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Burden and Depression Among Caregivers of Patients with Cancer at the End-of-life

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Abstract

Purpose/Objectives—The purpose of the study was to examine the patient and family caregiver variables that predicted caregiver burden and depression for family caregivers of patients with cancer at the end-of-life.

Design—A prospective, longitudinal study was implemented with an inception cohort of patients and their family caregivers who were followed after the diagnosis and treatment of cancer. Data were analyzed using quantitative methods to determine the effect of caregiver age, sex, education, relationship to the patient, employment status, reports of patients' symptoms, patient cancer type, stage of cancer, and time from the patient's diagnosis to death on caregiver burden and depression at the patient's end-of-life. This report examines the experiences of family caregivers whose patients died during the study.

Setting—Patients and caregivers were accrued from community oncology sites in the Midwestern United States.

Sample—152 family caregivers of patients with cancer who died during the course of the study.

Methods—Telephone interviews with patients were conducted at 6–8 weeks, 12–16 weeks, 24–30 weeks, and 52 weeks following patients' diagnoses. In addition, patient medical records and state death certificates were reviewed.

Findings—Caregivers aged 45–54 reported the highest levels of depressive symptoms; caregivers aged 35–44 reported the strongest sense of abandonment. Caregivers who were the adult children of patients with cancer and who were employed reported high levels of depressive symptoms. Feeling abandoned (a portion of caregiver burden) was more prevalent in female, non-spouse, and adult

children caregivers, and adult children caregivers of patients with early stage cancer and patients with multiple symptoms reported a high perception of disruption in their schedule due to providing care. Caregivers whose patients died early following diagnosis (between waves I and II) reported the highest depressive symptoms, burden, and impact on schedule.

Implications—Very little research exists that prospectively analyzes family caregiver experiences of burden and depression when providing end-of-life cancer care for a family member. Interventions aimed at decreasing caregiver depressive symptoms should be targeted at caregivers who are middle aged, adult children, and those who are employed. Interventions aimed at decreasing the burden associated with feeling abandoned and having schedules disrupted due to providing care should be targeted at caregivers who are female, non-spouse and adult children, and caregivers of patients with early stage cancer and multiple symptoms.

Key Points

- Increasingly, cancer care is provided in the home, with family members taking on the role of primary caregivers, assisting patients with activities related to everyday tasks and with medical procedures at home.
- The effects of providing care for patients with cancer at the end-of-life on caregiver burden and depression have not yet been adequately explored.
- Middle aged, adult children, and employed family caregivers reported higher levels of depressive symptoms than their counterparts. Regarding caregiver burden, female, non-spouse, and adult children caregivers reported a high perception of feeling abandoned, and adult children caregivers of patients with early stage cancer and patients with multiple symptoms reported a high perception of disruption in their schedule due to providing care.

Introduction

The American Cancer Society estimates that there will be 1,334,100 new cancer diagnoses in the United States in 2003. Each year, cancer claims the lives of more than 555,500 Americans (American Cancer Society, 2003). The burden of providing care for the more than one million American patients with newly diagnosed cancer falls increasingly upon families. This burden of care extends from diagnosis through treatment, and — in more than a half-million cases per year — to death (Ferrell, Grant, Chan, Ahn, & Ferrell, 1995; Given, Given, & Stommel, 1994; Miaskowski, Kragness, Dibble, & Wallhagen, 1997).

Despite the recent research directed toward the role of family caregivers in cancer care, there have been few descriptions of the role of caregivers in end-of-life care. [Throughout the article, ‘caregiver’ is used to denote a *family* caregiver, rather than a professional caregiver.] The available studies focus on patient pain, hospice care, and bereavement (Cleeland et al., 1997; Coyle, 2001) rather than on the effects of care provision on family caregivers for patients with cancer at the end-of-life. Describing the factors that affect family caregivers of patients with cancer at the end-of-life is an essential first step in designing interventions that might prevent or reduce caregiver burden and depression for this subset of caregivers (Aranda & Hayman-White, 2001; Aranda & Pearson, 2001). The purpose of this study was to employ a prospective longitudinal design with a cohort of patients newly diagnosed with cancer to describe the factors related to caregiver burden and depression during the final months of the patient’s life.

Specifically, the following research questions were addressed:

1. What are the effects of the following variables on caregiver depressive symptoms for caregivers of patients with cancer at the end-of-life: caregiver age, sex, education,

relationship to the patient, employment status, reports of patients' symptoms, patient cancer type, stage of cancer, and time from the patient's diagnosis to death?

2. What are the effects of the following variables on caregiver burden for caregivers of patients with cancer at the end-of-life: caregiver age, sex, education, relationship to the patient, employment status, reports of patients' symptoms, patient cancer type, stage of cancer, and time from the patient's diagnosis to death?

An inception cohort of patients newly diagnosed with cancer and their caregivers were interviewed to obtain data on caregiver reactions during the last months of the patient's life, and to determine how patient and caregiver characteristics affected levels of caregiver burden and depression. Focusing on caregivers in the period immediately prior to the patient's death has several advantages. First, based on the date of diagnosis, the duration of care was known, allowing examination of data from the same time point in the care trajectory. Second, the interval between observation and death was specifically described. Third, all caregiver observations were gathered within months prior to the patient's death in a real-time approach rather than a retrospective view.

Literature Review

Caregiver distress is typically operationalized as caregiver depression or caregiver burden. Caregiver depression is a mood disturbance resulting from the stress of providing care (Fortinsky et al., 2002; Harris, Godfrey, Partridge, & Knight, 2001), which may be manifested as feelings of loneliness, isolation, fearfulness, and being easily bothered. Caregiver burden is considered "a multidimensional biopsychosocial reaction resulting from an imbalance of care demands relative to caregivers' personal time, social roles, physical and emotional states, financial resources, and formal care resources given the other multiple roles they fulfill" (Given et al., 2001, p. 5). Together, caregiver burden and depression may be considered as a general distress response for caregivers. Although there is a great deal of research on correlates of distress for caregivers who are at various points in the care trajectory, little work has been done to assess the impact of providing end-of-life care on the distress of family caregivers of patients with cancer. Predictors for caregiver distress in the general caregiving literature were reviewed to identify potential predictors of burden and depression for caregivers of patients with cancer at the end-of-life.

Caregiver distress

Family members of patients with cancer experience distress due to caregiving roles, and this distress has been shown to continue over time and may be exacerbated by changes in the patient's condition (Given, Sherwood, & Given, 2003; Given, Stommel, Given, Osuch, Kurtz, & Kurtz, 1993; Given, Stommel, Collins, King, & Given, 1990; Northouse, Mood, Templin, Mellon, & George, 2000; Northouse & Peters-Golden, 1993; Oberst & Scott, 1988; Raveis, Karus & Siegel, 1998; Toseland, Blanchard, & McCallion, 1995). The emotional impact of providing care is linked to caregiver negotiations of the caregiving role, as caregivers may be unfamiliar with the care they must provide and may not be aware of or able to utilize available resources (Given, & Given, 1992; Oberst, Thomas, Gass, & Ward, 1989).

The distress resulting from assuming the role of caregiver can be manifested as anxiety, depression, helplessness, burden, and fear (Blank, Clark, Longman, & Atwood, 1989; Nijboer, Tempelaar, Triemstra, van den Bos, & Sanderma, 2001; Northouse, Dorris, & Charron-Moore, 1995; Oberst et al., 1989; Siegel, Raveis, Mor, & Houts, 1991; Weitzner, Moody, & McMillan, 1997), and is often related to providing direct care, performing complex medical procedures, coping with disruptions in daily routine, and negotiating the need to provide emotional support to the patient and to other family members. Specifically, caregivers may

experience distress from assuming the responsibility for communicating with healthcare professionals, managing symptoms, administering medications, performing medical/nursing treatments, and handling patient behavioral problems and emotional reactions (Given & Given, 1991; Kurtz, Kurtz, Given, & Given, 1995; Kurtz, Kurtz, Stommel, Given, & Given, 2002; Laizner, Yost, Barg & McCorkle, 1993; Sarna & McCorkle 1996; Schumacher 1996; Stommel, Given, Given, & Collins, 1995; Weitzner, Haley & Chen, 2000).

Correlates of caregiver distress

Caregiver distress may stem from the reprioritization or relinquishment of responsibilities related to childcare and employment, the prioritization of home-care demands, and the negotiation and renegotiation of factors related to familial and generational relationships (Lyons, Zarit, Sayers, & Whitlatch, 2002; Sales, 1991; Weitzner, McMillan & Jacobsen, 1999). Consistently reported predictors for caregiver distress include caregiver gender (Northouse et al., 2000), level of personal and social support, patient functional status (Stommel, Given, & Given, 2002; Williamson, Shaffer, & Schulz, 1998), and patient symptom status (Clipp & George, 1993; Foxall & Gaston-Johannson, 1996; Given et al., 1993; Kozachik et al., 2001; Kurtz, Kurtz, Given, & Given, 1995; Nijboer, Triemstra, Tempelaar, Mulder, Sanderman, & van den Bos, 2000; Nijboer et al., 2001; Schultz, Obrien, & Borhwala, 1995; Schumacher, Dodd, & Paul, 1993; Song, Biegel, & Mulligan, 1997). In general, female caregivers (Northouse et al., 2000; Sales, Schulz, & Beigel, 1992; Schulz & Williamson, 1991) and caregivers with lower levels of personal and social support (Williamson et al.) experience higher levels of distress.

Caregiver distress resulting from the patient's functional status involves the caregiver's level of assistance with activities of daily living (ADL; eating, dressing, bathing), and instrumental activities of daily living (IADL; household tasks, shopping, transportation). Decreases in the patient's functional status increase the amount of tasks with which the patient requires assistance. Caregivers who must assist with multiple tasks, or with tasks they find difficult or unappealing (such as performing medical procedures at home or toileting) may have higher levels of distress (Given & Given, 1992; Kurtz, Kurtz, Stommel, Given, & Given, 2001). Research has shown that providing assistance with both ADLs such as bathing and toileting (Vitaliano, Russo, Young, Teri, & Maiuro et al., 1991), as well as IADLs such as errands or transportation (Gonzalez-Salvador, Arango, Lyketsos, & Barba, 1999) can increase caregiver distress (Weitzner et al., 1999).

The patient's symptom status (including number, type, and severity of symptoms) can also affect caregiver distress (Given, Given, Azzouz, Kozachik, & Stommel, 2001). As patients' symptom distress increases and results in depressive symptoms and deteriorations in quality of life for the patient (Sarna, 1993, 1998; Sarna & Brecht, 1997), functional limitations may increase and caregiver responsibilities to help manage symptoms and assist with functional limitations may increase. Patient symptom status requires caregiver assistance not only with recognizing emerging and changing patient symptoms related to the disease and its treatment, but also with the management of those symptoms (Kozachik et al., 2001; Nijboer et al., 1998; Williamson, Schaffer, & Schulz, 1998). For the patient with advanced disease, family assistance with symptoms may increase as the patient's disease progresses and the patient's health declines. In addition, caregivers have varying emotional reactions to patient symptoms, which can cause distress as the patient's health declines (Carey, Oberst, McCubbin, & Hughes 1991; Toseland et al., 1995).

Caregiver distress related to the patient's end-of-life

Much of the reported work on caregiver distress has focused on caregivers at various points in the care trajectory, on caregivers in the period *following* the death of a loved one, or on

caregivers of patients with advanced stage of disease (without reference to the time point of the patient's death). Wyatt, Friedman, Given, and Given (1999) studied the family caregivers of terminally ill patients within three months following the patient's death. This work is a significant contribution to understanding the burden family caregivers face in the final stages of patient life. However, interviewing caregivers after the patient has died can be problematic, in that caregiver grief may cloud memories and expressions of burden and depression. The different coping strategies caregivers rely upon to control emotional distress and to negotiate the impact of a family member's death may also affect the manner in which caregivers report their levels of burden prior to patient death (Schwartz, & Sprangers, 2000).

Cameron, Franche, Cheung, and Stewart (2002) examined family caregivers of patients with advanced cancer and found that regardless of the amount of care provided, caregivers experienced emotional distress when providing care limited caregivers' ability to participate in usual daily activities (work, recreation, and social activities). This finding suggests that emotional distress may occur somewhat independently of the objective tasks and potential burden imposed by the demands of caregiving. It is possible that advanced disease may signal caregivers in many subtle ways that patient death is imminent and, despite relatively few demands for care, may lead to emotional distress among caregivers. Except for gender, sociodemographic characteristics have been less likely to be associated with emotional distress; although Cameron and colleagues (2002) found that those caregivers with less than a high school education were more distressed than those with higher levels of education. This work emphasizes the hypothesis that reactions to providing care may differ along the care trajectory.

The previously described research examines the effect of caregiver and patient characteristics on caregiver distress from the caregiver's perspective related to challenges in taking on the caregiver role, caregiver and patient demographics, and tasks of care. However, caregiving studies that examine the factors associated with distress for caregivers of patients with cancer at the end-of-life are largely absent. Most previous research has employed cross sectional designs and there has not been an effort to include time from interview point to patient death as a potential predictor of caregiver distress. Determining how caregiver distress is affected as the patient nears the end-of-life would allow practitioners to change and modify interventions according to the patient's trajectory of disease, and implement appropriate interventions to improve caregiver health.

Conceptual Framework

The primary framework (based on the work of Given & Given, 1991 and Given & Given, 1994) posits the perspective that to adequately analyze the effects of end-of-life cancer care on family caregivers, the interaction of patient and caregiver characteristics must be considered *along with* the patient symptom experience. The family caregiver model of Nijboer et al. (2001) contributes to this framework. In applying this framework, it is possible to examine how patient and family characteristics, the care situation (demands), and the care process influence patient and caregiver outcomes. This model suggests that caregiver reactions to care situations are multidimensional and include the impact on daily schedule, financial concerns, involvement in care, and loss of self-esteem about caring. This perspective guides us to examine how caregiver and patient characteristics, patient symptom experiences, losses in patient function, and other demands on the caregiver affect levels of caregiver distress, manifested as caregiver depressive symptoms and burden.

This study focused on how patient and caregiver characteristics interact with patient symptoms as well as how this interaction affects caregiver burden (schedule and abandonment) and depressive symptoms. Further, this work looks at time to death as a patient characteristic that contributes to caregiver burden and depressive symptoms. Caregiver relationships to patients

and site of cancer as influences on these caregiver outcomes are also examined. Caregiver depressive symptoms at the start of care are also considered as a caregiver characteristic.

Methods

Design

This secondary analysis was performed on a prospective, longitudinal study of patients following a new diagnosis of cancer.

Sample

The study sample consisted of 152 English-speaking caregivers whose patients had been diagnosed with breast, colon, lung, or prostate cancer and who had died. To qualify for participation in the study, patients had to have received a diagnosis of cancer within the eight weeks prior to their enrollment in the study, be receiving chemotherapy, and had to have identified a family caregiver. Patients and caregivers were accrued from 24 community oncology sites in the Midwestern United States. Nurses employed by the project identified patients who met the criteria and explained the study to the patients and their family caregivers. If patients and their caregivers agreed to participate, they were asked to sign consent forms and were enrolled in the study. Data collection consisted of telephone interviews at 6–8 weeks, 12–16 weeks, 24–30 weeks, and 52 weeks following enrollment. During the telephone interviews, sociodemographic and disease related information was collected and measures of patient symptoms, caregiver burden, and caregiver depressive symptoms were obtained. An audit of patient medical records was also done at the end of the study to verify site and stage of disease and treatment data, and state death certificates were reviewed to verify death of the patient. Approval from the Institutional Review Board at each participating site and educational institution was obtained prior to the beginning of the study.

Measures

Data collected included general sociodemographic information, caregiver employment status, patient stage of cancer, caregiver/patient family relationship, caregiver report of number of patient symptoms, caregiver depressive symptoms, and caregiver burden.

Sociodemographic characteristics including caregiver age, sex, education, relationship to patient, and employment status were collected at the intake interview (see Table 1); 84% of the caregivers were female and 75% were 55 years of age or older; 28% were employed. Spouses made up 65% of family caregivers; daughters, sons, and daughters- and sons-in-law were the next most frequent relationship to the patient. Most of the patients who died had lung cancer, and most of the patients entered the study with a diagnosis of late stage cancer. Because lung cancer contributed close to 70% of all deaths, site of cancer was collapsed into lung cancer and all other sites.

Stage of disease at diagnosis (I through IV) was obtained from patient medical records and was collapsed into early (stages I and II) and late (stages III and IV) stage. Caregiver reports of number of patient symptoms were collected at all observations using a symptom checklist; the possible range was from 0–17 symptoms, with a mean of 6.5 symptoms. Scores were calculated by adding the number of symptoms caregivers reported observing in patients during the previous 2 weeks. Symptoms included pain, fatigue, insomnia, nausea, anorexia, diarrhea, and constipation, as well as other symptoms reported frequently by patients at the end-of-life.

The final interview immediately prior to patient death was classified as 1 through 4: 1 identified patients who died between waves I and II; 2 identified patients who died between waves II and III; 3 identified patients who died between waves III and IV; 4 identified patients who died

following wave IV. Classification 4 had the largest variation, as patients could have died at any time from the end observation (the final telephone interview conducted at 52 weeks following diagnosis) through the 4-year study duration. Dates of death were confirmed by matching patient names, addresses, and social security numbers with the Michigan Death Certificate.

Caregiver distress was operationalized as caregiver depressive symptoms and burden and the following standardized tools were used. Caregiver depressive symptoms at the observation prior to patient death were evaluated using the Center for Epidemiologic Studies Depression measure (CESD; Radloff, 1977; Radloff & Terri, 1996), a widely used 20-item assessment of symptoms of depression. Scoring of this instrument is on a 0 through 3 scale where 0 indicates “rarely or none of the time,” 1 indicates “some of the time,” 2 indicates “most of the time,” and 3 indicates “almost all of the time”; the sum across the 20 items represents the level of depressive symptomatology. Respondents are asked how they felt in the past month; a typical question is: “Were you bothered by things that usually do not bother you?”. The composite score is 0–60, with higher scores representing greater depressive symptomatology; the alpha coefficient for this instrument exceeded .87.

To assess caregiver levels of burden relevant to those caring for patients with advanced disease at the interview prior to patient death, two subscales from the Caregiver Reaction Assessment (CRA) were employed (Given, Given, Stommel, Collins, King, & Franklin, 1992). The CRA is a five subscale instrument designed to measure caregiver burden in multiple dimensions, which has proven valid and reliable in both cancer and non-cancer caregiver populations (Given et al., 1992; Stommel, Wang, Given, & Given, 1992; Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999). Two 5-item Likert-type (strongly agree to strongly disagree) burden subscales were used to 1) assess the impact of providing care on caregiver daily schedules and 2) to evaluate caregiver sense of abandonment by other family members. Higher scores represent greater levels of perceived burden (Given et al., 1992; Nijboer & Andrews, 2001). Cronbach’s alpha for these two subscales exceeded .80 at all four measurement points (at 6–8 weeks, 12–16 weeks, 24–30 weeks, and 52 weeks following diagnosis).

Analyses

First, categorical variables were evaluated and classified to describe the sample of patients and caregivers. Second, a series of univariate correlations were prepared to evaluate multicollinearity among the predictor variables and to determine the uniqueness of each dependent variable. None of the predictor measures were eliminated based upon high levels of association with one another.

The three dependent variables exhibited surprisingly low correlations. The correlations between caregiver burden (impact of caring on caregiver daily schedule and caregiver sense of abandonment) with levels of depressive symptoms were .14 and .06 respectively. Impact on schedule and caregiver sense of abandonment were correlated at .26. Based on these modest levels of association, each measure seems to tap into a different component of caregiver reactions to caring for patients approaching the end-of-life.

To test the research questions, a series of multivariate regressions were calculated. Each variable was assessed along with a number of interaction terms. Although all variables and their interactions were tested for each outcome variable, only those variables that were significant or were part of an interaction term were retained in the final model and used to explain the outcome variables. Finally, the equations for the impact of caring on caregiver daily schedule and sense of abandonment were rerun, with caregiver depressive symptoms at baseline added as a covariate. This was done to describe how the original set of predictors explained the two dimensions of caregiver burden after adjusting for a depressive effect.

Using these analyses, the following relationships are examined: a) how the number of patient symptoms identified by caregivers is linked to caregiver reports of depressive symptoms and burden; b) how time following diagnosis—a potentially important covariate accounting for the time that caregivers were involved in care—could explain caregiver distress (caregiver depressive symptoms and burden); c) how several important interaction terms—for example, sites of cancer and caregiver/patient relationship—might together affect the outcomes of depressive symptoms and burden; and d) how, after controlling for depressive symptoms, other factors affect caregiver burden and what level of importance can be assigned to depression in explaining burden.

Results

Sample characteristics

The sociodemographic characteristics of the sample are listed in Table 1. Most of the patients who died had lung cancer; most came into the study with a diagnosis of late stage cancer. Mean scores for caregiver depressive symptoms, impact on caregiver schedule, and caregiver sense of abandonment (the burden measures) are presented in Table 2 and broken down by caregiver characteristics. The correlations among the number of patient symptoms caregivers observed and the outcome variables were .33 for depression, .23 for impact on daily schedule, and .04 for caregiver sense of abandonment correlations (not shown).

Overall, the sample appeared to have moderate to high levels of depressive symptomatology; caregivers in the study had depression scores on the CESD at or near the cut off of 16 for clinical depression. Female caregivers were more depressed than males and were very close to an average mean score of 16. Adult children providing care were clearly above the cutoff for clinical depression on the CESD. Caregivers who were employed and caregivers who were unemployed but were looking for work (data not shown) were more depressed than those who were unemployed. Caregivers of patients with lung cancer were more depressed than caregivers of patients with other cancers. Caregivers of patients who died between intake and wave II were the most depressed. Of the caregivers of patients who died within the first three waves of the study, then, caregivers of patients with the shortest time to death had the highest levels of depressive symptoms.

Comparison scores for impact on schedule (see Table 2) and sense of abandonment suggest that caregivers did not perceive that caring for patients had impacted their daily schedule or that other family members had abandoned them. Scores ranged on average between 2 and 3, with none exceeding 4 on a 5-point scale. The impact on schedule was highest for female spouses, adult children, unemployed caregivers, caregivers of patients with lung cancer, and caregivers of patients with early stage disease.

Research question #1: What are the effects of the following variables on caregiver depressive symptoms for caregivers of patients with cancer at the end-of-life: caregiver age, sex, education, relationship to the patient, employment status, reports of patients' symptoms, patient cancer type, stage of cancer, and time from the patient's diagnosis to death?

The regression model for predictors of caregiver depressive symptoms at the observation prior to patient death is presented in Table 3. This model accounted for 31% of the variance in caregiver depressive symptoms; the overall model was statistically significant at $p < .01$. Table 4 describes levels of caregiver depressive symptoms as the number of patient symptoms increases. Most caregivers reporting seven or more patient symptoms scored 16 or higher on the depression measure, suggesting that they exceeded the threshold of risk for clinical depression on the CES-D.

Table 5 includes mean caregiver depression scores for each significant predictor and each interaction term adjusted for all other covariates. In the wave prior to patient death, spouse caregivers were less depressed than adult child or non-spouse caregivers. Spouse caregivers of patients with late stage disease were more depressed than spouses caring for patients with earlier stage disease. Non-spouse and adult children caring for patients with early stage disease were more depressed than unemployed adult children. Spouse and non-spouse caregivers of the same generation as their patients, who were not employed, were also more depressed than employed spouse and non-spouse caregivers. Adult children who were employed were significantly more depressed. For patients with lung cancer, spouses were more depressed than non-spouse caregivers.

Finally, caregiver employment status, patient stage of cancer at the time of diagnosis, and patient's site of cancer diagnosis appear to explain variations in levels of reported depressive symptoms at the wave prior to patient death. For employed caregivers, later stage patient disease was associated with higher levels of depressive symptoms, while early stage patient disease was associated with higher levels of depressive symptoms for unemployed caregivers. This pattern extends to cancer or diagnosis site as well: Employed caregivers had more depressive symptoms when caring for patients with cancers other than lung cancer; unemployed caregivers had more depressive symptoms when caring for patients with lung cancer. These differences may be related to caregiver relationship (i.e., spouse vs. non-spouse), but same generation caregivers who were not employed contrasted with adult children who were employed. Among spouse and employed non-spouse caregivers, later stage and not lung cancer appears related to depressive symptoms; however, among spouse and employed non-spouse but same generation caregivers, early stage and lung cancer appear to be related to risk for depressive symptoms. Later stage disease and numbers of symptoms approached, but did not reach, significance. Thus, it seems unlikely that number of patient symptoms overrides relationship to patient and employment status as "ultimate" predictors of depressive symptoms.

Research question #2: What are the effects of the following variables on caregiver burden for caregivers of patients with cancer at the end-of-life: caregiver age, sex, education, relationship to the patient, employment status, reports of patients' symptoms, patient cancer type, stage of cancer, and time from the patient's diagnosis to death?

Predictors of caregiver sense of abandonment (burden) by family members are listed in Table 6. This model explains 60% of the variation in sense of abandonment; the overall model is significant ($p < .00$). It is clear that variation in the sense of abandonment dimension of burden is explained almost entirely by family relationship: Spouses reported virtually no sense of abandonment (mean = 1.6) while non-spouses (mean = 2.0) and adult children (mean = 2.8) reported considerably more feelings of abandonment. Female caregivers reported a stronger sense of abandonment (mean = 2.4) than did male caregivers (mean = 1.9). None of the other terms reached significance, and the impact of the interaction terms was modest and not significant.

Table 7 contains the variables used to explain 61% of the variation in reported impact on caregiver daily schedule. The overall model was highly significant ($p < .00$). Table 8 describes the adjusted means for perceived impact on caregiver schedule by number of patient symptoms. Again, increasing symptoms led to greater impact on schedule. Family relationship also explained significant variations in perceived impact on caregiver daily schedule. Spouse caregivers reported the lowest impact and adult children the highest impact on daily schedule. Family members caring for patients with early stage disease also reported high levels of impact on daily schedule.

A number of variables originally thought to explain caregiver burden and depressive symptoms in the period immediately preceding patient death were evaluated but not included. First, as reported by the caregivers, limitations in instrumental activities of daily living (IADLs) and activities of daily living (ADLs) were evaluated. Although patients were close to death, virtually all caregivers reported that patients were *independent* with regard to these activities. Neither of these measures revealed variation among the sample of patients. The correlation between limitations in ADLs/IADLs and symptomatology as reported by the caregivers was weak to non-existent and thus these measures were excluded from the analyses. However, these variables suggest that patients with cancer undergoing treatment and patients with cancer within the first year following diagnosis may experience few limitations in activities in the immediate interval prior to their death, contrary to common belief. In the months prior to death, patients with cancer in this study were not as “disabled” or dependent as other reported literature suggests (Sarna & McCorkle, 1996).

Discussion

In contrast to earlier work, caregivers in this study reported levels of depressive symptoms that, in many instances, equaled or exceeded thresholds for clinical depression on the CESD scale (Given, Given, Helms, Stommel, DeVoss, 1997). Patient symptoms played a critical role in accounting for levels of caregiver depressive symptoms: A linear relationship existed between increasing number of patient symptoms reported by caregivers and level of depressive symptoms. The amount of assistance provided by the caregiver with ADLs and IADLs and patient disease status were not predictive of caregiver depressive symptoms.

An association emerged between levels of depressive symptoms and caregiver/patient relationships. Caregiver employment status was also a depression-related variable: Employed sons and daughters reported higher levels of depressive symptoms than their unemployed counterparts. In contrast, employed spouses reported lower levels of depressive symptoms than those spouses who were unemployed. This finding suggests that employment outside the home may act as a buffer to or as respite from the care experience for spouses. However, this study also supports earlier research suggesting that employment adds to overall level of psychological distress due to the ways caregivers negotiate caregiving and employment, which includes withdrawal from work, absences from work, and/or reduction in work productivity (Given, Given, & Stommel, 1994). Employment and stage of patient cancer had an interactive effect on caregiver depressive symptoms: Employed caregivers whose patients were diagnosed with lung cancer or with later stage disease reported higher levels of depressive symptoms than other caregivers. In contrast, amount of assistance with ADLs and IADLs provided by the caregiver was not predictive of caregiver depressive symptoms.

Perhaps the most notable finding was the high level of depressive symptoms reported by caregivers in the presence of relatively low levels of reported demands of care. These findings are consistent with those of Aranda and Hayman-White (2001) and Aranda and Pearson (2001), who found that caregiver depression and burden can exist in the presence of lower levels of patient dependence. The relative independence of these constructs is confirmed by weak correlation and by the fact that depressive symptoms failed to explain the burden factors (i.e., sense of abandonment and impact of caring on daily schedule). Thus, caregiver levels of emotional distress—at least among the group of caregivers of patients with cancer at the end-of-life included in this study—come from their relationship to their patient, the outside demands placed upon them through employment, and the number of symptoms they perceived patients to be experiencing. Yet, types of emotional distress, caregiver burden and depression, appear to separate.

Limitations

The major limitation of the study is in the area of generalizability. The majority of the sample were females over the age of 55. Generalizing results to male caregivers, caregivers of varying ethnic groups, and younger caregivers is not possible from these results. Noting the role of employment in affecting burden and depressive symptoms, it is likely that younger caregivers who are less well established in their professional careers and thus less likely to be able to make adjustments in occupational obligations may suffer higher levels of burden related to impact on schedule. Finally, the group as a whole had moderate to high levels of depressive symptoms. The impact of caregiver and patient characteristics on caregiver burden and depression for caregivers of patients at the end-of-life who have low levels of depressive symptoms is less clear.

Conclusion and Recommendations

Caregivers who identify their patients as experiencing many cancer and cancer treatment-related symptoms are more likely to react to the caregiving situation in ways that contribute to burden and depression. Except for number of patient symptoms, burden and depression were primarily associated with caregiver factors rather than patient characteristics. This association indicates that professional healthcare providers may be able to predict—and, ideally, moderate—caregiver reactions to providing care by identifying caregivers at risk (due to, for example, their relationship to the patient), and by helping the caregiver to evaluate factors that may increase feelings of burden, such as employment pressures.

A debate in the caregiving literature centers on the relationships between caregiver burden and depression (Schultz et al., 1995). Some researchers argue that burden and depression are virtually synonymous (Stommel, Given, & Given, 1990), while others assert that they are unique constructs (Gitlin et al., 2003; Schultz et al., 1995). This study favors the latter argument; the two dimensions of caregiver burden explored here—impact on schedule and sense of abandonment—were not related to caregiver depression. Rather, they were explained by *different* variables. Thus, although depression and burden may both be forms of caregiver distress, interventions aimed at decreasing burden and depressive symptoms should differ. Consistent with Cameron, Franche, Cheung, and Stewart (2002), inability to maintain participation in usual activities may account for emotional distress in younger/non-spouse caregivers.

In this study, caregiver burden and depression were similar to those levels reported by caregivers of patients with non-advanced cancer (Given et al., 1993; Given et al., 1997; Given, Given, Stommel, & Azzouz, 1999). This finding suggests that caregiver reactions do not increase with time, at least in the year following the initiation of caregiving, even for caregivers of patients with advanced disease. This study supports the previous work of Given, King, Collins, and Given (1988), Chapman and Pepler (1998), and Siegel et al. (1991) about the responses of spouse caregivers being lower and less negative than adult children, due to differences in role expectations.

This study adds to previous work by employing a longitudinal approach to examine outcomes related to caregiver burden (abandonment and impact on schedule) and depression with respect to an observation close to the time of patient death. Using an inception cohort allowed us to follow caregivers from the onset of the care situation, and examine caregiver reactions to end-of-life care throughout the care situation using a prospective, rather than retrospective, method. The study has implications for both researchers and clinicians. In the area of caregiver research, this study contributes to a *much larger need* to continue research that evaluates factors contributing to caregiver burden and depression. More research is needed to examine how burden and depression relate; the emotional, psychological, physical, and financial effects of

care provision on caregivers providing care for a loved one with a serious disease such as cancer are complex and complicated. Future research must continue to examine the distinction between burden and depression, and to continue to explore the myriad other factors that may contribute to negative caregiver outcomes for those caring for patients with advanced cancer. Research focused in these directions will, ideally, allow investigators to create, test, and recommend interventions to healthcare providers that will affect the path and patterns of care provided in the home by family caregivers for patients with cancer.

The results of the study are applicable to health care practitioners in two ways. First, study data indicate that specific groups of caregivers are at risk for negative outcomes, and that identification of groups at risk requires that the practitioner be aware of sociodemographic characteristics of the caregiver. Interventions designed to improve the emotional health of caregivers of cancer patients at the end-of-life should be targeted at employed children caregivers, unemployed spouse caregivers, and caregivers of persons with lung and later stage cancers. Furthermore, study findings emphasized the interrelationship of caregiver and patient variables – that patient variables can affect caregiver outcomes. Thus, health care practitioners should be aware that interventions aimed at decreasing symptom severity can affect caregiver burden and depression. Practitioners should treat the patient as a ‘patient-caregiver dyad’, be aware that caregivers are at risk from negative outcomes from both caregiver and patient characteristics, and be aware that to provide care at the end-of-life, concern should be given to the caregiver’s wellbeing, in addition to that of the patient.

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Table 1
Sociodemographic Characteristics of Caregivers and Patients (N=152)

	Frequency	%
Caregiver sex (<i>n</i> =152)		
Male	25	16
Female	127	84
Relation of caregiver to patient (<i>n</i> =135)		
Spouse	88	65.19
Daughter/son	28	20.74
Daughter-/son-in-law	7	5.19
Sister/brother	1	0.74
Granddaughter/grandson	1	0.74
Niece/nephew	2	1.48
Other	5	3.70
Caregiver employment status (<i>n</i> =147)		
Employed full-time	26	17.69
Employed part-time	15	10.20
Homemaker	35	23.81
Retired	63	42.86
Not employed	8	5.44
Caregiver age (<i>n</i> =139)		
25–34	2	1.44
35–44	13	9.35
45–54	23	16.55
55–64	36	25.90
65–74	50	35.97
75–84	15	10.79
Patient primary cancer site (<i>n</i> =143)		
Breast	9	6.29
Colon	18	12.59
Lung	101	70.33
Prostate	15	10.49
Patient cancer stage (<i>n</i> =130)		
Early	48	36.92
Late	82	63.08
Wave patient died (<i>n</i> =152)		
Between waves I and II	35	23.03
Between waves II and III	41	26.97
Between waves III and IV	37	24.34
After wave IV	39	25.66

Table 2
Summary Statistics for Caregiver Depression, Abandonment, and Impact on Schedule at Wave Prior to Death

	DEPRESSION			ABANDONMENT			IMPACT ON SCHEDULE		
	Mean	SD	n	Mean	SD	n	Mean	SD	n
Caregiver sex	N=128			N=113			N=113		
Male	12.96	9.16	23	1.98	.68	20	2.86	0.64	20
Female	15.30	9.08	105	2.12	.30	93	3.03	0.80	93
Relation of caregiver to patient	N=114			N=103			N=103		
Spouse	14.24	8.62	75	1.85	0.65	69	2.84	0.67	69
Daughter/son (or d/s in-law)	17.97	9.26	29	2.70	0.95	26	3.45	0.89	26
Other	15.10	13.7	10	2.25	0.35	8	3.00	0.65	8
Caregiver employment status	N=125			N=111			N=111		
Employed full- or part-time	15.34	10.2	35	2.36	0.90	32	3.11	0.86	32
Homemaker	14.26	6.92	31	2.20	0.79	29	3.15	0.72	29
Retired	14.87	9.55	54	1.83	0.59	47	2.80	0.69	47
Not employed	17.40	12.2	5	2.33	1.22	3	3.73	0.99	3
Caregiver age	N=139			N=139			N=118		
25-34	6.00	N/A	1	2.00	N/A	1	2.20	N/A	1
35-44	14.17	5.76	12	2.64	0.92	11	3.55	0.69	11
45-54	17.91	11.3	22	2.58	0.98	19	3.44	0.91	19
55-64	14.25	6.74	28	2.02	0.67	24	2.93	0.74	24
65-74	14.74	8.70	42	1.82	0.53	38	2.81	0.71	38
75-84	15.69	12.3	13	2.00	0.79	11	2.98	0.49	11
Patient primary cancer site	N=122			N=108			N=108		
Breast	10.25	7.89	8	2.30	0.81	8	2.65	0.45	8
Colon	13.18	9.48	17	2.14	0.96	16	2.99	0.82	16
Lung	16.29	9.28	83	2.06	0.78	71	3.14	0.76	71
Prostate	10.43	7.86	14	2.03	0.53	13	2.54	0.74	13
Stage of patient cancer	N=108			N=94			N=94		
Early	12.90	9.07	42	2.18	0.79	37	3.15	0.83	37
Late	14.70	7.79	66	2.09	0.79	57	2.88	0.71	57
Wave patient died	N=152			N=113			N=113		
Between waves I and II	18.60	9.39	25	2.23	0.93	24	3.08	0.78	24
Between waves II and III	14.03	8.60	35	2.07	0.80	28	2.99	0.71	28
Between waves III and IV	15.58	10.5	31	1.97	0.68	30	2.90	0.70	30
After wave IV	12.59	7.48	37	2.13	0.73	31	3.04	0.91	31

Table 3
Regression Model for Caregiver Depression Prior to Patient Death

	DF	Sum of Squares	F Value	P
Number of patient symptoms	1	433.24	7.45	0.00
Family relationship	2	102.31	0.88	0.41
Lung cancer	1	47.61	0.82	0.36
Stage of patient cancer	1	132.43	2.28	0.13
Caregiver employment status	1	1.37	0.02	0.87
Family relationship x cancer stage	2	494.59	4.25	0.01
Family relationship and employment	2	436.23	3.75	0.02
Family relationship and lung cancer	2	318.75	2.74	0.07
Wave of patient death	3	54.97	0.31	0.82
Cancer stage x employment	1	386.82	6.65	0.01
Lung cancer x employment	1	204.56	3.52	0.06
Number of patient symptoms x family	2	267.39	2.30	0.10
Relationship new x number of symptoms x stage	1	220.53	3.79	0.05

Note: Amount of variance explained 31%.

Table 4
Number of Patient Symptoms and Caregiver Depression Scores (CESD)

Number of patient symptoms	Number of caregivers	Mean	SD
1	7	8.16	6.55
2	13	10.07	6.31
3	11	12.70	6.07
4	14	12.42	8.32
5	18	15.00	10.50
6	17	12.40	6.48
7	10	17.13	10.92
8	18	20.75	11.38
9	13	19.64	5.51
10	6	19.17	9.43
11	3	12.00	7.02
12	5	20.00	5.29

Table 5
Adjusted Depression Means for Significant Predictors and Interactions

Caregiver Relationship to Patient	(N)	Spouse Mean Depression Score	(N)	Non-Spouse/Non-Child Mean Depression Score	(N)	Adult Child Mean Depression Score
Stage of Cancer	(69)	8.7	(8)	12.7	(26)	12.4
Early	(21)	12.5	(5)	15.7	(13)	15.2
Late	(41)	15.0	(5)	10.2	(9)	9.6
Caregiver Employment Status						
Employed	(7)	5.3	(2)	8.8	(22)	18.9
Unemployed	(66)	12.2	(7)	16.6	(7)	5.9
Site of Cancer						
Lung	(51)	6.1	(4)	18.4	(36)	12.8
Not lung	(20)	11.3	(6)	11.9	(14)	12.0

Table 6
Regression Model for Caregiver Sense of Family Abandonment Prior to Patient Death

	DF	Sum of Squares	F Value	P
Number of patient symptoms	1	0.92	1.99	0.16
Family relationship	2	10.40	11.18	<.00
Stage of patient cancer	1	0.40	0.88	0.35
Caregiver employment status	1	0.20	0.45	0.50
Wave of patient death	3	2.71	1.94	0.13
Caregiver sex	1	1.68	3.63	0.06
Wave of patient death x caregiver sex	3	3.29	2.36	0.08
Family relationship x stage of patient cancer	2	2.08	2.21	0.11
Caregiver employment status x wave of patient death	3	2.49	1.79	0.15

Note: Amount of variance explained 60%.

Table 7
Regression Model for Caregiver Perceived Impact of Caring on Daily Schedule Prior to Patient Death

	DF	Sum of Squares	F Value	P
Number of patient symptoms	1	1.36	3.83	0.05
Family relationship	2	4.07	5.69	0.00
Stage of patient cancer	1	2.74	7.67	0.00
Caregiver employment status	1	0.06	0.18	0.67
Wave of patient death	3	2.13	1.99	0.12
Caregiver sex	1	0.45	1.26	0.26
Lung cancer	1	0.43	1.21	0.27
Caregiver sex x lung cancer	1	0.95	2.68	0.10
Caregiver sex x wave of patient death	3	2.17	2.02	0.12
Caregiver employment status x wave of patient death	3	2.46	2.29	0.08

Note: Amount of variance explained 61%.

Table 8

Relationship Between Increasing Number of Patient Symptoms and Caregiver Perceived Impact of Caring on Daily Schedule

Number of patient symptoms	N	Mean	SD
0	2	1.60	0.30
1	7	2.83	0.46
2	13	2.62	0.71
3	11	2.60	0.69
4	14	3.23	0.93
5	18	2.87	0.54
6	17	3.04	0.75
7	10	3.11	0.72
8	18	3.16	0.76
9	13	3.27	0.85
10	6	3.33	0.76
11	3	4.00	0.32
12	5	3.90	0.42