Prevalence and Predictors of Depressive Symptoms Among Cancer Caregivers 5 Years After the Relative’s Cancer Diagnosis

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Objective: Few studies address the longer term psychological adjustment of family caregivers who provide care to a relative with cancer. This study aimed to document levels of depressive symptoms among caregivers 5 years after their relative’s initial diagnosis and to identify psychosocial factors that may prospectively predict caregivers’ depressive symptoms at that time. Method: Cancer caregivers participated in a prospective longitudinal study (N = 416; mean age = 55, 65.4% female, 92.9% non-Hispanic White). Demographics and caregiving experiences were measured 2 years after their relative’s cancer diagnosis at Time 1 (T1). Depressive symptoms were assessed with the Center for Epidemiologic Studies–Depression scale (Radloff, 1977) at T1 and again at 5 years postdiagnosis (T2). By T2, caregivers had emerged into 3 groups: former caregivers whose recipients were now in remission, current caregivers, and bereaved caregivers. Results: Controlling for T1 depressive symptoms, T1 caregiving stress and lack of social support were both significant prospective predictors of greater depressive symptoms at T2 (p < .02). Independently, bereaved caregivers reported the greatest depressive symptoms both prior to and after the relative’s death. Those who were actively caregiving at T2 displayed the largest increase in depressive symptoms from T1 to T2 (p < .001). Conclusions: The findings highlight the importance of caregiving stress and social support early in caregivership, even for outcomes that emerge 3 years later. Findings suggest that family members who are actively involved in cancer care at the 5-year mark may benefit from programs designed to improve their adjustment to long-term caregiving.

Keywords: caregivers, depression, long-term effects, bereavement, social support

Providing care to a family member with cancer is often difficult and stressful (Hull, 1992; Kim & Schulz, 2008). Informal cancer care carried out by family caregivers requires meeting the survivor’s multidimensional needs, including treatment monitoring; treatment-related symptom management; emotional, financial, and spiritual support; and assistance with personal and instrumental care (B. A. Given, Given, & Kozachik, 2001; Kim & Given, 2008). Caregiving may be greatest during periods of treatment, but it is by no means limited to those periods.

Cancer caregivers commonly report dysphoric mood (B. A. Given et al., 2001; Kim, Duberstein, Sörensen, & Larson, 2005; Langer, Abrams, & Syrjala, 2003; Pitceathly & Maguire, 2003) and sometimes clinical levels of depression (Vanderwerker, Lafr, Kadan-Lottick, McColl, & Prigerson, 2005). Studies have found that 20% to 50% of caregivers report clinically meaningful levels of depressive symptoms during early survivorship (around the time of diagnosis and treatment) and end-of-life phases (Butler, Turner, Kaye, Ruffin, & Downey, 2005; Carter, 2003; Covinsky et al., 2003; Kim et al., 2005; Raveis, Karus, & Siegel, 1998; Siminoff, Wilson-Genderson, & Baker, 2010; Swore Fletcher, Dodd, Schumacher, & Miaskowski, 2008).

Elevated depressive symptoms while engaged in caregiving is a legitimate concern in its own right (Kim & Given, 2008). It is also a concern because caregivers’ depressive symptoms may affect the quality of the care they provide to the patients (Williamson & Shaffer, 2001). Furthermore, depressive symptoms at this time are a risk factor for clinical depression and complicated grief during later bereavement (Grassi, 2007; Robinson-Whelen, Tada, MacCallum, McGuire, & Kiecoll-Glaser, 2001) and for poorer longer term physical health and mortality (Schulz & Beach, 1999; Vitaliano, Zhang, & Scanlan, 2003). For these reasons, identifying factors that underlie caregivers’ depressive symptoms is important.

Guided by various stress and coping frameworks (Lazarus & Folkman, 1984; Pearlin, Mullan, Semple, & Skaff, 1990), studies have linked both demographic characteristics (e.g., younger age and female gender) and caregiving-related factors (e.g., greater caregiving burden, patient’s poor functioning status) with greater depressive symptoms among cancer caregivers (Butler et al., 2005; Covinsky et al., 2003; B. Given et al., 2004; Haley, LaMonde, Vivar’s multidimensional needs, including treatment monitoring; emotional, financial, and spiritual support; and assistance with personal and instrumental care (B. A. Given, Given, & Kozachik, 2001; Kim & Given, 2008). Caregiving may be greatest during periods of treatment, but it is by no means limited to those periods.

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Han, Burton, & Schonwetter, 2003; Kim et al., 2005). Self-perceived competence in caregiving and social support have both been linked with lower levels of depressive symptoms (Kim et al., 2005; Kurtz, Kurtz, Given, & Given, 2005; Nijboer, Temelaar, Triemstra, Van Den Bos, & Sanderman, 2001). Results thus suggest that both negative factors (e.g., caregiving stress) and positive factors (e.g., social support) are significant contributors to caregivers’ depressive symptoms.

The majority of these findings come from studies employing a cross-sectional design. Although a few studies have examined depressive symptoms longitudinally up to 12 months (Kurtz et al., 2005; Langer et al., 2003; Swore Fletcher et al., 2008), information about prevalence and predictors of depressive symptoms among caregivers years after the patient’s initial cancer diagnosis remains lacking. This is an important gap in our knowledge, partly because a notable characteristic of cancer caregiving is the diversity of the caregiver role. Over the years of the illness trajectory, some family members cease caregiving because the care recipients no longer need help, others cease caregiving because the recipient has died, and still others provide help continuously or intermittently for long periods after the relative’s initial cancer diagnosis (Kim & Given, 2008; Kim, Spillers, & Hall, 2012). The extent to which the different caregiving paths influence depressive symptoms, however, is unknown, though certainly there is evidence that bereavement is associated with elevated depressive symptoms (Stroebe, Hansson, Schut, & Stroebe, 2008; Zisook & Kendler, 2007).

Thus, this study aimed to provide four unique sorts of information. First, we documented the levels of depressive symptoms among cancer caregivers at 5 years postdiagnosis, a time that is often considered a landmark of long-term survivorship. To our knowledge, this is the first report of depressive symptoms among cancer caregivers 5 years after their relative’s initial diagnosis. Second, we investigated how demographic variables and caregiving experiences reported at 2 years postdiagnosis prospectively predicted caregivers’ depressive symptoms 3 years later. Third, we examined the impact of caregivers’ role status at 5 years postdiagnosis (i.e., active caregiving, recipient in remission, or recipient deceased) on their depressive symptoms at that time. Finally, we identified psychosocial factors that predicted the changes in the levels of depressive symptoms (and whether they met an accepted criterion that indicates heightened levels of depression) from 2 to 5 years postdiagnosis.

It was predicted that caregiving stress and inadequate social support while engaging in care provision (at 2 years) would have adverse residual effects on caregivers’ depressive symptoms at 5 years. Independent of those factors, bereaved caregivers and those who were actively providing care to the index case at the 5-year point were expected to report significantly greater depressive symptoms than the caregivers whose relatives were in remission.

Method

Participants

The National Quality of Life Survey for Caregivers (Kim & Spillers, 2010) was designed to longitudinally assess the impact of cancer on the quality of life of family members and close friends who were caring for cancer survivors. The survivors were identified using multiple state cancer registries as diagnosed with one of the 10 most common cancers (Smith et al., 2007). Caregivers were nominated by the survivor as “adult family or family-like individuals who provided consistent help during the survivor’s cancer experience.”

As shown in Figure 1, a total of 896 caregivers completed the baseline survey that contained study variables. At baseline (Time 1 [T1]), survivors were 2.2 years (SD = 0.6 years) postdiagnosis. Follow-up data collection (Kim et al., 2012) at 5 years postdiagnosis (T2) involved three surveys: (a) for caregivers whose relatives with cancer were in remission (Main Survey), (b) for caregivers who were actively providing cancer-related care to the index case at the time of T2 survey completion (Current Caregiver Survey), and (c) for caregivers whose index case had passed away by T2 (Bereaved Caregiver Survey). A total of 416 caregivers provided complete data for the study variables at both T1 and T2. Family caregivers who provided complete information did not differ from those with incomplete data (ps > .21), with three exceptions: Completers were more educated, more affluent, and more likely to be the spouse of the cancer survivor than were caregivers with incomplete information (ps < .04). As shown in Table 1, caregivers across the three subgroups were primarily middle-aged, relatively educated and affluent, employed, and usually the spouse of the cancer survivor.

Procedure

This study was conducted in compliance with the regulations of the Emory University Institutional Review Board. A packet containing an introductory letter, survey, self-addressed stamped envelope, and $10 gift card as an incentive was mailed to the sample of nominated family caregivers. Returning the completed survey served as evidence of informed consent to participate. Two cycles of mailing and telephone follow-up calls were made during an 8-week data collection period corresponding to each time point.

Measures

Demographic characteristics. Caregivers’ self-reported age, gender, education, employment status, ethnicity, household income, and relationship to the care recipient were measured at T1. These variables were used as covariates, since studies have shown

![Diagram](https://via.placeholder.com/150)

Figure 1. Participant flowchart. T1/T2 = Time 1/Time 2; FCR = former caregivers–remission; CC = current caregivers; FCB = former caregivers–bereaved.)
they are related to our study outcomes (Haley et al., 2003; Parker, Baile, Moor, & Cohen, 2003).

Caregiving experiences at 2 years postdiagnosis. At 2 years postdiagnosis (T1), four indicators had been included to assess aspects of the caregiving experiences that had occurred during the preceding 2 years. First, subjective caregiving stress (i.e., the extent to which caregivers had felt overwhelmed by care tasks and responsibilities) was measured by the four-item stress overload subscale of the Pearlin Stress Scale (Pearlin et al., 1990; e.g., “When I feel lonely, there are several people I can talk to”). The mean of the six items represented the level of perceived caregiving stress (negative subjective caregiving experience). This subscale has shown good reliability in cancer caregiver populations (α = .79; Gaugler et al., 2005) and had good internal consistency in our sample (α = .80).

Second, an index of the severity of the care recipients’ cancer across the 10 different types of cancer (cancer severity index) was created for each survivor based on the mortality rate for the type and stage of cancer and the time since diagnosis (Kim, Baker, & Spillers, 2007; Ries et al., 2007). Information about cancer type, and stage of cancer and the time since diagnosis (Kim, Baker, & Elliott, Giger, & Bartolucci, 2001; Martire, Schulz, Mittelmark, & Newsom, 1999).

Caregiver status at 5 years postdiagnosis. The T2 Main Survey included two questions that were used to identify three subgroups of caregivers. Caregivers who responded “no” to the question “Is [survivor’s name] alive?” were asked to stop filling out the Main Survey and return it in order to receive the Bereaved Caregiver Survey. This subgroup of caregivers was termed former caregivers—bereaved (FCBs). The average time since their care
recipients’ death was 2.4 years (SD = 0.8). Caregivers who responded “yes” to the question “Are you currently providing help to [survivor’s name] for his/her cancer experience?” were called current caregivers (CCs). The subgroup of caregivers whose survivors were alive and currently not receiving any cancer-related help were called former caregivers–remission (FCRs).

**Depression.** The level of depressive symptoms experienced in the past 4 weeks was measured at both 2 years (T1) and 5 years (T2) postdiagnosis by the 20-item Center for Epidemiologic Studies–Depression scale (CES-D; Radloff, 1977). CES-D scores of 16 or above are often considered as indicating clinically meaningful levels of depressive symptoms. Criterion validity has been shown in populations of older adults (Beekman et al., 1997), and acceptable reliability scores have also been shown in populations of cancer caregivers (α = .92–.97; Gaugler et al., 2008; Nijboer et al., 2001). The items had good internal consistency in our sample (α = .92 at T1 and T2).

**Statistical Analyses**

Basic descriptive information is presented for the entire sample as well as by the three caregiver role groups that emerged at T2. The three groups were compared by univariate analyses of variance for continuous variables and chi-square tests for categorical variables. The prevalence of elevated depressive symptoms (CES-D ≥ 16 or above vs. less than 16) was tallied at each assessment time by caregiver role groups. A chi-square test then compared the prevalence of such elevation at T1 with that at T2 across the three caregiver role groups that emerged at T2.

The role of demographic variables and caregiving experiences was tested prospectively, predicting depressive symptoms at T2 by variables assessed at T1. Logistic regression modeling was used to predict the caseness of CES-D ≥ 16 at T2, and linear regression modeling was used to predict the CES-D score (continuous) at T2. In both models, CES-D at T1 was entered in Step 1, followed by demographics in Step 2, T1 caregiving experiences in Step 3, and two dummy variables indicating caregiving status at T2 in Step 4.

Finally, multinomial regression modeling was used to predict the four depression group memberships that were created based on the caregivers being depressed or not (CES-D ≥ 16 vs. CES-D < 16) at T1 or T2: depressed at both T1 and T2, depressed at only T1, depressed at only T2, and not depressed at either time. The “not depressed at either time” served as a reference group. Significant levels in all analyses were set at p < .05. All tests were two-sided.

**Results**

As shown in Table 1, participating caregivers were overall middle-aged, slightly more female and spouses, and relatively educated and affluent. Caregivers who would go on to be active caregivers or bereaved at the 5-year assessment (T2) were more likely to be older and female and less likely to be educated and employed at T1. Those who would become bereaved were less likely than the other groups of caregivers to be affluent or spouses of the deceased and were more likely to be mother or child of the deceased. Active or bereaved caregivers at T2 were also more likely to be providing care to a relative with a regional or distant cancer at T1.

Table 2 shows that the caregiver groups—which were not defined until T2—were already differentiated at T1 by levels of perceived caregiving stress and cancer severity. Those who would go on to be actively providing cancer care at T2 or be bereaved at T2 already had higher levels of caregiving stress, and their care recipient had more severe cancer at T1. These caregivers also had already higher depressive symptoms than did caregivers in the other group at T1. By T2, the CES-D scores of those providing active care more closely resembled those of the bereaved group than those whose survivors were then in remission.

**Prevalence of Elevated Depressive Symptoms at 2 and 5 Years Postdiagnosis**

Overall levels of depressive symptoms at T1 and at T2 (see Table 2) were comparable to those in other studies with cancer caregivers (Kim et al., 2005; Kurtz et al., 2005). Approximately one fourth of caregivers reported CES-D symptoms ≥16 at T1 (25.0%) and T2 (26.9%). The prevalence of these cases of elevated symptoms across caregiver role groups (see Table 3) closely resembled the profile of raw depressive symptom scores. When considering the groups separately, at T1 (2 years postdiagnosis), the CES-D criterion of 16 was met by 19.4% of the FCRs, 28.3% of the CCs, and 48.4% of the FCBs. Thus, the prevalence of clinically meaningful levels of depressive symptoms at T1 already reflected a divergence among what would be defined at the 5-year mark as the three separate caregiver role groups. Caregivers who became bereaved showed the highest prevalence of T1 depression, χ² = 23.38, p < .001.

At T2, those with CES-D ≥16 were 19.7% of the FCRs, 41.7% of the CCs, and 46.8% of the FCBs, χ² = 26.78, p < .001 (see

Table 2

<table>
<thead>
<tr>
<th>Variable</th>
<th>Scale range</th>
<th>Total sample (N = 416)</th>
<th>Former caregivers–remission (N = 294)</th>
<th>Current caregivers (N = 60)</th>
<th>Former caregivers–bereaved (N = 62)</th>
<th>F</th>
<th>η²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiving stress at T1</td>
<td>1–4</td>
<td>1.60 (0.59)</td>
<td>1.53 (0.54)</td>
<td>1.74a (0.65)</td>
<td>1.82a (0.68)</td>
<td>8.83***</td>
<td>.04</td>
</tr>
<tr>
<td>Cancer severity at T1</td>
<td>0–1</td>
<td>0.17 (0.25)</td>
<td>0.10 (0.11)</td>
<td>0.20a (0.24)</td>
<td>0.46 (0.30)</td>
<td>72.25***</td>
<td>.26</td>
</tr>
<tr>
<td>Caregiver esteem at T1</td>
<td>1–5</td>
<td>4.40 (0.48)</td>
<td>4.37 (0.46)</td>
<td>4.50 (0.50)</td>
<td>4.42 (0.56)</td>
<td>1.77</td>
<td>.01</td>
</tr>
<tr>
<td>Social support at T1</td>
<td>1–4</td>
<td>3.35 (0.60)</td>
<td>3.34 (0.62)</td>
<td>3.38 (0.54)</td>
<td>3.35 (0.59)</td>
<td>0.10</td>
<td>.00</td>
</tr>
<tr>
<td>CES-D at T1</td>
<td>0–60</td>
<td>10.42 (9.55)</td>
<td>8.94 (8.43)</td>
<td>12.18a (10.75)</td>
<td>15.77 (11.15)</td>
<td>15.32</td>
<td>.07</td>
</tr>
<tr>
<td>CES-D at T2</td>
<td>0–60</td>
<td>10.87 (10.15)</td>
<td>9.26 (9.14)</td>
<td>14.37a (12.26)</td>
<td>15.15a (10.56)</td>
<td>13.55***</td>
<td>.06</td>
</tr>
</tbody>
</table>

*Note.* Values in parentheses are standard deviations. Values that do not share the same subscripts differ from each other at p < .05. T1 = Time 1 (initial survey at 2 years postdiagnosis); T2 = Time 2 (follow-up survey at 5 years postdiagnosis); CES-D = Center for Epidemiologic Studies–Depression scale. ***p < .001.
Predicting Depressive Symptoms at 5 Years Postdiagnosis

Two sets of analyses predicted caregivers’ depressive symptoms 5 years after the cancer diagnosis from variables assessed 2 years after the diagnosis, as well as from caregiving status at the 5-year mark. Caregiving status at 5 years was operationalized by two dummy variables. One compared FCRs with FCBs and CCs. The other compared FCBs with FCRs and CCs. These dummy codes made CCs the reference group, because this is the group whose role had not changed between assessment times. These codes permitted testing separately the effects of becoming a former caregiver whose recipient was in remission or a former caregiver whose recipient had died. The dummy codes were entered after all T1 variables had been entered.

The first set of analysis used logistic regression, with caregivers’ depressive symptom scores at T2 as outcome, dichotomized using a CES-D score of 16 or more as a cutoff score. Caseness at T2 was predicted by caseness at T1 and the other predictors (see the “ CES-D ≥ 16; T2” columns in Table 4). The second set of analysis used linear regression, with continuous CES-D scores at T2 as outcome predicted by continuous CES-D scores at T1 and other predictors (see the “CES-D raw score at T2” columns in Table 4). Unsurprisingly, in both analyses depression at T1 made a substantial contribution to predicting depression at T2. In Step 2, being female and having lower education made significant incre-
mental contributions to greater depression. In Step 3, both greater caregiving stress at T1 and lack of social support at T1 made additional unique contributions to greater depression at T2.

The two dummy variables indicating caregiving status at T2 were entered in Step 4. The FCR dummy effect was significant. This indicated that becoming a former caregiver because of the care recipient’s remission at T2 made another unique contribution to lower depression at T2 than other caregiver groups. The FCB dummy variable was not significant, indicating that those whose care recipients were deceased did not differ in depressive symptoms from those actively providing care at T2.

### Predicting Depression Groups at 2 and 5 Years Postdiagnosis

A final set of analyses examined stability and change in depression status between assessments. Caregivers were grouped into four categories based on a CES-D score of 16 or more versus less than 16 at T1 and T2, separately: The resulting groups were depressed at both T1 and T2, depressed at T1 but not T2, depressed at T2 but not T1, and not depressed at either time. Not depressed at either time was used as the reference group in the multinomial regression analysis. As shown in Table 5, caregivers who were depressed at both T1 and T2, compared with caregivers who were not depressed at either time, were more likely to have low income at T1, greater caregiving stress at T1, less social support at T1, and either being an active caregiver or bereaved at T2. Caregivers who were depressed only at T1, compared with caregivers who were not depressed at either time, were likely to be unemployed at T1, have greater caregiving stress at T1, provide care to a relative with more severe cancer at T1, and have less social support at T1. Finally, caregivers who were depressed only at T2, compared with caregivers who were not depressed at either time, were likely to have had greater caregiving stress at T1, actively provided care at T2, and tended to have had less social support at T1 ($p = .056$).

### Discussion

The results of this study make several important and novel points. The first concerns the relatively high level of depressive symptoms of cancer caregivers at the 5-year mark. This is the first evidence in the cancer caregiving literature of such elevations at that later time. There was a substantial prevalence of depressive symptoms severe enough to be viewed as clinically meaningful (CES-D score $\geq 16$): 40% for current caregivers and 50% for bereaved caregivers, though the incidence was a good deal lower for those whose recipients who were in remission (20%).

This finding, in turn, leads to the second point: The survivors’ status played a major role in caregivers’ depressive symptoms at T2. The prevalence rate for elevated symptoms in our bereaved subgroup is at a typical level for those during the first year of bereavement (Gilbar & Ben-Zur, 2002; Holtslander & McMillan, 2011). However, our bereaved caregivers had experienced their loss an average of 2.4 years prior to the T2 assessment. It is also noteworthy that a substantial proportion of caregivers who were actively engaged in cancer caregiving at the 5-year mark had elevated depressive symptoms at that time. Their symptom levels at T1 had been similar to those of caregivers whose care recipients subsequently remained in remission, but by T2 their depression had increased significantly. Typically, caregiving for cancer patients is acute but intense (Kim & Schulz, 2008). Thus, extended or renewed caregiving 5 years after the initial cancer diagnosis of the relative can be unexpected and upsetting. Extended or renewed involvement in cancer care after the time of diagnosis and initial treatment—whether due to long-term side effects, palliative care needs of the patient, or recurrence or new cancer—seems to take a further toll on the caregivers. This finding highlights that caregiver support programs should not limit their scope to new, inexperienced caregivers, but should also extend services to those with a long history of providing care. It needs to be recognized that

<table>
<thead>
<tr>
<th>Variable</th>
<th>CES-D $\geq 16$ at both T1 and T2</th>
<th>CES-D $\geq 16$ only at T1</th>
<th>CES-D $\geq 16$ only at T2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at T1</td>
<td>$-0.02$</td>
<td>$-0.02$</td>
<td>$0.01$</td>
</tr>
<tr>
<td>Female gender</td>
<td>$0.09$</td>
<td>$0.74$</td>
<td>$0.51$</td>
</tr>
<tr>
<td>Higher education$^a$</td>
<td>$-0.54$</td>
<td>$0.60$</td>
<td>$-0.63$</td>
</tr>
<tr>
<td>Higher income$^b$</td>
<td>$-0.70$</td>
<td>$0.10$</td>
<td>$0.11$</td>
</tr>
<tr>
<td>Spouse$^c$</td>
<td>$0.29$</td>
<td>$0.06$</td>
<td>$0.02$</td>
</tr>
<tr>
<td>Employed$^d$</td>
<td>$0.65$</td>
<td>$-0.97$</td>
<td>$0.02$</td>
</tr>
<tr>
<td>Caregiving stress</td>
<td>$1.22$</td>
<td>$1.30$</td>
<td>$1.03$</td>
</tr>
<tr>
<td>Cancer severity</td>
<td>$0.71$</td>
<td>$1.88$</td>
<td>$1.12$</td>
</tr>
<tr>
<td>Caregiver esteem</td>
<td>$0.21$</td>
<td>$0.37$</td>
<td>$0.09$</td>
</tr>
<tr>
<td>Social support</td>
<td>$-1.30$</td>
<td>$-0.74$</td>
<td>$-0.58$</td>
</tr>
<tr>
<td>Active caregiving at T2$^e$</td>
<td>$1.00$</td>
<td>$0.15$</td>
<td>$1.00$</td>
</tr>
<tr>
<td>Bereaved at T2$^e$</td>
<td>$1.55$</td>
<td>$1.03$</td>
<td>$0.75$</td>
</tr>
</tbody>
</table>

Note. $N = 416$. Reference group was not depressed at either time. CES-D = Center for Epidemiologic Studies–Depression scale; CI = confidence interval; T1 = Time 1 (2 years postdiagnosis); T2 = Time 2 (5 years postdiagnosis).

$^a$ More than high school as opposed to high school or less. $^b$ $40,000 or more as opposed to less than $40,000. $^c$ Spouse as opposed to non-spouse. $^d$ Employed as opposed to unemployed. $^e$ Reference group for the effects of active caregiving at T2 and bereaved at T2 was former caregivers whose relatives were in remission at T2.
some carry out that role for years or have to resume it unexpectedly, yielding depressive symptoms.

Recognizing the substantial levels of depressive symptoms among subgroups of cancer caregivers who either were still actively engaged in cancer care or had become bereaved 5 years after their relative’s initial diagnosis is an important first step. A next step will be to develop psychosocial programs that address key concerns of these subgroups of cancer caregivers. As cancer survivors transition out of treatment into recovery, recurrence, or end-of-life, it is important for the oncology health care team to acknowledge the impact this transition has on the family caregiver. It is also critical for clinicians to monitor the caregiver’s depressive symptoms throughout various phases of the cancer trajectory.

A third key point concerns the longer term effects of earlier caregiving experiences. That is, both caregiving stress and lack of social support at 2 years were significant predictors of level of depressive symptoms and elevated depression incidence (CES-D ≥ 16) at 5 years, even after controlling for the depressive symptoms at 2 years. It is notable as well that the caregivers’ subjective stress rather than objective disease severity played this important role. These results are the first of their kind in documenting the prospective longitudinal effect of caregiving stress and social support on cancer caregivers’ depression. They thus pinpoint the importance of addressing cancer caregivers’ stress and need for social support resources earlier in caregivership, to minimize adverse effects on their well-being years later. The findings suggest that programs for cancer caregivers incorporate information on how to manage caregiving-related stress and how best to identify and recruit effective social support early in survivorship.

### Limitations and Directions for Future Studies

Several limitations of this study should be noted. First, all variables were self-reported and therefore may be affected by social desirability or defensive reactions (Paulhus, 1991). Second, we examined only basic demographic and caregiving factors, and the effect sizes observed were modest. Future studies should investigate other factors that may affect the caregiving experience, such as the cancer survivors’ objective functional status, the presence of other caregiving help, caregivers’ physical health and morbidities, use of mental health services, and participation in support groups. Third, there is inevitably a self-selection process in the recruitment and retention of participants in a study of this sort. Caregivers who completed the 5-year follow-up were more educated, more affluent, and more likely to be the spouse of the cancer survivor than were caregivers who did not. Caregivers who remained at the 5-year follow-up were less than half of those who initially participated in this study. This has implications for the limited generalizability of the findings. It will be important to replicate these findings with ethnic minorities and individuals of lower socioeconomic status.

### Conclusion

Despite these limitations, this study makes a significant contribution to the cancer caregiver literature by providing the first evidence that 5 years after the initial cancer diagnosis in the family, many family members who remain in an active caregiver role or who have become bereaved suffer from depressive symptoms serious enough for concern. Early stressful caregiving experiences and lack of proper social support also played significant roles in depressive symptoms 3 years later. Findings suggest that programs to improve personal and social resources for caregivers early in caregivership may be enhanced by recognizing that depression is a long-term challenge for this population.

### References


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