Quality of life of family caregivers 8 years after a relative’s cancer diagnosis: follow-up of the National Quality of Life Survey for Caregivers

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Abstract

Background: The long-term impact of cancer caregiving on the family caregivers’ quality of life (QOL) is currently not known. This study aimed (a) to characterize family caregivers of cancer survivors at 8 years post-diagnosis in terms of multidimensional aspects of QOL and (b) to identify demographic and early caregiving experience characteristics that may play significant roles in predicting the caregivers’ longer-term QOL.

Methods: A total of 1087 caregivers participated in the 8-year follow-up National Quality of Life Survey for Caregivers. Demographics and early caregiving experiences were measured 2 years post-diagnosis of their relative’s cancer. Multidimensional aspects of QOL were assessed, including mental and physical health, psychological adjustment, and spirituality at both 2-year and 8-year post-diagnosis.

Results: Approximately 90% of family caregivers ceased the caregiver role by 8 years. One-fourth of them were due to bereavement. Caregivers’ demographic and early caregiving characteristics were significantly associated with QOL. In addition, being bereaved by the 8-year mark predicted poorer mental health and greater psychological distress independent of contributions of demographic and early caregiving characteristics.

Conclusions: Findings provided the first evidence that 8 years after the initial cancer diagnosis in the family, family members who became bereaved suffer from poorer mental health and greater psychological distress. Findings have theoretical implications for better understanding bereavement to cancer and practical implications for developing integrative programs to improve QOL among family members in the various phases of caregivership.

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Approximately 14.6 million Americans living today, or one in 21 people, are either currently undergoing treatment for cancer or have done so in the past [1–3]. The overall 5-year survival rate of cancer rose from 50% in 1970 to 67% in 2010 [2]. This improvement in survival rate reflects various trends, including advances in medicine and the public’s use of cancer screening. Coupled with the trend of aging population, increases of cancer survivor population are expected to continue for the next decades [4].

An emerging trend in psycho-oncology research has been acknowledging the impact of cancer not only on the person with the disease but also on their family caregivers. This is reflected in the fact that the number of publications between 2010 and 2014 on cancer caregivers tripled compared with that between 2000 and 2004. However, only one-fourth of the published studies between 2000 and 2014 dealt with one or more aspects of cancer caregivers’ quality of life (QOL). QOL is a multidimensional construct with mental/social, physical, psychological, and spiritual components [5–8]. Of those, one in eight papers involved in documenting changes over time in a QOL indicator among cancer caregivers by either longitudinal observations (e.g., [9–12]) or pre-intervention and post-intervention assessments (e.g., [13–16]).

Only two studies, however, have extended the follow-up assessments beyond 3 years after the relative’s initial diagnosis. One is the Partners & Caregivers Study conducted in Australia to describe QOL among informal caregivers of cancer survivors over the first 5 years post-diagnosis [17]. This project found prolonged psychological distress among family caregivers over 5 years following the diagnosis [18]. The other is the National Quality of Life Survey for Caregivers conducted in the USA. This project distinguished three groups of caregivers at the 5-year mark. Family members who were actively providing care to the index patient at that time reported the worst QOL of the three. They and bereaved caregivers reported lower levels of psychological and spiritual adjustment than former caregivers whose recipients were in remission [19]. In addition to highlighting the significant effects of caregiving status on QOL at the 5-year mark, this study found...
that caregivers’ age and earlier caregiving stress were predictors of QOL across all three caregiver groups at that time.

Although both studies are large-scale, nationwide studies and provided valuable information about family caregivers’ QOL at 5-year post-diagnosis, the QOL of family members beyond 5 years and the extent to which early caregiving experiences predict later QOL among the family caregivers are unknown. Also unknown are the distribution of caregivers by caregiving status at more than 5 years after the initial cancer diagnosis and the effect of caregiving status on longer-term QOL. The lack of evidence regarding longer-term QOL outcomes of having cancer in the family from the family caregivers’ perspective is a substantial gap in knowledge. The impact on family caregivers is likely not limited to the time of diagnosis and treatment nor a couple of years afterward but many years afterward. As the population of long-term cancer survivors is growing rapidly, complementary information about their family caregivers is timely. Thus, the current study extended its initial assessment of the National Quality of Life Survey for Caregivers that took place 2 years after the relative who have provided consistent help during a survivor’s cancer experience. The help provided could include emotional support, financial support, symptom management, personal care, or transportation [20,21].

A packet containing an introductory letter, survey, self-addressed stamped envelope, and a $10 gift card as an incentive was mailed to the pool of family caregivers who had been nominated by the survivor at the initial assessment, which targeted 2-year post-diagnosis. If the caregivers had not returned the survey by 3 weeks after the initial mailing, telephone follow-up calls were made. A second packet, which included the same materials except the gift card, was mailed 5 weeks after the initial mailing. A second follow-up call was made 8 weeks after the initial mailing if the caregivers had not returned the survey. A total of 1635 close family members returned the initial survey (61.7% response rate). At that time, the survivors’ cancer had been diagnosed an average of 2.1 years (standard deviation [SD]=0.5 year).

Caregivers who made hard refusal at the initial assessment phase were excluded from any follow-up contact. The follow-up data collection targeted 8-year post-diagnosis. Returning the completed survey served as informed consent to participate. The same follow-up procedure employed for the initial survey was used for the 8-year follow-up data collection. The 8-year follow-up consisted of three surveys: (a) for all eligible family caregivers (Main Survey), (b) for family caregivers whose index survivor had passed away (Bereaved Caregiver Survey), and (c) for family caregivers who were actively providing care to the index survivor at the time of 8-year follow-up survey (Current Caregiver Survey). Descriptive data reported here about QOL are from caregivers whose caregiving status information was available at 8 years after their index patient’s initial cancer diagnosis. Analyses predicting QOL at 8-year mark included all who provided complete information for the study variables at both 2 and 8 years. The study was approved by the Emory University Institutional Review Board.

Measures

Demographic characteristics
Self-reported age, gender, education, employment status, household income of the caregivers, and their familial relationship to the care recipient were measured at the 2-year assessment point (T1).

Early caregiving experiences
Four indicators were included to assess caregiving experience at T1, when all the caregivers were providing cancer care to the survivor. First, caregiving stress, the extent to which caregivers felt overwhelmed by care tasks and responsibilities, was measured by the stress overload subscale of the Pearlin Stress Scale (response scale 1=not at all, 4= completely) [22]. The mean of the four items represented the level of caregiving stress, with higher scores reflecting a greater perceived level of stress related to caregiving. The subscale score had acceptable internal consistency in the present study (α=.78). Second, as an objective indicator of the severity of the care recipient’s cancer across the 10 different types of cancer, a severity of cancer index was created for each survivor based on the mortality rate for the type and stage of cancer and

Method

Participants and procedure
The National Quality of Life Survey for Caregivers longitudinally assessed the impact of cancer on the QOL of family members who were caring for cancer survivors. Family caregivers were nominated by cancer survivors (one per survivor), who were identified through state cancer registries as having one of the ten most common cancers (bladder, breast, colorectal, kidney, lung, non-Hodgkin’s lymphoma, ovarian, prostate, skin, and uterine cancer). Caregivers were referred to as family-like individuals who have provided consistent help during a survivor’s cancer experience. The help provided could include emotional support, financial support, symptom management, personal care, or transportation [20,21].

A packet containing an introductory letter, survey, self-addressed stamped envelope, and a $10 gift card as an incentive was mailed to the pool of family caregivers who had been nominated by the survivor at the initial
the time since diagnosis [2]. Information about cancer type, stage of cancer (localized, regional, or distant), and date of cancer diagnosis was obtained from the state cancer registry. Higher scores reflect diagnosis with a more severe cancer. Third, caregiver’s esteem, the extent to which caregiving imparts individual self-esteem, was measured by the caregiver’s esteem subscale of the Caregiver Reaction Assessment (1 = strongly disagree, 5 = strongly agree) [23]. The mean of the seven items represented the level of caregiver’s esteem, with higher scores reflecting a greater sense of value and worth as a caregiver. The subscale score had acceptable internal consistency in the present study (α = .73). Fourth, the extent to which the caregivers perceived that emotional, informational, and instrumental support were available to them was measured, using the Interpersonal Support Evaluation List (1 = definitely false, 4 = definitely true) [24]. The mean of the six items represented the level of perceived availability of social support. This scale had been validated in other caregiver populations [25] and had acceptable internal consistency in the present study (α = .80).

Caregiver status at 8-year post-diagnosis

Three caregiver groups were identified at 8-year post-diagnosis, by two questions in the Main Survey. Caregivers who responded ‘no’ to the question ‘Is [Survivor’s Name] alive?’ were asked to stop filling out the Main Survey and return the survey in order to receive the Bereaved Caregiver Survey. This subgroup of caregivers was called Former Caregivers–Bereaved (FCB). Caregivers who responded ‘yes’ to the question ‘Are you currently providing help to [Survivor’s Name] for his or her cancer experience?’ were asked to continue completing the Main Survey. Upon the receipt of the completed Main Survey, this group of caregivers received another survey, the Current Caregiver Survey. This subgroup of caregivers was called Current Caregivers (CC). The subgroup of caregivers whose survivors were alive and currently did not need any help with the cancer experience was called Former Caregivers–Remission (FCR). They completed only the Main Survey.

Quality of life indicators

Four measures served as indicators of the QOL of caregivers at both 2-year and 8-year post-diagnosis: mental health, physical health, psychological distress, and spirituality. Self-reported levels of mental and physical health of participants were measured using the Medical Outcomes Study Short Form Health Survey [26,27]. The mental health score was a composite of weighted vitality, social functioning, role-emotional, and mental health subscale scores. The physical health score was a composite of weighted physical functioning, role-physical, bodily pain, and general health subscale scores. Both scores have been normalized [26,27]. Higher composite scores reflect better mental and physical health.

Another indicator was psychological distress, which was measured using the Profile of Mood States–Short Form [28,29] and answered on a five-point Likert format (0 = not at all, 4 = extremely). A psychological distress composite score was calculated by summing the mean scores of anger, anxiety, confusion, depression, and fatigue subscales, and subtracting the mean of vigor subscale score from the sum. Thus, higher scores on this composite reflected a greater level of psychological distress. The psychological distress composite score had good internal consistency (α = .89 at 2 years; α = .67 at 8 years).

Finally, the extent to which caregivers experienced meaning, peace, and faith in the context of the care recipient’s illness was measured using the 12-item Functional Assessment of Chronic Illness Therapy–Spirituality [30]. Items were slightly reworded to refer to the care recipient’s illness rather than one’s own illness. A composite score of spirituality was calculated by averaging the 12 items (after reverse coding, as needed). Higher scores reflected greater levels of finding meaning and faith in the context of dealing with cancer as a caregiver. The spirituality composite score had good internal consistency (α = .90 at 2 years; α = .89 at 8 years).

Analysis plan

Descriptive information about the sample’s demographics, early caregiving experience characteristics, caregiving status, and QOL indicators is presented in Tables 1 and 2. The sample’s demographics, caregiving experiences, and multidimensional aspects of QOL were compared across caregiving status groups at the 8-year mark using F-tests and chi-square tests (Table 1). The associations among the four QOL indicators were examined by zero-order correlations (Table 2). Prediction of aspects of caregivers’ QOL (i.e., mental, physical, psychological, and spiritual) by their demographic and early caregiving experience characteristics as well as caregiving status at 8 years was carried out by a multivariate general linear modeling analysis using pairwise deletion, in which demographic and early caregiving experience characteristics as predictors were entered in step 2 after controlling for the effects of corresponding QOL measures at the 2-year mark. Thus, the effects of demographic and early caregiving experience characteristics on the QOL at 8 years were above and beyond what the same QOL at 2 years accounted for. In step 3, two dummy codes to test the effects of being a current caregiver or bereaved at the 8-year mark, compared with being a former caregiver whose care recipient was in remission, were added to the equation in order to test the effects of caregiver status at 8-year post-diagnosis (Table 3).
Table 1. Demographic characteristics of cancer caregivers by caregiving status at 8-year post-diagnosis

<table>
<thead>
<tr>
<th>Demographic characteristics at 2 years</th>
<th>Former Caregivers–Remission</th>
<th>Former Caregivers–Bereaved</th>
<th>Current Caregivers</th>
<th>F or χ²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>483 56.03 (11.95)</td>
<td>185 57.22 (12.88)</td>
<td>112 53.85 (11.09)</td>
<td>2.74</td>
</tr>
<tr>
<td>Gender (female %)</td>
<td>501 63.5%</td>
<td>194 75.8%</td>
<td>117 68.4%</td>
<td>9.69**</td>
</tr>
<tr>
<td>Education (&gt;high school)</td>
<td>487 73.1%</td>
<td>191 73.3%</td>
<td>115 71.3%</td>
<td>0.17</td>
</tr>
<tr>
<td>Employed at 2 years</td>
<td>499 72.5%</td>
<td>191 71.7%</td>
<td>117 80.3%</td>
<td>3.35</td>
</tr>
<tr>
<td>Income (≥$40,000)</td>
<td>410 74.9%</td>
<td>164 70.7%</td>
<td>105 76.2%</td>
<td>1.34</td>
</tr>
<tr>
<td>Spouse</td>
<td>501 73.5%</td>
<td>194 60.3%</td>
<td>116 79.3%</td>
<td>16.16***</td>
</tr>
</tbody>
</table>

Caregiving characteristics at 2-years

| Caregiving stress                     | 493 1.55 a (0.55)           | 191 1.86 b (0.72)         | 115 1.67 a (0.57) | 18.69***|
| Cancer severity                       | 581 0.09 a (0.16)           | 225 0.30 b (0.28)         | 130 0.12 a (0.18) | 92.98***|
| Caregiver esteem                      | 493 4.39 (0.50)             | 192 4.41 (0.53)           | 117 4.42 (0.44)   | 0.20   |

Quality of life at 2 years

| Mental health                         | 489 39.94 (14.87)           | 186 39.15 (13.54)         | 115 38.28 (13.82) | 0.70   |
| Physical health                       | 489 38.73 (10.10)           | 186 36.20 (17.50)         | 115 38.02 (17.48) | 0.88   |
| Psychological distress                | 480 1.21 a (3.19)           | 186 3.17 b (3.93)         | 113 2.55 b (3.72) | 18.61***|
| Spiritual adjustment                  | 488 2.96 (0.70)             | 185 2.82 (0.82)           | 115 2.85 (0.83)   | 2.50   |

Values that do not share the same subscripts differ from each other at p < .05.
SD, standard deviation.

**p < .01.
***p < .001.

Table 2. Quality of life indicators of cancer caregivers at 8-year post-diagnosis

<table>
<thead>
<tr>
<th>Former Caregivers–Remission</th>
<th>Former Caregivers–Bereaved</th>
<th>Current Caregivers</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental health</td>
<td>553 51.17 (9.39)</td>
<td>224 48.71 (10.23)</td>
<td>129 48.20 (10.62)</td>
</tr>
<tr>
<td>Physical health</td>
<td>553 48.73 (10.10)</td>
<td>224 48.62 (17.50)</td>
<td>129 47.69 (11.28)</td>
</tr>
<tr>
<td>Psychological distress</td>
<td>550 1.63 a (3.19)</td>
<td>226 3.17 b (4.49)</td>
<td>128 2.55 b (3.72)</td>
</tr>
<tr>
<td>Spiritual adjustment</td>
<td>558 2.78 (0.72)</td>
<td>225 2.72 (0.80)</td>
<td>130 2.82 (0.78)</td>
</tr>
</tbody>
</table>

Former Caregivers–Remission

- Mental health: r = -.07, p = .091
- Physical health
- Psychological distress
- Spiritual adjustment

Former Caregivers–Bereaved

- Mental health: r = .10, p = .882
- Physical health
- Psychological distress
- Spiritual adjustment

Current Caregivers

- Mental health: r = .11, p = .231
- Physical health
- Psychological distress
- Spiritual adjustment

SD, standard deviation.

***p < .001.

### Results

**Characterizing cancer caregivers 8 years after their relative’s initial diagnosis**

A total of 1909 caregivers who had been nominated by the index survivors and had not made hard refusal either at the time of initial caregiver survey or in responding to annual newsletters sent to them by the time of 8-year follow-up received the 8-year follow-up survey regardless of whether they had completed the initial caregiver survey. Of those, 1087 returned an 8-year follow-up survey (56.9% response rate). At 8-year follow-up, the majority of the caregivers were no longer actively providing care to the relative with cancer because the relative passed away (21.2%; FCB). The remaining caregivers were actively providing care to the relative (66.2%; FCR) or because the relative was in remission (25.4%: FCR). Not surprisingly, care recipients of the FCB group were more likely to have a more severe type of cancer, compared with caregivers in the FCR and CC groups. Bereaved caregivers at 8 years also had reported greater levels of caregiving stress while they had been providing care to the index case (which was approximately 6 years prior to the 8-year survey), and their care recipient had had a lung and distant cancer. On the other hand, the three groups of caregivers did not differ significantly in their self-esteem as a caregiver and perceived availability of social support at the 2-year mark. Average time since care recipient’s death among the FCB at 8 years was 3.6 years (SD = 2.4).

<table>
<thead>
<tr>
<th>Table 3. Predictors of cancer caregivers’ quality of life at 8-year post-diagnosis: demographic and caregiving characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mental health</strong></td>
</tr>
<tr>
<td><strong>B</strong></td>
</tr>
<tr>
<td>---------------------------------</td>
</tr>
<tr>
<td>Step 1: corresponding outcomes at 2 years</td>
</tr>
<tr>
<td>Mental health</td>
</tr>
<tr>
<td>Physical health</td>
</tr>
<tr>
<td>Psychological distress</td>
</tr>
<tr>
<td>Spiritual adjustment</td>
</tr>
<tr>
<td><strong>R²</strong></td>
</tr>
<tr>
<td>Step 2: demographics and early caregiving experiences</td>
</tr>
<tr>
<td>Demographic characteristics</td>
</tr>
<tr>
<td>Age</td>
</tr>
<tr>
<td>Gender (female)</td>
</tr>
<tr>
<td>Education (&gt;high school)</td>
</tr>
<tr>
<td>Employed</td>
</tr>
<tr>
<td>Income (≥$40,000)</td>
</tr>
<tr>
<td>Spouse</td>
</tr>
<tr>
<td>Caregiving experiences at 2-year post-diagnosis</td>
</tr>
<tr>
<td>Caregiving stress</td>
</tr>
<tr>
<td>Cancer severity</td>
</tr>
<tr>
<td>Caregiver esteem</td>
</tr>
<tr>
<td>Social support</td>
</tr>
<tr>
<td><strong>R²</strong></td>
</tr>
<tr>
<td>Step 3: caregiving status at 8-year post-diagnosis</td>
</tr>
<tr>
<td>CC versus FCR</td>
</tr>
<tr>
<td>FCB versus FCR</td>
</tr>
<tr>
<td><strong>R²</strong></td>
</tr>
</tbody>
</table>

N = 234; B = unstandardized coefficient; gender: 1 for female, 0 for male; education: 1 for greater than high school education, 0 for high school or less; employed: 1 for employed, 0 for non-employed; income: 1 for household income ≥$40,000, 0 for household income ≤$40,000; spouse: 1 for spouse, 0 for non-spouse.

CC, Current Caregiver; FCR, Former Caregiver—Remission; FCB, Former Caregiver—Bereaved.

*p < .05, **p < .01, ***p < .001.
Quality of life of caregivers 8 years after their relative’s initial cancer diagnosis

As shown in Table 1, among the family caregivers who provided valid QOL data at 8 years, they reported at 2 years on average below the 25th percentile of both mental and physical health of the US population [26,27]. These were comparable across the three caregiver groups that emerged 6 years later. A similar pattern was noticed with regard to spiritual adjustment at 2-year post-diagnosis. In contrast, caregivers who would become bereaved or current caregivers by 8-year post-diagnosis reported greater levels of psychological distress at 2-year post-diagnosis than those who became former caregivers with their care recipients in remission.

Across all three groups at 8 years (Table 2), family caregivers on average reported levels of mental and physical health that are comparable with the US population [26,27]. Caregivers reported higher levels of psychological distress than that of a normative geriatric sample (a mean of 1.06) [28], whereas the levels of spirituality were lower than that found in patients with cancer (a mean of 3.2) [30]. However, the levels of the QOL indicators at 8-year post-diagnosis differed across the three caregiver groups. Caregivers who became bereaved and those currently caregiving for the index case 8 years after the initial diagnosis reported poorer mental health than those whose care recipients were in remission. The same pattern was observed with psychological distress. There were no significant group differences in physical health and spiritual adjustment across the three caregiver groups at the 8-year mark.

As shown in Table 2, mental health at the 8-year mark was not significantly related to physical health, but significantly correlated with psychological distress (negatively) and spiritual adjustment (positively); this was true for all three groups of caregivers. Physical health at 8 years was significantly correlated with psychological distress (negatively) among all three caregiver groups and significantly correlated with spiritual adjustment (positively) only among bereaved caregivers. Finally, psychological distress was significantly and negatively correlated with spiritual adjustment, which was the case among all three caregiver groups.

Predicting longer-term quality of life of caregivers

As shown in Table 3, the four QOL indicators at the 8-year mark were strongly predicted by the corresponding QOL indicator at 2 years. QOL indicators at 8 years were not significantly predicted by other QOL indicators from 2 years except psychological distress. Psychological distress at 8 years was negatively associated with mental and physical health at 2 years, in addition to the positive association with psychological distress at 2 years. QOL indicators at 2 years accounted for a substantial portion of variance in each of the QOL indicators at 8 years (25.4% ≤ $R^2$ ≤ 43.6%).

Demographics and early caregiving characteristics made additional contributions to predicting QOL at 8 years, although the variances accounted for were small (2.2% ≤ $\Delta R^2$ ≤ 6.5%). Among demographics, age was the only factor to significantly predict mental and physical health at 8 years: older caregivers reported better mental health and poorer physical health at 8 years. Among early caregiving experience characteristics, greater caregiving stress at 2 years significantly predicted greater psychological distress at 8 years. Greater caregiver esteem at 2 years, unexpectedly, predicted poorer physical health 6 years later.

Caregiving status at 8 years made an independent contribution to predicting QOL indicators at 8 years, above and beyond those effects of corresponding QOL indicators at 2 years, demographics, and early caregiving characteristics (0.8% ≤ $\Delta R^2$ ≤ 2.6%). Caregivers bereaved by the 8-year mark reported poorer mental health and greater psychological distress at 8 years, compared with caregivers who were no longer involved in caregiving as the care recipients were in remission. QOL at 8 years did not differ, however, between caregivers who were actively engaging in cancer caregiving to the index survivor and those whose care recipients were in remission.

Discussion

This study aimed to characterize the family cancer caregivers and their QOL at around 8 years after the relative’s initial diagnosis and to identify significant predictors of the caregivers’ longer-term QOL.

Faces of family members touched by cancer 8 years ago

The implications of cancer for the family members and close friends of the person with the disease, even many years after the diagnosis, have generally been underacknowledged. Eight years after the relative’s initial cancer diagnosis, approximately 90% of family caregivers became former caregivers. One-fourth of that number was due to bereavement. Just as cancer survivors are at risk for greater morbidity and mortality, coupled with aging, their family members’ QOL at the 8-year mark remains partially dependent on the survivors’ prognostic status by that time. Family members who either became bereaved or were actively engaging in cancer care to the index survivor at 8 years had worse mental health and greater psychological distress than those whose survivor was in remission.

We could characterize these three groups of family members that emerged by the 8-year post-diagnosis partly by distinct features assessed 6 years earlier. Female gender, feeling overwhelmed by cancer caregiving, having patients with more severe types of cancer, and having greater distress during the time of initial caregiving to the index patient were all related to a greater likelihood of being
bereaved 6 years later. On the other hand, family members
who were actively engaging in cancer care to the index
patient at 8 years were not distinguishable 6 years earlier
from those whose patients went into remission, except
for reporting greater levels of distress during the initial
caregiving period.

These findings support the notion that cancer caregiving
trajectories are diverse [31], as opposed to a uniformly
deteriorating pattern of illness that is often observed in
dementia caregiving. Family members of cancer patients
and survivors are in and out of the caregiving role
throughout the entire spectrum of the illness, with no
clear precursors that can help predict years ahead when
or whether they would be called into the caregiver role
again for the index patient. Along with evidence that
fear of recurrence and uncertainty are long-lasting ma-
jor concerns among cancer survivors and their family
members [9,32,33], our findings suggest that cancer
survivorship programs not only include family members
but also extend psychosocial services periodically to
them beyond the early survivorship phase.

Quality of life of family members 8 years after the initial
cancer diagnosis in the family

Bereaved or currently caregiving family members at the
8-year mark reported poorer mental health and greater
distress than family members of survivors who were in
remission, suggesting a psychological toll evoked by
the unexpected and undesirable event of the loss or con-
tinued cancer care. Psychological distress was highly
correlated with other aspects of QOL (mental health,
physical health, and spirituality) among all three groups
of caregivers at 8 years. The findings suggest that programs
that primarily target reducing psychological distress of
family members may yield improvement in their overall
QOL 8 years after the initial cancer diagnosis in the family.
Furthermore, our finding that psychological distress at
8 years was predicted by diverse QOL indicators at 2 years
suggests that integrative programs targeting multiple as-
pects of the QOL may be most effective in managing
long-term psychological distress. The long-lasting effect
of early caregiving stress on psychological distress on
average 6 years later should also be recognized.

Becoming a former caregiver due to the death of the
care recipient, as opposed to due to the care recipient
being in remission and no longer requiring cancer care,
was associated with poorer mental health and greater
psychological distress at the 8-year mark. In contrast,
becoming a current caregiver at 8 years was not signifi-
cantly related to any aspect of QOL studied, after being
accounted for by the caregivers’ demographic and early
caregiving characteristics. Our findings suggest that the
death of the care recipient is an additional stress to cancer
caregivers who are already depleted psychologically and
socially from carrying out the family caregiver role, which
supports the wear-and-tear model of caregiving [34–36], as
opposed to the death ceasing the caregiving stress that is
proposed by the stress-relief model of bereavement [37].

In addition to this theoretical implication, the finding
has critical implications for clinical practice. Although
one-third touched by cancer goes through bereavement
as the current long-term (>5 years) cancer survival rate
is 67% [2,4], the death of a relative with cancer 8 years
after the initial diagnosis accompanies major disturban-
ces in surviving family members’ well-being. Bereaved family
population is likely to increase as cancer survivors are at
greater risk for morbidity and mortality and as the cancer
survivors are aging, which will be markedly composed of
families touched by cancer. Investigating the factors that
will help the family members prepare effectively for the
death of the patient and implementing evidence-based
programs incorporating such factors will help improve
the QOL of those who are living for many years with
cancer in their family.

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 [38]. Second,
we examined only basic demographic and caregiving pre-
dictors of QOL, and the effect sizes observed were small
to modest. It may also be fruitful to investigate behavioral
e.g., cancer screening, healthy diet, and physical activity)
and physical (e.g., immune functioning, illness develop-
ment, and mortality) predictors of caregivers’ QOL during
longer-term survivorship and bereavement phases. Simi-
larly, future studies should also further investigate other
factors that may affect the caregiving experience, such as
the cancer survivors’ objective functional status during
the long-term survivorship, presence of other caregiving
help, use of support programs, and other major life events
that occurred during the study period that might equally
affect the family members’ QOL. Third, although we in-
vestigated common predictors among three different groups
of caregivers (whose recipients were in remission, deceased,
or in active care), unique predictors and outcomes for each
group of caregivers should be further investigated. Fourth,
previous or subsequent cancer caregiving experience to
other relatives with cancer, changes in perception about
cancer caregiving, and their influence on longer-term QOL
of the family caregivers over many years should be
systematically examined in future studies. Finally, the
generalizability of the current findings is limited to family
members who are Caucasian, relatively educated and affluent,
and were willing to participate in the study. It will also 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 family members, who became bereaved by 8 years after the initial cancer diagnosis in the family, suffer from poorer mental health and greater psychological distress years after the loss. The finding that the corresponding aspect of QOL assessed at 2 years after the relative’s diagnosis played a substantial role in predicting the same aspect of QOL 6 years later highlights the needs for addressing poorer QOL of subgroups of caregivers during the early phase of survivorship, which may help in preventing chronically impaired QOL.

Findings have theoretical implications for better understanding bereavement to cancer and practical implications for developing integrative programs whereby family members in the various phases of caregivership will benefit by improving their QOL.

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