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Psychiatric Disorders and Mental Health Service Use Among Caregivers of Advanced Cancer Patients

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Abstract

Purpose—Despite research demonstrating the psychological burden of caregiving for advanced cancer patients, limited information exists on the prevalence of psychiatric disorders and mental health service use among these informal caregivers.

Methods—Two hundred informal caregivers of advanced cancer patients were interviewed and administered the Structured Clinical Interview of the *Diagnostic and Statistical Manual of Mental Disorders Fourth Edition* and an assessment of mental health service use.

Results—Thirteen percent of caregivers met criteria for a psychiatric disorder; 25% accessed treatment for mental health concerns since the patient's cancer diagnosis. The frequencies of current psychiatric disorders were as follows: panic disorder, 8.0% (95% CI, 4.6% to 12.7%), major depressive disorder, 4.5% (95% CI, 2.1% to 8.4%), post-traumatic stress disorder, 4.0% (95% CI, 1.7% to 7.7%), and generalized anxiety disorder, 3.5% (95% CI, 1.4% to 7.1%). Among caregivers with a current psychiatric disorder, 81% discussed mental health concerns with a health professional before the patient's cancer diagnosis compared with 46% after the diagnosis (McNemar test = 5.40; $P = .02$). Only 46% of caregivers with a current psychiatric disorder accessed mental health services. Caregivers who discussed mental health concerns with a clinician before the patient's cancer diagnosis (odds ratio [OR] = 3.51; 95% CI, 1.42 to 8.71) and after the diagnosis (OR = 21.23; 95% CI, 9.02 to 49.94) were more likely than caregivers not having these discussions to receive mental health services.

Conclusion—Many caregivers of advanced cancer patients either meet criteria or are being treated for psychiatric problems. Discussing mental health issues positively influences the receipt of mental health services and should be actively pursued in this vulnerable population.

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INTRODUCTION

Approximately 25% of the United States population provides care to a family member or friend with a chronic or terminal illness.¹ As the proportion of the United States population greater than age 65 years increases,² so will the number of chronically and terminally ill patients requiring care.³ Because treatments for cancer and other life-threatening diseases are increasingly provided on an outpatient basis, much of the burden of care has shifted from health care professionals to patients and their families.^{4,5} Consequently, changes in demographics and health care delivery have heightened the burden of caregiving for terminally ill older adults.

Informal caregivers provide the equivalent of more than 250 billion dollars in caregiving services each year.⁶ In a study of over 2,000 families caring for a family member with a serious illness, nearly 20% of family caregivers quit work or made major life rearrangements to provide care, 31% of families lost most or all of their savings, and 29% of families reported loss of their main source of income.⁷ For many family caregivers, caregiving becomes a full time job.⁸⁻¹⁰ Given the magnitude of services provided and the sacrifices made by family caregivers,^{9,11} the adverse consequences of caregiving have emerged as a serious public health concern.

In addition to economic consequences, caregiving for a terminally ill loved one has been shown to have adverse effects on caregivers' physical and mental health,¹²⁻¹⁶ manifesting as depression,^{17,18} decreased immune function,¹⁹⁻²¹ cardiovascular morbidity,^{22,23} and chronic sleep disturbances.²⁴⁻²⁶ Caregivers are more likely than noncaregivers to disregard their own health care needs.²⁷ In a cohort of 392 caregivers older than 66 years of age, individuals who reported mental and emotional strain associated with caregiving had a 63% higher mortality risk than noncaregiver controls.¹⁶ In light of the essential role that caregivers play in the provision of care, it is important to identify and address their mental health needs to sustain the well-being and quality of life of this large and growing group of informal health care providers.

Despite research demonstrating the psychological burden of end-of-life caregiving,^{10,28-30} limited information exists on the prevalence of psychiatric disorders and mental health service use among caregivers of terminally ill cancer patients. Studies examining the psychological distress of caregivers have previously relied on symptom inventories, such as the Hamilton depression and anxiety scales,¹⁸ the Profile of Mood States and the Caregiving Impact Scale,¹⁴ the Zarit Burden Inventory,²⁸ the State Trait Anxiety Inventory,^{17,31} the Geriatric Depression Scale,^{17,32} and the Center for Epidemiological Studies Depression Scale.^{10,29} Although such measures provide important information about an individual's degree of distress, they do not produce sufficient information necessary for making clinically sensitive and specific *Diagnostic and Statistical Manual of Mental Disorders* (DSM) diagnoses of mood and anxiety disorders. Because few studies have administered structured clinical interviews using *DSM Fourth Edition* (DSM-IV) criteria to caregivers, the rates of psychiatric illness based on current psychiatric diagnostic criteria have not been well established. Similarly, although there are limited published data regarding utilization of mental health services by advanced cancer patients,³³⁻³⁵ we are aware of no such published data for their caregivers.

Using data from a multisite study of psychiatric disorders in advanced cancer patients and their informal caregivers, the objectives of the current study were to determine the prevalence of psychiatric disorders and describe communications about, referrals to, and receipt of mental health interventions among caregivers of advanced cancer patients. In addition, we sought to identify factors associated with mental health service use among caregivers of advanced cancer patients.

METHODS

Study Design and Sample

Data for this report came from the Coping with Cancer Study (MH63892, CA106370), an ongoing, multisite, longitudinal investigation of the prevalence and treatment of psychiatric disorders, mental health service use, quality of death, and bereavement adjustment among advanced cancer patients and the individual they designated as their primary informal caregiver (eg, spouse or adult child). The current report is focused on the baseline assessment of caregivers. Caregivers were eligible if patients identified them as providing the majority of their unpaid, informal care. Caregivers were not required to live in the same household as the patient or provide care for a specified number of hours per week. Excluded were caregiver-patient dyads in which either individual was not proficient in English or Spanish, met criteria for dementia or delirium (by Neurobehavioral Cognitive Status Examination),³⁶ or less than 20 years old. We chose to exclude individuals younger than 20 years old because of the relative infrequency of children and adolescents in primary caregiving roles. Children and adolescents may be affected differently than adults by the caregiving experience; thus, their experience would not generalize to adults, who compose the vast majority of caregivers.

Participating sites included the Yale Cancer Center (New Haven, CT), the Veterans Affairs Connecticut Healthcare System Comprehensive Cancer Clinics (West Haven, CT), Memorial Sloan-Kettering Cancer Center (New York, NY), and the Parkland Hospital Palliative Care Service (Dallas, TX). Consecutively enrolled cancer patients were identified from weekly lists of outpatients and inpatients scheduled for a visit at one of the participating oncology clinics. Research staff reviewed the clinic patient lists and talked with clinic staff to identify potentially eligible patients. Eligibility required the patients to have advanced cancer as indicated by the presence of distant metastases and the failure of first-line therapy. On the basis of the judgment of the interviewer, if a patient seemed to be too weak or incapacitated to complete the interview and/or provide reliable and valid responses, that patient was not approached.

Potentially eligible patients were then asked if we could determine their actual eligibility and, if eligible, contact them within the week to describe the study in further detail to them and ask for their participation. Careful review of medical records and consultation with clinic staff confirmed eligibility. Patients who declined to participate were asked to answer a brief set of questions regarding their age, reason for refusal, and level of distress. All study documents were approved by the Human Investigations Committee of Yale University and the participating institutions.

Of the 321 potentially eligible patients who were approached for participation from September 18, 2002 to April 8, 2004 and confirmed to be eligible, 205 (64%) were enrolled onto the study. Given that our study required agreement to both a baseline and follow-up caregiver interview, involved a fairly time-consuming interview, did not provide any direct benefit to the patient (in contrast to the potential benefit of clinical trials that test some potentially beneficial treatment), and required the consent of both the patient and the caregiver during a late stage in a life-threatening illness, our participation rate of 64% can be considered reasonable. Although information on caregivers who refused to participate was not gathered, the most frequent reasons for patient nonparticipation included not interested ($n = 49$), caregiver refused ($n = 18$), and too upset ($n = 13$). Compared with patient participants, patient nonparticipants had completed fewer years of schooling (mean, 12.1 v 13.3 years, respectively; $P = .02$) and were more distressed on a 5-point scale ranging from 1 (minimal distress) to 5 (distracted; mean score, 3.2 v 2.2, respectively; $P < .0001$). Participating patients did not differ significantly from nonparticipating patients with respect to age, race/ethnicity, or sex. Given the absence of data on nonparticipating caregivers, we cannot conclude that the nonparticipating caregivers were more distressed or less educated. To the extent that patients and caregivers were similar and

given that caregiver refused was the second most common reason patients listed for nonparticipation, it is possible that nonparticipating caregivers were also more distressed.

Of the caregivers who agreed to participate, 67.4% said that they provided 80% to 100% of the patient's informal care, and 14.4% said they provided 60% to 79% of the patient's informal care. The majority of caregivers reported that their loved one needed either a great deal of help (38.2%) or a moderate amount of help (31.2%). Specifically, 96.9% provided emotional support, 81.8% helped with shopping and transportation, 80.5% helped with household tasks such as cooking and cleaning, 50.3% administered medications, 42.1% helped with bathing, dressing, feeding, and/or toileting, and 38.6% handled the patient's finances. Many caregivers (41.6%) had decreased the number of hours they worked per week to care for their loved one, and the majority (66.7%) had witnessed their loved one in severe pain or discomfort on at least one occasion.

Consenting patient/caregiver dyads were scheduled for separate interviews, the majority of which took place in the outpatient clinic (45.5%), at the patient or caregiver's home (33.5%), or in the hospital (10.5%). Interviewers (two to three at each site) were trained by the Yale team in interview administration and in the evaluation of subject responses and only permitted to conduct interviews once their ratings were deemed accurate and reliable based on a high degree of concordance with the Yale Project Director's rating (S.M.; eg, $K > 0.85$ with the Project Director's rating of the Structured Clinical Interview for the DSM-IV [SCID] diagnoses). When needed, interviews were conducted in Spanish by a well-trained bilingual interviewer using interviews that had been translated and back-translated from English to Spanish.

Measures

Demographics and patient-related variables. Information was collected on caregivers' age, sex, race, level of education, and income. Caregivers were asked how many months they had been providing care for the patient and whether or not the patient had health insurance. Patients' type of cancer was obtained from their medical chart. The severity of patients' cancer symptoms was assessed using the Zubrod performance scale,³⁷ which provides a summary measure of current health status based on four categories (activity, pain, food intake, and nausea). A Zubrod score of 2 or greater (on a scale of 0 to 5) is considered poor performance.

Major depressive disorder and anxiety disorder diagnoses. The SCID Axis I Modules³⁸ were used to diagnose current psychiatric disorder among the caregivers. The SCID is a widely used instrument with proven reliability and validity ($K = 0.56$ for generalized anxiety disorder; $K = 0.58$ for panic disorder,³⁸ and $K = 0.92$ for a Hamilton Rating Scale for Depression score of more than 17 and SCID-diagnosed major depressive disorder³⁹). The disorders assessed included major depressive disorder and the following anxiety disorders: post-traumatic stress disorder, generalized anxiety disorder, and panic disorder.

Mental health discussions with clinicians and service use. Interviewers asked caregivers a series of questions regarding whether or not they had discussed their mental health with a health care professional (eg, primary care physician or mental health professional) both before and after the patient's initial diagnosis of cancer. Respondents who had discussed mental health concerns with a clinician were asked to identify the type of health care professional (eg, nurse, oncologist, or primary care doctor) with whom they had had this conversation. All caregivers were asked whether they had accessed any type of mental health intervention since the patient was diagnosed with cancer. A mental health intervention was defined as any type of supportive service that the caregiver sought for the purpose of alleviating psychological distress (eg, psychotherapy, psychotropic medications, support groups, or counseling with a member of the clergy). If they had accessed an intervention, they were asked to identify the type of intervention

and who provided the service (eg, oncologist, mental health professional, or clergy). The caregivers were also asked whether they had initiated the service themselves (eg, asked their physician about antidepressants or sought a support group) or the health care professional had initiated the service (eg, physician prescribed anxiolytics or caregiver's ongoing therapist suggested a session to deal with stress related to caregiving). Caregivers who did not access any type of mental health service were asked to give a reason why (eg, no concerns, did not believe in mental health treatment, or financial reasons). Finally, caregivers were asked whether they would seek mental health services if they were aware that they had an emotional problem.

Statistical Analyses

Fisher's exact or χ^2 test statistics were used to determine whether the rates of mental health discussions and mental health service use differed significantly between caregivers who met current criteria for any psychiatric disorder and caregivers who did not. The McNemar test for paired comparisons was used to determine whether the proportion of mental health discussions or service use was significantly lower after compared with before the cancer diagnosis. Logistic regression models estimated the effects of the prepatient cancer diagnosis mental health discussions, postpatient cancer diagnosis mental health discussions, caregiver psychiatric diagnosis, sex, race/ethnicity, age, education, duration of caregiving, health insurance, and severity of patient's symptoms on the receipt of mental health services by the caregiver after the cancer diagnosis. The first set of models were the unadjusted, bivariate effects of each predictor on the likelihood of postpatient cancer diagnosis mental health service use. A second set of adjusted models simultaneously estimated all significant bivariate effects.

RESULTS

The characteristics of the 200 caregiver participants are listed in Table 1. Caregivers tended to be middle aged, female, at least high school educated, white, and spouses of the patients. The median duration of caregiving was 11 months. The most common types of cancer among patients were GI (43.5%) and lung cancer (19.7%). Patients' mean Zubrod score was 1.3. The majority of patients (85.8%) had at least one form of health insurance.

Frequency of Psychiatric Disorders

Table 2 lists the current frequency of psychiatric disorders among caregivers applying DSM-IV diagnostic criteria at the time of the interview. Twenty-six caregivers (13.0%; 95% CI, 8.7% to 18.5%) met criteria for one or more psychiatric disorders, the most common of which was panic disorder (8.0%; 95% CI, 4.6% to 12.7%), followed by major depressive disorder (4.5%; 95% CI, 2.1% to 8.4%), posttraumatic stress disorder (4.0%; 95% CI, 1.7% to 7.7%), and generalized anxiety disorder (3.5%; 95% CI, 1.4% to 7.1%). No significant differences in rates of psychiatric diagnosis were detected between recruitment sites.

Discussions of Mental Health With Health Care Professionals

Table 3 lists the frequencies of discussions of mental health concerns between caregivers and health professionals before and after the patient's cancer diagnosis, both overall and stratified by the presence of a current psychiatric disorder. The proportion of caregivers who discussed mental health concerns with a health professional was 36% before the patient's cancer diagnosis and 29% after the cancer diagnosis. The greatest difference between rates of discussions before and after the cancer diagnosis was observed in caregivers with a diagnosed psychiatric disorder (80.8% before and 46.2% after the cancer diagnosis; McNemar test = 5.40; $P = .02$). Caregivers reported having initiated 77.1% and 71.6% of discussions before and after the diagnosis, respectively.

Table 4 presents a cross tabulation of caregivers who discussed mental health issues before versus after the patient's cancer diagnosis. Of caregivers who had discussed mental health issues before the diagnosis, 40.3% (29 of 72 caregivers) discussed mental health issues after the diagnosis. Of caregivers who discussed mental health issues after the diagnosis, 49.5% (29 of 58 caregivers) had discussed mental health issues before the diagnosis.

Receipt of Mental Health Services

Table 5 lists the rates at which caregivers accessed mental health interventions after the patient's cancer diagnosis, stratified by presence or absence of current psychiatric disorder. Overall, after the patient's cancer diagnosis, 25.5% of caregivers (n = 51) reported accessing at least one form of mental health service. Fewer than half of caregivers (46%; 12 of 26 caregivers) with a diagnosable psychiatric disorder accessed a mental health intervention. The most frequent mental health interventions used by the caregivers were psychotherapy (37%), antidepressants (35%), anxiolytics (28%), visits with clergy (20%), and support groups (14%; services were not mutually exclusive). Caregivers with a psychiatric diagnosis reported considerably more use of antidepressants than caregivers without a diagnosis (26.9% v 6.3%, respectively; $P = .003$, Fisher's exact test). The most frequent sources of mental health interventions for caregivers were mental health professionals (41.2%), primary care physicians (31.4%), and clergy (15.7%). No caregiver reported accessing mental health services from the patient's oncologist; only 5.9% of caregivers reported accessing support from oncology social workers. Caregivers reported having initiated 66.7% of mental health interventions. There were no significant differences in rates of mental health service use between recruitment sites.

The 142 caregivers who did not access mental health interventions reported the following reasons: no concerns (67.6%), no one mentioned or offered them (6.3%), reliance on other source of social support (5.6%), no time (4.9%), financial reasons (3.5%), did not think it could help (2.8%), and did not believe in mental health treatment (2.1%). Seven caregivers did not offer a reason for not accessing services; none of these seven caregivers met criteria for a psychiatric disorder. Ninety-three percent of all caregivers said that they would seek help if they were aware that they had an emotional problem.

Predictors of Mental Health Service Use

Table 6 lists factors associated with the caregiver accessing a mental health intervention after the patient's cancer diagnosis. In bivariate analyses, caregivers who discussed their mental health concerns after the cancer diagnosis (odds ratio [OR] = 22.2; 95% CI, 9.9 to 49.8), discussed mental health concerns before the cancer diagnosis (OR = 4.1; 95% CI, 2.1 to 8.0), met criteria for a psychiatric disorder (OR = 3.0; 95% CI, 1.3 to 6.9), and were more educated (OR = 1.1 per additional year of education; 95% CI, 1.0 to 1.2) were more likely to receive mental health interventions than caregivers without each of these characteristics.

In multivariate models that simultaneously estimated the effects of education, meeting criteria for a psychiatric disorder, and discussing mental health concerns before and after the cancer diagnosis, the discussions of mental health concerns were the most robust factors predicting receipt of mental health services. Caregivers who had discussed their mental health concerns before the patient's cancer diagnosis were greater than three times more likely than caregivers who had not discussed mental health concerns before the patient's cancer diagnosis to access mental health interventions after the cancer diagnosis (adjusted OR = 3.5; 95% CI, 1.4 to 8.7), and caregivers who discussed their mental health concerns after the patient's cancer diagnosis were greater than 21 times more likely than caregivers who had not discussed mental health concerns after the patient's cancer diagnosis to access a mental health intervention (adjusted OR = 21.2; 95% CI, 9.0 to 49.9). Meeting criteria for a psychiatric disorder did not significantly influence the receipt of a mental health intervention (adjusted OR = 1.5; 95% CI, 0.5 to 4.6).

DISCUSSION

Research has established the considerable psychological burden placed on caregivers of patients who are close to the end of life,^{10,12,15,18,28,30} yet there is little information on the prevalence of psychiatric disorders and mental health service use among family caregivers. The literature has primarily focused on symptoms of depression and anxiety in caregivers using a variety of self-report symptom scales.^{10,28,31,32} As a result, the rates of diagnosable psychiatric illness among caregivers of terminally ill cancer patients have not been determined. The present study applied DSM-IV criteria using a structured clinical interview and found that 32% of caregivers either met criteria for a major psychiatric condition (13%) and/or had accessed services to address mental health concerns since the family member's cancer diagnosis (25%). Although discussing mental health concerns with a clinician was the most important determinant of the receipt of mental health interventions, less than one third of caregivers had such discussions after the patient's cancer diagnosis. Our results document the magnitude of clinically significant psychological distress among advanced cancer patient caregivers and highlight the need for more clinical attention to the mental health needs of this vulnerable group.

Although the rates of psychiatric illness among our caregivers were lower than the rates of symptomatic distress among caregivers reported in other studies, it is important to consider the measure used to assess caregiver distress. For example, Nijboer et al⁴⁰ found a 20% frequency of depression in caregivers of cancer patients 6 months after the patients had been discharged from the hospital after surgery. However, this rate was based on a cut point score of 15 on the Center for Epidemiologic Studies Depression Scale, a measure that can effectively screen for high levels of depressive symptoms but does not provide a clinical diagnosis.⁴¹ The number of individuals in a given population classified as high risk based on a screening tool will, by design, be greater than the number of individuals in that same population who qualify for a clinical diagnosis. Similarly, Chentsova-Dutton et al¹⁸ reported that 23% of their hospice patient caregiver sample had Hamilton Rating Scale for Depression scores greater than a cut point of 12 at approximately 2 weeks before the patient's death. A Hamilton Rating Scale for Depression cut point score of 12 is a low-threshold score that is typically associated with subsyndromal depression, whereas a score of 18 to 24 is considered moderate depression, and a score of 25 or greater indicates severe depression.⁴² Thus, it is not surprising that use of the Center for Epidemiologic Studies Depression Scale and Hamilton Rating Scale for Depression resulted in higher frequencies compared with a diagnostic measure.

The severity of illness of the corresponding patient population is another important consideration when comparing results across caregiver studies. The caregivers studied by Chentsova-Dutton et al¹⁸ were assessed in the patient's final weeks of life. A study of a similar population of hospice caregivers assessed within the 2-month period surrounding the death of the patient reported a 30.3% frequency of major depressive disorder (clinical diagnosis obtained via the SCID).⁴³ However, unlike the hospice patient caregivers, the caregivers in the present study were not necessarily caring for patients confronting death at the time of the caregiver baseline interview. Most caregivers in the present study were assessed while the patient was still receiving treatment as a cancer clinic outpatient. The relative health of the patients in our study is demonstrated by a mean Zubrod score of 1.3. Considering the results of the aforementioned studies of caregivers closer to the end of the patient's life, the rates of psychiatric illness in our cohort of caregivers are likely to increase as the patients' cancer progresses.

The low rates of diagnosable psychiatric illness may also be a function of selection biases. Patients who were too incapacitated to complete the interview were not approached for the study; thus, their caregivers, whom we would expect to be the most burdened, were not

included. Patients who refused to participate in the study were also significantly more distressed than patients who did participate. Although we have no definitive data about caregivers who did not participate, it is possible that the caregivers who did not participate were also more distressed. Both of these factors would make the frequencies we report here conservative estimates. In addition, because we limited our investigation to the major psychiatric disorders, we did not assess adjustment disorder or report rates of minor depression, which would have added to the prevalence of psychiatric morbidity found in the present sample. Finally, the frequency of psychiatric disorders in our study population should be understood in the context of 25.5% of caregivers who accessed a mental health service, which presumably reduced the rates of diagnosable psychiatric illness at our baseline assessment by the administration of effective treatment. Even with the modest rates of psychiatric disturbance reported here, the combined rates of current psychiatric diagnosis and mental health service use among the cancer patient caregivers support substantial levels (32%) of psychological distress among the studied caregivers.

With respect to specific psychiatric diagnoses, it was somewhat unexpected to find that panic disorder was the most frequent among the sampled caregivers. The 8% frequency of panic disorder among caregivers in our study was higher than the 3% prevalence of panic disorder reported in the general US population.⁴⁴ To our knowledge, no data on the prevalence of panic disorder in caregivers have previously been published. Panic disorder has been reported in cancer patients,^{45,46} and it was the most common anxiety disorder found among patients in our Coping With Cancer Study, with a frequency of 4.8%.⁴⁷ Although we do not know whether the onset of panic disorder in caregivers occurred before or after their loved one's cancer diagnosis, the relatively high rate of panic disorder suggests that the physical and psychological stresses of caring for cancer patients may create an increased risk for panic disorder. If confirmed in subsequent studies, our findings would suggest that panic disorder may be an important disorder to screen for and treat among caregivers of cancer patients.

Nearly a quarter of all caregivers accessed some type of mental health intervention (eg, psychotherapy or antidepressants). However, less than half (46.2%) of the caregivers with a current DSM-IV disorder had discussed their mental health with a clinician since the patient's cancer diagnosis. These individuals, whose need for treatment is evidenced by their clinical diagnosis, may be disinclined to discuss their mental health concerns when faced with the demands of caregiving. Of further concern is the fact that the majority of caregivers who met criteria for a psychiatric diagnosis but did not access a mental health intervention also reported no concerns about their mental health. Although structured clinical interviews indicate that they are experiencing clinically significant levels of depression and/or anxiety, these caregivers seem to be either unaware of or unwilling to admit to their mental health needs.

There is reason to believe that caregivers of advanced cancer patients are neglecting their mental health needs, just as other studies have shown that, when experiencing greater perceived strain related to caregiving, caregivers may neglect their physical health needs.²⁷ Given the fact that screening and treatment for many psychiatric disorders, including depression and anxiety, can be done quickly and relatively inexpensively,⁴⁸⁻⁵¹ more caregivers should be receiving the treatment they need. Palliative care and oncology clinic staff should recognize the need to probe about mental health concerns among the dying patient's caregivers, particularly among caregivers who seem to be the most distressed.

Several limitations of this study should be acknowledged. Our report is based on a sample that was drawn from an ongoing, multisite, longitudinal study. Because we only examined the first 200 patients, our sample does not yet represent the targeted racial and socioeconomic diversity needed to test for important subgroup differences. We also cannot definitively conclude that caregivers' distress was a result of caregiving per se because the experience of coping with a

loved one's impending death would be distressing even for an individual without caregiving responsibilities. In addition, we did not have screening data evaluating reasons for nonparticipation among the caregiver sample. Although the patients who refused to participate in this study were significantly more distressed than those who agreed to participate, we cannot state definitively that nonparticipating caregivers were also more distressed. Finally, we were unable to measure the effectiveness of the mental health interventions caregivers used.

More research is needed to establish the prevalence of psychiatric disorders among family caregivers and patients with terminal cancer using standardized diagnostic criteria. Identifying caregivers who experience clinically significant levels of psychological symptoms is essential to provide adequate mental health treatment. Even caregivers whose symptoms do not reach the level of a clinical diagnosis may benefit from an intervention designed to alleviate the distress associated with both caregiving and the impending loss of a loved one. We certainly acknowledge the fact that clinicians are under considerable time restraints and face tremendous pressure to see as many patients as possible in a limited amount of time, and they may not be reimbursed for discussing mental health issues with caregivers, so such discussions become a low priority within the context of the current health care system. However, although an extensive review of financial and logistical barriers to access to mental health services among caregivers is beyond the scope of this article, identification of individuals with the greatest need is a necessary first step. Future research evaluating the effectiveness of various mental health interventions on the long-term psychological adjustment and quality of life of caregivers will provide important information on how best to meet caregivers' mental health needs. Research and interventions are also needed to improve communication between health care professionals and caregivers about mental health needs and services in the context of terminal cancer care.

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Table 1.
Sample Characteristics of Caregivers of Patients With Advanced Cancer

Characteristic	No. of Patients (N = 200)	%
Sex		
Male	53	26.5
Female	147	73.5
Race		
White	156	78.0
Black	25	12.5
Hispanic	15	7.5
Asian	4	2.0
Relationship to patient		
Spouse/partner	136	68.0
Child	38	19.0
Sibling	9	4.5
Friend	7	3.5
Parent	6	3.0
Other family member	4	2.0
Age, years		
Mean	52.4	
SD	13.7	
Median	53	
Range	20-86	
Education, years		
Mean	14.2	
SD	3.2	
Median	14	
Range	4-21	
Income		
\$0-\$10,999	11	5.5
\$11,000-\$20,999	19	9.5
\$21,000-\$29,999	7	3.5
\$30,000-\$50,999	20	10.0
\$51,000-\$99,999	67	33.5
\$100,000 or more	6	3.0
Refused	18	9.0
Don't know	24	12.0
Missing	28	14.0
Treatment center		
Yale Cancer Center (CT)	118	59.0
Veterans Affairs Connecticut Healthcare System Cancer Center (CT)	20	10.0
Memorial Sloan-Kettering Cancer Center (NY)	31	15.5
Parkland Palliative Care Service (TX)	31	15.5

Abbreviation: SD, standard deviation.

Table 2.Frequency of Psychiatric Conditions Meeting *Diagnostic and Statistical Manual of Mental Disorders Fourth Edition* Criteria

Diagnosis	No. of Patients (N = 200)	%	95% CI (%)
Major depressive disorder	9	4.5	2.1 to 8.4
Generalized anxiety disorder	7	3.5	1.4 to 7.1
Panic disorder	16	8.0	4.6 to 12.7
Post-traumatic stress disorder	8	4.0	1.7 to 7.7
At least one of above diagnoses	26	13.0	8.7 to 18.5

Table 3.
Discussion of Mental Health Concerns Among Caregivers, Stratified by Presence of Psychiatric Condition*

Discussion	Full Sample (N = 200)		Psychiatric Diagnosis (n = 26)		No Psychiatric Diagnosis (n = 174)		P
	No. of Patients	%	No. of Patients	%	No. of Patients	%	
Discussed mental health concerns before patient's cancer diagnosis [†]	72	36.0	21	80.8	51	29.3	< .0001 [‡]
Primary care physician	16	22.2	5	23.8	11	21.6	.04 [§]
Mental health professional	66	91.7	21	100	45	88	< .0001 [‡]
Clergy	2	2.8	0	0	2	3.9	NE
Other	3	4.2	0	0	3	5.9	NE
Discussed mental health concerns after patient's cancer diagnosis [†]	58	29.0	12	46.2	46	26.4	.04 [‡]
Oncologist	4	6.9	1	8.3	3	6.5	.43 [§]
Oncology social worker	8	13.8	1	8.3	7	15.2	NE
Other oncology clinic staff	4	6.9	1	8.3	3	6.5	.43 [§]
Primary care physician	15	25.9	5	41.7	10	21.7	.03 [§]
Mental health professional	25	43.1	5	41.7	20	43.5	.36 [§]
Clergy	10	17.2	2	16.7	8	17.3	.62 [§]
Palliative care doctor	1	1.7	0	0	1	2.1	NE
Other	3	5.2	1	8.3	2	4.3	.34 [§]

Abbreviation: NE, not estimable.

* Caregivers who meet criteria for a psychiatric disorder at evaluation.

[†] Categories are not mutually exclusive; some caregivers discussed with more than one professional.

[‡] χ^2 statistic.

[§] Two-sided Fisher's exact test.

Table 4.
 Caregiver Discussions of Mental Health Concerns Before Versus After Patient's Cancer Diagnosis

Discussed Mental Health Concerns Before Patient's Cancer Diagnosis	Discussed Mental Health Concerns After Patient's Cancer Diagnosis			χ^2	df	P
	Yes	No	Total			
Yes				6.9	1	.008
No.	29	43	72			
%	14.5	21.5	36.0			
Row %	40.3	59.7				
Column %	50.0	30.3				
No.	29	99	128			
%	14.5	49.5	64.0			
Row %	22.7	77.3				
Column %	50.0	69.7				
Total						
No.	58	142	200			
%	29.0	71.0	100.0			

Table 5.
Mental Health Service Use Among Caregivers, Stratified by Presence of Psychiatric Condition*

Mental Health Service	Full Sample (N = 200)		Psychiatric Diagnosis (n = 26)		No Psychiatric Diagnosis (n = 174)		P
	No. of Patients	%	No. of Patients	%	No. of Patients	%	
Accessed mental health interventions after patient's cancer diagnosis [†]	51	25.5	12	46.2	9	22.4	.01 [‡]
Interventions							
Psychotherapy	19	37.3	3	25	16	41	.72 [‡]
Antidepressants	18	35.3	7	58.3	11	28.2	.003 [§]
Anxiolytics	14	27.5	3	25	11	28.2	.40 [§]
Antipsychotics	1	2	0	0	1	3.6	NE
Visits with clergy	10	19.6	2	16.7	8	20.5	.62 [§]
Participation in support groups	7	13.7	1	8.3	6	15.4	NE
Participation in day hospital	1	2	0	0	1	3.6	NE
Inpatient hospitalization	1	2	0	0	1	3.6	NE
Other	6	11.8	0	0	6	15.4	NE
Provider of the service							
Oncologist	0	0	0	0	0	0	NE
Oncology social worker	3	5.9	0	0	3	7.7	NE
Other oncology clinic staff	1	2	0	0	1	3.6	NE
Primary care physician	16	31.4	5	41.7	11	28.2	.04 [§]
Mental health professional	21	41.2	4	33.3	2	5.1	.49 [§]
Clergy	8	15.7	2	16.7	6	15.4	.28 [§]
Palliative care doctor	0	0	0	0	0	0	NE
Other	4	7.8	1	8.3	3	7.7	.43 [§]

Abbreviation: NE, not estimable.

* Caregivers who meet criteria for a psychiatric disorder at evaluation.

[†] Categories are not mutually exclusive; some caregivers accessed multiple types of services.

[‡] χ^2 -statistic.

[§] Two-sided Fisher's exact test.

Table 6.
Determinants of the Receipt of Mental Health Treatment Among Caregivers

Variable	Bivariate Odds Ratio		Adjusted Odds Ratio	
	Odds Ratio	95% CI	Odds Ratio	95% CI
Discussion of mental health concerns before cancer diagnosis	4.08 *	2.10 to 7.96	3.51 [†]	1.42 to 8.71
Discussion of mental health concerns after cancer diagnosis	22.24 *	9.93 to 49.81	21.23 *	9.02 to 49.94
Current major psychiatric diagnosis	2.97 [‡]	1.27 to 6.94	1.45	0.45 to 4.60
Education	1.12 [‡]	1.01 to 1.24	1.06	0.92 to 1.22
Female sex	1.23	0.59 to 2.59		
White, non-Hispanic race	1.21	0.55 to 2.67		
Age	1.01	0.98 to 1.03		
Length of caregiving	1.00	1.00 to 1.01		
Severity of patient's symptoms, Zubrod score	1.11	0.79 to 1.56		
Insurance status, patient	1.67	0.60 to 4.65		
Income	1.17	0.89 to 1.53		

* $P > .0001$.

[†] $P > .01$.

[‡] $P > .05$.