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Symptom Experience of Family Caregivers of Patients With Cancer

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Purpose/Objectives: To review the literature on depression, anxiety, sleep disturbance, fatigue, and pain in family caregivers of patients with cancer in the context of the Symptom Management Model (SMM) developed at the University of California, San Francisco (UCSF).

Data Sources: Published research studies and systematic reviews from 1990–2007.

Data Synthesis: Studies of depressive symptoms in caregivers of patients with cancer were the most numerous. A limited number of studies examined anxiety, fatigue, sleep disturbance, and pain. Most studies focused on the symptom experience dimension of the UCSF SMM.

Conclusions: Based on the small sample sizes, cross-sectional nature of the studies, and lack of comparison groups, little is known about the prevalence and effects of symptoms in caregivers of patients with cancer.

Implications for Nursing: Additional research is needed to determine the prevalence, severity, and effects of symptoms on caregivers. Better descriptive, correlational studies will lead to the development of interventions to improve symptom management for this group of caregivers.

According to a recent survey by the National Alliance for Caregiving and AARP (2004), an estimated 44.4 million American caregivers (21% of the adult population) provide unpaid care to an adult. Family caregivers fulfill an important role not only for the people they assist but also for society as a whole because their work results in a savings of \$257 billion annually (Moalosi et al., 2003; National Alliance for Care Giving & AARP). As medical management of cancer becomes more complex, caregivers deal with extensive coordination of care as well as with patients' physical and emotional needs.

In the face of increasing challenges and responsibilities, caregivers often report feeling depressed. However, little is known about the prevalence and severity of other symptoms in this group. The presence of preexisting symptoms in caregivers may interfere with their ability to assume and

Key Points . . .

- ▶ Approximately 21% of the adult population in the United States provides unpaid care to an adult aged 18 years or older.
- ▶ Faced with the increasing challenges and responsibilities of providing care to patients with cancer, family caregivers often report feelings of depression or burden. However, little is known about the prevalence, severity, and effects of anxiety, sleep disturbance, fatigue, and pain on family caregivers.
- ▶ Because of a paucity of research, additional studies are needed to describe the symptom experience of family caregivers of patients with cancer.

fulfill the caregiving role. In addition, caregivers may develop new symptoms or have existing symptoms worsen during the course of their caregiving activities. Finally, unrelieved symptoms and the demands of caregiving may have an effect on their functional status and quality of life (QOL).

A review of the literature failed to find any systematic evaluation of the symptom experience of caregivers of patients with cancer. Therefore, the purpose of this article is to provide

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Prevalence and Severity

Depression was the most frequently studied symptom (67% of the studies) included in this review (see Table 1). The Center for Epidemiologic Studies-Depression (CES-D) Scale (Radloff, 1977) was used in 69% of the studies to measure depressive symptoms. A grand weighted mean CES-D score of 13.4 was found, which is close to the CES-D cutoff score (≥ 16) for depression, indicating a relatively high level of depressive symptoms. Prevalence rates for depression in the studies that used the CES-D cutoff score ranged from 20%–73%.

Changes in Severity and Duration

Only 14 studies assessed for changes in the severity and duration of depressive symptoms over four weeks (Passik & Kirsh, 2005) to 12 months (Kurtz, Kurtz, Given, & Given, 2004; Langer, Abrams, & Syrjala, 2003). All but one study (Given & Given, 1992) reported that depressive symptoms decreased over time.

Relationship Between Depression and Other Symptoms

Eight studies examined the association between depression and other symptoms. Carter and Chang (2000) and Cho, Dodd, Lee, Padilla, and Slaughter (2006) found that caregivers who reported higher levels of depression also reported higher levels of sleep disturbance. Chronic sleep disturbance led them to feel irritable, which led to anger, guilt, and depressive symptoms (Carter, 2002). In addition, increased levels of anxiety (Flaskerud, Carter, & Lee, 2000; Gaston-Johansson, Lachica, Fall-Dickson, & Kennedy, 2004; Iconomou, Viha, Kalofonos, & Kardamakis, 2001) and fatigue (Cho et al.) were associated with higher depression scores. Finally, Kozachik et al. (2001) found that the baseline depression score was a significant predictor of higher depression scores in subsequent weeks.

Management

Only 17% of the studies tested an intervention to decrease depressive symptoms. A randomized clinical trial (RCT) that examined changes in the psychological status of caregivers of patients surgically treated for cancer (Jepson, McCorkle, Adler, Nuamah, & Lusk, 1999) found that the overall psychosocial status of family caregivers improved from baseline to three months and remained the same at six months in the intervention and control groups. No differences in any of the outcome measures were found between the two groups except in caregivers with physical problems. Among the individuals with physical problems, the psychosocial status of the treatment group declined at three months compared to the control group and the opposite pattern was seen at six months. Findings from the study suggest that caregivers with physical problems are at increased risk for psychological morbidity with delayed onset. In addition, the homecare intervention may have been an extra burden to those with physical problems.

An RCT that tested the effects of a psychoeducational intervention for depressive symptoms in caregivers of patients with cancer found no differences in depression scores between the experimental and control groups (Kozachik et al., 2001). However, in both groups, depressive symptoms decreased over time.

a review and synthesis of the studies on five highly prevalent symptoms (depression, anxiety, sleep disturbances, fatigue, and pain) in caregivers of patients with cancer. Because of the large number of studies on depression in caregivers of patients with cancer, the section on depression in this review focuses only on those studies. With regard to anxiety, recent reviews have summarized the prevalence and covariates for anxiety in caregivers of patients with dementia (Cooper, Balamurali, & Livingston, 2007), as well as the effectiveness of interventions for anxiety with that group (Cooper, Balamurali, Selwood, & Livingston, 2007). Therefore, this article summarizes the findings from those two reviews and synthesizes the findings from studies of anxiety in caregivers of patients with cancer. Because of the paucity of research on the other three symptoms specific to caregivers of patients with cancer, studies of caregivers of patients with dementia and Parkinson disease are included in this review. To provide clear direction for future research, the authors reviewed and synthesized the studies in the framework of the Symptom Management Model (SMM) that was developed at the University of California, San Francisco (Dodd et al., 2001; Larson et al., 1994).

Symptom Management Model

Briefly, the SMM is a multidimensional model embedded in the three domains of nursing (person, environment, and health and illness) (Dodd et al., 2001; Larson et al., 1994). The SMM consists of three dimensions (symptom experience, symptom management strategies, and symptom outcomes) that interact within and between each other. This review examines the research on the symptoms of depression, anxiety, sleep disturbance, fatigue, and pain in family caregivers within the context of the symptom experience, the various components of the symptom management dimension, the effects of symptoms on caregiver outcomes (i.e., functional status and QOL), and how the domains of person, environment, and health and illness influence the symptom experience. It is an ideal model to use for this review because it provides a comprehensive framework to synthesize and critique the literature as well as direction for future research.

Literature Search

The authors performed comprehensive searches of PubMed® and the Cumulative Index to Nursing and Allied Health Literature (CINAHL) databases from 1990–2007 using the search terms of *caregivers with symptoms, problems, depression, fatigue, sleep problems, anxiety, and pain*. More than 75 abstracts were reviewed and a total of 49 studies identified. The studies were evaluated, and the reference lists were checked for additional studies. Five additional articles were identified in that way. A total of 54 studies met the following inclusion criteria: evaluated caregivers from the adult cancer, dementia, or Parkinson disease populations; evaluated some aspect of one of five common symptoms (depression, anxiety, sleep disturbance, fatigue, and pain); used a subjective or objective measure to assess one or more of those symptoms; and were published in English. Studies that evaluated caregivers of patients with end-stage disease, bereavement, caregivers of patients younger than 18 years, or caregivers of patients with other chronic medical conditions were excluded.

Table 1. Studies That Evaluated Depression in Family Caregivers of Patients With Cancer

Study	Sample	Design	Measurement and Findings ^a	Domains
Campbell et al., 2004	40 caregivers (97.5% female), aged 57.6 ± 10.2 years	Cross-sectional	Symptom experience was measured with the POMS Depression Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Person: Lower depression scores were found in caregivers who reported greater overall confidence in assisting patients with symptom control and in caregivers who reported greater confidence in helping patients cope with their symptoms.
Carter & Chang, 2000	51 caregivers (80.4% female), aged 53.7 ± 14.3 years	Cross-sectional	Symptom experience was measured with the CES-D Scale. Symptom management strategies were not evaluated. Association with other symptoms: Higher depression correlated with higher sleep disturbance. Outcomes were not evaluated.	Environment: Higher patient pain intensity scores were associated with higher depression in caregivers.
Carter, 2002	47 caregivers (sample from Carter & Chang, 2000)	Cross-sectional	Symptom experience was measured with the CES-D Scale. Symptom management strategies were not evaluated. Association with other symptoms: Chronic sleep loss led to irritability, anger, guilt, and depression. Outcomes were not evaluated.	Person: Spouse caregivers reported significantly lower CES-D scores than nonspouse caregivers.
Carter, 2003	10 caregivers (80% female), aged 61.0 years	Longitudinal, 10 weeks	Symptom experience was measured with the CES-D Scale. Symptom management strategies were not evaluated. Association with other symptoms: Depression and sleep disturbance fluctuated over time. Outcomes were not evaluated.	Domain was not evaluated.
Carter, 2006	30 caregivers (63% female), aged 53.0 ± 17.0 years	Longitudinal, four months	Symptom experience was measured with the CES-D Scale. Symptom management strategies were evaluated with the Brief Sleep Intervention but did not improve caregiver depression. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Domain was not evaluated.
Cho et al., 2006	103 caregivers (78% female), aged 48.3 ± 11.4 years	Cross-sectional	Symptom experience was measured with the CES-D Scale. Symptom management strategies were not evaluated. Association with other symptoms: Higher depression correlated with higher levels of fatigue and sleep disturbance. Outcomes: Higher depression correlated with lower QOL scores.	Person: Female caregivers had significantly higher depression scores than male caregivers.
Clavarino et al., 2002	19 caregivers (42% female), aged 49.5 ± 9.9 years	Cross-sectional	Symptom experience was measured with the Hospital Anxiety and Depression Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Person: No differences were found in depression scores between patients and caregivers. Environment: The prevalence of depression in caregivers was higher than in the general population (15%).

(Continued on next page)^a If not specifically noted, symptom management strategies, association with other symptoms, and outcomes were not evaluated.

CES-D—Center for Epidemiologic Studies—Depression; POMS—Profile of Mood States; QOL—quality of life

Table 1. Studies That Evaluated Depression in Family Caregivers of Patients With Cancer (Continued)

Study	Sample	Design	Measurement and Findings ^a	Domains
Cliff & MacDonagh, 2000	135 caregivers (100% female), aged 73.9 ± 7.4 years	Cross-sectional	Symptom experience was measured with the Hospital Anxiety and Depression Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Domain was not evaluated.
Ferrario et al., 2003	50 caregivers (56% female), aged 46.7 ± 15.0 years	Cross-sectional	Symptom experience was measured with the Depression Questionnaire. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes: Higher depression correlated with less life satisfaction.	Environment: Higher depression scores were associated with higher levels of caregiver strain and greater need for knowledge of the patient's disease.
Ferrell et al., 1999	231 caregivers (72% female), aged 56 years	Cross-sectional	Symptom experience was measured with the caregiver QOL tool mean depression score. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Domain was not evaluated.
Flaskerud et al., 2000	41 caregivers (100% female), aged 51.5 ± 14.2 years	Cross-sectional	Symptom experience was measured with the CES-D Scale. Symptom management strategies were not evaluated. Association with other symptoms: Higher depression correlated with higher anxiety, anger, and sleep disturbance. Outcomes were not evaluated.	Environment: Higher patient pain scores were associated with higher depression scores in caregivers. An increased number of years of caregiving was associated with increased depression in caregivers.
Gaston-Johansson et al., 2004	102 caregivers (25% female), aged 47.6 ± 10.8 years	Cross-sectional	Symptom experience was measured with the Beck Depression Inventory. Symptom management strategies were not evaluated. Association with other symptoms: Higher depression correlated with higher anxiety. Outcomes were not evaluated.	Environment: Higher caregiver depression scores were correlated with higher subjective and objective burden scores.
Given & Given, 1992	49 caregivers (20% female); 21 caregivers (aged 54.0 years) caring for patients with new disease; 28 caregivers (aged 55 years) caring for patients with recurrent disease	Longitudinal, six months	Symptom experience was measured with the CES-D Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Environment: Caregivers of patients with recurrent disease reported higher levels of depression than caregivers of newly diagnosed patients at intake and at six months. Higher caregiver depression scores were associated with worse function and more symptom distress in patients.
Given et al., 1993	196 caregivers (63% female), aged 55.5 ± 12.7 years	Cross-sectional	Symptom experience was measured with the CES-D Scale. Symptom management strategies were not evaluated.	Person: Caregivers who scored higher on optimism scored lower on depression. Environ-

(Continued on next page)^a If not specifically noted, symptom management strategies, association with other symptoms, and outcomes were not evaluated.

CES-D—Center for Epidemiologic Studies—Depression; POMS—Profile of Mood States; QOL—quality of life

Table 1. Studies That Evaluated Depression in Family Caregivers of Patients With Cancer (Continued)

Study	Sample	Design	Measurement and Findings ^a	Domains
			Association with other symptoms was not evaluated. Outcomes were not evaluated.	ment: Caregiver depression scores correlated with patient variables of immobility, symptom distress, and dependencies in activities of daily living and with increased disruption in caregivers' schedules. Health and Illness: Higher depression scores were associated with an increased effect on caregiver health.
Hagedoorn et al., 2000	253 caregivers (58% female), aged 53.5 years	Cross-sectional	Symptom experience was measured with the CES-D Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes: Female caregivers perceived more psychological distress and poorer QOL than women in healthy couples.	Person: Higher depression scores were reported by female caregivers. Wives reported higher depression scores than husbands. Environment: Caregivers of patients with cancer reported higher depression scores than women in healthy couples.
Iconomou et al., 2001	65 caregivers (56.9% female), aged 47.6 ± 15.7 years	Cross-sectional	Symptom experience was measured with the Hospital Anxiety and Depression Scale. Symptom management strategies were not evaluated. Association with other symptoms: Depression and anxiety scores were positively correlated. Outcomes: Higher depression was associated with poorer QOL.	Person: Female caregivers reported significantly more depression than male caregivers. Those with higher education were significantly less depressed. Partners were more depressed than nonpartners. Environment: Positive correlations were found between depression scores and effect of caregiving scores. Health and Illness: Higher depression scores were associated with poorer health status scores.
Jepson et al., 1999	161 caregivers (67.7% female), aged 62.3 years	Longitudinal, six months	Symptom experience was measured with the CES-D Scale. Symptom management strategies: Depression decreased over time for the intervention and control groups. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Health and Illness: Caregivers in the intervention group who had physical problems reported increased depression scores over the first three months and then decreased depression scores over the next three months of the intervention, whereas the control group with physical problems showed the opposite pattern.
Kim et al., 2005	120 caregivers (66% female), aged 63.1 ± 10.0 years	Cross-sectional	Symptom experience was measured with the CES-D Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Person: Higher caregiver depression scores were associated with increased levels of neuroticism and decreased levels of interpersonal self-efficacy.
Kozachik et al., 2001	91 caregivers; control group (48% female), aged 53.0 + 14.6 years; treatment group (53% female), aged 51.3 ± 12.8 years	Longitudinal, 24 weeks	Symptom experience was measured with the CES-D Scale. Symptom management strategies: The educational intervention had no effect on depression scores. Association with other symptoms: Baseline depression score was a significant predictor of depression at 9 and 24 weeks. Outcomes were not evaluated.	Person: Higher depression scores were reported by male caregivers than female caregivers. Environment: Number of patient symptoms at baseline and at 9 and 24 weeks was a significant predictor of caregivers' depression scores.
Kurtz et al., 1994	208 caregivers (63.5% female), aged 55.0 years	Longitudinal, 12 months	Symptom experience was measured with the CES-D Scale. Symptom management strategies were not evaluated.	Environment: Caregivers of older patients were less depressed. Higher depression

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^a If not specifically noted, symptom management strategies, association with other symptoms, and outcomes were not evaluated.
CES-D—Center for Epidemiologic Studies—Depression; POMS—Profile of Mood States; QOL—quality of life

Table 1. Studies That Evaluated Depression in Family Caregivers of Patients With Cancer (Continued)

Study	Sample	Design	Measurement and Findings ^a	Domains
			Association with other symptoms was not evaluated. Outcomes were not evaluated.	scores were found in caregivers with shorter survival times. Higher depression scores in caregivers were associated with increased number of patient symptoms, patient depression, immobility, and dependence. Health and Illness: As the stage of illness progressed, caregivers experienced increased levels of depression and greater effects on health.
Kurtz et al., 1995	150 caregivers (62% female), aged 55.1 years	Longitudinal, six months	Symptom experience was measured with the CES-D Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Person: Caregivers who were more optimistic reported lower levels of depression. Environment: Patient symptoms were strong predictors of patient depression, which, in turn, predicted caregiver depression.
Kurtz et al., 2004	491 caregivers (76.2% female), 64% older than 65 years	Longitudinal, 12 months	Symptom experience was measured with the CES-D Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Person: Higher levels of depression in caregivers were associated with more education, increased feelings of abandonment, and worse caregiver social functioning. Environment: Higher levels of caregiver depression were associated with patient depression, more severe patient symptoms, greater impact on caregiver schedule, and caregivers who lived with the patient.
Kurtz et al., 2005	237 caregivers (53.4% female), aged 55.2 ± 13.7 years	Longitudinal, 20 weeks	Symptom experience was measured with the CES-D Scale. Symptom management strategies: No differences were found in caregivers' depression scores as a result of an educational intervention. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Person: Younger caregivers had less sense of mastery of care tasks; with worse social functioning, they had higher levels of depression. Environment: Caregivers who provided more symptom assistance and caregivers of patients with late-stage disease had higher levels of depression. Health and Illness: Caregivers who reported more comorbid conditions had higher levels of depression.
Langer et al., 2003	131 caregivers of patients with cancer (50.4% female), aged 48.1 ± 9.8 years; 88 caregivers in a normative sample (55% female), aged 45.9 ± 9.2 years	Cross-sectional	Symptom experience was measured with the POMS Depression Scale. Symptom management strategies: No differences existed in depression scores in caregivers assigned with patients to a 90-minute group format recovery workshop compared to standard care. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Person: Caregivers' depression scores decreased over 12 months. Prior to transplantation, caregivers reported higher depression scores than patients. Female caregivers reported higher depression scores than male caregivers. Environment: When compared to a normative sample, caregivers reported elevated levels of depression prior to and six months after transplantation.
Miaskowski et al., 1997	128 caregivers; caregivers of patients with pain (64% female), aged 52.9 years; caregivers of pain-free patients (52% female), aged 54.9 years	Cross-sectional	Symptom experience was measured with the POMS Depression Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Environment: Caregivers of patients with pain had significantly higher depression scores than caregivers of pain-free patients.

(Continued on next page)^a If not specifically noted, symptom management strategies, association with other symptoms, and outcomes were not evaluated.

CES-D—Center for Epidemiologic Studies—Depression; POMS—Profile of Mood States; QOL—quality of life

Table 1. Studies That Evaluated Depression in Family Caregivers of Patients With Cancer (Continued)

Study	Sample	Design	Measurement and Findings ^a	Domains
Nijboer et al., 1999	148 caregivers (64% female), aged 63.0 ± 11.0 years	Longitudinal, six months	Symptom experience was measured with the CES-D Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes: Higher levels of depression correlated with poorer QOL.	Person: Caregivers' initial levels of depression, lower educational status, and lower self-esteem were associated with higher levels of depression at six months. Environment: Caregivers of a patient with a stoma and those with a poorer quality relationship with the patient had higher levels of depression at six months. More disruptions in schedule, financial problems, and lack of family support were associated with higher levels of depression at six months. Health and Illness: Caregivers who reported a loss of physical strength had higher levels of depression at six months.
Nijboer et al., 2001	Same sample as Nijboer et al., 1999	Longitudinal, six months	Symptom experience was measured with the CES-D Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Person: Caregivers' initial levels of depression, higher levels of neuroticism, and lower levels of mastery and self-esteem were associated with higher levels of depression at six months. Environment: Higher caregiver depression scores at six months correlated with higher levels of patient depression, increased number of care tasks, increased negative interactions, and decreased emotional and social support.
Passik & Kirsh, 2005	25 caregivers (16% female), aged 54.5 ± 12.5 years	Longitudinal, one month	Symptom experience was measured with the Zung Self-Rating Depression Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Person: Caregivers' ratings of depression were lower than patients' at baseline and at the one-month follow-up. Environment: Higher fatigue scores in patients were correlated with higher caregiver depression scores.
Raveis et al., 1998	164 caregivers (100% female), aged 38.6 ± 7.6 years	Cross-sectional	Symptom experience was measured with the CES-D Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Person: Caregivers with less education, fewer additional roles, an increased sense of filial obligation, and less favorable attitudes toward the caregiving experience reported higher depression scores. Environment: An increased number of patient symptoms and fewer domains of patient need were associated with higher depression scores in caregivers. Health and Illness: A report of a limiting health condition in the caregiver was associated with higher depression scores.
Schumacher et al., 1993	75 caregivers (51% female), aged 43.8 ± 14.7 years	Cross-sectional	Symptom experience was measured with the POMS Depression Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Person: Caregivers who perceived that their coping strategies were less efficacious were more depressed. Environment: Caregivers of male patients and caregivers with less social support were more depressed.
Sherwood et al., 2006	95 caregivers (74% female), aged 51.0 ± 12.0 years	Cross-sectional	Symptom experience was measured with the CES-D Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Environment: Higher levels of neuropsychiatric symptoms in patients were associated with higher levels of depression and higher levels of burden in caregivers. Higher levels of depression in caregivers were associated

(Continued on next page)

^a If not specifically noted, symptom management strategies, association with other symptoms, and outcomes were not evaluated.
CES-D—Center for Epidemiologic Studies—Depression; POMS—Profile of Mood States; QOL—quality of life

Table 1. Studies That Evaluated Depression in Family Caregivers of Patients With Cancer (Continued)

Study	Sample	Design	Measurement and Findings ^a	Domains
				with higher levels of caregiver burden. Health and illness: Higher levels of caregiver burden were associated with a higher impact on caregivers' health.
Stetz & Brown, 2004	11 patients with cancer (91% female), 51.0 years; 15 patients with AIDS (80% female), aged 39.0	Cross-sectional	Symptom experience was measured with the CES-D Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Environment: Caregivers of patients with cancer reported that the work of caregiving disrupted their ability to socialize to a greater degree than caregivers of patients with AIDS. Caregivers of patients with cancer experienced a greater impact on their normal activities of daily living than caregivers of patients with AIDS. Caregivers of patients with AIDS reported more rewards from caregiving than caregivers of patients with cancer.
Toseland et al., 1995	78 caregivers; 38 in control group and 40 in treatment group (50% female), aged 53.5 years	Longitudinal pre- and post-six-week intervention	Symptom experience was measured with the CES-D Scale. Symptom management strategies: A six-session intervention of support, problem solving, and coping skills did not decrease depression scores in caregivers. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Domain was not evaluated.
Tuinstra et al., 2004	137 caregivers (65% female); age of females = 58.8 ± 11.3 years; age of males = 59.4 ± 10.6 years	Longitudinal, six months	Symptom experience was measured with the CES-D Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Person: Female caregivers reported higher depression scores at three and six months after the patients' surgery than male caregivers. At the time of the patients' surgery, male caregivers reported higher depression scores than male patients.
Williamson & Schultz, 1995	82 caregivers (67.1% female), aged 60.2 ± 11.3 years	Cross-sectional	Symptom experience was measured with the CES-D Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Environment: Caregivers, who were in a relationship with the patient prior to the onset of illness, characterized by mutual demonstrations of concern and responsiveness to each others' needs, reported lower levels of burden and depression. Caregivers who cared for patients with more severe symptoms reported higher levels of depression.
Williamson et al., 1998	75 caregivers (68% female), aged 62.2 ± 8.6 years	Cross-sectional	Symptom experience was measured with the CES-D Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Environment: Activity restrictions in caregivers totally mediated associations between caregiver stress (operationalized as the severity of the patients' symptoms) and caregiver resentment and depressed affect. In other words, the severity of the patients' symptoms was associated with negative affective outcomes for caregivers largely to the extent that it disrupted the caregivers' normal activities.

^a If not specifically noted, symptom management strategies, association with other symptoms, and outcomes were not evaluated.

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In another RCT that focused on teaching caregivers and patients the skills to better manage the patients' symptoms, depressive symptoms in family caregivers were not reduced (Kurtz, Kurtz, Given, & Given, 2005). In a fourth study that

evaluated the effects of a problem-solving intervention, no significant differences in levels of depressive symptoms were found between the experimental and control groups (Toseland, Blanchard, & McCallion, 1995). In the only study that focused

on patients who underwent bone marrow transplantation, a recovery workshop conducted in a group format did not affect caregivers' depression scores (Langer et al., 2003). Finally, in a pilot study of a brief behavioral sleep intervention, no improvements were noted in the depression scores of caregivers in the intervention group (Carter, 2006).

Depression and Symptom Outcomes

Only 14% of the studies evaluated the relationship between depression and one of the eight outcomes from the SMM. Four of them focused on QOL as the outcome measure and found that higher levels of depressive symptoms were associated with lower QOL scores. In another study, higher levels of depression were associated with less satisfaction with life (Rossi Ferrario, Zotti, Massara, & Nuvolone, 2003).

Depression and the Person Domain

Fifty-three percent of the studies evaluated the relationship between some aspect of the person domain and depression. Only Kurtz et al. (2005) examined the relationship between age and depression and found that younger caregivers had higher depression scores. In five studies (Cho et al., 2006; Hagedoorn, Buunk, Kuijer, Wobbles, & Sanderman, 2000; Iconomou et al., 2001; Langer et al., 2003; Tuinstra et al., 2004), female caregivers reported higher depression scores than males, whereas Kozachik et al. (2001) found the exact opposite. Findings on the relationship between education and depression are contradictory. Three studies (Iconomou et al.; Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999; Raveis, Karus, & Siegel, 1998) found that lower levels of education were associated with higher levels of depression, whereas Kurtz et al. (2004) found exactly the opposite relationship. Finally, examinations of the relationship between marital status and depression produced contradictory results (Carter, 2002; Iconomou et al.).

The relationship between depression and a number of personality characteristics of caregivers was assessed in four studies (Given et al., 1993; Kim, Duberstein, Sorensen, & Larson, 2005; Kurtz et al., 1995; Nijboer, Tempelaar, Triemstra, van den Bos, & Sanderman, 2001). Caregivers who were more optimistic reported lower levels of depressive symptoms (Given et al., 1993; Kurtz et al., 1995). In contrast, those with higher levels of neuroticism had more depressive symptoms (Kim et al.; Nijboer et al., 2001). Four studies (Campbell et al., 2004; Kurtz et al., 2004, 2005; Nijboer et al., 2001) found that caregivers with higher levels of self-esteem or a sense of mastery of care reported lower levels of depressive symptoms.

Depression and the Environmental Domain

In this review, patients are seen as part of the environment in the sense that they make up a very large part of the caregiving environment and can influence the responses of the caregivers. More than 60% of the studies assessed the relationship between a number of environmental variables and depressive symptoms. Of note, caregivers were found to have higher depression scores than the general population or age-matched controls (Clavarino, Lowe, Carmont, & Balanda, 2002; Hagedoorn et al., 2000). In addition, caregivers of patients with recurrent cancer (Given & Given, 1992) or with advanced disease (Kurtz et al., 2005) reported higher levels of depression than those of patients with newly diagnosed cancer.

In a study of the interaction of age, symptoms, and survival status of patients on the physical and mental health of caregivers (Kurtz, Given, Kurtz, & Given, 1994), the patient variables of younger age, increased symptoms, and more immobility were associated with increased depressive symptoms in caregivers. In a subsequent study (Kurtz et al., 2004), all patient characteristics listed above, as well as various aspects of the caregiver experience (i.e., increased impact on schedule, increased sense of family abandonment, and decreased social function), were associated with increased levels of depressive symptoms. Finally, increased disruptions in caregivers' schedules were associated with increased levels of depressive symptoms (Given & Given, 1992; Given et al., 1993).

Eleven studies found that a larger number of symptoms and increased symptom severity in patients were associated with increased depressive symptoms in caregivers. In three studies (Carter & Chang, 2000; Flaskerud et al., 2000; Miaskowski, Kragness, Dibble, & Wallhagen, 1997), higher levels of pain in patients were associated with higher caregiver depression scores. In addition, higher levels of caregiver strain or burden were associated with higher levels of depression (Flaskerud et al.; Gaston-Johansson et al., 2004; Iconomou et al., 2001; Rossi Ferrario et al., 2003; Sherwood et al., 2006).

Depression and the Health and Illness Domain

Only 22% of the studies examined the relationship between the health and illness domain and depressive symptoms. In general, higher depression scores were associated with increased numbers of comorbid conditions or poorer health status in caregivers of patients with cancer.

Anxiety

Anxiety in Caregivers of Patients With Dementia

A synthesis of the 33 studies that evaluated the prevalence of and covariates for anxiety in caregivers of patients with dementia found that clinically significant levels of anxiety were present in 25% and that it was more common than in age-matched controls (Cooper, Balamurali, & Livingston, 2007). Covariates associated with higher levels of anxiety included confrontative and escape avoidance coping, higher caregiver burden, and poorer caregiver health. In a second systematic review (Cooper, Balamurali, Selwood, et al., 2007), 24 intervention studies for anxiety in caregivers of patients with dementia were evaluated. Of note, only one study had anxiety as the primary outcome variable; most of the intervention studies focused on depression. Based on the review, no cognitive-behavioral intervention was found to be effective for the treatment of anxiety in caregivers of patients with dementia.

Prevalence and Severity

As shown in Table 2, only 14 studies (26%) assessed anxiety in caregivers of patients with cancer. Multiple instruments were used to evaluate anxiety in the individuals. Across the studies, caregivers reported mild to moderate levels of anxiety. In two studies, the prevalence rates for anxiety ranged from 20%–40% (Clavarino et al., 2002; Cliff & MacDonagh, 2000). Flaskerud et al. (2000) found that a higher percentage of caregivers of patients with cancer

Table 2. Studies That Evaluated Anxiety in Family Caregivers of Patients With Cancer

Study	Sample	Design	Measurement and Findings ^a	Domains
Campbell et al., 2004	40 caregivers (97.5 female), aged 57.6 ± 10.2 years	Cross-sectional	Symptom experience was measured with the POMS Anxiety Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Person: Lower anxiety scores were found in caregivers who reported greater overall confidence in assisting patients with symptom control and in caregivers who reported greater confidence in helping patients cope with their symptoms.
Clavarino et al., 2002	19 caregivers (42% female), aged 49.5 ± 9.9 years	Cross-sectional	Symptom experience was measured by the Hospital Anxiety and Depression Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Person: No differences in anxiety scores were found between patients and caregivers. Environment: The prevalence of anxiety was higher in caregivers than in the general population.
Cliff & MacDonagh, 2000	135 caregivers (100% female), aged 73.9 ± 7.4 years	Cross-sectional	Symptom experience was measured by the Hospital Anxiety and Depression Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Domain was not evaluated.
Ferrario et al., 2003	50 caregivers (56% female), aged 46.7 ± 15.0 years	Cross-sectional	Symptom experience was measured with the Spielberger Anxiety Inventory. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes: Higher anxiety correlated with less life satisfaction.	Environment: Higher trait and state anxiety scores were associated with higher levels of caregiver strain and a greater need for knowledge about the patient's disease.
Ferrell et al., 1999	231 caregivers (72% female), aged 56 years	Cross-sectional	Symptom experience was measured by the Caregiver QOL Tool Mean Anxiety Score. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Person: Caregivers' anxiety was higher than patients' anxiety.
Flaskerud et al., 2000	41 caregivers of patients with cancer or dementia (100% female), aged 51.5 ± 14.2 years	Cross-sectional	Symptom experience was measured by the SCL-90 Revised three-item anxiety scale. Symptom management strategies were not evaluated. Association with other symptoms: Higher anxiety correlated with higher depression, anger, and sleep disturbance. Outcomes were not evaluated.	Environment: Higher anxiety scores correlated with higher patient pain scores. Caregivers of patients with cancer experienced more anxiety than caregivers of patients with dementia.
Gaston-Johansson et al., 2004	102 caregivers (25% female), aged 47.6 ± 10.8 years	Cross-sectional	Symptom experience was measured by the Spielberger Anxiety Inventory. Symptom management strategies were not evaluated. Association with other strategies: Correlations were found between anxiety, depression, and fatigue. Outcomes: Decreased QOL correlated with increased anxiety and burden.	Person: Higher anxiety scores were reported by female caregivers. Higher anxiety scores were reported by nonmarried caregivers. Higher anxiety scores were associated with lower reported income.
Iconomou et al., 2001	65 caregivers (56.9% female), aged 47.6 ± 15.7 years	Cross-sectional	Symptom experience was measured by the Hospital Anxiety and Depression Scale. Symptom management strategies were not evaluated.	Person: Female caregivers reported significantly more anxiety than male caregivers. Caregivers with higher education were significantly more anxious. <i>(Continued on next page)</i>

^a If not specifically noted, symptom management strategies, association with other symptoms, and outcomes were not evaluated.

POMS—Profile of Mood States; QOL—quality of life; SCL-90R—Symptom Checklist-90 Revised

Table 2. Studies That Evaluated Anxiety in Family Caregivers of Patients With Cancer (Continued)

Study	Sample	Design	Measurement and Findings ^a	Domains
			Association with other symptoms: Depression and anxiety scores were correlated. Outcomes: Higher anxiety scores correlated with lower QOL.	nificantly less anxious. Environment: Positive correlations were found between anxiety scores and impact on caregiving scores. Health and Illness: Higher anxiety scores associated with poorer health status scores.
Langer et al., 2003	131 caregivers of patients with cancer (50.4% female), aged 48.1 ± 9.8 years; 88 caregivers in a normative sample (55% female), aged 45.9 ± 9.2 years	Longitudinal, 12 months	Symptom experience was measured by the POMS Anxiety Scale. Symptom management strategies: No differences were found in anxiety scores in caregivers who participated in a workshop compared to standard care. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Person: Caregivers' anxiety decreased over 12 months. Caregivers reported higher anxiety scores than patients prior to and 12 months after transplantation. Female caregivers reported higher anxiety scores than male caregivers. Environment: Caregivers compared to a normative sample reported elevated levels of anxiety prior to and 6 and 12 months after transplantation.
Matthews, 2003	135 caregivers (47% female), aged 55.2 ± 11.6 years	Cross-sectional	Symptom experience of anxiety was measured by the QOL-F Questionnaire. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Person: Female caregivers reported higher anxiety scores than male caregivers.
Miaskowski et al., 1997	128 caregivers of patients with pain (64% female), aged 52.9 ± 14.1 years, and of pain-free patients (52% female), aged 54.9 ± 13.8 years	Cross-sectional	Symptom experience was measured by the POMS Anxiety Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Environment: Caregivers of patients with pain had significantly higher anxiety scores than caregivers of pain-free patients.
Segrin et al., 2006	96 caregivers (26% female), aged 51.7 ± 14.8 years	Cross-sectional	Symptom experience was measured by the Composite Measure of Anxiety. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Person: Caregivers with higher anxiety scores reported poorer-quality relationship with the patient. Environment: Caregivers' anxiety scores were correlated with patients' anxiety scores.
Toseland et al., 1995	80 caregivers (50% female), aged 53.5 years	Longitudinal, before and after a six-week intervention	Symptom experience was measured by the Spielberger Anxiety Inventory. Symptom management strategies: A program of support, problem solving, and coping skills resulted in no change in caregiver anxiety. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Domain was not evaluated.
Walsh et al., 2004	40 caregivers (75% female), aged 51.4 ± 15.4 years	Longitudinal	Symptom experience was measured by the Beck Anxiety Inventory. Symptom management strategies: A creative-arts intervention decreased anxiety. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Domain was not evaluated.

^a If not specifically noted, symptom management strategies, association with other symptoms, and outcomes were not evaluated.

POMS—Profile of Mood States; QOL—quality of life; SCL-90R—Symptom Checklist-90 Revised

(85%) reported feeling nervous or shaky compared to only 38% of those of patients with dementia ($p = 0.007$). Only Walsh, Martin, and Schmidt (2004) assessed changes in anxiety over time and found decreases in anxiety.

Relationship Between Anxiety and Other Symptoms

Three studies examined the relationship between anxiety and other symptoms (Flaskerud et al., 2000; Gaston-Johansson et al., 2004; Iconomou et al., 2001), and all three found positive correlations between anxiety and depression. In addition, higher anxiety scores were associated with higher anger scores, higher levels of sleep disturbance (Flaskerud et al.), and increased levels of fatigue (Gaston-Johansson et al.).

Management

Only three studies tested an intervention to decrease anxiety (Langer et al., 2003; Toseland et al., 1995; Walsh et al., 2004). In a group intervention with patients and caregivers that focused on recovery after bone marrow transplantation, Langer et al. found no differences in anxiety scores between the intervention and control groups. Positive results were reported by Walsh et al., who used a creative-arts intervention to reduce caregivers' anxiety. A significant reduction in anxiety scores was found immediately after the intervention ($t = -5.0$, $p < 0.001$). However, in a six-session intervention program that consisted of support, problem solving, and coping skills, no significant changes in anxiety scores were reported (Toseland et al.).

Anxiety and Symptom Outcomes

Only 21% of the studies evaluated the relationship between anxiety and one of the eight outcomes from the SMM. Two of the studies that focused on QOL (Gaston-Johansson et al., 2004; Iconomou et al., 2001) found that higher anxiety scores were associated with decreases in QOL. Rossi Ferrario et al. (2003) reported that higher levels of trait and state anxiety were associated with less satisfaction with life.

Anxiety and the Person Domain

Eight studies evaluated the relationship between some aspect of the person domain and anxiety. In four studies (Gaston-Johansson et al., 2004; Iconomou et al., 2001; Langer et al., 2003; Matthews, 2003), higher anxiety scores were reported by female caregivers. In addition, caregivers who were not married and had lower incomes reported higher anxiety scores (Gaston-Johansson et al.). Segrin, Badger, Dorros, Meek, and Lopez (2007) reported that caregivers with higher anxiety scores had poorer-quality relationships with patients. Finally, Campbell et al. (2004) found that lower anxiety scores were reported by caregivers who reported greater overall confidence in assisting patients with symptom control and in helping patients cope with their symptoms.

Anxiety and the Other Domains

Approximately 50% of the studies assessed anxiety levels and some aspect of the environmental domain. In two studies (Clavarino et al., 2002; Langer et al., 2003), family caregivers of patients with cancer had higher anxiety scores than non-family caregivers. In the only comparison study of two patient samples (Flaskerud et al., 2000), caregivers of patients with

cancer reported higher anxiety scores than those of patients with dementia. In two studies (Flaskerud et al.; Miaskowski et al., 1997), caregivers who cared for patients with cancer pain reported higher anxiety scores than those of pain-free patients. Iconomou et al. (2001) and Rossi Ferrario et al. (2003) reported that higher anxiety scores were associated with higher levels of caregiver strain.

Only Iconomou et al. (2001) evaluated the relationship between anxiety and the health and illness domain. Of note, higher anxiety scores in caregivers were associated with reports of poorer health status.

Sleep Disturbance

Prevalence and Severity

Sleep disturbance was assessed in only 20 studies that examined a variety of symptoms in caregivers of patients with cancer, dementia, or Parkinson disease (see Table 3). The Pittsburgh Sleep Quality Index (PSQI) (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989) was used to measure sleep disturbance in 50% of the studies. A grand weighted mean PSQI score of 8.5 was found, which is above the tool's cutoff for moderate levels of sleep disturbance. The remaining studies used a variety of instruments to evaluate sleep, and only one used polysomnography (Sato, Kanda, Anan, & Watanuki, 2002).

Changes in Severity and Duration

Only one descriptive study assessed for changes in sleep disturbance over time and found that sleep disturbance scores were highly variable from week to week (Carter, 2003). Of note, caregivers typically under-rated sleep disturbance when compared with actigraphic measures. They reported a mean sleep duration of 6.1 hours, whereas actigraphy estimated 4.8 hours. Likewise, self-reports of sleep efficiency were at 80%, but actigraphy revealed 74%. Sleep latency was highly variable across time.

Relationship Between Sleep Disturbance and Other Symptoms

Nine studies examined the associations between sleep disturbance and other symptoms in family caregivers. Eight of the studies found that caregivers who reported higher sleep disturbance scores reported higher levels of depression. Cho et al. (2006) and Sato et al. (2002) found that higher sleep disturbance scores were associated with higher levels of fatigue. A similar relationship was found between sleep disturbance and anxiety (Flaskerud et al., 2000; Pal et al., 2004) and between sleep disturbance and anger (Carter, 2002; Flaskerud et al.).

Management of Sleep Disturbance

Six studies tested an intervention to decrease sleep disturbance. Three of them demonstrated significant improvements in sleep disturbance scores. McCurry, Logsdon, Vitiello, and Teri (1998) tested two interventions to improve sleep in caregivers of patients with dementia. The first intervention, given over a six-week period, consisted of group sessions about sleep hygiene, stimulus control, and sleep compression strategies. The second intervention covered the same information on an individual basis over four weeks. Data from

Table 3. Studies That Evaluated Sleep Disturbance in Family Caregivers of Patients With Cancer, Dementia, or Parkinson Disease

Study	Sample	Design	Measurement and Findings ^a	Domains
Carter & Chang, 2000	51 caregivers of patients with cancer (80.4% female), aged 53.7 ± 14.3 years	Cross-sectional	Symptom experience was measured by the PSQI. Symptom management strategies were not evaluated. Association with other symptoms: Higher sleep disturbance correlated with higher depression scores. Outcomes were not evaluated.	Domains were not evaluated.
Carter, 2002	47 caregivers of patients with cancer from the subset of Carter and Chang's (2000) sample	Cross-sectional	Symptom experience was measured by the PSQI. Symptom management strategies were not evaluated. Association with other symptoms: Chronic sleep loss led to irritability, anger, guilt, and depression. Outcomes were not evaluated.	Domains were not evaluated.
Carter, 2003	10 caregivers of patients with cancer (80% female), aged 61 years	Longitudinal, 10 weeks	Symptom experience was measured by the PSQI. Symptom management strategies were not evaluated. Association with other symptoms: Sleep disturbance and depressive symptoms fluctuated over time. Outcomes were not evaluated.	Domains were not evaluated.
Carter, 2006	30 caregivers of patients with cancer (63% female), aged 53.0 ± 17.0 years	Longitudinal, four months	Symptom experience was measured by the PSQI. Symptom management strategies: Brief behavioral sleep intervention improved sleep quality. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Domains were not evaluated.
Cho et al., 2006	103 caregivers of patients with cancer (78% female) aged 48.3 ± 11.4 years	Cross-sectional	Symptom experience was measured with the PSQI. Symptom management strategies were not evaluated. Association with other symptoms: Higher sleep disturbance correlated with higher depression and fatigue. Outcomes: Higher levels of sleep disturbance correlated with lower QOL scores.	Person: No differences were found in sleep disturbance scores between male and female caregivers.
Ferrell et al., 1999	231 caregivers of patients with cancer (72% female), aged 56 years	Cross-sectional	Symptom experience was measured with the Caregiver QOL Tool. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Domains were not evaluated.
Flaskerud et al., 2000	41 caregivers of patients with cancer or dementia (100% female), aged 51.5 ± 14.2 years	Cross-sectional	Symptom experience was measured with the PSQI. Symptom management strategies were not evaluated. Association with other symptoms: Higher sleep disturbance correlated with higher depression, anger, and anxiety. Outcomes were not evaluated.	Environment: Caregivers of patients with cancer experienced more difficulty staying asleep and more restless sleep than caregivers of patients with dementia.

(Continued on next page)

^a If not specifically noted, symptom management strategies, association with other symptoms, and outcomes were not evaluated.

PSQI—Pittsburgh Sleep Quality Index; QOL—quality of life

Table 3. Studies That Evaluated Sleep Disturbance in Family Caregivers of Patients With Cancer, Dementia, or Parkinson Disease (Continued)

Study	Sample	Design	Measurement and Findings ^a	Domains
Happe & Berger, 2002	101 caregivers of patients with Parkinson disease (63% female), aged 62.3 ± 10.0 years	Cross-sectional	Symptom experience was measured with a single item of the Center for Epidemiologic Studies–Depression Scale. Symptom management strategies were not evaluated. Association with other symptoms: Higher sleep disturbance correlated with higher depression. Outcomes were not evaluated.	Environment: Bad night-time sleep in caregivers was correlated with motor symptom severity and bad sleep in patients, male gender of the patients, and the frequency of caregiving.
Hosaka & Sugiyama, 2003	20 caregivers of patients with dementia (100% female), aged 54.7 ± 4.4 years	Longitudinal	Symptom experience was measured with the General Health Questionnaire-30. Symptom management strategies: A multidimensional intervention did not improve sleep. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Domains were not evaluated.
McCurry et al., 1998	36 caregivers of patients with dementia (78% female), aged 68.7 ± 10.6 years	Longitudinal, three months	Symptom experience was measured with the PSQI. Symptom management strategies: Caregivers had improvements in sleep after treatment and at three months. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Person: Caregivers who responded to treatment tended to be younger and more adherent with procedures.
McKibbin et al., 2005	113 caregivers and noncaregiver controls; caregivers of patients with moderate to severe dementia (66.7% female), aged 73.5 ± 9.4 years; caregivers of patients with mild dementia (75.0% female), aged 71.1 ± 8.3 years; non-caregiver controls (71.2% female), aged 67.6 ± 6.8 years	Cross-sectional	Symptom experience was measured with the PSQI and polysomnography. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes: Increased sleep disturbance correlated with decreased functional status.	Person: Older caregivers of patients with moderate to severe dementia slept less than older noncaregivers. Older caregivers had lower sleep efficiency, less slow wave sleep, and more stage 1 sleep than younger caregivers. Environment: Caregivers of patients with moderate to severe dementia reported significantly more sleep problems than noncaregivers.
Mizuno et al., 1999	42 caregivers of patients with dementia or disability (90.5% female), aged 56.7 ± 9.7 years	Longitudinal	Symptom experience was measured with the General Health Questionnaire-30. Symptom management strategies: A structured five-week psychoeducational intervention program had no effect on sleep disturbance scores. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Domains were not evaluated.

(Continued on next page)

^a If not specifically noted, symptom management strategies, association with other symptoms, and outcomes were not evaluated.

PSQI—Pittsburgh Sleep Quality Index; QOL—quality of life

Table 3. Studies That Evaluated Sleep Disturbance in Family Caregivers of Patients With Cancer, Dementia, or Parkinson Disease (Continued)

Study	Sample	Design	Measurement and Findings ^a	Domains
Pal et al., 2004	23 caregivers of patients with Parkinson disease (65.2% female) aged 65.2 ± 11.3 years	Cross-sectional	Symptom experience was measured with the PSQI. Symptom management strategies were not evaluated. Association with other symptoms: Correlations were found between anxiety, depression, and sleep disturbance. Outcomes were not evaluated.	Environment: Caregivers had significantly lower PSQI global scores than patients with Parkinson disease.
Passik et al., 2005	25 caregivers of patients with cancer (16% female), aged 54.5 ± 12.5 years	Longitudinal, one month	Symptom experience was measured using a numeric rating scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Environment: Higher fatigue scores in patients were correlated with higher sleep disturbance scores in caregivers.
Sato et al., 2002	9 female caregivers aged 56 years and 9 female noncaregivers aged 67 years	Cross-sectional	Symptom experience was measured with the Sleep Evaluation Questionnaire–Quality of Sleep Score. Symptom management strategies were not evaluated. Association with other symptoms: Poorer-quality sleep correlated with increased levels of morning fatigue. Outcomes were not evaluated.	Environment: Caregivers reported poorer-quality sleep than noncaregivers.
Secker & Brown, 2005	15 caregivers in the control group (40% female), aged 58.9 ± 11.4 years; 15 caregivers in the intervention group (46.7% female), aged 59.1 ± 12.2 years	Longitudinal, six months	Symptom experience was measured using the General Health Questionnaire-28. Symptom management strategies: 12–14 sessions of cognitive behavioral therapy over 12–14 weeks resulted in improvements in anxiety and insomnia at three months compared to standard care. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Domains were not evaluated.
Smith et al., 1997	256 caregivers of patients with Parkinson disease and healthy controls (63.7% female), aged 64.8 years	Cross-sectional	Symptom experience was measured using a single item from the Zung Self-Rated Depression Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Person: Overall, women reported higher sleep disturbance scores than men. Environment: Female caregivers reported higher sleep disturbance scores than female controls. The strongest predictor of disrupted sleep in caregivers was the disease severity of the patient.
Teel & Press, 1999	125 caregivers of patients with cancer, dementia, or Parkinson disease (52% female), aged 72.3 years	Cross-sectional	Symptom experience was measured using the Verran and Snyder-Halpern Sleep Scale–Sleep Disturbance Subscale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Environment: All three groups of caregivers reported higher levels of sleep disturbance and lower levels of sleep effectiveness than noncaregivers.
Wilcox & King, 1999	90 caregivers of patients	Cross-sectional	Symptom experience was measured with the PSQI.	

(Continued on next page)

^a If not specifically noted, symptom management strategies, association with other symptoms, and outcomes were not evaluated.

PSQI—Pittsburgh Sleep Quality Index; QOL—quality of life

Table 3. Studies That Evaluated Sleep Disturbance in Family Caregivers of Patients With Cancer, Dementia, or Parkinson Disease (Continued)

Study	Sample	Design	Measurement and Findings ^a	Domains
	with dementia (100% female), aged 62.8 ± 9.5 years		Symptom management strategies were not evaluated. Association with other symptoms: Higher levels of sleep disturbance were correlated with higher levels of depression and lower levels of internalized anger. Outcomes were not evaluated.	Person: Higher levels of sleep disturbance were found in caregivers with less education; higher levels of daytime dysfunction were found in younger caregivers. Environment: Higher levels of sleep disturbance were found in caregivers than in the general population; higher levels of sleep disturbance were associated with more night-time disruptions by the patient.
Woods et al., 2003	128 caregivers of patients with dementia; control group caregivers (20% female), aged 58.8 ± 13.2 years; intervention group caregivers (74% female), aged 62.4 ± 15.9	Longitudinal, eight months	Symptom experience was measured with the General Health Questionnaire-30. Symptom management strategies: Caregivers referred to a specialist in mental health nursing service reported significant decreases in sleep disturbance at eight months compared to caregivers in the standard care group. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Domains were not evaluated.

^a If not specifically noted, symptom management strategies, association with other symptoms, and outcomes were not evaluated.

PSQI—Pittsburgh Sleep Quality Index; QOL—quality of life

both intervention studies were pooled, and results showed significant improvements in sleep scores from baseline.

In a study of caregivers of patients with dementia (Woods, Wills, Higginson, Hobbins, & Whitby, 2003), referral to a specialist in mental health nursing services resulted in a significant reduction in sleep disturbance scores in caregivers eight months after the intervention. Finally, the use of a cognitive behavioral therapy (CBT) intervention given over 12–14 weeks resulted in significant improvements in insomnia in caregivers of patients with dementia three months after the intervention (Secker & Brown, 2005). The three negative intervention studies evaluated a structured five-week psycho-educational intervention (Mizuno, Hosak, Ogihara, Higano, & Mano, 1999), an education, relaxation training, and group discussion intervention (Hosaka & Sugiyama, 2003), and a brief behavioral sleep intervention.

Sleep Disturbance and Symptom Outcomes

Only two studies examined the relationship between sleep disturbance and outcomes. Higher levels of sleep disturbance were associated with lower QOL scores in caregivers of patients with cancer (Cho et al., 2006) and with decreased functional status in caregivers of patients with dementia (McKibbin et al., 2005).

Sleep Disturbance and the Person Domain

Five studies evaluated the relationship between some aspect of the person domain and sleep disturbance. Conflicting results were reported on gender differences in sleep disturbance. In a study of caregivers of patients with cancer (Cho et al., 2006), no differences in sleep disturbance scores were found

between men and women. In contrast, in a study of caregivers of patients with Parkinson disease (Smith, Ellgring, & Oertel, 1997), women reported significantly higher sleep disturbance scores than men.

In terms of age differences, one study found that older caregivers of patients with dementia (McKibbin et al., 2005) reported lower levels of sleep efficiency, less slow wave sleep, and more stage 1 sleep than younger individuals. Wilcox and King (1999) reported higher levels of daytime dysfunction in younger caregivers of patients with dementia. Finally, caregivers of patients with dementia who responded to an intervention were younger and more adherent with treatment procedures (McCurry et al., 1998).

Sleep Disturbance and the Other Domains

Nine studies assessed the relationship between the environmental domain and sleep disturbance. In three studies that evaluated caregivers of patients with dementia (Sato et al., 2002; Smith et al., 1997; Wilson, 1989), family caregivers had higher sleep disturbance scores than nonfamily caregivers. In studies that evaluated caregivers of patients with cancer (Passik & Kirsh, 2005), Parkinson disease (Wilcox & King, 1999), or dementia (McKibbin et al., 2005; Wilcox & King), those who cared for sicker patients reported more sleep disturbance. In the only study that compared two groups of caregivers (Flaskerud et al., 2000), those caring for patients with cancer reported more sleep disturbance than those who cared for patients with dementia. No studies assessed the relationship between the health and illness domain and sleep disturbance in caregivers of patients with cancer, dementia, or Parkinson disease.

Table 4. Studies That Evaluated Fatigue in Family Caregivers of Patients With Cancer, Dementia, or Parkinson Disease

Study	Sample	Design	Measurement and Findings ^a	Domains
Campbell et al., 2004	40 caregivers of patients with cancer (97.5% female), aged 57.6 ± 10.2 years	Cross-sectional	Symptom experience was measured with the POMS Fatigue Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Person: Lower fatigue scores were found in caregivers who reported greater overall confidence in assisting patients with symptom control and in caregivers who reported greater confidence in helping patients cope with their symptoms.
Cho et al., 2006	103 caregivers of patients with cancer (78% female), aged 48.3 ± 11.4 years	Cross-sectional	Symptom experience was measured with the Lee Fatigue Scale. Symptom management strategies were not evaluated. Association with other symptoms: Higher fatigue correlated with higher depression and sleep disturbance. Outcomes: Higher levels of fatigue were associated with lower QOL scores.	Person: Female caregivers had higher fatigue scores than male caregivers.
Clark, 2002	67 caregivers of patients with dementia (91% female), aged 55 ± 12.6 years	Cross-sectional	Symptom experience was measured using the Piper Fatigue Scale. Symptom management strategies were not evaluated. Association with other symptoms: Higher fatigue correlated with higher depression. Outcomes were not evaluated.	Person: Lower caregiver fatigue scores were correlated with higher individual hardiness scores. Environment: Higher occurrences of memory and behavior problems in the care recipient were associated with increased fatigue in caregivers.
Ferrell et al., 1999	231 caregivers of patients with cancer (72% female), aged 56 years	Cross-sectional	Symptom experience was measured by the caregiver QOL score for fatigue. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Domains were not evaluated.
Gaston-Johansson et al., 2004	102 caregivers of patients with cancer (25% female), aged 47.6 years	Cross-sectional	Symptom experience was measured with the Piper Fatigue Scale. Symptom management strategies were not evaluated. Association with other symptoms: Higher fatigue correlated with higher depression and anxiety. Outcomes: Higher levels of fatigue were associated with lower QOL scores.	Person: Higher caregiver fatigue scores correlated with lower income levels.
Hosaka & Sugiyama, 2003	20 caregivers of patients with dementia (100% female), aged 54.7 ± 4.4 years	Longitudinal	Symptom experience was measured with the POMS Fatigue Scale. Symptom management strategies: A multidimensional intervention resulted in a decrease in fatigue. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Domains were not evaluated.
Jensen & Given, 1991	248 caregivers of patients with cancer (65% female) aged 54.8 ± 12.6 years	Cross-sectional	Symptom experience was measured with the Piper Fatigue Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Environment: Higher caregiver fatigue scores were correlated with higher impact on schedule scores.

(Continued on next page)^a If not specifically noted, symptom management strategies, association with other symptoms, and outcomes were not evaluated.

POMS—Profile of Mood States; QOL—quality of life; VAS-F—visual analog scale-fatigue

Table 4. Studies That Evaluated Fatigue in Family Caregivers of Patients With Cancer, Dementia, or Parkinson Disease (Continued)

Study	Sample	Design	Measurement and Findings ^a	Domains
Miaskowski et al., 1997	128 caregivers of patients with cancer; caregivers of patients with pain (64% female), aged 52.9 ± 14.1 years; caregivers of patients without pain (52% female), aged 54.9 ± 13.8 years	Cross-sectional	Symptom experience was measured by the POMS Fatigue Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Domains were not evaluated.
Passik & Kirsh, 2005	25 caregivers of patients with cancer (16% female), aged 54.5 ± 12.5 years	Longitudinal, one month	Symptom experience was measured with the Fatigue Severity Inventory. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Environment: Caregivers with higher levels of caregiver strain reported higher levels of fatigue at baseline.
Sato et al., 2002	18 caregivers of patients with dementia (100% female), aged 66.1 years	Cross-sectional	Symptom experience was measured with the Perceived Symptoms of Fatigue. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Environment: Higher levels of perceived and physiologic fatigue were reported by caregivers compared to noncaregivers.
Teel & Press, 1999	125 caregivers of patients with cancer, dementia, and Parkinson Disease (52% female), aged 72.3 years	Cross-sectional	Symptom experience was measured using the VAS-F and the POMS Fatigue Scale. Symptom management strategies were not evaluated. Association with other symptoms was not evaluated. Outcomes were not evaluated.	Environment: All three groups of caregivers reported more fatigue and less energy than an age-matched control group.

^a If not specifically noted, symptom management strategies, association with other symptoms, and outcomes were not evaluated.

POMS—Profile of Mood States; QOL—quality of life; VAS-F—visual analog scale—fatigue

Fatigue

Prevalence and Severity

As shown in Table 4, fatigue was assessed in 11 studies that examined the symptom experience of caregivers of patients with cancer, dementia, or Parkinson disease. Three studies used the Piper Fatigue Scale (PFS) (Piper et al., 1998) to measure fatigue severity (Clark, 2002; Gaston-Johansson et al., 2004; Jensen & Given, 1991). Calculating a grand weighted mean PFS score was not possible because the studies used different versions of the PFS. On average, caregivers reported moderate levels of fatigue. However, wide variability in fatigue scores was noted in the three studies. Campbell et al. (2004), Hosaka and Sugiyama (2003), and Miaskowski et al. (1997) used the Profile of Mood States (POMS) (McNair, Lorr, & Droppleman, 1992) to evaluate fatigue. The grand weighted mean fatigue score was 8.8, reflecting a moderate

level of fatigue. Cho et al. (2006); Ferrell, Grant, Borneman, Juarez, and ter Veer (1999); Passik and Kirsh (2005); Sato et al. (2002); and Teel and Press (1999) each used a different instrument to assess fatigue. All of the studies found moderate levels of fatigue.

Relationship Between Fatigue and Other Symptoms

Only three studies (Cho et al., 2006; Clark, 2002; Gaston-Johansson et al., 2004) evaluated relationships between fatigue severity and other symptoms. Higher fatigue scores were associated with higher depression scores. Similar relationships were found between fatigue and anxiety (Gaston-Johansson et al.) and between fatigue and sleep disturbance (Cho et al.).

Management

Only one study evaluated the effect of a fatigue intervention for caregivers of patients with dementia (Hosaka & Sugiyama,

2003). A five-week intervention that consisted of education, progressive relaxation, and group discussion resulted in a significant decrease in fatigue.

Fatigue and Symptom Outcomes

Only Cho et al. (2006) and Gaston-Johansson et al. (2004) evaluated the relationship between fatigue and one of the eight outcomes from the SMM. Both found that higher levels of fatigue were associated with lower QOL scores.

Fatigue and the Person Domain

Only four studies evaluated the relationship between some aspect of the person domain and fatigue. Cho et al. (2006) found higher fatigue scores in female caregivers of patients with cancer. In another study of caregivers of patients with cancer, Gaston-Johansson et al. (2004) reported higher fatigue scores in those with lower incomes.

Two studies assessed the relationships between fatigue and some personality characteristics of caregivers. Those with greater overall confidence in their ability to assist patients with symptom control or with coping reported lower levels of fatigue (Campbell et al., 2004). Caregivers of patients with dementia who reported higher levels of individual hardiness reported lower fatigue scores (Clark, 2002).

Fatigue and the Other Domains

Five studies assessed the relationship between fatigue and some aspect of the environmental domain. In two studies (Sato et al., 2002; Teel & Press, 1999), family caregivers of patients with cancer, dementia, or Parkinson disease had higher fatigue scores than nonfamily caregivers. In addition, those who cared for patients with a higher number of memory and behavior problems reported higher levels of fatigue (Clark, 2002). Finally, those who reported higher levels of caregiver strain (Passik & Kirsh, 2005) or a greater impact of caregiving on their schedules (Jensen & Given, 1991) reported higher levels of fatigue. No studies were found that assessed the relationship between the health and illness domain and fatigue.

Pain

Only one study evaluated pain in caregivers of patients with cancer, dementia, or Parkinson disease (Kuzu et al., 2005). In the study of caregivers of patients with dementia, the mean pain intensity score was 37.5 using the Duke Health-Related Quality-of-Life Scale (score = 0–100, with a higher score indicating more dysfunction), suggesting a moderate level of dysfunction resulting from pain. An educational intervention that included structured and tailored components focused on patients' and caregivers' problems had no effect on the caregivers' pain.

Two other studies mentioned pain in caregivers. In a study of caregivers and cancer pain management (Ferrell et al., 1999), caregivers reported concerns about their own QOL and about the management of cancer pain. Their own pain was rated as one of the top five symptoms on the physical well-being subscale of a QOL questionnaire (Ferrell, Dow, & Grant, 1995). In a study of sleep in older female caregivers of patients with dementia (Wilcox & King, 1999), the most common reasons for sleep difficulties were "needing to use the bathroom" (83%), "feeling too hot" (39%), and "having pain" (34%).

Summary and Critique

This article is the first to provide a comprehensive review of five common symptoms in caregivers of patients with cancer, dementia, or Parkinson disease within the context of the UCSF SMM. Despite the large number of individuals currently providing care to adults in the United States, little is known about their symptoms. Only 54 studies evaluated some aspect of their symptoms. Of note, studies of depressive symptoms in caregivers of patients with cancer were the most numerous (a total of 36 studies). In contrast, only 14 studies evaluated anxiety, 9 evaluated sleep disturbances, and 8 evaluated fatigue in caregivers. No studies examined pain in cancer caregivers. Given the fact that the burden of caregiving will increase as the U.S. population ages, more research is needed on caregivers' symptoms.

Across the five symptoms, most of the studies focused on some aspect of the symptom experience dimension of the SMM. However, based on the cross-sectional nature of the studies, the relatively small sample sizes, and the lack of comparison groups, little is known about the incidence or prevalence rates of the five symptoms. In addition, virtually no information is available on the multiple dimensions of each symptom and changes in the symptom experience over time.

Only 13 studies tested interventions to decrease symptoms. Six of them tested psychoeducational interventions to decrease depressive symptoms. The total number of individuals enrolled in the studies ranged from 30–161, and evaluations occurred following one session or after 12 months. Five of the interventions had no effect on depression, and one study reported worsening and improvement of depression scores based on specific caregiver characteristics.

Only one study tested a creative-arts intervention for anxiety and found that the intervention decreased anxiety. Only six studies attempted to test interventions to improve sleep in caregivers of patients with cancer, dementia, or Parkinson disease. Findings from four of the studies suggest that several interventions were effective in improving sleep. Interestingly, one study tested the effectiveness of an intervention on four symptoms (depression, fatigue, anxiety, and sleep disturbance) simultaneously. The intervention, which had both psychosocial and psychoeducational components, reduced depression, anxiety, and fatigue but had no effect on sleep disturbance.

At least eight outcomes (i.e., functional status, symptom status, self-care, costs, QOL, morbidity and comorbidity, mortality, and emotional status) can be evaluated within the context of the SMM. Of the seven studies (13%) that examined the relationship between a symptom and an outcome, only QOL, functional status, and satisfaction with life were evaluated.

In reviewing the various components of the SMM in relationship to the symptom studies of caregivers, the vast majority of the 54 studies examined one or more interdependent factors that affect the various dimensions of the SMM (i.e., person, environment, or health and illness). In the 28 studies (52%) that examined some aspect of the person domain, the most common characteristics evaluated were gender, education, income, and a variety of personality characteristics (e.g., self-esteem, optimism, self-efficacy). However, because most of the studies evaluated rather disparate characteristics from the person domain, no definitive conclusions can be drawn about the relationships among the person characteristics and the symptom experiences of caregivers.

Thirty-five studies (65%) examined some aspect of the environmental domain and the symptoms. The two aspects of the environmental domain that were examined most frequently were some characteristic of the patient as part of the caregiver's environment or some aspect of the caregiver experience (e.g., caregiver burden, demands of caregiving on schedule). One consistent finding across the various studies was that individuals who cared for patients who were sicker (e.g., more symptoms, advanced-stage disease) reported higher symptom scores. In addition, in most of the studies, higher symptom scores in patients were associated with higher caregiver burden scores.

Only eight studies (15%) examined the relationship between symptoms in caregivers and their health or illness. All of them focused on the symptom of depression. Again, based on the limited amount of research, no definitive conclusions can be drawn about the effects of symptoms on caregivers' health.

Methodologic Issues in the Studies of Symptoms in Family Caregivers

In terms of the demographic characteristics of the caregivers evaluated in the 54 symptoms studies (two studies had more than one publication on the same sample), a total of 5,645 participants were included, with sample sizes that ranged from 10–491. The mean age of the caregivers was 56.3 years, and approximately 66% of the participants were female. In addition, most of the caregivers were Caucasian and well educated and had middle-income levels. The number of individuals included in the studies is extremely small given the fact that an estimated 44.4 million Americans are caregivers. In addition, the similar demographic characteristics of these caregivers limit generalizability of the study findings to other groups.

In terms of study design, 32 of the 54 studies (59%) used a cross-sectional design, and 22 (41%) used a longitudinal design. Because of the limited number of studies on the symptoms of depression, anxiety, fatigue, and sleep disturbance, no definitive conclusions can be drawn about the prevalence rates for the symptoms; the demographic characteristics of caregivers who are at higher risk for experiencing the symptoms; the negative consequences associated with the symptoms; or the relationships between symptoms and other aspects of the caregiver experience. In addition, with the exception of depression, very little is known about changes in symptoms over time.

Only 13 of the 54 studies (24%) were intervention studies. Three of them focused only on depression, one only on anxiety, four only on sleep, and one only on pain. One study

evaluated the effects of the intervention on sleep and depression, two on depression and anxiety, and one on depression, anxiety, sleep, and fatigue.

Five used a pretest/post-test design, and the remainder were randomized clinical trials. In terms of the types of interventions that were evaluated to improve symptoms, 10 tested educational and support-based interventions, one evaluated the effect of referral to an advanced practice nurse to improve sleep, and one tested a creative-arts intervention to decrease stress and anxiety. Five of the trials demonstrated improvements in caregivers' symptoms, four failed to demonstrate improvements, and three trials produced mixed results.

Directions for Future Research

This review demonstrates the paucity of research on common symptoms in caregivers. Almost any research study would add to the body of knowledge in this emerging field of inquiry. The UCSF SMM provides an excellent conceptual framework for researchers to begin to develop descriptive, cross-sectional studies to examine the prevalence, characteristics, management strategies, and outcomes of symptoms in caregivers of patients with cancer. Given the fact that the number of patients with cancer who are cared for at home will increase, a need exists to examine the effects of symptoms on caregivers and on their ability to provide care. Nurses should identify patients' primary caregivers, assess symptoms in them, and consider developing symptom management plans for patients and their caregivers. If such an approach is not possible, oncology nurses may need to assess symptoms in caregivers and recommend referrals to primary care physicians.

The limited findings from this review suggest that the symptoms in caregivers are prevalent and have negative effects. In particular, longitudinal studies of male and female caregivers are needed to determine how symptoms change over time, as well as in relationship to changes in patients' conditions or courses of treatment. One critical question that needs to be addressed is the effect of symptoms on caregivers' ability to provide care, as well as the impact of caregiving on their symptom status. Without such descriptive studies and the data they provide, designing intervention studies to improve outcomes in caregivers will be difficult.

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