

Depression Symptoms in Cancer Caregivers

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Patients with cancer are living longer as the disease has become a more chronic condition. Family and friends assume the role of caregiver as more cancer care shifts to the home. The value of informal caregivers and the support they provide to patients will continue to increase. However, caregiving has physical and psychological consequences, including depression. The purpose of this article is to increase awareness of the problem of caregiver depression because of its impact on health deterioration and early death in caregivers. This article discusses caregiving, depression, factors that may contribute to caregiver depression, and implications for oncology nurses. A case study, examples of instruments that can be used to identify caregivers exhibiting depressive symptoms, caregiver resources, and mental health resources are provided.

A 50-year-old woman with colon cancer and metastasis had been receiving chemotherapy after surgery. Her husband, her primary caregiver, reported increased fatigue and a general feeling of malaise to his primary care provider. After an extensive physical examination and complete diagnostic workup, the 52-year-old caregiver was found to be in good general health. He was advised to avoid stress and get more rest.

Several weeks later, the caregiver accompanied his wife to a visit to her nurse practitioner. When the nurse practitioner casually asked the caregiver how he was, he reported he had been having difficulty sleeping, increased fatigue, weight loss, and frequent colds. Upon further inquiry, the caregiver revealed he was worried about his wife's condition and their finances. His wife was often fatigued and not well enough to assist in most of her previous roles, including those at work and in the home. Their children were helpful, but one was away at college and the teenage child at home had many school and social activities. The caregiver reported he was often too busy with job and home responsibilities to attend meetings and social activities of the community organizations to which he belonged. He and his wife were less able to socialize with their friends since she began treatment. The caregiver revealed he often felt sad, overwhelmed, and unsure he was providing adequate care and support to his wife.

In a separate conversation with the oncology nurse practitioner, the caregiver's wife reported fatigue, trouble sleeping, sadness, loss of interest in activities she once enjoyed, and guilt over the burden her illness was to her family.

Caregivers

Each year, more than 44 million individuals in the United States are primary caregivers for a chronically ill, disabled, or

At a Glance

- ◆ Caregiver depression has a negative impact on health and contributes to early death in caregivers.
- ◆ Oncology nurse practitioners—as with their routine discussions of the physical, psychological, and social impact of cancer and treatment with patients—should have similar discussions with caregivers to identify those exhibiting symptoms of depression.
- ◆ Referral of caregivers to their primary care providers for depression screening may result in early identification and treatment of depression, which can improve their physical and mental health, improve their quality of life, limit suffering, and support their service to patients with cancer.

aged family member or friend, with the value of their services estimated at \$306 billion annually (Administration on Aging, 2008). The value of caregiver services has increased from early estimates of \$196 billion in 1997 to \$257 billion in 2000—more than twice as much as was actually spent on professional home-care and nursing home services (Arno, 1999, 2000). Families provide approximately 80% of home-care services (Feinberg, 2003), with one of every four people serving as a caregiver for a family member or friend (Administration on Aging). Historically, caregivers have not been a focus of extensive research;

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however, with declining healthcare resources and rising healthcare costs, informal caregiving has grown increasingly important.

As illnesses such as cancer become more chronic, many individuals will require informal voluntary caregivers. The need will magnify as the number of individuals older than 65 increases and the mortality rate decreases. The value of informal caregiving services and the support they provide to patients will continue to increase.

Depression

Depression in caregivers is a specific emotional reaction to the stress of caregiving (Sherwood et al., 2004). Recent studies have found that 32%–50% of caregivers had depressive symptoms at a level suggesting clinical depression (Butler, Turner, Kaye, Ruffin, & Downey, 2005; Covinsky et al., 2003). Early researchers suggested that caregiver depression may result from anticipatory grieving of losses resulting from the patient's illness as well as the eventual death of the patient (Lindemann, 1994; Walker & Pomeroy, 1996). Caregivers may experience anticipatory grief, but that does not preclude symptoms of depression. Although anticipatory grieving may contribute to caregiver depression, the identification of caregivers experiencing depressive symptoms is important not only to offer further evaluation, but also to provide interventions (Haley, LaMonde, Han, Narramore, & Schonwetter, 2001). Caregiver depression may reveal patient depression, an association that has been found in a number of studies (Bambauer et al., 2006; Fleming et al., 2006; Land, Hudson, & Stiefel, 2003). Caregivers experiencing symptoms of depression also are at risk for chronic depression during bereavement (Robinson-Whelen, Tada, MacCallum, McGuire, & Kiecolt-Glaser, 2001). Assessing individuals with depressive symptoms may help to identify individuals who are experiencing a dysfunctional grief pattern that may lead to higher levels of depression (Grassi, 2007). The identification of depression therefore is important to relieve caregiver suffering during and after the caregiving experience.

Physical Effects of Caregiving and Depression

Caregiving is known to have physical and emotional effects on caregivers (Ferketich, Schwartzbaum, Frid, & Moeschberger, 2000; Sherwood et al., 2004; Vitaliano et al., 2002). A study comparing four-year mortality of spousal caregivers of individuals with physical problems or mental confusion found a 63% higher mortality rate for caregivers (Schulz & Beach, 1999). Caregiving also has significant negative effects on cells of the immune system, including T cells and natural killer cells (Pariante et al., 1997; Scanlan, Vitaliano, Zhang, Savage, & Ochs, 2001; Vitaliano et al., 1998). In addition to effects at the cellular level, caregivers have increased levels of coronary heart disease and metabolic syndrome when compared to noncaregivers (Vitaliano et al., 2002).

In addition to the known physiologic effects of caregiving, depression also has physical effects. Depression in women has been associated with risk for nonfatal coronary heart disease, as well as mortality and nonfatal coronary heart disease in men (Ferketich et al., 2000). The physical effects of depression compound the other deleterious effects of caregiving, particularly for those with existing physical problems.

Caregivers of Patients With Cancer

Patients with cancer, particularly those receiving intensive therapies and those at the end of life, require informal caregivers. Cancer incidence increases with age; 77% of all cancers are diagnosed in individuals 55 or older, and patients with cancer account for approximately 50% of hospice admissions (American Cancer Society, 2008; Connor, Tecca, Lundperson, & Teno, 2004).

In addition to requiring more hours of care, patients with cancer have more symptoms, such as pain, constipation, nausea, and depression, than patients with Alzheimer disease (Haley et al., 2001). Caregivers experiencing depressive symptoms, which may include fatigue, insomnia, excessive sleep, indecisiveness, and inability to concentrate (American Psychiatric Association, 2000), may be unable to meet the caregiving needs of multi-symptomatic patients with cancer. The physical, emotional, and mental energy required during the caregiving experience may overwhelm depressed caregivers (Scanlan et al., 2001; Schulz & Beach, 1999). Caregivers and patients often are depressed at the same time, making the experience even more difficult (Fleming et al., 2006; Land et al., 2003). The effects of caregiver depression can factor into patient care decisions, such as removing a patient from the familiar home environment to be placed in long-term care facility (Arai, Sugiura, Washio, Miura, & Kudo, 2001).

Factors Contributing to Caregiver Depression

Many physical, psychological, and social factors may contribute to depression in caregivers. Some are related to the caregiver, whereas others pertain to the patient, and still others are related to both together. Most caregiver studies focus on caregivers for patients with Alzheimer disease or dementia; few have compared the impact of caregiving between dementia and cancer (Haley et al., 2001). A study examining both found that, although caregivers of patients with dementia provided care for many more months, caregivers of patients with cancer provided many more hours of caregiving during a week (Haley et al., 2001). Many of the patient and caregiver factors that influence depression symptoms in caregivers of patients with Alzheimer disease or dementia also may be factors for depressive symptoms in caregivers of patients with cancer. Table 1 provides factors that may help identify caregivers at risk.

Depression Screening

Many depression screening tools have been shown to be valid and reliable measures and are used commonly in clinical and research settings. Shorter screening tools often are preferable to limit the burden on caregivers. Three examples of short instruments, of the many used to screen for depression, are reviewed in this article. The Center for Epidemiologic Studies–Depression Scale (CES-D) (Radloff, 1977) is used frequently to identify symptoms of depression in caregivers (Gallagher-Thompson et al., 2006; Grant et al., 2006; Williams, 2005). The CES-D is a 20-item scale of depression symptomology, with each item scored on a scale of 1–4 (higher scores indicate more depressive

Table 1. Factors Contributing to Depressive Symptoms in Cancer Caregivers

FACTOR	RESULTS
Age	An analysis of caregivers found that age younger than 57 correlated with more depression symptoms (Butler et al., 2005). Other studies also have found younger age to be associated with increased caregiver depression symptoms (Given et al., 2004; Williams, 2005). In a study of caregivers that examined race and age, younger white and African American caregivers had higher levels of depression symptoms than Hispanic caregivers (Sorensen & Pinqart, 2005). Younger caregivers may have more social, family, and employment responsibilities and less life experience to cope with the caregiver role. However, Covinsky et al. (2003) found that caregivers older than 65 were more likely to be depressed. They are more likely to have physical problems and may not have financial and social resources.
Care and burden	Caregiver burden has been correlated with caregiver depression. Assessing burden includes asking whether caregiving interferes with personal relationships, time for themselves, relationship with family and friends, and their social life. Caregivers also are asked whether caregiving has caused their health to suffer and caused stress from trying to meet work and family obligations (Bedard et al., 2001). A study of caregivers of older adults, using the short form of the Zarit Burden Interview (Zarit et al., 1980), found caregiver burden to be highly correlated with caregiver depression (Butler et al., 2005).
Functional status	The extent to which a patient cannot perform essential activities of daily living (ADLs), also known as ADL dependency, has been found to be associated with caregiver depression. A study of patients with cancer and their caregivers found that ADL dependency correlated not only with increased patient depression symptoms, but also with caregiver depression symptoms (Given et al., 1993). A study of terminally ill patients, most with cancer, found that caregivers of patients with high care needs (e.g., transportation, nursing, home-making, personal care) also had higher depressive symptoms (Emanuel et al., 2000). A study of patients with cancer or dementia and their spousal caregivers found caregivers' increased negative appraisal of the patients' ability to perform self-care to be a predictor of caregiver depression (Haley et al., 2003).
Gender	Several studies have found that female caregivers have higher levels of depression than male caregivers (Covinsky et al., 2003; Haley et al., 2003; Thompson et al., 2004).
Health status	Caregiver health status has been associated with caregiver depression, with those reporting caregiving strain being more likely to have lower levels of perceived health, greater depression, less rest, lower likelihood to rest when ill, and less time to exercise (Schulz et al., 1997). Caregivers reporting better health have lower levels of depressive symptoms (Haley et al., 2003).
History of depression symptoms, mood, and physical health	Caregivers with a history of depression and a past depressive-anxiety disorder may be more likely to experience depression and have a higher rate of depression (Russo et al., 1995). Caregiver mood has been related to caregiver depression and health. A study of caregivers over 10 years found that caregivers with higher optimism had significantly lower levels of depression. Those with higher pessimism had significantly higher levels of depressive symptoms and poor physical health, with a faster decline in health (Lyons et al., 2004). The higher levels of depression and poor physical health also confirmed other studies linking depression with poor health (Ferketich et al., 2000; Schulz & Beach, 1999; Vitaliano et al., 2002). Negative mood has also been correlated with poorer health (Billings et al., 2000).
Mastery of patient	Caregivers' perception of their competency in providing patient care is referred to as mastery (Kurtz et al., 2005). Caregivers with high mastery had lower levels of depression symptomology with lower scores on mastery predictive of higher levels of depression symptomology over time (Nijboer et al., 2001). Caregivers who report less preparedness for caregiving have more mood disturbance (Schumacher et al., 2008)
Patient depression	Depression level in patients with cancer has been correlated with caregiver depression level (Fleming et al., 2006). A study of patients with advanced cancer found that when patients met criteria for any psychiatric diagnosis, their caregivers were 7.9 times more likely to meet the criteria for any psychiatric diagnosis and vice versa (Bambauer et al., 2006).
Patient symptom distress	Depression symptoms in most caregivers increase as the number of patient symptoms increase (Given et al., 2004).
Race	Studies of caregivers have found that Caucasians have significantly more depression symptoms than African Americans and Hispanics (Gallagher-Thompson et al., 2006; Williams, 2005). A study comparing Latino and Caucasian caregivers found no significant difference in depression symptoms; a study of African American, Japanese American, Caucasian American, and Mexican American caregivers found higher rates of depression in Mexican Americans (Adams et al., 2002; Coon et al., 2004). Although the effects of culture and race on caregiver depressive symptoms may vary, their potential influence on caregivers should be considered.
Sense of coherence	A caregiver's general attitude about life and ability to cope with stress have been measured with the Sense of Coherence Scale (Antonovsky, 1993). In a study of male and female caregivers, men were found to have significantly higher Sense of Coherence scores associated with lower levels of depression (Thompson et al., 2004). Caregivers who evaluated caregiving as less stressful and had greater perceived benefits of caregiving were found to have less depression and greater life satisfaction (Haley et al., 2003).
Sleep disturbance	Sleep problems of patients with advanced cancer predicted 64% of caregiver depression (Carter & Chang, 2000). Sleep disturbance has been correlated with increased patient symptom distress (Berger & Higginbotham, 2000).
Social support	Several studies of caregivers have found that lower social support was significantly associated with increased caregiver depression (Chang et al., 2001; Haley et al., 2003; Williams, 2005). Higher levels of support were associated with lower levels of depression in caregivers (Grant et al., 2006). A study of patients with cancer and their caregivers found that caregivers with a low level of caregiver social support were more depressed over time while those who reported a high amount of social support reported a lower level of depression symptoms at baseline and over time (Nijboer et al., 2001).

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symptoms). A score of 16 or greater generally is considered the cutoff score associated with depressive symptoms warranting further evaluation for depression (Radloff). The 10-item version, the CES-D 10 (Andresen, Malmgren, Carter, & Patrick, 1994), also has been found to have factorial validity with the optimal cutoff score of 4 (Irwin, Artin, & Oxman, 1999). The brevity of the CES-D 10 makes it optimal for assessment of depressive symptoms in caregivers of patients with cancer.

The Beck Depression Inventory (Beck & Beck, 1972) is a 21-item measure and has been used to screen for caregiver depression (Pirraglia et al., 2005). Each item is scored on a scale of 0–3, with higher scores indicating more depressive symptoms. A cutoff score of 10 suggests mild depression, 16 indicates mild to moderate depression, 20 suggests moderate to severe depression, and 30 means severe depression (Beck, Steer, & Carbin, 1988).

The 15-item Geriatric Depression Scale focuses on the nonsomatic symptoms of depression and has a recommended cutoff score of 6 or higher (Burke, Roccaforte, & Wengel, 1991; Sheikh & Yesavage, 1986; Yesavage et al., 1982). It also been used to screen for caregiver depression (Covinsky et al., 2003).

Shorter screening methods have been used, such as asking, “Are you depressed?” (Chochinov, Wilson, Enns, & Lander, 1997) or “Over the past two weeks, have you felt down, depressed, or hopeless?” or “Over the past two weeks, have you felt little interest or pleasure in doing things?” (Pignone et al., 2002). A caregiver can be asked during a patient’s routine history and physical examinations as well as follow-up appointments. The answers to the questions may reveal the need to refer the caregiver to his or her primary care provider for further depression screening.

In addition to screening for depressive symptoms, caregivers’ healthcare providers should assess the risk of suicide carefully. The presence of suicidal or homicidal ideation; suicidal intent, plans, means, and lethality of means of suicide; history of previous attempts and seriousness of those attempts; alcohol or substance abuse; psychotic symptoms; command hallucinations; severe anxiety; family suicide history; and recent exposure to suicide must be considered. Caregivers at high risk may require immediate referral to a mental health provider and, in some cases, involuntary hospitalization to prevent suicide. In the absence of a high risk of suicide, caregivers with symptoms of depression also should receive a complete physical examination, including indicated diagnostic testing, to determine the patient’s medical condition prior to referral to a mental health provider (American Psychiatric Association, 2000).

Pharmacology and Psychotherapy Interventions for Depression

Once a caregiver is screened, referred, and diagnosed with depression by his or her primary care provider or mental health provider, specific treatment guidelines should be followed. Severity of symptoms and patient preferences should be considered for initial treatment of the acute phase of depression, which may include antidepressant medication (see Table 2), psychotherapy, or a combination, depending on symptom severity. Antidepressant medication may be used for initial treat-

ment of mild-major depression and should be used for moderate to severe-major depression. Antidepressant medication may cause an increase in suicidal thoughts and behavior initially. Therefore, patients should be monitored closely after treatment begins (American Psychiatric Association, 2000).

Specific, effective psychotherapy alone, based on patient preferences, may be used as an initial treatment for mild to moderate depression, whereas a combination of psychotherapy and antidepressant medications may be used for individuals with psychosocial and interpersonal issues and moderate to severe depression. Antipsychotic and antidepressant medications or electroconvulsive therapy should be used for psychotic depression. Electroconvulsive therapy should be considered as an initial treatment for major depression with severe symptoms and functional impairment, or when a rapid response is needed in patients who are suicidal, catatonic, or nutritionally compromised and refusing food (American Psychiatric Association, 2000).

A response to treatment of the acute phase of depression should be seen in six to eight weeks, with a return to the patient’s baseline level of symptom severity and functioning considered a remission. If a remission is achieved, the 16–20 weeks following the acute phase is considered the continuation phase, during which patients treated with antidepressant medication should be continued on the medications to prevent relapse. A relapse is considered the return of significant depressive symptoms or dysfunction after a remission. Although the use of psychotherapy in the continuation phase to prevent relapse has been studied less, increasing evidence supports the use of effective psychotherapy, with the patient’s clinical condition and specific treatments determining the number of visits. Patients for whom medication and psychotherapy alone or in combination have not been successful may benefit from electroconvulsive therapy during the continuation phase, although little formal study has been done (American Psychiatric Association, 2000).

Patients who complete the continuation phase without relapse enter the maintenance phase of treatment, during which the effective treatments used during the acute and continuation phases should be continued. The length of the maintenance phase varies based on the frequency and severity of past major depression episodes. The goal is to protect individuals from relapse (American Psychiatric Association, 2000). The decision to discontinue active treatment is based on the persistence of symptoms, the probability of recurrence, the frequency and severity of past episodes of depression, and the benefits and undesirable effects of treatments.

The treatment course presented is generalized and simplified. Many patients progress at different rates through treatment, with modifications to treatment as required. The complete *Practice Guidelines for the Treatment of Patients With Major Depressive Disorder* are available from the American Psychiatric Association (2000).

Implications for Nurse Practitioners and Nurses

This article used a case-study approach to increase awareness of the incidence of depression in caregivers in an effort

Table 2. Major Classes of Antidepressants, Examples, and Potential Side Effects

CLASS	EXAMPLE(S)	POTENTIAL SIDE EFFECTS
Dopamine-norepinephrine reuptake inhibitors	Bupropion	Nausea, vomiting, insomnia, seizures, and headaches
Monoamine oxidase inhibitors	Phenelzine and tranylcypromine	Orthostatic hypotension, hypertensive crisis, weight gain, myoclonus, serotonin syndrome, and orgasm dysfunction
Norepinephrine-serotonin modulator	Mirtazapine	Sedation, weight gain, and agranulocytosis
Selective serotonin-norepinephrine reuptake inhibitors	Duloxetine	Nausea, dry mouth, insomnia, constipation, decreased libido, and urinary hesitation
Selective serotonin reuptake inhibitors	Citalopram and fluoxetine	Insomnia, nausea, vomiting, activation (e.g., hypomania, agitation), headaches, extrapyramidal symptoms, tardive dyskinesia, sexual arousal dysfunction, erectile dysfunction, orgasm dysfunction, and serotonin syndrome
Serotonin modulators	Nefazodone and trazodone	Orthostatic hypotension, sedation, and priapism (trazodone)
Serotonin-norepinephrine reuptake inhibitors	Venlafaxine	Hypertension and activation (e.g., hypomania, agitation)
Tricyclics and tetracyclics	Amitriptyline and doxepin	Orthostatic hypotension, reduced cardiac output, arrhythmias, dry mouth, constipation, urinary hesitancy, visual changes, delirium, sedation, weight gain, myoclonus, decreased arousal, erectile dysfunction, and orgasm dysfunction

Note. Refer to package inserts or other pharmacology references for starting, usual therapeutic, and maximum doses.

Note. Based on information from Deglin & Vallerand, 2009; Wells et al., 2009.

to prevent suffering, deterioration of health, and early death in caregivers. In their routine discussions of the physical, psychological, and social impact of cancer and treatment with patients, nurse practitioners should have similar discussions with caregivers. The factors that may contribute to caregiver depression discussed earlier in this article should be considered. Caregivers should be referred to their primary care providers for depression screening and management. For caregivers without a primary care provider, oncology nurse practitioners and nurses should offer screening and referral to mental health providers when appropriate. Early screening and intervention may prevent more serious and protracted depressive episodes.

Case Study Result

In the case study, the patient and caregiver expressed symptoms consistent with depression. Figure 1 outlines symptoms of depression that may indicate the need for screening. As part of holistic, family-based care, the nurse practitioner asked the caregiver, based on the information he had provided previously, whether he was depressed. When the caregiver stated he thought he was a little depressed, the nurse practitioner suggested he see his primary care provider for depression screening and provided resources for caregivers and mental health services.

The patient's early statements indicated the need for depression screening using the CES-D 10 (Andresen et al., 1994). The result indicated that the patient was likely to be suffering from depression. After a discussion of potential benefits and side effects, a

course of antidepressant medication was started. The patient was asked to return to the clinic in one week so that the nurse practitioner could assess the patient's initial response to the medication and determine whether she was having side effects. The patient was encouraged to have her caregiver accompany her at follow-up appointments to evaluate the efficacy of her antidepressant medication and assess whether referral to a mental health provider was required for additional treatment, including psychotherapy. During discussions with the patient and caregiver over the next few visits, the nurse practitioner would have the opportunity to assess the caregiver's mood. The patient and caregiver agreed with the plan of treatment for the patient.

The presence of at least four of the following symptoms over a two-week period, with one of the symptoms required to be either of the first two listed, may indicate depression.

- Depressed or irritable mood
- Loss of interest or pleasure in usual activities
- Suicidal thinking or attempts
- Motor retardation or agitation
- Disturbed sleep
- Fatigue and loss of energy
- Feelings of worthlessness or excessive guilt
- Changes in appetite and weight

Figure 1. Symptoms of Depression in Caregivers

Note. Based on information from American Psychiatric Association, 2000.

Caregiver Resources

AARP Caregiving Resources

www.aarp.org/family/caregiving

American Cancer Society

www.cancer.org/docroot/MBC/MBC_5.asp

Caregiver Resource Directory

www.netofcare.org/crd/resource_form.asp

Caregivers Marketplace

www.caregiversmarketplace.com

Caring.com

www.caring.com

Empowering Caregivers

www.care-givers.com

Family Caregiver Alliance

www.caregiver.org

Hospice Caregivers

www.hospicenet.org

National Alliance for Caregiving

www.caregiving.org

National Council on Aging

www.ncoa.org

National Family Caregiver Association

www.nfcacares.org

National Cancer Institute

www.cancer.gov/cancertopics/caring-for-the-caregiver

Strength for Caring

www.strengthforcaring.com/index.html

Today's Caregiver Magazine

www.caregiver.com

U.S. Administration on Aging, National Family Caregiver Support Program

www.aoa.gov/prof/aoaprogram/caregiver/caregiver.aspx

Mental Health Resources

Mental Health America

www.nmha.org

Depression Screening.Org

www.depression-screening.org

National Institute of Mental Health

www.nimh.nih.gov/health/publications/depression/complete-publication.shtml

Mental Health Organizations by State

www.cdc.gov/mentalhealth/state_orgs.htm

National Alliance on Mental Illness

www.nami.org

Figure 2. Resources

Conclusion

Although the duration of the cancer illness may be shorter than that of other serious diseases, such as dementia, caregivers of patients with cancer provide many more hours of care during

a week (Haley et al., 2001). Caregivers of patients with cancer are subjected to an intense caregiving experience; they may not have adequately prepared for that or anticipated it. Identifying caregivers at risk for depression is particularly important in the cancer setting, not only for the physical and emotional health of caregivers but also that of the patients, whose quality of care and life may be affected. Figure 2 provides Internet resources about caregiving and depression.

Depression is highly treatable; most people experience relief of symptoms and are able to return to their daily routines (National Alliance on Mental Illness, 2006; National Institute for Mental Health, 2008). Caregivers need assessment for depression and early intervention. Early treatment is more effective and decreases the probability of recurrence (National Institute for Mental Health). Early identification of depression can improve the physical and mental health of caregivers, improve their quality of life, limit suffering, and support their invaluable service to patients with cancer.

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