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## Psychosocial Adjustment of Family Caregivers of Head and Neck Cancer Survivors

**Stephanie Ross,**

Department of Psychiatry and Behavioral Sciences, Northwestern University Feinberg School of Medicine, Abbott Hall, Suite 1205, 710 North Lake Shore Drive, Chicago, IL 60611

**Catherine E. Mosher,**

Department of Psychiatry and Behavioral Sciences, Memorial Sloan-Kettering Cancer Center, 641 Lexington Avenue, 7<sup>th</sup> Floor, New York, NY 10022

**Victor Ronis-Tobin,**

Department of Psychiatry and Behavioral Sciences, Memorial Sloan-Kettering Cancer Center, 641 Lexington Avenue, 7<sup>th</sup> Floor, New York, NY 10022

**Sandy Hermele,** and

Psychological Centers, Inc., Center for Integrated Behavioral-Medical Health Care, 765 Allens Avenue, Providence, RI 02905

**Jamie S. Ostroff**

Department of Psychiatry and Behavioral Sciences, Memorial Sloan-Kettering Cancer Center, 641 Lexington Avenue, 7<sup>th</sup> Floor, New York, NY 10022

### Abstract

**Purpose**—This study examined the psychosocial adjustment and needs of family caregivers of head and neck cancer survivors at 6–24 months post-treatment.

**Methods**—Family caregivers of head and neck cancer survivors ( $N = 89$ ) completed mailed questionnaires that assessed demographic variables, mental health, quality of life, and practical and informational needs.

**Results**—Thirty-eight percent of caregivers reported moderate to high distress. However, quality of life scores for the entire sample ( $N = 89$ ) were better than the scores reported in initial validation studies on caregivers of patients undergoing active cancer treatment. Greater time spent caregiving was associated with worse psychological well-being, but also more positive adaptation to caregiving. In addition, 39% of caregivers reported that all of their practical and informational needs were being met.

**Conclusions**—Findings suggest that research and clinical efforts are needed to address the psychosocial concerns of this population.

### Keywords

head and neck cancer survivors; quality of life; distress; family caregivers

## Introduction

In recent years clinicians and researchers have focused increased attention on the impact of cancer on the entire family [6, 21]. Given the proliferation of outpatient care and the decline in health care resources, family caregivers have been increasingly called upon to conduct many tasks previously performed by health care providers. Family caregivers include those who assist ill loved ones with self-care, financial management, and medical care tasks as well as those who provide informational and emotional support [28]. Many family caregivers face multiple stressors including disruptions in daily household routines, financial and emotional strain, family role changes, occupational strain, and personal physical limitations [5, 12]. Spouses and other family members must contend with their own, as well as the patient's, support needs [37].

Although numerous studies have investigated the impact of positive family support on cancer patients' quality of life and psychological distress [26, 27, 33], far fewer studies have specifically focused on caregivers' quality of life [21]. Family caregivers have reported increases in psychological distress and reductions in quality of life outcomes that are often comparable to or more pronounced than those reported by cancer patients themselves [5, 15]. In general, 20% to 30% of cancer patients' family caregivers report clinically significant distress [36], and, with few exceptions [30, 45], there are significant associations between patients' and family members' psychological adjustment [7, 31, 32].

Demographic and psychosocial factors associated with family caregivers' distress during the acute cancer survivorship phase (i.e., up to 2 years post-diagnosis) have been identified. Younger age [13], female gender [16], and lower socioeconomic status [29] have been associated with greater distress among caregivers. Gender has been found to interact with family role (spouse or offspring), such that adult daughters report the most cancer caregiving stress, whereas sons report the least stress [19]. In addition, lack of social support and caregiving burden have predicted distress [6, 20, 28]. National surveys indicate that levels of caregiving burden and emotional and physical strain among cancer patients' caregivers are equivalent to those reported by caregivers of dementia patients [22]. Finally, unmet needs for instrumental and emotional support have been correlated with increased emotional strain among caregivers of older adults [11, 25].

To date, very few studies have examined the needs and psychological adjustment of family caregivers of head and neck cancer patients, particularly during the post-treatment phase of the illness trajectory. Among spouses of patients treated for head and neck cancer, prior research has found that 20% report high distress and disruptions in daily schedule [41]. In another study, partners reported greater anxiety than patients following treatment for head and neck cancer [42]. Finally, 44% of German family caregivers of head and neck cancer patients expressed a need for personal psychosocial support [4].

Although the incidence of head and neck cancers is relatively rare, these cancers and their treatment are associated with complex psychosocial issues [4, 41] and often result in numerous debilitating functional impairments, including facial disfigurement and problems in speaking, swallowing, and eating that may require the assistance of family members [3, 14]. Tobacco and alcohol use are the primary etiologic factors for head and neck cancer [1, 38], and those who continue tobacco and alcohol use are at highest risk for treatment complications, second primary cancers, disease recurrence, and death [8, 10]. "Blaming" responses, particularly when the patient persists in alcohol or tobacco use, and caregiving demands associated with the disease and its treatment may negatively affect family functioning.

The current study was designed to expand upon prior psychosocial investigations of family caregivers of head and neck cancer patients through the use of multiple, standardized assessment tools and a relatively large sample size. In addition, the current study provides initial data regarding the unmet practical and informational needs of family caregivers in the acute phase of cancer survivorship. The aims of the study are: 1) to examine the extent to which family caregivers of head and neck cancer survivors report psychosocial impairment and unmet needs; and 2) to examine the extent to which demographic variables (e.g., age, gender, education), time spent caregiving, and unmet needs are associated with family caregivers' psychosocial outcomes. We hypothesized that a significant minority of family caregivers would report psychosocial impairment and unmet needs. Based on prior research [13, 16, 21, 29], we also hypothesized that greater psychosocial impairment would be associated with greater unmet needs, shorter time since diagnosis, younger age, female gender, and less income and education.

## Patients and Methods

### Participants and Procedures

Participants were family caregivers of adult survivors who were diagnosed and had completed treatment for nonmetastatic, upper aerodigestive tract malignancies within 6–24 months prior to the assessment. Study procedures were approved by the Memorial Sloan-Kettering Cancer Center institutional review board. Head and neck cancer survivors identified and provided permission to contact family caregivers. A research assistant then contacted family caregivers by phone to explain the study and seek their permission to mail consent forms and quality of life surveys to them. Family caregivers who did not return completed surveys in a timely fashion were contacted by telephone up to three times to encourage their participation.

### Measures

**Quality of life**—Participants completed the 35-item Caregiver Quality of Life Index-Cancer (CQOLC) [43], a valid and reliable measure of perceived life quality that has been widely used with family caregivers of cancer patients. The CQOLC yields a total score as well as four subscale scores that assess caregiving burden, disruptiveness, positive adaptation, and financial concerns. Items are rated on a 5-point scale from 0 (*not at all*) to 4 (*very much*). The CQOLC has a maximum score of 140, with higher scores indicating better quality of life [43].

**Mental health**—The 38-item Mental Health Inventory (MHI) [40] was used to assess global mental health. The MHI includes Psychological Distress and Positive Psychological Well-being subscales and has excellent reliability and validity [40]. Participants were instructed to indicate how they have been feeling during the past month on 5-point or 6-point Likert scales.

**Practical and informational needs**—The Family Inventory of Needs (FIN) [24] was used to assess the practical and informational needs of caregivers and whether their needs were currently being met. Participants rated the importance of 20 practical and informational needs on an 11-point scale ranging from 0 (*not at all important*) to 10 (*very important*) and classified each need as currently met or unmet. This measure has adequate validity and reliability for use in research and clinical settings [24].

### Statistical Analyses

Data were analyzed with SPSS statistical software (version 15.0; SPSS Inc., Chicago, IL). Descriptive statistics were used to characterize the demographic and psychosocial

characteristics of the study sample. T-tests were used to compare quality of life, Psychological Distress, and Psychological Well-being scores in the present research to those of the standardization samples [40, 43]. Finally, Pearson correlations were computed to examine associations between demographic variables, percentage of caregiver's needs that were met, hours of caregiving per week, quality of life, and mental health.

## Results

### Sample Characteristics

Eighty-nine head and neck cancer survivors identified 174 family caregivers. All of the family caregivers received an explanation of the study by phone and agreed to receive a consent form and quality of life surveys via postal mail. A total of 102 caregivers (59%) consented to participate and returned the surveys. Thus, 81 of 89 survivors (91%) had family caregivers who provided informed consent and survey responses. Although the majority of caregivers who did not return the surveys did not provide reasons for their refusal, a small minority of caregivers cited reasons for nonparticipation, including unstable health, conflicting obligations, and not wanting to be reminded of the illness and treatment.

Eighty-nine family caregivers (65 female, 24 male) completed the quality of life questionnaires. Data from 13 caregivers were not included in the present analyses due to missing values. Demographic characteristics of the sample appear in Table 1. Participants were primarily female (73.0%), Caucasian (87.6%), married or partnered (89.9%), and spouses or partners of the survivors (80.9%). Other caregivers were adult offspring (12.4%) or siblings (6.7%) of the survivors. Age ranged from 33 to 85 years with a mean of 55 years. The majority of participants were employed (55%) and had a college degree (56.2%), and 45% reported annual household incomes greater than \$90,000 per year. At the time of data collection, an average of 19 months ( $SD = 6.39$ ) had elapsed since the patient's head and neck cancer diagnosis. Forty-four percent of family caregiver participants reported spending 0 hours per week engaged in caregiving activities for their family member with head and neck cancer. Among participants who spent one or more hours per week in the past month engaged in caregiving tasks ( $N = 36$ ), their average hours of caregiving per week was 16 ( $SD = 15$ ).

**Descriptive Statistics**—Means, standard deviations, and alphas for measures of quality of life and mental health appear in Table 2. Total quality of life scores were higher than those reported for family caregivers of patients undergoing active cancer treatment in the Weitzner et al. initial validation study (CQOLC;  $M = 96.2$ ,  $SD = 21.7$ ;  $t(348) = 3.36$ ,  $p < .001$ ) [44]. On the other hand, Psychological Distress scores were higher than those of the general population in the Veit and Ware initial validation study,  $t(5175) = 2.46$ ,  $p < .05$ , and Psychological Well-Being scores were lower than those of the general population,  $t(5175) = 2.28$ ,  $p < .05$  [40]. When comparing participants' Psychological Distress scores to population norms from the initial validation study, 18.2% of scores fell in the Low Distress range, 21.6% of scores were in the Moderate Distress range, and 15.9% were in the High Distress range [40].

Table 3 displays means and standard deviations for the perceived importance of 20 practical and informational needs and the percentage of caregivers who indicated that each need was met. Caregivers' mean rating of the perceived importance of each need was 9.3 on a 10-point scale ( $SD = 1.7$ ). Thirty-nine percent of caregivers reported that all of their practical and informational needs were being met, and the majority of caregivers (67% to 88%) classified each need as met. Information regarding available services and the family members' medical symptoms was the most frequently reported unmet need, whereas the

receipt of honest answers to questions and assurance that their family member was receiving the best possible care were the most frequently met needs.

**Intercorrelations among Study Variables**—Correlations were computed between demographic variables (i.e., caregiver gender, age, education, income, caregiver role, and time since the family member's cancer diagnosis), percentage of caregiver's needs that were met, hours of caregiving activities per week, and study outcomes (i.e., quality of life and mental health). Older age was associated with greater hours of caregiving per week ( $r = .34$ ,  $p < .01$ ), whereas greater income (i.e., \$50,000 or higher per year) was associated with fewer hours of caregiving ( $r = -.33$ ,  $p < .01$ ). Better perceptions of financial well-being were related to greater income ( $r = .23$ ,  $p < .05$ ) and having a college or graduate degree ( $r = .22$ ,  $p < .05$ ). Spouses and partners reported worse financial well-being than other caregivers ( $r = -.26$ ,  $p < .05$ ). Contrary to hypotheses, gender, time since the family member's cancer diagnosis, and the percentage of caregivers' met needs were not significantly correlated with caregiver quality of life or mental health.

Hours of caregiving per week showed mixed associations with study outcomes. Greater hours of caregiving per week were associated with less perceived disruptiveness of the caregiving ( $r = -.45$ ,  $p < .001$ ) and greater positive adaptation to caregiving ( $r = .24$ ,  $p < .05$ ). However, hours spent caregiving were negatively correlated with overall mental well-being ( $r = -.31$ ,  $p < .01$ ) and positive psychological well-being ( $r = -.27$ ,  $p < .05$ ). None of the other correlations were statistically significant.

## Discussion

This study is one of the first investigations to use standardized assessment tools to examine the post-treatment quality of life of family caregivers of head and neck cancer survivors. Our sample reported higher levels of psychological distress and lower levels of psychological well-being than the general population [40]. In addition, 37.5% of our sample reported moderate to high distress on the MHI [40], which suggests that the acute (re-entry) survivorship period may pose psychosocial challenges for a significant minority of caregivers. In addition, only 39% of participants reported that all of their practical and informational needs were being met. Although unmet care needs have been associated with negative psychological outcomes among caregivers [11, 25], the proportion of met needs was not associated with caregivers' quality of life or psychological adjustment in this study. The restricted range of responses to the inventory of needs may have contributed to the current findings. In addition, this inventory does not focus on personal needs for assistance with emotional or relational concerns.

Although many caregivers reported elevated distress and unmet needs, their post-treatment quality of life was higher than that reported for caregivers of cancer patients undergoing active treatment [44]. This finding is not surprising because this measure specifically evaluates the impact of caregiving on a number of quality of life dimensions (e.g., finances, engagement in activities, relationships) [43], and 44% of participants were not providing care at the time of assessment. The extent to which demographic factors were associated with family caregivers' quality of life and mental health was assessed. In contrast to our predictions and the general cancer caregiving literature in which younger age [13], female gender [16], and lower socioeconomic status [29] are risk factors for distress, these variables generally were not associated with quality of life or mental health in the current study. The limited demographic variability may partially explain the present findings. Also contrary to our hypothesis, time since diagnosis was not associated with quality of life or mental health. Exceptions to this pattern of findings included positive relationships between education, income, and financial well-being. In addition, spouses and partners reported worse financial

well-being than other caregivers. Further research is needed to examine relationships between demographic factors and post-treatment quality of life outcomes among caregivers of lower socioeconomic status.

Although few associations emerged between caregiver characteristics and psychosocial outcomes, hours of caregiving per week were correlated with both demographic and psychosocial factors. Specifically, older age and lower annual income level (< \$50,000) were associated with greater hours of caregiving per week. In addition, greater hours spent caregiving were associated with worse psychological well-being. However, greater hours spent caregiving also were correlated with more positive adaptation to caregiving and less perceived disruptiveness of the caregiving. The present results parallel previous research that found both positive and negative consequences of caring for a family member with chronic illness [2, 23]. Although devoting greater time to caregiving may have negative emotional, social, and financial effects, caregivers have also reported intrinsic rewards from caregiving [2, 23]. Taken together, these findings support a multidimensional model of adjustment to caregiving in which positive and negative adaptational outcomes may occur either simultaneously or sequentially for the same caregiver [35].

Limitations of the current findings and directions for future research warrant discussion. First, participants were primarily White and well educated women, and, thus, further research is needed to document the adjustment of male caregivers and those with greater ethnic and socioeconomic diversity. Second, although the 59% response rate is comparable to that recommended by survey experts as acceptable for the general population [9, 39], respondents may have differed in important ways from nonrespondents. For example, the most distressed individuals may have been more likely to refuse participation, as observed in prior psychological research [18]. Third, the present study relied on self-report measures and examined a restricted range of potential correlates of psychosocial adjustment outcomes. For example, the extent to which perceived cancer-related stigma, illness-related attributions (e.g., blame), health behaviors (e.g., smoking, alcohol use), and coping efforts are associated with caregivers' quality of life requires study. Finally, the cross-sectional design precluded assessment of causal relations among variables and, thus, further work is needed to establish predictors of caregivers' adjustment.

Despite limitations, findings carry implications for future research and clinical practice. Results suggest that time spent caregiving may have significant positive and negative psychosocial consequences for family caregivers that should be jointly considered when developing future research studies and assessment tools for this population. In addition, findings suggest that a sizable proportion of family caregivers experience elevated distress during the acute survivorship phase of head and neck cancer, and, thus, research and clinical efforts should be made to identify and provide greater support for caregivers with significant psychosocial needs. Such efforts may result in improved quality of life for both patients and caregivers [17].

Research is required to identify whether there are any barriers to the use of psychosocial support services among caregivers of head and neck cancer survivors and to develop and evaluate psychosocial interventions that are tailored to the needs of this population [21, 34]. Although few research-based psychosocial interventions have been developed for cancer survivors' caregivers [21], a recent Institute of Medicine (IOM) [17] report concluded that a range of services, including counseling, pharmacotherapy, and educational interventions, are widely available to cancer survivors and their family members. However, the reduced access to mental health care among individuals with low socioeconomic status, ethnic minorities, and those with low health literacy also was noted. The IOM committee further concluded that it is the responsibility of every health care provider to monitor caregivers' distress and

refer them to appropriate services. A multidisciplinary approach is often needed to address caregivers' practical concerns (e.g., financial or transportation difficulties), health maintenance, and psychosocial needs. Given the complex psychosocial issues related to the etiology and potentially severe side effects of head and neck cancer and its treatment, determining how best to meet caregivers' needs should be a high priority for future research and clinical care.

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**Table 1**

## Sample Characteristics

Characteristic	No. of caregivers (N = 89)	%
<i>Caregiver Role</i>		
Spouse/Partner	72	80.9
Adult offspring	11	12.4
Sibling	6	6.7
<i>Gender</i>		
Male	24	27.0
Female	65	73.0
<i>Ethnicity</i>		
Caucasian	78	87.6
African American	4	4.5
Asian	5	5.6
Other	2	2.2
<i>Age</i>		
Mean	54.77	
SD	11.63	
Range	33–85	
<i>Education</i>		
Partial high school	2	2.2
High school graduate	21	23.6
Partial college	16	18.0
College graduate or higher	50	56.2
<i>Annual Household Income</i>		
Below \$30,000	4	4.5
\$30,000–\$49,999	11	12.4
\$50,000–\$89,999	25	28.1
\$90,000 or higher	40	44.9
Not reported	9	10.1
<i>Occupational Status</i>		
Employed	49	55.1
Homemaker	15	16.9
Retired	21	23.6
Unemployed	1	1.1
Not reported	3	3.4
<i>Marital Status</i>		
Single	6	6.7
Married or marriage equivalent	80	89.9
Divorced or separated	2	2.2
Widowed	1	1.1

Note. SD = standard deviation.

**Table 2**

Descriptive Statistics for Study Variables

Variable	n	Mean	SD	$\alpha$	General Population Mean (N = 5,089)	General Population SD
MHI: Total	88	177.2	35.7	.91	177.6	25.5
MHI: Positive Psychological Well-Being	88	56.2	14.6	.93	59.2	12.2
MHI: Psychological Distress	88	51.6	19.3	.84	47.5	15.4
Caregiver QOL: Total	83	105.3	21.0	.91		
Caregiver QOL: Burden	89	25.9	9.2	.90		
Caregiver QOL: Disruptiveness	88	23.4	5.2	.85		
Caregiver QOL: Positive adaptation	89	16.8	6.1	.75		
Caregiver QOL: Financial	87	9.3	3.4	.86		

Note: SD = standard deviation; QOL = quality of life; MHI = Mental Health Inventory.

**Table 3**

Descriptive Statistics for the Family Inventory of Needs

Item I need to:	Met	Unmet	Not Reported	Mean Importance Rating
Be assured that the best possible care is being given to my family member	79 (88.8%)	2 (2.2%)	8 (9.0%)	9.87 (0.75)
Have my questions answered honestly	78 (87.6%)	1 (1.1%)	10 (11.2%)	9.73 (0.88)
Have explanations given in terms that are understandable	77 (86.5%)	1 (1.1%)	11 (12.4%)	9.61 (1.27)
Be informed of changes in my family member's condition	77 (86.5%)	1 (1.1%)	11 (12.4%)	9.46 (1.76)
Know what treatment my family member is receiving	76 (85.4%)	2 (2.2%)	11 (12.4%)	9.35 (1.97)
Feel that the professionals care about the patients	76 (85.4%)	4 (4.5%)	9 (10.1%)	9.46 (1.04)
Know exactly what is being done to my family member	75 (84.3%)	3 (3.4%)	11 (12.4%)	9.34 (1.74)
Know the names of the health professionals involved in my family member's care	73 (82.0%)	4 (4.5%)	12 (13.5%)	8.98 (2.37)
Feel there is hope	73 (82.0%)	6 (6.7%)	10 (11.2%)	9.62 (1.41)
Know why things are done for my family member	72 (80.9%)	3 (3.4%)	14 (15.7%)	9.40 (1.59)
Have someone be concerned with my family member's health	72 (80.9%)	4 (4.5%)	13 (14.6%)	8.95 (2.37)
Know specific facts concerning my family member's prognosis	72 (80.9%)	6 (6.7%)	11 (12.4%)	9.59 (1.18)
Help with my family member's care	70 (78.7%)	3 (3.4%)	16 (18.0%)	8.72 (2.70)
Feel accepted by the health professionals	70 (78.7%)	4 (4.5%)	15 (16.9%)	8.36 (2.81)
Be told about changes in treatment plans while they are being made	69 (77.5%)	1 (1.1%)	19 (21.3%)	9.25 (2.12)
Have information about what to do for my family member at home	68 (76.4%)	6 (6.7%)	15 (16.9%)	9.03 (2.33)
Know what symptoms the treatment or disease can cause	65 (73.0%)	9 (10.1%)	15 (16.9%)	9.25 (1.88)
Know the probable outcome of my family member's illness	65 (73.0%)	11 (12.4%)	13 (14.6%)	9.48 (1.21)
Know when to expect symptoms to occur	62 (69.7%)	12 (13.5%)	15 (16.9%)	9.18 (1.70)
Be told about people who could help with problems	60 (67.4%)	11 (12.4%)	18 (20.2%)	8.58 (2.46)

Note: Standard deviations are in parentheses.