

Interventions to Facilitate Family Caregiving at the End of Life

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ABSTRACT

Informal family caregivers provide care in a variety of situations, including care for patients receiving active curative treatment for cancer and other life-threatening diseases, for Alzheimer's patients over the long trajectory of their disease, and for hospice patients who are near the end of life. Especially at the end of life, these caregivers are essential because they provide needed help with activities of daily living, medications, eating, transportation, and emotional support, as well as communicating with health care professionals about the patients' condition. As health care increasingly moves out of acute care settings and into homes, the role of the caregiver becomes more critical and the burden becomes heavier.

There is a paucity of data regarding which caregivers are at greatest risk for distress and which interventions are likely to relieve that distress. Although both educational and supportive interventions have been tested, including both telephone and face-to-face meetings, it still is not clear which approach is best for which groups of caregivers. Much of the research that has been done has been descriptive and evaluative, and only a very limited number of clinical trials have been conducted with caregivers of patients near the end of life. There is limited evidence about whether caregiver interventions at the end of the patient's life have the potential to provide long-term benefits to caregivers. In addition, issues exist in adapting such interventions to work with culturally diverse populations. Sadly, there appears to be a limited number of investigators doing this important work. More research is needed to provide complete evidence on which to base practice and policy decisions.

INTRODUCTION

INFORMAL FAMILY CAREGIVERS provide care in a variety of situations, including care for patients receiving active curative treatment for cancer and other life-threatening diseases, for Alzheimer's patients over the long trajectory of their disease, and for hospice patients who are near the end of life. Especially at the end of life, these caregivers are essential because they provide needed help with activities of daily living, medications, eating, transportation, and emotional support, as

well as communicating with health care professionals about the patient's condition.¹⁻⁴ As health care increasingly moves out of acute care settings and into homes, the role of the caregiver becomes more critical and the burden becomes heavier. Although there are rewards involved for the caregiver, serving as a caregiver over a period of time can be stressful, negatively affecting many aspects of quality of life.

Two general types of studies contribute to the current knowledge base for facilitating family caregiving: (1) descriptive research that details

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who provides informal family care and identifies relevant patient and caregiver outcomes; and (2) intervention research designed to improve patient and caregiver outcomes by increasing caregiver skills, reducing stress, and enhancing coping ability.

Descriptive research

Who provides informal care. In many cases, the caregiver is a spouse. In their study of terminally ill patients, Emanuel and colleagues found that 54% of caregivers were spouses.⁵ In our work with hospice patients with cancer, we have found 60% of the caregivers were spouses, with wives accounting for most of that number at 44%. The mean age of our patients was about 71 years and caregivers were about a decade younger, on average.^{6,7} However, this gives a somewhat distorted picture. The younger mean age is to some extent a reflection of the caregivers who are likely to be adult children, thus pulling the average down. Only 20% were adult children and the remaining 19% reported other types of relationships. About 33% of caregivers were between 70 and 91 years. So, in reality, many of these caregivers are as old as the patients and often very frail themselves. In addition, they have myriad health problems of their own to manage, even as they attempt to care for an ill spouse. However, we also should note that 23% of our caregivers were in the age group of 20–49 years, and we do not yet know what special problems and needs this group of younger caregivers might have.

Caregivers as a source of data. As previously noted, these caregivers frequently are a source of information about the patient.⁸ However, our research with cancer patients in hospice care reveals that although nurses report depending on caregivers for data about patients, those data are frequently unreliable. We have found that there are only weak-to-moderate correlations between patient and caregiver reports, with caregivers reporting symptoms to be more severe than do patients.⁹ This suggests a need to train caregivers to report more accurately patient symptoms and problems.

Caregiver needs. Descriptive research about caregiver needs is summarized in Table 1. Studies have shown that all aspects of caregiver quality of life may suffer, including physical

well-being, emotional well-being, and social well-being.^{6,10,11} Caregivers may experience anxiety, depression, physical symptoms, restrictions of roles and activities, strain in marital relationships, and diminished physical health.^{2,10,12–13}

Research has found that ineffective coping and decreased social support for caregivers are associated with increased caregiver depression.¹⁴ Furthermore, patient characteristics such as increasing levels of immobility, depression, symptoms, symptom distress, and dependencies in activities of daily living have been associated with increased depression in caregivers,¹⁴ although these relationships have not always been found to be strong.^{15,16}

Many caregivers of persons with cancer exhibit not only psychological distress but physical symptoms as well. Caregivers are more likely to be distressed when patients are in more advanced stages of cancer and have more symptoms, greater loss of physical function, and more complex care needs. Furthermore, as the physical condition of the patient worsens, greater demands for personal care, instrumental tasks, and transportation are made on caregivers. These increasing demands are associated with greater perceived burden for the caregivers.^{17,18}

Caregiving also can result in economic burden for caregivers. Emanuel and colleagues¹ surveyed 988 terminally ill patients, 52% of whom had cancer, along with 893 primary caregivers. Identified needs of these patients included transportation, nursing care, homemaking, and personal care. Caregivers of patients with substantial care needs were more likely to report greater economic burden. Some caregivers described economic burden to include selling assets, taking out a mortgage, using savings, or taking an additional job.

In a study of 152 caregivers of patients with cancer who were near the end of life, 65% of caregivers were spouses.¹⁹ However, the investigators found that caregivers in the age groups between 45 and 54 years reported the highest levels of depressive symptoms. Furthermore, the investigators found that caregivers who were the adult children of patients (26% of the sample) and caregivers who were employed (28% of the sample) were more likely to be depressed. Caregivers of patients with multiple symptoms reported a high perception of disruption in their schedules because of providing care. Caregivers of patients who were closer to death reported the highest

TABLE 1. CAREGIVER NEEDS REVEALED BY DESCRIPTIVE STUDIES IN CHRONOLOGICAL ORDER

<i>Reference Results: caregiver needs</i>	
Given et al., 1993	Cancer caregiver depression was associated with patient depression.
McMillan and Mahon, 1994	Cancer caregiver quality of life was lower among hospice caregivers compared to non-caregivers and lower also for caregivers of patients with more advanced disease and lower functional status.
Kurtz et al., 1994	Among cancer caregivers, there is a weak but significant relationship between patient symptoms and caregiver depression, and between patient depression and caregiver health.
Given et al., 1999	Cancer caregiver depression was associated with new or increasing demands for assistance.
Weitzner et al., 1999	Hospice caregiver quality of life correlated with overall caregiver mental health.
Emanuel et al., 2000	Needs of terminally ill patients included transportation, nursing care, homemaking, personal care. Caregivers of patients with substantial care needs were more likely to report higher economic burden.
Nijboer et al., 2000	Cancer caregivers' experiences are both positive and negative. More negative experiences are reported by women, younger caregivers, and caregivers with higher socioeconomic status.
Robinson-Whelan et al., 2001	Dementia caregivers experienced depression and loneliness for up to 3 years after the death, with levels similar to current caregivers.
Haley et al., 2001	Hospice caregivers of patients with lung cancer reported same levels of depression as hospice caregivers of dementia patients and both reported more depressive symptoms than non-caregivers.
Haley et al., 2003	Among hospice caregivers, female gender, caregiver health problems, and negative social interactions predicted poorer caregiver well-being.
Schulz et al., 2004	Dementia caregivers showed no improvement in depression or anxiety after institutionalizing the demented family member.
Given et al., 2004	Cancer caregivers of patients near the end of life reported depressive symptoms which were highest in the 45-54 years age group, in caregivers of patients who were nearer to death, in adult children, and in those who were employed. Caregivers of patients with multiple symptoms reported the greatest disruption in their schedules.

levels of depressive symptoms, burden, and impact on schedule.

There is evidence that caregiving may lead to sustained distress related to problems that began during caregiving.²⁰ Research suggests that some caregivers, particularly those who experience very high stress while caregiving, do not show increases in depression after the death of their loved ones and may even show improvements in certain aspects of their health.^{21,22} However, other caregivers have long-term depression that is sustained as much as 1 year after highly stressful caregiving ends.²⁰ The depletion of caregivers' resources, alterations in social supports and activities, and the lingering reminders of caregiving and loss may make the bereavement process more difficult for some caregivers.

In summary, descriptive studies have revealed some of the variables that need focus in future intervention studies. The outcome variables include overall quality of life as well as depressive symptoms, burden, distress from patient symptoms, loneliness, anxiety, marital strain, economic burden, and physical and mental health (Table 2).

Furthermore, variables that enhance or decrease caregiver outcomes also should be included in studies. These variables include caregiver characteristics such as coping style, social support, age, employment status, and knowledge about both symptoms and disruptive behavior, as well as patient characteristics including stage of disease, proximity to death, symptom distress, immobility, and depression.¹⁻²²

Intervention studies

Interventions for Alzheimer's patients caregivers. Although limited research has been conducted with caregivers in hospice care and other settings where end-of-life care is provided, intervention studies with Alzheimer's disease (AD) caregivers across the disease trajectory may shed some light on which approaches to supporting caregivers would be effective. Although these studies were not all conducted with patients who were near the end of life, they are worth reviewing here.

Several recent reviews document that interventions with dementia caregivers demonstrate

TABLE 2. OUTCOME AND RELATED VARIABLES TO EVALUATE IN CAREGIVERS OF PATIENTS NEAR THE END OF LIFE

<i>Outcome variables</i>	<i>Related variables</i>
Quality of Life:	Caregiver characteristics
Physical well-being	Coping style
Psychological well-being	Social support
Social well-being	Age
Spiritual well-being	Employment status
Depressive symptoms	Health
Burden	Knowledge about symptom assessment
Loneliness	Knowledge about symptom management
Anxiety	Knowledge about managing disruptive behavior
Distress from patient symptoms	Patient characteristics
Marital strain	Stage of disease
Economic burden	Proximity to death
Physical health	Symptom distress
Mental health	Complexity of care needs
Mastery of caregiving	Immobility/functional status
Satisfaction in caregiving	Depression

clinically significant effects in decreasing caregiver depression and improving other aspects of well-being that are long-lasting.^{23,24} Mittelman and colleagues²⁵ studied 406 spousal caregivers providing homecare to AD patients. After controlling for baseline differences, caregivers in the group that received the supportive intervention had significantly fewer depressive symptoms after the intervention compared to the controls. Results indicated that the intervention had an increasingly stronger effect on depressive symptoms in the first year after enrollment in the study. These effects were sustained for 3 years after enrollment, were similar across gender and patient severity levels, and persisted after nursing home placement and death of the patient.

Sorenson and colleagues²⁴ conducted a meta-analysis of 78 caregiver intervention studies that included largely dementia caregivers but also included studies with heterogeneous samples including caregivers of elderly individuals, stroke victims, and patients with cancer. The results showed that psychoeducational interventions and psychotherapy had a significant effect on all caregiver outcome variables including burden, depression, subjective well-being, uplift (satisfaction in caregiving), and ability/knowledge. Supportive interventions reduced caregiver burden and increased ability/knowledge. Educational interventions increased caregivers' subjective well-be-

ing and reduced the patients' symptoms, but no significant effects were seen in reducing burden or depression or increasing ability/knowledge. Multicomponent interventions showed significant effects on burden, well-being, and ability/knowledge, but not on depression.

The Resources for Enhancing Alzheimer's Caregiver Health (REACH) study was an National Institutes of Health (NIH)-funded multisite study of caregivers of patients with dementia that evaluated the effectiveness of six structured interventions implemented at six sites around the U.S.²³ The interventions were variations of educational and support methods with some sites using computerized or telephonic technology. All interventions were found to be effective in improving some of the outcome variables assessed. In addition, these studies demonstrated that ethnically diverse dementia family caregivers show substantial benefit from caregiver interventions that incorporate culturally appropriate modifications to psychoeducational interventions.²⁶ The REACH samples, however, consisted of caregivers of patients who had mild-to-moderate cognitive impairment.²⁷⁻³¹ Thus, most were not considered to be near the end of life. Furthermore, some of these interventions involved caregiver group meetings, something that we have found to be impossible with caregivers of hospice patients who are much nearer to death. Hospice caregivers often are reluctant to leave patients alone even for short periods of time, so a group meeting is not feasible. However, the computerized and telephonic interventions deserve further scrutiny, and the multisite approach to include varied cultural groups could be a model for future intervention research with caregivers of patients near the end of life.

Interventions for caregivers near the end of life. Much of the end of life care in the United States is provided by hospices whose focus is on both patients and families. Often a family member is the delegated primary caregiver. Although some intervention research has been successfully conducted with caregivers of Alzheimer's disease patients, little has been done with caregivers of patients in hospice and other end-of-life settings. Intervention studies with cancer caregivers have sometimes included patients receiving palliative care, although these studies were not always specifically designed to focus on care at the end of life. These studies have offered two types of

TABLE 3. INTERVENTIONS USED WITH CAREGIVERS AND OUTCOMES IN CHRONOLOGICAL ORDER

<i>Reference</i>	<i>Intervention</i>	<i>Outcomes</i>
Goldberg and Wool, 1985	Twelve sessions of counseling support for caregivers of newly diagnosed lung cancer patients	No impact; only higher-functioning couples participated
Heinreich et al., 1985	Stress and Activity Management (SAM) for cancer caregivers focused on education, coping and problem-solving	Significantly better knowledge scores in treatment group
Ferrell et al., 1995	Cancer Pain Management education for cancer caregivers	Caregiver knowledge and quality of life improved at post-test
Blanchard et al., 1996	Coping with Cancer: Individual counseling; six 1-hour sessions for cancer caregivers	Significantly less depression in spouses in treatment group
McCorkle et al., 1998	Oncology Home Care: advanced practice nurses (APNs) taught symptom management vs. standard care or standard home care for cancer caregivers	Significantly less distress in intervention (oncology advance practice nurse home care) group
Smeenck et al., 1998	Transmural homecare intervention program for end-stage cancer patients and caregivers by a specialist nurse coordinator with continuity of care from hospital to community via telephone support	Quality of life was significantly higher in caregivers in the intervention group
Jepson et al., 1999	SNIP: advanced practice oncology nurses taught symptom management to cancer caregivers	Improved psychological status in treatment group
Kozachik et al., 2001	Nursing intervention to teach cancer caregivers to manage symptoms	No improvement in caregiver depression
McMillan et al., 2004	COPE: An educational intervention for hospice caregivers focused on coping with symptoms	Increased quality of life and mastery, and decreased burden from tasks and burden from symptoms in treatment group caregivers compared to controls

interventions: (1) educational or (2) supportive, or a combination of the two.

Educational interventions. Kozachik and colleagues³² and McCorkle and colleagues³³ have focused on nursing interventions with the nurses providing specialized education and symptom management for patients with cancer and their caregivers. These clinical trials had different outcomes. One found no effect of the intervention on caregiver depression,³² whereas the other found significant reduction in spousal distress after the death in the intervention group, and that effect was sustained for 13 months.³³ Ferrell and colleagues³⁴ studied the effects of cancer pain education by nurses on 50 caregivers of elderly patients experiencing cancer pain, 35% of whom were receiving palliative care. Results showed a significant improvement in pain knowledge and quality of life among caregivers from pre- to post-test. Jepson and colleagues³⁵ developed a program in which advanced practice oncology nurses taught symptom management to cancer caregivers to assist them with managing patient

symptoms. However, not all of these caregivers were caring for patients near the end of life. These investigators reported improved psychological status in the caregivers in the treatment group.

Supportive interventions. A 12-session counseling support intervention reported by Goldberg and Wool³⁶ showed no effect for spouses of patients with newly diagnosed lung cancer. However, it was noted that only highly functioning couples volunteered for the study, biasing the results. Heinrich and Schag³⁷ offered a Stress Activity and Management (SAM) intervention to cancer caregivers that was focused on education and coping as well as problem solving. Results showed significantly better knowledge scores in the treatment group. Coping with Cancer was the name given to the intervention offered to spousal cancer caregivers by Blanchard and colleagues.³⁸ The intervention involved individual counseling in six 1-hour sessions. At the end of the study, investigators found significantly less depression among caregivers in the treatment group.

A homecare intervention program was pro-

vided by a specialist nurse coordinator for end stage cancer patients and their caregivers in the Netherlands.³⁹ An individualized patient management protocol was developed for each patient to be used across the disease trajectory. The coordinator ensured continuity of care from hospital to community via telephone support that was available 24 hours per day from the hospital at which the patient received care. Quality of life was significantly higher in caregivers in the intervention group compared to the standard care group at 1 week after hospital discharge and at 3 months after the patient had died. However, it should be noted that the sample was small and was not randomized to experimental conditions.

A small pilot study of caregivers of patients with cancer included caregivers of 14 patients near the end of life. The intervention was offered by a nurse via teleconference calls. However, because of patient death and caregiver burden, only five caregivers completed the study. Results indicated that telephone conferencing with hospice caregivers is feasible.⁴⁰

A recent clinical trial was conducted that tested a cognitive behavioral intervention designed to help caregivers to provide better management of symptoms in the cancer patients for whom they were providing care.⁴¹ The investigators found that caregivers in the intervention group who were depressed at baseline were more likely to report a negative reaction at 10 weeks than those in the control group. In addition, they found that depressed male caregivers were less able to benefit from an intervention than male and female caregivers who were not depressed.

Our group in Tampa recently completed clinical trial to test a psychoeducational intervention for hospice caregivers called Creativity, Optimism, Planning, Expert Guidance (COPE). The intervention, which combined education with support, involved hospice nurses teaching caregivers how to cope with specific patient symptoms during three visits over 7–9 days. There were two control groups; one received standard hospice care, and the other received a supportive intervention designed to control for the effect of time spent with the caregivers. We found the intervention group to have significantly better outcomes compared to the groups receiving standard care or standard care with supportive visits. Specifically, caregiver quality of life was increased, whereas burden from caregiving and caregiver distress from patient symptoms were significantly decreased.⁷

The problems confronting investigators who work with populations near the end of life include both limited accrual and high attrition. Although we were conducting the clinical trial of the COPE intervention for hospice caregivers, we screened every patient admitted to the very large hospice where we were conducting the study, and called those who fit our inclusion criteria. Through this all-inclusive process, we accrued 5% of admitted patients and caregivers to our study, a strategy that still caused us to be short of our goal of 480 patient/caregiver dyads. Of course, many patient/caregiver dyads were not appropriate for the study because the patient had no cancer diagnosis or was too debilitated to participate. However, a large number of dyads refused participation during this initial telephone call. The reason for refusing was most often the caregiver. The caregivers either felt overwhelmed or believed that the patients were far too ill to participate in a study, so they blocked communication with our research staff and kept the latter from approaching the patients. Studies like ours that include self-report data from patients require that we accrue only the most highly functioning patients and therefore result in biased samples. Once the dyad was in the study, we needed them for 30 days. However, median length of stay in hospice care at that time was about 26 days. So we were likely to lose 50% of our sample to death by day 26 and to lose other patients because of physical and mental decline. Our attrition at day 16 was 50%, and at day 30 it was 63%. Reasons for attrition included the caregiver feeling too overwhelmed to continue and the patient declining or dying. Such attrition problems result in much missing data and require careful statistical analysis to ensure that we make the best use of the data we have collected.⁴²

Our group currently has an NIH-funded clinical trial underway that focuses on caregivers of patients who are being treated for pain caused by cancer; this trial also is using a coping intervention. Because cancer pain tends to occur in more advanced disease, it may be assumed that many of these patients, although not in hospice care, are nearing the end of life. The first intervention session is offered face-to-face. Subsequent sessions are offered via telephone. Although the clinical trial is in its early stages, it appears that the caregivers are benefiting from the education, coping, and support intervention that they are receiving over four interactions with the interventionists.

This work, although still in its early stages, also attests to the feasibility of telephone interventions for caregivers.⁴³

CONCLUSIONS

Although caregivers carry an increasing burden of care for patients near the end of life, very few caregiver intervention studies including patients near the end of life could be found for review, and all of these focused on caregivers of patients with cancer. Thus, there is a paucity of data regarding which caregivers are at greatest risk for distress and which interventions are likely to relieve that distress. What is needed is more research on primary caregivers. In addition, however, it would be useful for all intervention trials with patients near the end-of-life or in palliative care settings to include some focus on family caregiver outcomes. This is appropriate because of the focus on the patient and family as the unit of care when end-of-life care is provided in any setting.

Although both educational and supportive interventions have been tested, including both telephone and face-to-face meetings, it still is not clear which approach is best for which groups of caregivers. Much of the research that has been done has been descriptive and evaluative, and only a very limited number of clinical trials have been conducted with caregivers of patients near the end of life. There also is limited evidence about whether caregiver interventions at the end of the patient's life have the potential to provide long-term benefits to caregivers, and there are issues in adapting such interventions to work with culturally diverse populations. Furthermore, there appears to be a limited number of investigators doing this important work. More research is needed to provide complete evidence on which to base practice and policy decisions.

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