

Original Article

The Social Convoy for Family Caregivers Over the Course of Hospice

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Abstract

Context. Family caregivers play 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 were collected as part of a multisite 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.

Conclusion. This result illustrates the potential importance of ongoing comprehensive assessment of caregiver networks and attention to interventions that may assist in 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). *J Pain Symptom Manage* 2016;51:213–219. © 2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Convoy model, hospice, social networks, caregivers, social support

Introduction

Almost 2 million patients and their family members receive services from hospice agencies in the U.S. 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 U.S., 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. Although 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 Although these difficult experiences may negatively impact the physical and psychosocial well-being of caregivers,⁵ research shows that social relationships can

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moderate the emotional and physical strain that results from caregiving.^{6–8} Although 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.^{10–12}

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 Although, 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—have 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, Cheng et al.¹⁶ 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. This suggests that although 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 mother's terminal condition and 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, if at all, does the size of hospice family caregivers' social networks change over time? and 2) Are specific sociodemographic characteristics associated with the initial status of and longitudinal changes in the size of hospice family caregivers' social networks?

Methods

Sample

This study was part of a larger randomized clinical trial (described in detail elsewhere¹⁸) testing an intervention for hospice family caregivers. For the present 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.¹

Measures

Social Network. Family caregivers' social networks were measured using the Lubben Social Network Scale (LSNS-6), a six-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

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