

CONTINUING EDUCATION

Burden and Depression Among Caregivers of Patients With Cancer at the End of Life

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Purpose/Objectives: 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.

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

Main Research Variables: Effect of caregiver age, gender, education, relationship to the patient, employment status, reports of patient symptoms, patient cancer type, stage of cancer, time from the patient's diagnosis to death, caregiver burden, and depression.

Findings: Caregivers aged 45–54 reported the highest levels of depressive symptoms, and caregivers aged 35–44 reported the strongest sense of abandonment. Caregivers who were the adult children of patients with cancer and those who were employed reported high levels of depressive symptoms. Feeling abandoned (a portion of caregiver burden) was more prevalent in female, nonspouse, 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 because of providing care. Caregivers whose patients died early following diagnosis reported the highest depressive symptoms, burden, and impact on schedule.

Conclusions: Caregivers reported levels of depression at thresholds for screening of clinical depression. The number of patient symptoms was related to levels of caregiver depressive symptoms. An association also was found between depression and employment status. Caregiver distress was not dependent on demands of care.

Implications for Nursing: 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 to caregivers who are middle-aged, adult children, and employed. Interventions aimed at decreasing the burden associated with feeling abandoned and having schedules disrupted while providing care should be targeted to caregivers who are female, nonspouse, and adult children, and caregivers of patients with early-stage cancer and multiple symptoms.

Key Points . . .

- Increasingly, cancer care is being 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.
- The effects of providing care for patients with cancer at the end of life on caregiver burden and depression have not yet been explored adequately.
- Middle-aged, adult children, and employed family caregivers reported higher levels of depressive symptoms than their counterparts.

Goal for CE Enrollees:

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.

Objectives for CE Enrollees:

On completion of this CE, the participant will be able to

1. Identify caregivers of patients with cancer who report higher levels of depressive symptoms than their counterparts.
2. Identify caregivers of patients with cancer who report a high perception of feeling abandoned.
3. Identify caregivers of patients with cancer who report a high perception of disruption in their schedule because of providing care.

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The American Cancer Society (2004) estimated that 1,368,030 new cases of cancer will be diagnosed in the United States in 2004 and more than 563,000 Americans will die from the disease. The burden of providing care for the more than one million American patients with newly

diagnosed cancer falls increasingly on families. This burden of care extends from diagnosis through treatment and, in more than half of a 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, the role of caregivers in end-of-life care has been described infrequently. (*Note.* Throughout this 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 caregivers for patients with cancer at the end of life. Describing the factors that affect 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 authors wanted to know about the effects of caregiver age, gender, education, relationship to the patient, employment status, reports of patient symptoms, patient cancer type, stage of cancer, and time from the patient’s diagnosis to death on caregiver depressive symptoms and burden for caregivers of patients with cancer at the end of life.

An inception cohort of patients newly diagnosed with cancer and their caregivers was interviewed to obtain data on caregiver reactions during the last months of the patients’ lives and to determine how patient and caregiver characteristics affected levels of caregiver burden and depression. Focusing on caregivers in the period immediately before 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 specifically was described. Third, all caregiver observations were gathered in the months prior to the patient’s death in a real-time approach rather than a retrospective view.

Literature Review

Typically, caregiver distress is operationalized as depression or burden. Caregiver depression is a mood disturbance resulting from the stress of providing care (Fortinsky, Kercher, & Burant, 2002; Harris, Godfrey, Partridge, & Knight, 2001) that might 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, Kozachik, Collins, DeVoss, & Given, 2001, pp. 679–680). Together, caregiver burden and depression may be considered a general distress response for caregivers. Although a great deal of research has been performed 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 as a result of caregiving roles, and this distress has been shown to continue over time and may be exacerbated by changes in the patient’s condition (Given et al., 1993; Given, Sherwood, & Given, 2003; 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 because caregivers may be unfamiliar with the care they must provide and may not be aware of or able to use 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 often is related to providing direct care, performing complex medical procedures, coping with disruptions in daily routine, and negotiating the need to provide emotional support to patients and other family members. Specifically, caregivers may experience distress from assuming the responsibility for communicating with healthcare professionals, managing symptoms, administering medications, performing medical or 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 child care and employment, the prioritization of homecare 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 et al., 1995; Nijboer et al., 2000, 2001; Schulz, O’Brien, Bookwala, & Fleissner, 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) (e.g., eating, dressing, bathing) and

instrumental ADL (IADL) (e.g., 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 that they find difficult or unappealing (e.g., performing medical procedures at home, toileting) may be associated with higher levels of distress (Given & Given, 1992; Kurtz et al., 2001). Research has shown that providing assistance with ADL (Vitaliano, Russo, Young, Teri, & Maiuro, 1991) and IADL (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) also can affect caregiver distress (Given, Given, Azzouz, Kozachik, & Stommel, 2001). As symptom distress increases and results in depressive symptoms and deteriorations in the patient's quality of life (Sarna, 1993, 1998; Sarna & Brecht, 1997), functional limitations may increase, thereby possibly increasing caregiver responsibilities to help manage symptoms and assist with functional limitations. Patient symptom status requires caregiver assistance not only with recognizing emerging and changing symptoms related to the disease and its treatment but also with the management of the symptoms involving the patient's quality of life (Kozachik et al., 2001; Nieboer et al., 1998; Williamson et al., 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, caregivers in the period following the death of a loved one, or caregivers of patients with advanced 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 after the patient's death. This work is a significant contribution to understanding the burden that family caregivers face in the final stages of patient life. However, interviewing caregivers after the patient has died can be problematic because caregiver grief may cloud memories and expressions of burden and depression. The different coping strategies that caregivers rely on to control emotional distress and negotiate the impact of a family member's death also may affect the manner in which caregivers report their levels of burden prior to patient death.

Cameron, Franche, Cheung, and Stewart (2002) examined family caregivers of patients with advanced cancer and found that, regardless of the amount of care provided, the emotional distress that the caregivers experienced when providing care limited their ability to participate in typical daily activities (i.e., work, recreation, and social events). This finding suggests that emotional distress may occur somewhat independently of the objective tasks and potential burden imposed by the demands of caregiving. In many subtle ways, advanced disease may signal caregivers 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 et al. 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 examined 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 research has employed a cross-sectional design and has not included the length of 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 and Given [1991, 1994]) posits the perspective that to adequately analyze the effects of end-of-life care for patients with cancer on family caregivers, the interaction of patient and caregiver characteristics must be considered along with the patient symptom experience. Nijboer et al.'s (2001) family caregiver model contributes to this framework. In applying this framework, examining how patient and family characteristics, the care situation (demands), and the care process influence patient and caregiver outcomes is possible. This model suggests that caregiver reactions to care situations are multidimensional and includes the impact on daily schedule, financial concerns, involvement in care, and loss of self-esteem about caring. This perspective guided the authors in examining how caregiver and patient characteristics, patient symptom experiences, losses in patient function, and other demands on the caregiver affect levels of caregiver distress and manifest 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 looked at time to death as a patient characteristic that contributes to caregiver burden and depressive symptoms. Caregiver relationships to patients and the site of the cancer also were examined as influences on caregiver outcomes. Caregiver depressive symptoms at the start of care also were 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 of patients diagnosed with breast, colon, lung, or prostate cancer who had died. To qualify for participation in

the study, the caregivers had to be family members and their patients had to have received a diagnosis of cancer within eight weeks prior to study enrollment and be receiving chemotherapy. 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 (time I), 12–16 (time II), 24–30 (time III), and 52 weeks (time IV) after 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. At the end of the study, audits of patient medical records were conducted to verify site and stage of disease, as well as treatment data, and state death certificates were reviewed to verify the death of patients. Approval from the institutional review board at each participating site and educational institution was obtained before 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, gender, education, relationship to patient, and employment status, were collected at the intake interview.

Stage of disease at diagnosis (I–IV) was obtained from patient medical records and collapsed into early stages (I–II) and late stages (III–IV). Caregiver reports of the number of patient symptoms were collected at all observations using a symptom checklist; the possible range was 0–17 symptoms. Scores were calculated by adding the number of symptoms that caregivers reported observing in patients during the previous two 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 1–4, with 1 identifying patients who died between times I and II, 2 identifying patients who died between times II and III, 3 identifying patients who died between times III and IV, and 4 identifying patients who died following time IV. Classification 4 had the largest variation because patients could have died at any time from the end observation (i.e., the final telephone interview conducted at 52 weeks following diagnosis) through the four-year study duration. Dates of death were confirmed by matching patients' names, addresses, and social security numbers with their Michigan death certificates.

Caregiver distress was operationalized as caregiver depressive symptoms and burden, and standardized tools were used. Caregiver depressive symptoms at the observation before patient death were evaluated using the **Center for Epidemiological Studies–Depression (CES-D) Scale** (Radloff, 1977; Radloff & Teri, 1986), a widely used 20-item assessment of depression symptoms. Items in this instrument are scored on a 0–3 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 were asked how they felt in the past month (e.g., “Were you bothered by things that usually do not bother you?”). The composite score was 0–60, with higher scores representing greater depressive symptomatology; the alpha coefficient for this instrument exceeded 0.87.

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 et al., 1992). The CRA is a five-subscale instrument designed to measure caregiver burden in multiple dimensions, which has proven valid and reliable in cancer and noncancer caregiver populations (Given et al., 1992; Nijboer, Triemstra, Tempelaar, Sanderma, & van den Bos, 1999; Stommel, Wang, Given, & Given, 1992). Two five-item Likert-type (strongly agree to strongly disagree) burden subscales were used to assess the impact of providing care on caregiver daily schedules and to evaluate caregiver sense of abandonment by other family members. Higher scores represent greater levels of perceived burden

Table 1. Sociodemographic Characteristics of Caregivers and Patients

Characteristic	n	%
Caregiver gender (N = 152)		
Male	25	16
Female	127	84
Relation of caregiver to patient (N = 132)		
Spouse	88	65
Daughter or son	28	21
Daughter- or son-in-law	7	5
Sister or brother	1	1
Granddaughter or grandson	1	1
Niece or nephew	2	1
Other	5	4
Caregiver employment status (N = 147)		
Employed full-time	26	18
Employed part-time	15	10
Homemaker	35	24
Retired	63	43
Not employed	8	5
Caregiver age (N = 139)		
25–34	2	1
35–44	13	9
45–54	23	17
55–64	36	26
65–74	50	36
75–84	15	11
Patient primary cancer site (N = 143)		
Breast	9	6
Colon	18	13
Lung	101	70
Prostate	15	10
Patient cancer stage (N = 130)		
Early	48	37
Late	82	63
When patient died (N = 152)		
Between times I and II	35	23
Between times II and III	41	27
Between times III and IV	37	24
After time IV	39	26

Note. Because of rounding, not all percentages total 100.

(Given et al., 1992; Nijboer et al., 2001). Cronbach's alpha for these two subscales exceeded 0.80 at all four measurement points (i.e., 6–8, 12–16, 24–30, and 52 weeks following diagnosis).

Analyses

Categorical variables were evaluated and classified to describe the sample of patients and caregivers. Then, a series of univariate correlations was prepared to evaluate multicollinearity among the predictor variables and to determine the uniqueness of each dependent variable. None of the predictor measures was eliminated based on 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 0.14 and 0.06, respectively. Impact on caregiver schedule and sense of abandonment was correlated at 0.26. These modest levels of association led to the conclusion that 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 was 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 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 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 were 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 (e.g., sites of cancer, caregiver-patient relationship) together might affect the outcomes of depressive symptoms and burden, and (d) how, after controlling for depressive

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

Characteristic	Depression			Abandonment			Impact on Schedule		
	$\bar{X}$	SD	n	$\bar{X}$	SD	n	$\bar{X}$	SD	n
Caregiver gender									
Male	12.96	9.16	23	1.98	0.68	20	2.86	0.64	20
Female	15.30	9.08	105	2.12	0.30	93	3.03	0.80	93
Relation of caregiver to patient									
Spouse	14.24	8.62	75	1.85	0.65	69	2.84	0.67	69
Daughter or son (or daughter- or son-in-law)	17.97	9.26	29	2.70	0.95	26	3.45	0.89	26
Other	15.10	13.70	10	2.25	0.35	8	3.00	0.65	8
Caregiver employment status									
Employed full- or part-time	15.34	10.20	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	12.20	5	2.33	1.22	3	3.73	0.99	3
Caregiver age									
25–34	6.00	—	1	2.00	—	1	2.20	—	1
35–44	14.17	5.76	12	2.64	0.92	11	3.55	0.69	11
45–54	17.91	11.30	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	12.30	13	2.00	0.79	11	2.98	0.49	11
Missing data	—	—	21	—	—	35	—	—	14
Patient primary cancer site									
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									
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
When patient died									
Between times I and II	18.60	9.39	25	2.23	0.93	24	3.08	0.78	24
Between times II and III	14.03	8.60	35	2.07	0.80	28	2.99	0.71	28
Between times III and IV	15.58	10.50	31	1.97	0.68	30	2.90	0.70	30
After time IV	12.59	7.48	37	2.13	0.73	31	3.04	0.91	31
Missing data	—	—	24	—	—	—	—	—	—

symptoms, other factors affect caregiver burden and what level of importance can be assigned to depression in explaining burden.

Results

Sample Characteristics

Table 1 displays the sample’s characteristics. Eighty-four percent of the caregivers were female, 73% were 55 years of age or older, and 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 (26%). 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 to 70% of all deaths, site of cancer was collapsed into lung cancer and all other sites.

Mean scores for caregiver depressive symptoms, impact on caregiver schedule, and caregiver sense of abandonment (the burden measures) are presented in Table 2, broken down by caregiver characteristics. The correlations among the number of patient symptoms caregivers observed and the outcome variables were 0.33 for depression, 0.23 for impact on daily schedule, and 0.04 for caregiver sense of abandonment (not shown).

Overall, the sample appeared to have moderate to high levels of depressive symptomatology; caregivers in the study had depression scores on the CES-D at or near the cutoff 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 had scores that were clearly higher than the cutoff for clinical depression. Caregivers who were employed and those who were unemployed but 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 time II were the most depressed. Of the caregivers of patients who died within the first three time periods of the study, the caregivers of patients with the shortest time to death had the highest levels of depressive symptoms.

Comparison scores for impact on schedule and sense of abandonment suggest that caregivers did not perceive that caring for patients had affected their daily schedule or that other family members had abandoned them. Scores ranged, on average, between two and three, with none exceeding four on a five-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.

Caregiver Depressive Symptoms

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 $p < 0.01$. Table 4 describes levels of caregiver depressive symptoms as the number of patient symptoms increases. Most caregivers reporting seven or more patient symptoms scored higher than 16 on the depression measure, suggesting that they exceeded the threshold of risk for clinical depression on the CES-D.

Table 3. Regression Model for Caregiver Depression Prior to Patient Death

Variable	df	Sum of Squares	F	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 and 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
Time of patient death	3	54.97	0.31	0.82
Cancer stage and employment	1	386.82	6.65	0.01
Lung cancer and employment	1	204.56	3.52	0.06
Number of patient symptoms and family relationship	2	267.39	2.30	0.10
Family relationship, number of symptoms, and stage	1	220.53	3.79	0.05

Note. Amount of variance explained 31% of caregiver depressive symptoms.

Table 5 includes mean caregiver depression scores for each significant predictor and each interaction term adjusted for all other covariates. In the time prior to patient death, spouse caregivers were less depressed than adult child or nonspouse caregivers. Spouse caregivers of patients with late-stage disease were more depressed than spouses caring for patients with earlier stage disease. Nonspouse and adult children caring for patients with early-stage disease were more depressed than unemployed adult children. Unemployed spouse and nonspouse caregivers of the same generation as their patients also were more depressed than employed spouse and nonspouse caregivers. Employed adult children were significantly more depressed. For patients with lung cancer, nonspouses were more depressed than spouse caregivers.

Table 4. Number of Patient Symptoms, Number of Caregivers, and Caregiver Depression Scores

Caregiver Report of Patient Symptoms (n)	Caregivers (n)	Caregiver Depression Scores	
		$\bar{X}$	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

Note. Possible scores range from 0–60; higher scores indicate higher depressive symptomatology.

Table 5. Adjusted Depression Means for Significant Predictors and Interactions

Predictor	Caregiver Is the Patient's Spouse		Caregiver Is the Patient's Nonspouse or Nonchild		Caregiver Is the Patient's Adult Child	
	n	$\bar{X}$ Depression Score	n	$\bar{X}$ Depression Score	n	$\bar{X}$ Depression Score
Total mean depression	69	8.7	8	12.7	26	12.4
Stage of cancer						
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	11.3	4	18.4	36	12.8
Not lung	20	6.1	6	11.9	14	12.0

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 time prior to patient death. For employed caregivers, later-stage patient disease was associated with higher levels of depressive symptoms, whereas early-stage patient disease was associated with higher levels of depressive symptoms for unemployed caregivers. This pattern extends to 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 might be related to caregiver relationship (i.e., spouse versus nonspouse), but same-generation caregivers who were not employed contrasted with adult children who were employed. Between spouse and employed nonspouse caregivers, later stage and patient diagnosis other than lung cancer appear to be related to depressive symptoms; however, between spouse and employed nonspouse but same-generation caregivers, early-stage disease and a lung cancer diagnosis appear to be related to depressive symptoms. Later-stage disease and numbers of symptoms approached but did not reach significance. Thus, the number of patient symptoms overriding the relationship to patient and employment status seems unlikely to be an "ultimate" predictor of depressive symptoms.

Caregiver Burden

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 ($p < 0.00$). Variation in the sense of abandonment dimension of burden clearly is explained almost entirely by family relationship: Spouses reported virtually no sense of abandonment ($\bar{X} = 1.6$), whereas nonspouses ($\bar{X} = 2.0$) and adult children ($\bar{X} = 2.8$) reported considerably more feelings of abandonment. Female caregivers reported a stronger sense of abandonment ($\bar{X} = 2.4$) than male caregivers ($\bar{X} = 1.9$). 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 ($p < 0.00$). Table 8 lists 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, whereas adult children reported the highest impact on daily schedule. Family members caring for patients with early-stage disease also reported high levels of impact on daily schedule.

Numerous 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 ADL and IADL 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 ADL or IADL and symptomatology as reported by the caregivers was weak to nonexistent; thus, these measures were excluded from the analyses. However, these variables suggest that patients with cancer undergoing treatment and patients with cancer in the first year following diagnosis may experience few limitations in activities in the immediate interval prior to their death, which is contrary to common belief. In the months preceding death, patients with cancer in this study were not as

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

Variable	df	Sum of Squares	F	p
Number of patient symptoms	1	0.92	1.99	0.16
Family relationship	2	10.40	11.18	< 0.00
Stage of patient cancer	1	0.40	0.88	0.35
Caregiver employment status	1	0.20	0.45	0.50
Time of patient death	3	2.71	1.94	0.13
Caregiver gender	1	1.68	3.63	0.06
Time of patient death and caregiver gender	3	3.29	2.36	0.08
Family relationship and stage of patient cancer	2	2.08	2.21	0.11
Caregiver employment status and wave of patient death	3	2.49	1.79	0.15

Note. Amount of variance explained 60% of caregivers' sense of abandonment.

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

Variable	df	Sum of Squares	F	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
Time of patient death	3	2.13	1.99	0.12
Caregiver gender	1	0.45	1.26	0.26
Lung cancer diagnosis	1	0.43	1.21	0.27
Caregiver gender and lung cancer	1	0.95	2.68	0.10
Caregiver gender and time of patient death	3	2.17	2.02	0.12
Caregiver employment status and time of patient death	3	2.46	2.29	0.08

Note. Amount of variance explained 61% of impact on caregiver daily schedule.

“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 CES-D 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 an increasing number of patient symptoms reported by caregivers and level of depressive symptoms. The amount of assistance with ADL and IADL provided by the caregiver and patient disease status was 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 because of the ways that caregivers negotiate caregiving and employment, including withdrawal or absence from work and/or reduction in work productivity (Given et al., 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 later-stage disease reported higher levels of depressive symptoms than other caregivers. In contrast, the amount of assistance with ADL and IADL 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, 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 on them through employment, and the number of symptoms they perceived the patient to be experiencing.

Limitations

The major limitation of this study is in the area of generalizability. The majority of the sample consisted of women older than 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, younger caregivers who are less 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. 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 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 primarily were associated with caregiver factors rather than patient characteristics. This association indicates that healthcare professionals may be

Table 8. Relationship Between Increasing Number of Patient Symptoms and Caregiver Perceived Impact of Caring on Daily Schedule

Caregiver Report of Patient Symptoms (n)	Caregiver (n)	Perceived Impact on Daily Schedule	
		$\bar{X}$	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

Note. Possible scores ranged from 1–5.

able to predict and, ideally, moderate caregiver reactions to providing care by identifying caregivers at risk (resulting from, for example, their relationship to the patient) and by helping caregivers 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 (Schulz et al., 1995). Some researchers argue that burden and depression are virtually synonymous (Stommel et al., 1990), whereas others assert that they are unique constructs (Gitlin et al., 2003; Schulz et al.). 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, but they were explained by different variables. Thus, although depression and burden may be forms of caregiver distress, interventions aimed at decreasing burden and depressive symptoms should differ. Consistent with the findings of Cameron et al. (2002), an inability to maintain participation in usual activities may account for emotional distress in younger or nonspouse caregivers.

In this study, caregiver burden and depression were similar to those levels reported by caregivers of patients with nonadvanced cancer (Given et al., 1993, 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 work of Given, King, Collins, and Given (1988), Chapman and Pepler (1998), and Siegel, Raveis, Houts, and Mor (1991) about the responses of spouse caregivers being lower and less negative than adult children because of 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. Use of an inception cohort allowed the researchers to follow caregivers from the onset of the care situation and examine their reactions to end-of-life care throughout the care situation using a prospective, rather than retrospective, method. The study

has implications for researchers and clinicians. In the area of caregiver research, this study contributes to a much larger need to continue research that evaluates factors related to caregiver burden and depression. More research is needed to examine how burden and depression relate because the emotional, psychological, physical, and financial effects of 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 explore other factors that may contribute to negative caregiver outcomes for those caring for patients with advanced cancer. Ideally, research focused in these directions will 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 healthcare 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 practitioners be aware of sociodemographic characteristics of caregivers. Interventions designed to improve the emotional health of caregivers of patients with cancer at the end of life should be targeted to employed adult children caregivers, unemployed spouse caregivers, and caregivers of patients with lung and later-stage cancers. Furthermore, study findings emphasized the interrelationship of caregiver and patient variables, specifically that patient variables can affect caregiver outcomes. Thus, healthcare practitioners should be aware that interventions aimed at decreasing symptom severity could affect caregiver burden and depression. Practitioners should treat the patient and caregiver as a patient-caregiver dyad, be aware that the caregiver is at risk from negative outcomes from caregiver and patient characteristics, and be aware that concern for well-being should be given not only to the patient but also to the caregiver providing care at the end of life.

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