Support Needs of Informal Hospice Caregivers: A Qualitative Study

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Abstract

Background: Informal caregivers of hospice patients experience multiple stressors that can negatively impact physical, psychological, and emotional health. The goal of this qualitative study was to understand caregivers' needs to inform the feasibility, structure, and content of a telephone-based counseling intervention.

Methods: Focus groups and interviews with 36 former hospice caregivers and 11 hospice staff from 6 hospices were conducted. Interviews and focus groups were audio-recorded, transcribed, and analyzed using a constant comparative approach.

Results: Key content areas included coping, emotional support, self-care, logistical issues, and bereavement. Respondents supported telephone-based counseling, appreciating its relative anonymity and convenience. It was recommended that calls be initiated by the counselor, on a weekly basis, and that one counselor be assigned to each caregiver. Hospice staff emphasized the need to coordinate telephone counseling with hospice care, scheduling around and communicating with hospice staff. Most caregivers indicated that they would participate in telephone-based counseling were it available; hospice staff thought that half of caregivers would participate. A pervasive theme was that "there can never be enough support for a caregiver."

Conclusion: Informal caregivers of hospice patients have support needs that are amenable to telephone-based counseling designed to be complementary to existing hospice services. Based on these qualitative findings, we are pilot-testing a telephone-based cognitive-behavioral stress management program for informal caregivers of hospice patients.

Introduction

MULTIPLE STUDIES HAVE DOCUMENTED the emotional and physical impact of caregiving for a loved one who is at the end of life.¹⁻¹⁵ Although families are integral to hospice care, hospices are not able to provide extensive caregiver psychosocial support. We were thus interested in developing an innovative stress-management intervention to improve psychosocial functioning and quality of life of informal caregivers of hospice patients. The goal of this qualitative study was to understand the needs of informal hospice caregivers to inform the feasibility, structure and content of a telephone-based counseling intervention.

Methods

Telephone interviews and focus groups with informal hospice caregivers and hospice staff were conducted between March and November, 2007 by trained research staff who

utilized standardized guides. Informal caregivers were recruited via invitation letters sent from participating hospices to caregivers of patients who had died under hospice care between 3 months and one year prior. Hospice staff were recruited via "word of mouth," fliers, and brochures. Informed consent was completed via telephone or in person; participants received \$25 gift cards. This study was approved by the Colorado Multiple Institutional Review Board (CO-MIRB). Participants were asked about the caregiving experience and for specific feedback regarding the proposed telephone counseling program.

Interviews and focus groups were audio-recorded, transcribed verbatim, and entered into *Atlas.ti* for analysis. A primary coding structure was initially developed based on research questions and conceptual framework; a secondary structure was then developed to code within these primary categories. An inductive approach based on grounded theory allowed themes to emerge. A constant comparative

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method was used to compare new data to existing codes until all data were systematically reduced to codes. Themes and key findings were then developed from these codes. Data were first coded by the primary qualitative analyst, then reviewed and discussed with a second qualitative analyst; agreement was reached on coding categories through an iterative process. Data were next reviewed by the research team; discrepancies were resolved through discussion until consensus was reached.

Results

Characteristics of study participants are depicted in Table 1.

Caregiver needs: Caregiver perspective

Caregivers consistently identified several areas of need: coping, emotional support, self-care, logistical issues, and bereavement. Communication with medical staff and family members, stress management, and accessing resources were also viewed as important. All caregivers noted how extremely difficult caregiving was for them; many saw the value in having someone to talk with at the end of a hard day. One respondent said, when asked about the potential focus for telephone-based counseling:

...just coping maybe. Ways of coping because I was...on auto pilot... I was just in motion physically doing what had to be done...trips to the emergency room and keeping my emotions under control and I felt like I wanted just to...break down but I felt like...for my son I needed to keep myself under control.

Some respondents felt more of a need for support in the realm of logistical issues, such as administering medications, keeping track of appointments, moving and bathing the patient, handling transportation issues, managing financial and legal concerns, and funeral planning. Many said that it was difficult to get all of the "real-life" stuff accomplished while giving care 24 hours per day 7 days per week.

Caregivers also cited the negative impact of caregiving on relationships including feelings of resentment toward family members who did not help and strains on spousal relationships. Many caregivers experienced difficulty asking for help. The role shift from spouse, child, or parent to caregiver was difficult for many. A few felt that they did not have enough information about what was going on while others felt that it was impossible to look at what was happening objectively no matter how much information they had.

Physically, lack of sleep was frequently cited as a challenge; many felt they were physically and emotionally exhausted while they were giving care and were not truly able to assimilate what was happening:

I don't think I slept through the night for the last year and I don't think one realizes that you're at a point of total exhaustion...when he finally died...suddenly you realize...it suddenly hits you that you were physically and mentally finished off to the point where...you can't even really take in what's happening.

Emotionally, feelings of isolation and loneliness were mentioned, as well as doubts and uncertainty about whether they were making the right decisions, or if they were prepared to let the patient go. There was also guilt associated with leaving the patient, even for a short time, to take care of something else:

You can't give that job [caregiving] to somebody else. You can't do that...you can't give it to a hospice nurse... You can't give it to one of your kids...that's a big load to carry and it's exhausting. It wears you out because you can't give it away...you don't want to give it away.

Some respondents cited a sense of hopelessness. The emotional trauma of watching someone you love deteriorate was mentioned as well as strain associated with lack of communication with the patient at the end of life.

After the death, caregivers again cited feeling alone. Some, particularly elderly women who had lost their husbands, said that they did not know how to be self-sufficient after depending on someone for so long. Many thought that they would feel some relief after the death, but did not. Caregivers also described societal pressure to "get over it" and felt like they were only allowed to grieve for a short time. Despite the breadth of challenges faced by caregivers, there was also an emphasis on what a privilege it was to take care of a loved one at this vulnerable time.

Caregiver needs: Hospice staff perspective

Hospice staff echoed many of the needs raised by caregivers, emphasizing particularly: taking care of themselves, trying to do too much, and the conflicted feelings associated with a patient living longer than expected. Hospice staff noted that if a family is not with hospice for very long, they feel that they do not have enough time to adequately address the issues that the family will face after the patient's death.

TABLE 1. PARTICIPANT CHARACTERISTICS

	Caregivers (n = 36)	Hospice staff (n = 11)
Gender, Female	86.1%	90.1%
Ethnicity, White/Caucasian	97.2%	90.1%
Age, mean years (range, SD)	63 (33–83; SD 11.8)	50 (32–82; SD 10.8).
Caregiver relationship to hospice patient:		Not applicable
Spouse/partner	52.8%	
Child	41.7%	
Other family member	5.5%	
Time since caregiving experience		Not applicable
Currently caregiving ^a	5.6%	
Less than 6 months	30.6%	
6 months–1 year	22.2%	
1–2 years	22.2%;	
More than 2 years	19.4%	
Time working in hospice ^b	Not applicable	
One year or less		36.4%
2–6 years		27.2%
More than 6 years		27.2%

^aDespite original enrollment criteria that informal caregivers be at least 3 months removed from the death of their loved one, two participants (5.6%) were still providing care at the time of their study participation.

^bOne respondent did not provide this information.
SD, standard deviation.

Desired structural components of the proposed telephone-based counseling program

Both caregivers and hospice staff supported the use of telephone for counseling, appreciating its relative anonymity and convenience. Caregivers liked the idea that it would be someone who they would never meet and felt that they could express feelings of anger more openly than they could in person. One participant said:

But don't you think as caretakers . . . that there's things we can't say to our neighbors, or our family, our kids, our grandkids or sisters or brothers or even parents if they're still alive? I mean for me there is.

Hospice staff indicated that the telephone counseling program could provide needed psychosocial support, but also asked that it address self-care (i.e., adherence to medical advice, exercise and diet). The telephone was seen as a good way to deliver support since caregivers would not need to leave their loved one to participate. It was recommended that calls be initiated by the counselor, on a weekly basis, and that one counselor be assigned to each caregiver. An *a priori* concern was that the telephone-based counseling complement, rather than duplicate, existing hospice services. Hospice staff emphasized the need to coordinate telephone counseling with hospice care, scheduling around and communicating important issues to hospice staff.

Feasibility of the proposed telephone-based counseling program

Both caregivers and hospice staff thought at least half of caregivers would participate in telephone-based counseling; hospice staff unequivocally supported the concept of telephone-based counseling. A pervasive theme was that: "there can never be enough support for a caregiver." The most helpful aspects of the program were predicted to be: having someone to listen without judgment, venting anger and emotions, knowing others have gone through it and feeling less alone, as well as informational purposes or to get answers to questions quickly.

Discussion

This pilot qualitative study found that informal caregivers of hospice patients have support needs that are amenable to telephone-based counseling designed to be complementary to existing hospice services and that such an intervention would be acceptable to both caregivers and hospice staff. The telephone offers access and convenience and elimination of transportation and geographic barriers. Telephone-based counseling and psychotherapy have demonstrated effectiveness in treating depression^{16–18}; computer-telephone integrated systems and telephone-based support groups have been shown to alleviate distress in caregivers of persons with dementia.^{18–20} Research comparing telehospice programs to face-to-face visits have noted potential cost savings and high patient satisfaction.^{21,22}

While telephone-based counseling is not a new concept, it has not been applied to the needs of hospice caregivers. Based on these qualitative findings, we are pilot-testing a telephone-based cognitive-behavioral stress management program for informal caregivers of hospice patients. A fundamental premise is that the telephone can be used effectively and

efficiently to deliver counseling to hospice caregivers to address their significant unmet needs.

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No competing financial interests exist.

References

1. Aneshensel CS, Pearlin LI, Mullan JT, Zarit SH, Whitlatch CJ: *Profiles in Caregiving: The Unexpected Career*. New York: Academic Press, 1995.
2. Clark AM, Reid ME, Morrison CE, Capewell S, Murdoch DL, McMurray JJ: The complex nature of informal care in home-based heart failure management. *J Adv Nurs* 2008;61:373–383.
3. McMillan SC: Quality of life of primary caregivers of hospice patients with cancer. *Cancer Pract* 1996;4:191–198.
4. Blanchard CG, Toseland RW, McCallion P: The effects of a problem-solving intervention with spouses of cancer patients. *J Psychosoc Oncol* 1996;14:1–21.
5. Coristine M, Crooks D, Grunfeld E, Stonebridge C, Christie A: Caregiving for women with advanced breast cancer. *Psychooncology* 2003;12:709–719.
6. Emanuel EJ, Fairclough DL, Emanuel LL: Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers. *JAMA* 2000;284:2460–2468.
7. Flaskerud JH, Carter PA, Lee P: Distressing emotions in female caregivers of people with AIDS, age-related dementias, and advanced-stage cancers. *Perspect Psychiatr Care* 2000;36:121–130.
8. Chentsova-Dutton Y, Shuchter S, Hutchin S, Strause L, Burns K, Zisook S: The psychological and physical health of hospice caregivers. *Ann Clin Psychiatry* 2000;12:19–27.
9. Schulz R, Beach SR: Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *JAMA* 1999;282:2215–2219.
10. Wright LC, Clipp EC, George LK: Health consequences of caregiver stress. *Med Exerc Nutr Health* 1993;2:181–195.
11. Haley WE: Family caregiver of elderly patients with cancer: Understanding and minimizing the burden of care. *J Support Oncol* 2003;1(Suppl 2):25–29.
12. Schulz R, Newsom J, Mittelmark M, Burton L, Hirsch C, Jackson S: Health effects of caregiving: The caregiver health effects study: An ancillary study of the Cardiovascular Health Study. *Ann Behav Med* 1997;19:110–116.
13. Stroebe M, Schut H, Stroebe W: Health outcomes of bereavement. *Lancet* 2007;370:1960–1973.
14. Christakis NA, Allison PD: Mortality after the hospitalization of a spouse. *N Engl J Med* 2006;354:719–730.

15. Fleming DA, Sheppard VB, Mangan PA, Taylor KL, Tallarico M, Adams I, Ingham J: Caregiving at the end of life: Perceptions of health care quality and quality of life among patients and caregivers. *J Pain Symptom Manage* 2006;31:407–420.
16. Simon GE, Ludman EJ, Tutty S, Operskalski B, VonKorff M: Telephone psychotherapy and telephone care management for primary care patients starting antidepressant treatment: A randomized clinical trial. *JAMA* 2004;292:935–942.
17. Sandgren AK, McCaul KD: Short-term effects of telephone therapy for breast cancer patients. *Health Psychol* 2003;22:310–315.
18. Eisdorfer C, Czaja SJ, Loewenstein DA, Rubert MP, Argüelles S, Mitrani V B, Szapocznik J: The effect of a family therapy and technology-based intervention on caregiver depression. *Gerontologist* 2003;43:521–531.
19. Bank A, Argüelles S, Rubert M, Eisdorfer C, Czaja S: The value of telephone support groups among ethnically diverse caregivers of persons with dementia. *Gerontologist* 2006;46:134–138.
20. Salif J, Ploeg J, Black ME: Seeking to understand telephone support for dementia caregivers. *West J Nurs Res* 2005;27:701–721.
21. Cook DJ, Doolittle GC, Whitten PS: Administrator and provider perceptions of the factors relating to programme effectiveness in implementing telemedicine to programme effectiveness in implementing telemedicine to provide end-of-life care. *J Telemed Telecare* 2001;7(Suppl 2):17–19.
22. Whitten P, Doolittle G, Mackert M: Telehospice in Michigan: Use and patient acceptance. *Am J Hosp Palliat Care* 2004;21:191–195.

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