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THE IMPACT OF ADDITIONAL SUPPORT SERVICES ON CAREGIVERS OF HOSPICE PATIENTS AND HOSPICE SOCIAL WORKERS*,†

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Abstract

Family caregivers often suffer higher levels of physical and emotional distress when caring for a chronically or terminally ill family member. Providing this kind of care to a loved one at the end of life contributes to increased stress, health problems, and a decreased quality of life. The *Hospice Caregiver Support Project* provided support services to caregivers identified by the hospice social worker as needing this support and/or assistance. Results from the project show that offering additional services relieved caregiver stress by allowing the caregiver time away from their caregiving role and reducing feelings of guilt and worry, and increased hospice social worker satisfaction with their ability to respond to the needs of hospice patients and caregivers.

BACKGROUND

Family caregivers experience emotional and physical strain while caring for chronically or terminally ill family members (Family Caregiver Alliance, 2003, 2008; Kutner, Kilbourn, Costenaro, Lee, Nowels, Vancura, et al., 2009; Newton, Bell, Lambert, & Fearing, 2002). Caregivers are more likely to have symptoms of depression or anxiety; may be at higher risk for mental decline; and have serious long-term medical problems such as heart disease, cancer, and diabetes, among others (Office on Women's Health, 2008).

Caregivers of hospice patients provide a significant amount of care to the patient, and suffer from higher levels of stress, depression, anxiety, and physical ailments (Chentsova-Dutton, Shuchter, Hutchin, Strause, Burns, & Zisook, 2000; Office on Women's Health, 2008). Not only is this group of caregivers responsible for balancing their personal responsibilities with

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the medical and personal care needs of their loved one, but they also face anticipating their death. With the support of hospice and its focus on the patient and family as one unit of care, caregivers can receive additional assistance from the hospice social worker, who is skilled in providing resources and supportive counseling to patients and families (Centers for Medicare & Medicaid Services, 2010). However, unless a patient or their family have the financial means to hire help, few options exist in the community to offer caregivers “hands-on” assistance with their daily responsibilities.

The *Hospice Caregiver Support Project* was an innovative 1-year grant-funded project that covered costs related to additional services for caregivers of hospice patients, assessed the impact of that support on levels of caregiver stress and how this additional assistance impacted use of the hospice respite benefit. Services provided were tailored to the needs of the patient and caregiver, lasting from just a few hours to several months. At the conclusion of services, research staff followed up with the caregiver to administer a stress scale and gather their thoughts on the services that were provided.

OBJECTIVES

The objective of the *Hospice Caregiver Support Project* was to measure the impact of additional support provided to overwhelmed caregivers.

METHODS

Study Participants

Caregivers were eligible for services as long as they were not paid for their role as a caregiver, were able to communicate in English, the patient or caregiver was 55 years, and the patient was living at home (i.e., not in a skilled nursing or other assisted living facility). These criteria were all put in place by the foundation funding the project.

Social workers played a key role in the project; while all members of the hospice care team were encouraged to identify overwhelmed and stressed care-givers, referrals to the project were coordinated by the primary social worker. The project director was responsible for reviewing caregiver eligibility, appropriateness of the request, and working with community service providers participating in the project. The social worker and project director worked together to determine what services could be provided to alleviate the caregiver’s stress. Prior to the start of the caregiver’s requested services, the social worker obtained the informed consent and administered the role overload scale to determine the caregiver’s baseline stress level.

Post-Services Follow-Up

Approximately 2 weeks after the services ended, research staff contacted caregivers to complete the post-services role overload measure and collect comments they wished to share about assistance received through the project. Three attempts were made to contact the caregiver, after which they were considered to be lost to study follow-up.

RESULTS

In summary, 284 referrals for services were made, of which 182 caregivers received services; 102 (36%) did not receive services for various reasons such as the patient died before the service was able to start, patient/caregiver refused the service, patient/caregiver was less than 55 years, patient transferred to a hospital or skilled nursing facility, or the patient lived alone and had no caregiver. For most caregivers, the requested service was started the day following referral and informed consent; the remaining services started within 2 to 4 days unless the caregiver requested otherwise. A total of 123 caregivers were contacted (68%) post-services. Loss to follow-up was primarily due to death of the patient.

Not surprisingly, 82% of the caregivers were female. Patients were evenly distributed by sex (48% males and 52% females). The great majority of caregivers were related to the patient (95%), with spouses (43%) and children (40%) providing most of the care. Most patients were Caucasian (74%) and 70 years (79%).

Services

Services provided through the project fell into one of four general categories: direct patient care (90%), home delivered meals (4%), transportation/ medical equipment (4%), and housekeeping (3%). Most caregivers (90%) asked for hands-on help with the patient's activities of daily living or supervision of their loved one so they could sleep or leave the house without worrying. Several caregivers requested items associated with patient safety (e.g., purchase of a personal emergency response system or a specialized piece of medical equipment not covered by insurance), and transportation for the patient and caregiver to medical appointments.

Caregiver Feedback

Eighty-nine caregivers (72%) shared feedback during the post-services call. The comments were categorized as positive, mixed, or negative (see Table 1). Content analysis was conducted on each category, and dominant themes were identified.

Positive Comments

Twenty-six (36%) of the 73 caregivers with positive comments stated their stress had been alleviated, noting that getting out of the house or taking a break had helped reduce their stress because they didn't have to worry about the patient.

Crazy helpful, so grateful. Huge impact on stress level. (Daughter of patient)

Gave me a chance to get out without worrying about him. (Daughter of patient)

It was really a lot of help. It gave us time to spend with our family and do errands.
(Son of patient)

Others (11%) noted they were less exhausted because the services allowed them to sleep at night or take naps during the day.

We were awake for 24 hours to care for [patient]. We both work full-time and he needs 24-hour supervision. The program was wonderful. (Son-in-law of patient)

It allowed me to take a nap. I was sleep-deprived because I never left his room.
(Spouse of patient)

A small number of caregivers (5%) reported they were able to do other things around the house because they felt safer or comforted.

It was very helpful and comforting before those last difficult days. ... (Spouse of patient)

It absolutely did make a difference for me in every way. The device gave me more of a security feeling. (Son of patient)

Caregivers were also pleased with the agency and individuals who provided the service ($n = 22$; 30%), specifically noting the quality of care the patient received from the hired caregiver. A few caregivers' comments reflected they felt peace of mind because the individual was a good match for the patient.

We thought they were excellent. All were compassionate. (Parent of patient)

Caregiver was excellent. Patient opened up to him. (Sibling of patient)

Many caregivers (29% of the comments) were appreciative in more general terms:

From an emotional and physical stand-point, it was a lifesaver. (Daughter of patient)

It was the best thing you could guys could give someone. (Spouse of patient)

A small number of caregivers ($n = 8$) noted their appreciation of hospice for providing the service.

Mixed and Negative Comments

Although all the caregivers who provided mixed comments ($n = 8$) appreciated the service, they had specific issues with the paid caregiver or the service provider.

I was extremely happy to have the help. There were times that I was a little bit exasperated, not because of the help but because of the quality of the service.
(Spouse of patient)

All but one of the negative comments ($n = 8$) reflected unhappiness on the part of the caregiver with the quality of service provided by the service agency; one caregiver was unhappy with the paid caregiver and the hospice.

Impact on Social Workers

Initially, the feedback from the social workers was not the original intention; however, it became a valuable element. All of the social workers participating in the project (67% of social workers serving patients in the home-care setting) provided feedback; most verbally, some in writing. It was through their observations that themes emerged about how caregivers were reacting to the help and what challenges, if any, they were experiencing. It was also through their advocacy that the project expanded the variety of support available to

caregivers and improved the way services were being provided by the community agencies contracted for service delivery.

All social workers expressed gratitude and appreciation for access to the extra services. As the project came to an end, the social workers also shared disappointment, as without the grant funding the hospice organization was unable to continue providing these additional services to caregivers.

I can't thank you enough for such [a] wonderful grant. I know this grant saved many family members to do simple things—able to go to the store, take a nap, have restful nights, etc. We take so many things for granted when we are not in crisis.

Considering [the] population in [part of town], we often have many people who have very limited resources (financial, family support). It is wonderful that we have been able to provide custodial care through the grant.

This has been one of the most effective driven projects we've had in my 12 years at [hospice organization]. Our patients and social workers truly appreciated it.

The services were phenomenal and the relief that was shown on the faces of the caregivers was unforgettable. Thank you for giving them the chance to have additional help in the home.

A most sincere thank you. I've been privileged to witness a magical improvement in the spouse's disposition since the beginning of grant homemaker services.

This grant has been such a tremendous help to our patients and families! Too bad it cannot be extended ...

... patients sure benefitted from the grant and we will miss having the resource.

Hope the research is something that can be published to document the need, and the difference such intervention makes for patients and families.

However, the full impact of the extra services as perceived by the social workers is best captured through these stories:

Social Worker 1

[This patient] was a very independent, financially successful, well-educated person who spent his fortune on numerous alternative treatments not covered by insurance. By the time our team met this gentleman, he and his wife were being supported by close friends, as the patient could not even pay the rent. Patient was very tall, about 6'5~, and as his condition progressed his wife (who was considerably shorter) could not assist him. Despite benefiting from the services we could provide, patient and wife needed more help. Their friends could not afford to pay for private hire caregivers, although those services were desperately needed. Patient became significantly depressed, to the point where he became suicidal and had a viable plan. The team provided numerous interventions and the police were involved.

When the option of the [services] was explained, patient agreed to contract for safety, as his most pressing concern was that he was a burden to his wife ... patient

received services for about 2 weeks, then his condition worsened. ... Patient died 2 days later. Having had the opportunity to offer the [services] made all the difference for this family. Having this option was pivotal in patient agreeing to remain safe in his home and contracting for safety. I believe that if the option was not available, patient would have had to go to an in-patient psychiatric facility.

Social Worker 2

I had a ... patient with Alzheimer's Disease who had agitation during the night time. Although there are multiple family members at home, there was only one daughter who was able to provide hands-on care for him. She ended up having insomnia and chronic fatigue because of patient's night time agitation. We provided pcg [primary caregiver] 3 nights per week so that daughter was able to sleep. We received thank you card from this daughter after patient passed away—she says "... I know that my father wouldn't have lasted as long as he did. ..."

I have another who received MOW [Meals on Wheels]. Daughter was not sure initially because she was convinced that patient would not like MOW. She has depression and she was struggling with motivation and breaks for herself. I encouraged her to "just try and see." It turned out that patient liked MOW and the service was able to provide emotional support (daughter did not have to worry about what to prepare, etc.). They ended up continuing w/ MOW with own pay after grant was over.

DISCUSSION

The *Hospice Caregiver Support Project* was a grant-funded project to determine the impact of providing additional in-home support services to caregivers experiencing high levels of stress. Qualitative data showed that services relieved caregiver stress because caregivers were able to take a break, get sufficient rest, and take time for themselves or be with family and friends without worry or guilt. With the support provided by the project, caregivers were also able to continue caring for their loved one, thus allowing patients to remain at home longer.

While assessing hospice staff burn-out was not an objective of this project, studies have shown that the stress faced by hospice staff when they feel there is little else they can offer a patient and their family can lead to burn-out and compassion fatigue (Keidel, 2002). Having this special grant-supported fund for staff to access additional services, even for a short period of time, resulted in many social workers reporting greater satisfaction in their role because they were better able to meet the needs of patient and their caregiver.

IMPLICATIONS FOR PRACTICE

Most patients wish to spend their final days at home and often the challenge to fulfilling this wish is the inability to provide or pay for the care needed to meet their needs. Every hospice social worker has stories of overwhelmed and exhausted caregivers, the lack of community resources available to these care-givers ... and the strain that puts on them as professionals. The *Hospice Care-giver Support Project* was an innovative approach to supplementing the

services available through the hospice benefit by providing the help where it is needed most—at home.

Based on the results of this project, Medicare and other insurance providers are encouraged to consider including supportive assistance to hospice patients and their caregivers. The Medicare Hospice Benefit already provides a 5-day respite stay in a skilled nursing facility; an alternative approach would be to allow that to be used as 5 days of 24-hour in-home care. Not only would this make a difference to patients and their caregivers who, given the option to receive support in their home, may be more inclined to take advantage of the respite benefit, but to the social workers who would be empowered with options for greater support of the patients and families they assist.

Acknowledgments

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References

- Centers for Medicare & Medicaid Services. Medicare Hospice Benefits (CMS Publication No. 02154). 2010. Retrieved August 26, 2011 from <http://www.medicare.gov/publications/pubs/pdf/02154.pdf>
- Chentsova-Dutton Y, Shuchter S, Hutchin S, Strause L, Burns K, Zisook S. The psychological and physical health of hospice caregivers. *Annals of Clinical Psychiatry*. 2000; 12(1):19–27. [PubMed: 10798822]
- Empeño J, Raming NTJ, Irwin SA, Nelesen R, Lloyd LS. The hospice Caregiver Support Project: Providing support to reduce caregiver stress. *Journal of Palliative Medicine*. 2011; 14(5):593–597.10.1089/jpm.2010.0520 [PubMed: 21438707]
- Family Caregiver Alliance. Women and caregiving: Facts and figures. 2003. Retrieved August 2011 from http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=892
- Family Caregiver Alliance. California caregivers: A profile. 2008. Retrieved August 26, 2011 from http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1961
- Keidel CK. Burnout and compassion fatigue among hospice caregivers. *American Journal of Hospice & Palliative Care*. 2002; 19(3):200–205. [PubMed: 12026044]
- Kutner J, Kilbourn KM, Costenaro MA, Lee CA, Nowels C, Vancura JL, et al. Support needs of informal hospice caregivers: A qualitative study. *Journal of Palliative Medicine*. 2009; 12(12): 1101–1104.10.1089/jpm.2009.0178 [PubMed: 19764830]
- Newton M, Bell D, Lambert S, Fearing A. Concerns of hospice patient caregivers. *The ABNF Journal*. 2002; 13(6):140–144. [PubMed: 12592831]
- Office on Women's Health. Caregiver stress fact sheet. 2008. Retrieved August 2011 from www.womenshealth.gov

Table 1

Caregiver Comments Sorted by Theme

Theme	Comments (<i>n</i> = 98)		
	Positive (<i>n</i> = 81, 83%)	Mixed (<i>n</i> = 8, 8%)	Negative (<i>n</i> = 9, 9%)
1. Reduced stress, provided a break	26		
2. Relieved exhaustion	8		
3. Felt safer, comforted	4		
4. Patient/agency related	22		
5. General appreciation of services	21	8	
6. Not satisfied			9