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The social convoy for family caregivers over the course of hospice

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Abstract

Context—Family caregivers provide a central role in the care of those in hospice care. Little is known about the social support networks for those providing this day to day care without training.

Objectives—The purpose of this study was to explore changes in family and friend social networks among hospice caregivers over the course of the hospice stay.

Methods—Data on social support networks was collected as part of a multi-site randomized controlled trial and analyzed using structural equation modeling.

Results—A statistically significant decline in the caregivers' family network subscale score was found over the four-week period during which they received hospice services, reflecting a possible weakening of their family networks.

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Conclusion—This illustrates the potential importance of ongoing comprehensive assessment of caregiver networks and attention to interventions that may assist in both capitalizing on both the quantity of support (numbers of individuals asked to help) and the quality of social support (attending to issues of support burden).

Keywords

Convoy Model; Hospice; Social Networks; Caregivers; Social Support

Almost two million patients and their family members receive services from hospice agencies in the United States each year.^{1,2} The hospice model of care focuses on comfort and supportive care for patients as their terminal illness progresses through its natural course as well as supportive care for patients' family members, irrespective of how patients choose to define "family." In the United States, the prognosis of the patient (less than six months) determines hospice eligibility, independent of his or her specific medical diagnosis.¹ Hospice agencies provide physician services, nursing care, medical social services, home health aides, bereavement support, spiritual support, and volunteer services. The majority of patients receive hospice care in their place of residence.¹

Regardless of the setting in which patients receive hospice services, family members typically play a vital role in providing physical, emotional, and practical care. While many family members may assist in caring for a dying relative, research indicates that primary family caregivers who provide end-of-life care are on average female (78.9%), 64 years old, and are spouses (41.5%) or children (39%) of the hospice patient.³ These caregivers typically experience multiple stressors, including witnessing the progression of the patient's terminal illness, performing caregiving tasks, observing the patient's cognitive and behavioral changes, and feeling guilt and anticipatory grief.⁴ While these difficult experiences may negatively impact the physical and psychosocial well-being of caregivers,⁵ research shows that social relationships can moderate the emotional and physical strain that result from caregiving.⁶⁻⁸ While low levels of social support for caregivers have been associated with higher morbidity and mortality,⁹ higher levels of support have been found to protect against depression.^{10,11,12}

There are many terms found in research literature to describe aspects of social relationships, including *social support*, *social relationships*, *social integration*, *social ties*, *social bonds*, and *social networks*.⁶ At their basic core, social networks are simply constellations of relationships among people, including family relationships as well as friendships.¹³ While, as previously described, the importance of family caregivers' social support has been confirmed by existing research, how individuals' social networks change over the course of their caregiving trajectories has not been thoroughly researched. Similarly, the differences in changes in the specific types of social networks – family or friendships, has not been assessed. These networks develop over time in different ways and may fulfill different needs.

In one related study,⁵ researchers documented an apparent decline in caregivers' perceived social quality of life during the period of time in which they received hospice services. Shortly after their family member enrolled hospice, the mean score of caregivers' social

quality of life was higher than any of the other measured quality of life domains including physical, financial, and emotional quality of life. Thirty days later, however, the mean score of caregivers' social quality of life was the lowest of the four measured domains.⁵ Similarly, in studies of caregivers of individuals with dementia, it has been found that the number of people available to provide social support to caregivers decreased over time.¹⁴ This is consistent with national studies, which suggest that most caregivers spend less time with family members and friends while in the caregiving role.²

Conceptual Model

The convoy model of social relations¹⁵ suggests that individuals are embedded in personal networks of people from whom they receive and provide social support across the life course. Relationships within these social networks vary in terms of characteristics such as their function, closeness, and structure, which are influenced by both personal and situational factors. In ideal situations, the core of one's social network, an inner circle or "convoy" of close family members and friends, provides a protective layer of support that promotes health and well-being.¹⁵

However, research has shown that close social relationships do not always serve a supportive function during times of stress, such as when one is caring for a seriously ill family member. In their study of Chinese family caregivers of individuals with Alzheimer's Disease found that caregivers' positive and negative social exchanges were both higher with members of their "inner-circles" than with those with whom they had more distant relationships.¹⁶ This suggests that, while caregivers' close social relationships may be more intense than other types of relationships, they are not necessarily more positive. In addition, as hospice patients become increasingly debilitated, their ability to provide social support to family members may decrease.¹⁷ For example, a woman caring for her dying mother may be less able to rely on her mother for social support over time, particularly if her terminal condition and her ability to communicate clearly decline. Finally, family members of dying individuals may find themselves less able to provide support for one another because they are all experiencing distress associated with caregiving and with witnessing the decline of a loved one. Thus, hospice family caregivers' social convoys may be less capable of providing social support over time.¹⁷

The purpose of this study was to explore family caregivers' social networks during the period of time they received hospice services. This study addresses the following research questions: 1) How do the sizes of hospice family caregivers' social networks change over time? 2) Are specific socio-demographic characteristics associated with the initial status of and longitudinal changes in the sizes of hospice family caregivers' social networks?

METHOD

Sample

This study was part of a larger randomized clinical trial (described in detail elsewhere¹⁸) testing an intervention for hospice family caregivers. For the current study, we analyzed longitudinal trajectories of social networks for 430 caregivers who were interviewed shortly

after the initiation of hospice services for their family member and again two ($n = 337$) and four ($n = 256$) weeks later. Because almost two-thirds of all hospice patients die or are discharged (i.e., stop receiving hospice services) within 30 days of their hospice enrollment, participant attrition prevented us from examining caregiver social networks for a longer period of time.¹

Measures

Social network—Family caregivers' social networks were measured using the Lubben Social Network Scale (LSNS-6), a 6-item self-report instrument that measures the size, closeness, and frequency of contact with friends and family in a respondent's social network.¹⁹ Sample questions include "How many relatives do you see or hear from at least once a month?" and "How many friends do you feel close to such that you could call on them for help?" Individual items are scored (0 = none, 1 = one, 2 = two, 3 = three or four, 4 = five thru eight, 5 = nine or more) and summed. Overall scores range from 0 to 30, while subscale scores vary from 0 to 15. Higher scores on the overall scale indicate a larger social network and suggest a decreased risk for social isolation. Individuals with total scores less than 12 are considered socially isolated.^{20,21} The internal consistency of the overall scale with our data upon hospice enrollment was good ($\alpha = .84$). The internal consistency of the family ($\alpha = .81$) and friendship ($\alpha = .86$) subscales were also good.

Time-invariant covariates—The following exogenous predictor variables used to predict family caregiver differences were considered: age (in years), caregiver residence (0 = caregiver does not live with the patient, 1 = caregiver lives with the patient), marital status (0 = married, 1 = not married), race (0 = white, 1 = not white), and sex (0 = female, 1 = male).

Data Analysis

Descriptive statistics—Frequencies and percentages were calculated for caregiver residence, marital status, race, caregiver's relationship to the patient, and gender. Mean and standard deviation (SD) were calculated for the total score of the LSNS-6, its family and friend subscales, and age.

Missing data—We had very little missing data on either the outcome variable or the covariates. Missing data were handled using the full information maximum likelihood (FIML) algorithm, which allows the estimation of a likelihood function for each individual case using all the available information in the variables across cases.²²

Linear growth curve modeling—Structural equation modeling (SEM) is a flexible multivariate statistical modeling framework for specifying and testing relationships among sets of variables. Linear growth curve (LGC) modeling is an application of SEM that can be used to study intra-individual (i.e., within-person) and inter-individual (i.e., between-person) trajectories over time by modeling parameters of the trajectories as latent variables.^{23,24}

Unconditional model—We first fitted unconditional LGC models to characterize the trajectories of social network scores of hospice family caregivers upon entry ($n = 430$) and

then subsequently at the second ($n = 337$) and fourth ($n = 256$) weeks. The coefficients of each intercept factor were fixed at 1, which means that the intercept remains constant across time for each individual. The factor loadings for the intercept and slope factors were constrained at 0, 2, and 4 to establish linear trend, which represent the time intervals of initiation of hospice services, two weeks and four weeks later, respectively.

Conditional model—We then fitted conditional LGC models that incorporated time invariant covariates as predictors on the social network trajectories. The social network scores were regressed on age, caregiver residence, marital status, race, and gender to predict the trajectories. The coefficients of the intercepts remained fixed at 1 and factor loadings of the intercepts and slopes constrained at 0, 2, and 4.

Model fit—We evaluated model fit with several recommended indices and cutoff values: Comparative Fit Index (CFI) $.95$; Root Mean Square Error of Approximation (RMSEA) $.06$; Standardized Root Mean Square Residual (SRMR) $.08$, and the Tucker-Lewis Index (TLI) $.95$.²⁵ All statistical analyses were performed with Mplus 7.²⁶

RESULTS

Hospice family caregivers at baseline ($N = 430$) ranged in age from 21 to 91 years and were mostly White (92%), female (78%), or married (70%). Most were adult children (54%) who did not reside with the hospice patient (60%). Caregivers reported that their family networks (9.8, $SD = 3.2$) were larger than their friend networks (8.9, $SD = 3.6$), and that their overall social networks were large (18.7, $SD = 5.8$). See Table 1 for baseline caregiver characteristics.

Research Question 1: How, if at all, do the sizes of hospice family caregivers' social networks change over time? Overall, this sample reported large social networks upon hospice enrollment with a mean LSNS-6 score of 18.7. Caregivers' average family network subscale score upon enrollment was 9.81 and decreased an average of 0.12 over the initial four-week period during which they received hospice services. In contrast, caregivers' average friend network subscale score upon admission was 8.88 and did not significantly decrease (< 0.005) over the four-week hospice stay ($p = 0.944$). Overall, model fit statistics of the unconditional model are excellent (CFI = 0.993, TLI = 0.986, RMSEA = 0.049, SRMR = 0.018). See Table 2 for complete information on the model.

Research Question 2: Are specific socio-demographic characteristics associated with the initial status of and longitudinal changes in the sizes of hospice family caregivers' social networks? Certain socio-demographic characteristics were found to be associated with the initial status of hospice family caregivers' social networks. Specifically, at the time of enrollment in hospice, unmarried male caregivers had smaller family networks, and caregivers living with their patients had smaller friend networks. Other characteristics were found to be associated with longitudinal changes in hospice family caregivers' social network. Older caregivers experienced significant improvement in the size of their family networks during the first four weeks of hospice services, while Non-White caregivers experienced significant decline in the size of their friend networks. Overall, model fit

statistics of the conditional model are excellent (CFI = 0.972, TLI = 0.941, RMSEA = 0.065, SRMR = 0.023). See Table 3 for complete information on the model.

DISCUSSION

This study is a secondary analysis of data collected for another purpose, and is thus limited by the available data. Nonetheless, these data offer an opportunity to explore social networks during a very distinct timeframe for patients and caregivers. It should be acknowledged that the length of time patients are enrolled in hospice is not reflective of the entire health crisis of dying or the preceding life experiences related to the terminal illness journey. However, we believe there is value in understanding the social support networks in the context of this critical timeframe: the final weeks of the terminal illness trajectory.

In this study we explored hospice family caregivers' social networks during the first four weeks of hospice services which, for many caregivers, was comparable to the entire amount of time they received hospice care (median number of days = 28).¹ Results indicated that the size of caregivers' family networks declined during this time, while the size of their networks of friends did not. This suggests that, as the caregiving burden likely increased, the number of supportive family members available to these caregivers decreased.

These findings may be explained, at least in part, by the previously reviewed research on social support and family caregiving. The reduction in family networks, while statistically significant, was quite small (an average decrease of 0.12 family members) and could easily be explained by either loss of support from the patient due to increasing debility¹⁷, negative interactions with family members¹⁶, and/or the inability of distressed family caregivers to provide social support at a level comparable to what they provided in the past.¹⁷ It is important to note that social relationships might ebb and flow over a longer period of time than four weeks, and that the findings from our exploratory study must be interpreted with caution. With that said, these findings appear consistent with well-established theory on stress and family functioning, which indicates that family resources (e.g., family integration, adaptability) that are generally adequate to support family functioning may prove insufficient in the face of significant stressors²⁷ such as caregiving demands and the imminent death of a loved one.

Importantly, we found that the size of caregivers' social networks and changes in the size of these networks varied according to certain socio-demographic variables. Shortly after hospice services were initiated, unmarried male caregivers reported smaller family networks than others and caregivers who co-resided with their dying family member indicated that fewer supportive friends were available to them than their counterparts who lived apart from their hospice patient. With regard to changes over time, older caregivers experienced increases in the size of their family networks in the first month of hospice services, and non-White caregivers experienced a decrease in the size of their friend networks.

Additional research is required to provide logical explanations for these differences. Decidedly little is known about the experiences of male caregivers,²⁸ much less those who are unmarried, making it difficult to suggest reasons the size of their family networks may

be smaller than those of other caregivers. Studies of the general adult population, however, may hold some answers. For example, one study conducted in the Netherlands found that adult women were more likely than men to exchange emotional support with siblings, but only with sisters, not brothers.²⁹ If such a pattern exists among adult siblings in the United States, it may help explain the association between marital status and gender in our caregiver data.

The finding that caregivers who co-resided with their dying family member had statistically significantly smaller friend networks early in their hospice experience but not later is surprising. American society has long been labeled death-avoidant and witnessing another's death is a powerful reminder of one's own mortality,³⁰ suggesting that friends would be less likely to visit a caregiver as their loved one's death grows nearer. It is important to note, however, that while this difference was statistically significant between individuals at the time of hospice enrollment, the change over time was not statistically significant. Additional research is needed to interpret this complex and somewhat unexpected result.

Some socio-demographic differences in the size of social network changes over time are perhaps more aligned with existing research. For example, the increase in family support for older caregivers may be the result of family members rallying around older relatives, whose physical limitations may appear more pronounced as the caregiving role becomes more physically demanding.³¹ Other results, such as the statistically significant decrease in the size of friend networks for non-White caregivers but not White caregivers, require additional research to explain, as little is known about the minority hospice experience.³²

Practice Implications

Caregivers' perceived reduction in family support during the course of hospice presents a number of opportunities for intervention. While this study did not investigate the causes of changes in the size of family networks over time, it is possible that family conflicts played a role in at least some of the cases. Research supports what many health care providers anecdotally report: family conflicts at end of life are far from rare. In a study of interdisciplinary team members caring for low-income older adults in the last six months of life, health care professionals indicated that conflict occurred in over half of their patients' families and was an extremely important factor in 44% of their patients' deaths.³³ In a recent study, 57% of hospice family caregivers reported experiencing some family conflict.³⁴ This suggests that targeted psychosocial interventions, such as family counseling and conflict resolution skills training, might be beneficial offerings of hospice agencies to caregivers. In addition, because a lack of advance care planning has been shown to predict family conflict at end of life,³⁴ encouraging open discussions about one's end-of-life wishes early in the disease trajectory is recommended.

The findings from our study might also have implications for psychosocial caregiver assessments conducted in hospice. The statistically significant changes in the size of caregivers' social networks over time, while marginal, suggest that it might be insufficient to only assess caregivers' social resources at enrollment. Caregivers' social networks and resources might need to be assessed over the hospice stay, and care plans adapted

accordingly, because familial support may decrease just as patient frailty and caregiving demands increase. Additional research is needed in this area.

Finally, these results underscore the profound impact that the death of a significant loved one has on a caregiver. The death of the hospice patient, who quite often has played a central role in the caregiver's social convoy, may have a dramatic impact on the caregiver's social support and well-being. Research indicates that most bereaved caregivers are eventually able to adapt to their loved one's death in healthy ways; thus, experts discourage providing structured interventions to all bereaved individuals, emphasizing the need for an individualized approach based on an ongoing assessment of each caregiver's unique needs.³⁵

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Table 1Baseline Caregiver Characteristics ($N = 430$)

Characteristics	<i>n</i> (%)
LSNS-6, mean (SD)	18.7 (5.8)
<i>Family</i> , mean (SD)	9.8 (3.2)
<i>Friends</i> , mean (SD)	8.9 (3.6)
Age, yrs, mean (SD)	59.8 (12.7)
Lives with Patient (<i>yes</i>)	172 (40)
Marital Status	
<i>Never Married</i>	34 (7.9)
<i>Married</i>	302 (70.2)
<i>Separated</i>	10 (2.3)
<i>Divorced</i>	55 (12.8)
<i>Widowed</i>	26 (6)
<i>Other</i>	2 (<1)
Race and Ethnicity	
<i>American Indian / AK Native</i>	9 (2.1)
<i>African American</i>	22 (5.1)
<i>White</i>	395 (91.9)
<i>More than One Race</i>	2 (<1)
<i>Other</i>	2 (<1)
Relationship to Patient	
<i>Spouse</i>	106 (24.7)
<i>Adult Child</i>	231 (53.7)
<i>Sibling</i>	13 (3)
<i>Parent</i>	4 (<1)
<i>In-Law</i>	23 (5.3)
<i>Other Relative</i>	26 (6)
<i>Professional</i>	4 (<1)
<i>Non-Relative</i>	12 (2.8)
<i>Other</i>	9 (2.1)
Sex (<i>male</i>)	95 (22.1)

Note: LSNS-6 = Lubben Social Network Scale; SD = standard deviation; GED = general educational development.

Table 2

Unconditional Model of Social Support Scores of Hospice Family Caregivers

	Estimate	SE
Family Slope WITH		
Family Intercept	0.100	0.190
Friends Intercept WITH		
Family Intercept	5.386*	0.549
Family Slope	0.032	0.117
Friends Slope WITH		
Family Intercept	-0.107	0.105
Family Slope	0.121*	0.021
Friends Intercept	0.193	0.189
Means		
Family Intercept	9.808*	0.149
Family Slope	-0.122*	0.034
Friends Intercept	8.877*	0.172
Friends Slope	0.002	0.034
Variances		
Family Intercept	7.265*	0.745
Family Slope	0.031	0.079
Friends Intercept	10.271*	0.880
Friends Slope	0.086	0.088
Residual Variances		
Family1	2.833*	0.614
Family2	1.480*	0.276
Family3	2.240	0.732
Friends1	2.874*	0.652
Friends2	2.127*	0.393
Friends3	1.170	0.701

Note: SE = standard error;

* $p < 0.001$; Model fit: CFI = 0.993, TLI = 0.986, RMSEA = 0.049, SRMR = 0.018.

Table 3

Conditional Model of Social Support of Hospice Family Caregivers

	Estimate	SE	Estimate/SE	p-Value
Family Intercept ON				
Male	-0.134*	0.048		
Lives with patient	-0.032	0.052		
Not Married	-0.125*	0.057		
Non White	0.001	0.062		
Age	0.096	0.059		
Family Slope ON				
Male	0.155	0.160		
Lives with patient	0.168	0.163		
Not Married	-0.139	0.176		
Non White	-0.319	0.253		
Age	0.365	0.241		
Friends Intercept ON				
Male	-0.010	0.052		
Lives with patient	-0.123*	0.053		
Not Married	-0.088	0.056		
Non White	-0.001	0.053		
Age	0.061	0.054		
Friends Slope ON				
Male	0.072	0.109		
Lives with patient	0.083	0.109		
Not Married	-0.047	0.108		
Non White	-0.204*	0.104		
Age	0.087	0.112		

Note: SE = standard error;

* $p < 0.01$; Model fit: CFI = 0.972, TLI = 0.941, RMSEA = 0.065, SRMR = 0.023.