The Hospice Caregiver Support Project: Providing Support to Reduce Caregiver Stress

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Abstract

Introduction: The vast majority (80%) of care provided to hospice patients is given by informal and unpaid caregivers, who are often family members. They may be responsible for everything from management of the household and finances to medical and personal care. Providing this kind of care to a loved one at the end of life can contribute to increased stress, health problems, and decreased quality of life.

Methods: Hospice social workers referred caregivers identified as needing additional support into a special project that funded services not covered by hospice and that the family could not afford to purchase. There were no restrictions on the types of services that could be requested. The Pearlin role overload measure (ROM) was administered and the family selected a service provider from an approved list of agencies. Upon completion of the service period, the ROM was re-administered. Use of the hospice respite benefit by any hospice patient during this study was compared with use before the project began.

Results: Self-reported caregiver stress, as measured by the Pearlin ROM pre- and post-services, decreased by 52% ($t_{122} = 10.254$; $p < 0.0001$). Use of the hospice respite benefit requested by any hospice patient caregiver decreased during the project period (χ^2 , $p < 0.02$), and when respite was requested fewer days were used as compared with the same time period prior to the project (χ^2 , $p < 0.0043$).

Conclusion: The project results show that offering such services relieved caregiver stress, reduced use of respite, and reduced the number of respite days used.

Introduction

HOSPICE CARE is designed to support families and caregivers, as well as patients,¹ yet there are few options available to assist caregivers with their daily responsibilities of patient care. Most caregivers are family members, with some being friends and neighbors, and are commonly referred to as informal caregivers.

The vast majority (80%) of care for individuals with life-limiting illnesses is provided by informal caregivers,² who may be responsible for everything from management of the household and finances to medical and personal care of the patient. Informal caregivers contribute a significant number of hours to the care of individuals at the end of life, with estimates ranging from 43 to 97 hours of care per week.^{3,4} Women who are family caregivers are 2.5 times more likely than noncaregivers to live in poverty and 5 times more likely to receive Supplemental Social Security Income.⁵

Studies have shown the emotional and physical experiences involved with providing care can strain even the most capable caregiver.⁵ This is especially true for caregivers of hospice patients, as they face the dual challenges of providing physical and emotional care for their loved one while also coping with the anticipated death. The impact of caregiver stress on health and well-being is well recognized, and hospice caregivers have identified respite care as being one of their greatest needs.^{6,7} Although most caregivers are generally in good health, they are more likely to have: symptoms of depression or anxiety; a long-term medical problem such as heart disease, cancer, diabetes, or arthritis; higher levels of stress hormones; more sick days due to an infectious disease; a weaker immune response to the flu vaccine; and possible higher risk for mental decline, including problems with memory and attention.^{2,6,8} Distress in caregivers has been associated with decreased caregiver self-efficacy and increased occupational and economic stress⁹⁻¹¹; depressive distress has been associated with being the spouse of the

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patient.¹² Higher levels of mortality have also been found among caregivers.¹³

The goal of the Hospice Caregiver Support Project was to provide in-home support services to informal caregivers of hospice patients, which were not otherwise covered through the patient's insurance and which the family could not afford to purchase. The impact this additional support had on caregiver stress levels and use of the hospice respite benefit was measured.

Methods

Study participants

For purposes of the Hospice Caregiver Support Project, "caregiver" refers to an unpaid informal caregiver who assumed the primary responsibility of caring for a hospice patient at home; this project did not provide assistance to paid (i.e., formal) caregivers. Home was defined as where the patient resided, as long as it was not a skilled nursing or other assisted living facility. The study focused on caregivers/patients 55 years of age or older, because this age group is the largest proportion of hospice users. Other eligibility criteria included ability to communicate in English and the requested service was not covered through insurance. There were no restrictions on the types of services that could be requested and when exploring what would support the caregiver most, social workers were encouraged to be creative. Most caregivers however, requested services that gave them some level of respite, such as time to sleep, run errands, or spend with friends or family (Table 1).

Hospice clinicians are experienced in identifying caregiver stress and risk of burnout as part of their regular interactions with patients and families. Thus, during the 10 months the project was in place, any member of the hospice care team could identify a caregiver in need of additional support. This

assessment guided referrals into the project, which were then coordinated by the patient's primary social worker. The social worker and project director worked together to determine the appropriateness of the service and length of time requested by the caregiver. There was no limit on the length of time services could be provided, and services could be extended. Once approved, the patient's social worker obtained informed consent and baseline levels of stress were obtained. The caregiver then selected a service provider from an approved list of community agencies.

Study instrument

The Pearlin role overload measure (ROM),^{14,15} a four-item measure of caregiver stress ("You are exhausted when you go to bed at night"; "You have more things to do than you can handle"; "You don't have time just for yourself"; "You work hard but never seem to make any progress"), was administered before services were started and approximately 2 weeks after the services ended. Responses from a 4-point scale (not at all = 0, somewhat = 1, quite a bit = 2, completely = 3) were summed to create the overall stress score (range 0 to 12).

Post-services follow-up

Follow-up contact was initiated approximately 2 weeks after services ended. Caregivers were told the reason for the call and reminded of the type of service provided through the project as well as the duration of those services. Qualitative data were collected during the phone call through spontaneously shared comments and responses to the question, "Is there anything you would like to share with us?" Three attempts to contact the caregiver were made, after which they were considered "lost to follow-up."

Data analysis

Data were analyzed using frequency summaries. Inferential statistics, χ^2 , paired student *t*-tests, and multiple regression were performed where appropriate to determine differences. All analyses were performed with SPSS (SPSS Inc., Chicago, IL).

Content analysis was used for qualitative data analysis. Common themes were identified and responses coded by theme. Data were reviewed by the research team and coding decisions were made by consensus.

Results

Two hundred eighty-four referrals for caregiver assistance were made over a 10-month period. Of these, 102 did not receive or were not eligible for service: 49 died before the service started, 16 refused the service, and 37 were not eligible for various reasons (e.g., both patient and caregiver less than 55 years; no caregiver involved; patient transferred to a facility or higher level of care before services began). Of the 182 caregivers who received assistance through the project, 59 were lost to follow-up. Although follow-up could be difficult for several reasons, the primary challenge was connecting with the caregiver after the death of the loved one. The characteristics of the caregivers and patients are presented in Table 2. Data analyses are based on follow-up with 123 caregivers.

TABLE 1. ROLE OVERLOAD MEASURE SCORES PRIOR TO RECEIPT OF SERVICES AND THE TYPE OF SERVICE REQUESTED

Pre-ROM score*	Direct services**	House cleaning	Food/ Meals	Transportation/ Medical equipment/Safety monitoring
0	1	0	0	0
2	0	0	0	1
3	4	0	0	1
4	4	0	0	0
5	6	1	0	0
6	6	0	0	1
7	16	0	1	0
8	14	0	2	1
9	17	0	0	0
10	20	0	1	0
11	16	0	0	1
12	49	2	0	2

*Scale: Not at all=0, Somewhat=1, Quite a bit=2, Completely=3 are summed across the four items to create the overall stress score (0–12).

**Assistance with activities of daily living, taking the patient on outings, patient supervision/companionship.

ROM, role overload measure.

TABLE 2. CAREGIVER AND HOSPICE PATIENT CHARACTERISTICS

Demographics	Caregiver n = 182	Patient n = 182
Sex:		
Female	150 (82%)	88 (48%)
Male	32 (18%)	94 (52%)
Relationship to patient		
Spouse	78	N/A
Child/Child-in-law	75	
Grandchild/Niece	12	
Sibling	5	
Parent	3	
Friend/Other	6	
Unknown	3	
Age*		
90+		35
80–89		59
70–79		50
60–69		26
55–59		6
<55		6
Ethnicity*		
Caucasian		134
Non-Hispanic Black		14
Hispanic		9
Asian/Pacific Islander		7
Other		5
Unknown		13

*Caregiver 55 years or older was noted, not exact age; ethnicity for caregivers was not collected.

Services

Table 3 summarizes the four major areas of services and the number of hours of service provided to the caregivers. The mean number of days of service received was 29 (median: 21; range: 1–175). The great majority of caregivers (90%) received direct assistance with patient care, such as help with activities of daily living and taking the patient on outings. Within this group, most caregivers wanted someone to provide supervision and/or companionship for the patient; 17% requested overnight assistance. A smaller number of caregivers received home delivered meals (4%), whereas others requested house cleaning services (3%). Others (4%) received personal emergency response systems, transportation for patient and caregiver to medical appointments, assistance with the purchase of a specialized piece of medical equipment not covered by

TABLE 3. TYPE AND NUMBER OF HOURS OF SERVICE RECEIVED

Type of service received	Caregivers receiving service N	Hours of service	
		Total hours	Range
Direct services*	164	8378	3–260
Night	44 (17%)	1975	8–240
Day	120 (73%)	6403	3–260
Food/Meals	7	267	9–94
Housekeeping	3	32	4–20
Other**	8	1250	1–640

*Assistance with activities of daily living, taking the patient on outings, patient supervision/companionship.

**Transportation/Medical equipment/Safety monitoring.

insurance (e.g., a lift recliner that allowed the patient to stay home), and purchase of a handicapped placard for a car.

Hospice respite benefit

When comparing the project period (February–December 2009) with the same period the previous year, there were significant decreases in the number of any hospice caregiver using the hospice respite benefit, whether they received additional support or not (57 vs. 46; $\chi^2 = 5.5$, $p = 0.019$; these values represent 7.2% and 5.4% of the average daily census for each year, respectively) and the number of respite days used (350 vs. 252 days; $\chi^2 = 21.7$, $p = 0.0042$). The number of hospice respite days used by the 10 caregivers who received project services as well as used the hospice respite benefit in both 2008 and 2009, decreased from 10.7 to 6.5 days.

Stress reduction

The mean Pearlin ROM score (baseline: 9.33 ± 2.71) decreased significantly after services (post-ROM: 6.15 ± 3.05 , $t_{122} = 10.254$; $p < 0.0001$). No differences in ROM scores were found based on services requested either pre- or post-intervention. There was no relation between stress reduction and the type of service requested, receipt of night services, or the number of hours of service received ($R^2 = 0.01$, standard error of the estimate (SEE) = 3.5, $F = 0.58$ [df = 2106], $p = 0.56$).

Caregiver comments on services

Eighty-nine of the 123 caregivers also provided comments during the follow-up call. A total of 98 comments were collected and categorized as positive (85%), mixed (7%), or negative (8%). The positive comments were categorized into four groups: caregiver, patient, service provider, hospice provider. Themes were then identified within each group.

No demographic or Pearlin ROM differences were seen between the caregivers who provided comments and those who did not. As seen in the total group of caregivers, the majority of caregivers who provided comments were female (83%), 41% were the spouse of the patient, 46% were a child of the patient, and 10% were other family members.

The majority of positive comments were caregiver-focused ($n = 55$; 66%) and fell into five general themes:

1. Allowed the caregiver to get out of the house or take a break (27%):

Real helpful, it was like a weight being lifted off me. Helped me be able to get out without feeling guilty. Good program—too short! [Note: Project ended.]

2. Relieved stress (14%):

I would like to thank you guys, it was such a big relief when you guys came in. It was wonderful. It made mom's last days better because I wasn't so stressed. It helped more than you can imagine.

3. Allowed the caregiver to sleep/relieved exhaustion (14%):

Having the caregivers two nights a week helped a lot. Felt a decrease in stress level, getting a good night's sleep makes a big difference.

4. Felt safer/comforted (7%):

Having a caregiver here when I was showering made me feel safer; I just feel better because I know I had some extra help.

5. General appreciation of services (36%):

Around that time, I had to have stents put in my heart and they [the services] were such a big help because I couldn't give him the type of care that he needed. Without it, I would have been up a creek.

The second most frequent type of positive comment was about the agency and/or the staff provided ($n = 17$; 21%). The majority of the comments were about the quality of care (82%) (*Wasn't expecting all the help, very impressed and very appreciative*), whereas 3 were about the agency (18%).

A small number of comments ($n = 3$, 4%) reflected that the person providing the services had been a good match for the patient (*I was just so grateful that . . . help was on the way. I can't tell you how gentle she was. It was reassuring to my mother to have a woman [of the same ethnicity] take care of her. It was a godsend*). Some caregivers noted their appreciation of the hospice provider ($n = 8$, 8%) for providing the additional service (*It was the best thing you guys could give someone*).

All of the caregivers who provided mixed comments ($n = 7$) were appreciative of the service, but had specific issues with the service provider (*Very helpful overall. The caregiver [provided by the agency] ate several times, one time was an hour late; it's hard having someone in my house*).

Similarly, all but one of the caregivers with a negative comment ($n = 8$) were unhappy with the quality of service provided by the agency (*It was so-so. The day they were supposed to come they didn't come. It wasn't very good; they didn't know how to do a bed bath*). One caregiver was unhappy with the agency staff and the hospice provider (*Didn't do very much. Unhappy with the hospice*).

An unexpected consequence of the project was the empowerment of some caregivers to request additional help from family members, including financial support to continue the services received through the project, as summarized by a hospice social worker who referred a caregiver to the program:

[This service] did give relief, some fun, but now that she has used the three weekends, she realizes even more just how exhausted she is. As a result of this she has called a sibling and asked for caregiver help or money to pay for a [paid] caregiver and states intention to ask other siblings for help 1–2 weekends a month.

Discussion

The Hospice Caregiver Support Project was a pilot program to determine the impact of providing additional in-home support services to caregivers identified as needing additional support by the hospice care team. The results showed that qualitatively the project provided relief to the caregivers, which was supported by the decrease in self-reported stress as measured post-service by the Pearlin ROM. Additionally, the project significantly reduced the frequency and number of days of hospice respite benefit used. In line with caregiver statements reported by other authors,¹⁶ caregivers in the Hospice Caregiver Support Project stated that any additional support was helpful.

These findings show that the provision of additional services through this project reduced the need for hospice patients to be removed temporarily from their home due to caregiver overload, thereby reducing distress experienced by patients and family members. These data are in line with comments from caregivers that keeping their loved one at

home was important, and that the additional services made that possible. Without additional support and assistance, caregivers themselves are at risk of becoming a burden on the system as they may be hospitalized—as several of the caregivers in this project were prior to receipt of services—sustain injuries, and/or become unable to work. A comprehensive cost-benefit analysis was not part of the design of this pilot project. More research on the cost-efficiencies of supportive services versus inpatient hospice respite benefit days is needed to support advocacy efforts for policy changes, to allow funding additional support services for caregivers of hospice patients through the hospice benefit.

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Author Disclosure Statement

No competing financial interests exist.

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