well, it is possible that we were unable to adequately control for confounding in the multivariable analyses. The study is limited by the very small number of pairs relative to the entire sample. Future research is needed to discern if outcome differences exist between these two caregiver types and which one may be more in need of clinical intervention. The strengths of this study include rigorous methods, excellent follow-up with validated instruments, and considering the trajectory of change in anxiety and depression over time, which we have not seen in prior hospice studies.³²

Future research

This study demonstrated that caregivers involved in collective caregiving had higher anxiety and depression than solo caregivers, yet we do not know why caregiver pair outcomes differ from solo caregivers. Current caregiver

intervention research does not sufficiently address collective caregiving, although it has been suggested that secondary caregivers may play a pivotal role in reducing primary caregiver burden and delaying institutionalization of the patient.²⁶ More research is needed to learn about how caregiving pairs address decision making, negotiate care tasks, and interact with each other to provide caregiving support. Caregiver interventions should address the relational benefits of collective caregiving to better strengthen the primary and secondary caregiver relationship.⁸ Finally, most caregiving research to date has included few male caregivers, and there is a gap in our understanding about the male caregiving perspective.³³ Additional research should address the secondary caregiver role to ascertain the challenges present within collective caregiving structures.²⁶

Implications for clinical practice

Although early work on collective caregiving has assumed that secondary caregivers are involved due to the primary caregiver's need for support, our study findings indicate that caregiving pairs do not yield improved caregiving outcomes. Because caregiver disagreement and variability in caregiving pairs is not related to dyadic history, background, or demographic variables,⁴ we encourage clinical focus on the shared roles between caregiving pairs as the patient's needs increase or decrease.¹⁰ Disagreements between caregiving pairs may impede the provision of support offered by collective caregiving, and clinicians should address concerns over the primary caregiver's coping efficacy⁴ or what the secondary caregiver's support consists of for the primary caregiver.¹⁰ We caution clinicians to delve deeper into the rationale that caregiving pairs provide for collective caregiving, especially when limited hospice stays do not afford caregivers time to develop caregiving roles. Learning more about the needs and outcomes associated with collective caregiving may reveal the need to develop targeted interventions or explain why some targeted interventions fail.³²

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