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### Title

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### Permalink

<https://escholarship.org/uc/item/5b96b7fj>

### Journal

Supportive Care in Cancer, 22(12)

### ISSN

0941-4355

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### Publication Date

2014-12-01

### DOI

10.1007/s00520-014-2380-3

Peer reviewed



# HHS Public Access

Author manuscript

*Support Care Cancer*. Author manuscript; available in PMC 2015 December 01.

Published in final edited form as:

*Support Care Cancer*. 2014 December ; 22(12): 3331–3340. doi:10.1007/s00520-014-2380-3.

## Distress among caregivers of phase I trial participants: a cross-sectional study

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**Conflict of interest:** There are no further conflicts of interest to disclose. The authors have full control of all primary data, which is available for review.

## Abstract

**Purpose**—The number of patients with cancer enrolling in phase I trials is expected to increase as these trials incorporate patient selection and exhibit greater efficacy in the era of targeted therapies. Despite the fact that people with advanced cancer often require a caregiver, little is known about the experience of caregivers of people enrolling in oncology phase I clinical trials. We conducted a cross-sectional study assessing the distress and emotion regulation of caregivers of phase I trial participants to inform the design of future interventions targeting the unique needs of this population.

**Methods**—Caregivers of oncology patients were approached at the patient’s phase I clinical trial screening visit. Caregiver participants completed a one-time survey incorporating validated instruments to comprehensively assess distress and emotion regulation. Basic demographic information about both the caregiver and patient was collected.

**Results**—Caregivers exhibited greater distress than population norms. Emotion regulation was also moderately impaired. Respondents identified positive aspects of caregiving despite exhibiting moderate distress.

**Conclusion**—Enrollment of a patient in a phase I clinical trial is a time of stress for their caregivers. This pilot study demonstrates the feasibility of engaging caregivers of phase I trial participants and the need to better support them through this component of their caregiving experience.

## Keywords

Phase I; Caregiver; Distress; Clinical trial

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## Introduction

When an individual is diagnosed with cancer, family members, friends, and loved ones often assume new roles as caregivers, providing a broad range of unpaid assistance [1]. Caregivers are defined as family members or close friends who are identified by the patient as helping with emotional support; physical care; and management of medications, appointment schedules, or finances. The caregiver role requires physical strength and the cognitive capacity to navigate the complex cancer care process [2, 3]. Unfortunately, caregivers often sacrifice their own needs [4, 5], putting themselves at risk for increased burden and potential psychosocial detriment [6, 7]. The psychological toll on the caregiver may exceed that of the patient [8–12]. There is a need for further research detailing the cancer caregiver experience in order to offer improved support, yet there are few studies of the caregiving experience beyond initial cancer diagnosis or late palliative stage [13].

Patients enrolled in phase I oncology trials are fit enough to undergo cancer therapies but have exhausted approved treatments for their disease or have a diagnosis that lacks a standardized treatment approach. Thus, these patients may have undergone a number of treatment regimens, familiarizing them and their caregivers with the process of oncologic care. The decision to enroll in a phase I trial is paralleled with the realization that no further standard therapy is available. Although there has been considerable interest in the ethics of

consenting patients for phase I trials and in patient expectations for a treatment with unknown therapeutic benefit [14–16], there are no data on how phase I trial participation affects the caregiving experience [15, 17, 18]. Anecdotal experience suggests that caregivers of these patients experience increased stress prior to phase I trial enrollment. Phase I trial patients are less likely to seek support from palliative care, counselors, or home health providers; the caregiver may thus be called upon to fill all of these roles [19]. Additional unique stressors of phase I trial participation include the need for frequent, even weekly, clinic visits and monitoring while on trial and the occurrence of multiple stressful sentinel events such as the initial evaluation to determine if the patient fulfills enrollment criteria, anticipation of drug-related toxicities, awaiting imaging results, enrollment in future trials, or enrollment in hospice as disease progresses. This is a unique population of oncology caregivers; the nature of their experience in this role has not been previously evaluated or defined.

We conducted a cross-sectional study of the caregivers of phase I trial participants at the University of Colorado Cancer Center that assessed the distress experienced by caregivers as well as the emotional regulation strategies employed [20, 21]. These results inform future approaches to address the unique needs of this population.

## Methods

### Study population

Caregivers were recruited from the adult Phase I Clinic at the National Cancer Institute-designated University of Colorado Comprehensive Cancer Center. An eligible caregiver was broadly defined as any individual identified by the phase I trial patient as being involved with their care, for example, helping with emotional support; physical care; and management of medications, appointment schedules, or finances. For the purposes of this study, caregivers included family members or close friends and excluded professional health care providers. Inclusion criteria encompassed persons able to read and understand English, between 18 and 89 years of age, and able to complete the study instruments independently.

### Procedures

This was a single-institution, cross-sectional pilot study of caregivers of adult phase I oncology patients. Study participants were asked to complete an anonymous one-time self-administered paper survey composed of validated instruments measuring caregiver distress and experiences, emotion regulation and coping, and physical and mental health-related quality of life. The survey included questions pertaining to demographics of both the caregiver and patient, as well as questions about the nature of the caregiving relationship. Eligible candidates were approached at the patient's phase I study screening visit; the survey was completed between the course 1, day 1, and day 15 visits. Participants returned completed surveys to a secure repository within the clinic. The Colorado Multiple Institutional Review Board approved the study.

## Instruments

**Caregiver distress**—Caregiver distress was assessed using the *Perceived Stress Scale* (PSS), the *Positive and Negative Affect Scale* (PANAS), the *State-Trait Anxiety Inventory* (STAI), and the *Center for Epidemiologic Studies Depression Scale* (CES-D). The PSS, a 14-item questionnaire with extensive population norms, measures the degree to which respondents feel their lives have been unpredictable, uncontrollable, and overwhelming over the prior month. Participants ranked these feelings on a 5-point Likert scale, with a higher score indicating greater stress [22, 23]. The PANAS [24] was used as a self-reported measurement of mood with the positive affect portion of the scale reflecting energy and enthusiasm and the negative portion reflecting fear and guilt. A higher score indicates a greater reflection of the affect in question. The STAI, a 40-item tool, asks participants to rate how they feel “right now” (state) and “in general” (trait) on a 4-point Likert scale with higher scores reflecting higher anxiety [25]. The CES-D, which was used to document depressive symptoms, is a 20-item scale scored from 0 to 60 [26], with a score above 16 reflecting significant depressive symptomatology.

The caregiver experience was measured by the *Caregiver Reaction Assessment* (CRA) and *Benefit Finding Scale* (BFS). The CRA assesses the burden of caregiving and evaluates the caregiving experience. Caregivers rank the domains of self-esteem, family support, finances, schedule, and health [27] in this 24-item questionnaire, which is scored on a 5-point Likert scale [28]. Higher scores indicate a more negative experience. The BFS, a 17-item scale in which caregivers rank items on a 5-point Likert scale, assesses the degree to which caregivers find meaning in their experience [29].

**Caregiver emotion regulation and coping**—Emotional regulation was assessed via the *Emotion Regulation Questionnaire* (ERQ) and the *Difficulties in Emotion Regulation Scale* (DERS). The ERQ is a 10-item questionnaire in which reappraisal and suppression are rated on a 7-point scale to capture individual differences in these two emotional regulation processes, thus carrying implications for affect, relationships, and well-being [21]. Higher scores indicate an increased likelihood to adopt the strategy in question such as suppression or reappraisal. The DERS assesses emotion regulation and dys-regulation [30]. This scale measures emotional awareness, emotional clarity, acceptance of negative emotions, strategy, control of impulsive behaviors, and the ability to fulfill goals even under the influence of negative emotions. Higher scores indicate greater difficulty with emotional regulation.

Coping and support were assessed via the *Positive Aspects of Caregiving* (PAC), *ENRICHD Social Support Inventory* (ESSI), and *Brief COPE Inventory*. The PAC includes nine items which address the caregiver’s affective state in relation to caregiving as ranked on a 5-point Likert scale [31]. A higher score correlates with a more positive assessment of caregiving. The ESSI is a short social support measure [32] with seven items that address the availability of support; a higher score indicates greater social support. The Brief COPE Inventory [33] is a shortened version of the COPE inventory in which respondents indicate how often they use a particular coping strategy under stress as ranked on a 4-point scale.

**Health-related quality of life**—Health-related quality of life was assessed using the 36-item *SF-36 health survey version 1.0*, documenting the extent of limitations in a number of domains [34–36]. Higher scores on the SF-36 indicate better physical and mental health-related quality of life.

Demographic data about both caregivers and patients were obtained. Caregivers were asked their age, sex, education level, income level, marital status, current living situation, and employment status. Questions also pertained to caregiving such as amount of time spent as a caregiver, whether the caregiver lived with the patient prior to illness, prior caregiving experience, and concurrent caregiving for a child. Patient-related information included the following: cancer subtype, age, sex, marital status, living situation, education history, and income.

### Statistical analysis

Descriptive statistics summarized the characteristics of the study population. Kendall's Tau correlation coefficients were computed to quantify the associations between caregiver distress, emotion regulation and support, and health-related quality of life. Additional analyses were performed comparing responses to these scales to caregiver demographics. The cutoff to identify strong associations was a common variance greater than or equal to 5 % ( $r^2 \geq 0.05$ ). Standardized differences between the SF-36 subscale scores and the US population age and gender SF-36 norms were evaluated as effect sizes or z scores. Effect sizes (z) between 0.2 and 0.5 indicate small to moderate effects and effect sizes larger than 0.5 indicating moderate to large effects. The data were analyzed using SAS version 9.3.

## Results

A total of 88 of 110 identified (80 %) eligible caregivers completed the survey (mean age=56.5 years, SD=11.8; 62.4 % female). As depicted in Table 1, most (78 %) were spouses or significant others, lived with the patient (85 %), and spent 50 or more hours per week in caring (72 %). The majority had previous caregiver experience (77 %) with most having provided care for the patient for 1–5 years (57 %). Many caregivers (42 %) were employed full-time; 24 % were retired. Thirty-nine percent of patients had received their cancer diagnosis less than 2 years previously; 17 % had a diagnosis of cancer for more than 5 years. Gastrointestinal, lung, and ovarian cancers were the most common diagnoses.

Data for the outcome measures, along with reference data when available, are depicted in Tables 2 and 3.

### Caregiver distress and experience

Perceived stress [Perceived Stress Scale (PSS) mean 23.5, SD 8.4] and anxiety [State-Trait Anxiety Inventory (STAI)—trait mean 37.8, SD 10.4] were elevated relative to population norms (Table 2) [22, 25]. The mean Center for Epidemiologic Studies Depression Scale (CESD) score was 13.6 (SD 9.6). Scores above 16 indicate depression; 38 % of the study participants exceeded this threshold. Caregivers reported higher positive (mean 34.5, SD 7.1) than negative affect (mean 21.5, SD 7.8) on the PANAS. Caregiver Reaction Assessment (CRA) scores indicated moderate distress (CRA total mean 9.97, SD 2.56).

Caregivers identified Positive Aspects of Caregiving (Benefit Finding Scale (BFS) mean 3.7, SD 0.7; Positive Aspects of Caregiving (PAC) mean 36.2, SD 6.7).

### Emotion regulation and coping

Respondents had neutral Emotion Regulation Questionnaire (ERQ) scores (means 3.6–5.0), suggesting that participants were not significantly engaging in cognitive reappraisal (Table 3). Difficulties in Emotion Regulation Scale (DERS) scores indicated moderate difficulties (total mean 70.4, SD 14.9). Caregivers reported adequate perceived social support (ENRICH Social Support Inventory (ESSI) mean 33.1, SD 6.5). Brief COPE Inventory scores were highest for the use of the coping strategies of acceptance (mean 6.5, SD 1.3) and use of emotional support (mean 5.8, SD 1.5) and lowest for behavioral disengagement (mean 2.3, SD 0.7) and substance use (mean 2.4, SD 0.8).

### Health-related quality of life

The majority of caregivers (72 %) rated their health as excellent or very good; 8 % rated their health as fair or poor. The SF-36 scores for caregivers are compared against population norms in Fig. 1. The mental component mean scores were lower than those of the population norms (emotional well-being  $z=-0.37$ , role limitations due to emotional health  $z=-0.48$ , social functioning  $z=-0.28$ ). Study participants scored higher than population norms on three of the four physical component mean scores (physical functioning  $z=0.31$ , pain  $z=0.36$ , general health  $z=0.40$ ). Study participants thus demonstrated preserved physical functioning-related quality of life in spite of elevated behavioral distress.

### Correlational analyses

The PSS, CRA, CESD, and SF-36 were each correlated with caregiver demographic characteristics. The subscales of the SF36 were correlated with the subscales of the CRA and with the PSS. While there was no correlation between time spent caregiving per week and the outcomes of interest, there were a number of significant associations between caregiver characteristics and caregiver experience. Previous caregiving experience and years as a caregiver were associated with greater impact of caregiving on health (CRA impact on health  $r -0.29$ ), and the number of years spent as a caregiver correlated with lower health status (SF-health change  $r -0.28$ ).

Caregivers who reported higher perceived stress on the PSS were younger ( $r -0.25$ ) and were more likely to have a child in the household ( $r -0.25$ ). Being unmarried was associated with a greater impact on finances (CRA impact on finances  $r 0.27$ ). Older caregivers had lower physical function scores (SF physical function  $r -0.25$ ) and reported higher emotional well-being (SF-emotional well-being  $r 0.24$ ).

There were also significant associations between health-related quality of life, caregiver burden, and perceived stress. Lower caregiver burden (CRA total) was associated with better general health (SF-general health  $r -0.22$ ), social function (SF-social function  $r -0.29$ ), energy (SF-energy/fatigue  $r -0.24$ ), and health change (SF-health change  $r -0.25$ ). Lower caregiver perceived stress (PSS total) was associated with better general health (SF-general health  $r 0.24$ ) and emotional well-being (SF-emotional well-being  $r -0.50$ ), better social



function (SF-social function  $r = -0.39$ ), less impact on energy/ fatigue (SF-energy/fatigue  $r = 0.41$ ), and less role limitations due to emotional problems (SF-role limitations due to emotional problems  $r = -0.38$ ).

## Discussion

The most striking findings from this cross-sectional pilot study are the high levels of distress and anxiety and the high prevalence of depressive symptoms among caregivers of phase I clinical trial participants. These data confirm the necessity of effective approaches tailored to the unique needs of this population. In addition, this pilot study demonstrated feasibility of engaging caregivers of phase I clinical trial participants in research, as demonstrated by the high response rate (80 %) and comprehensiveness of data collection.

Notably, this study included a broad spectrum of instruments that assessed the mental and physical health experiences of this caregiver population. Other caregiver studies include measures of general health and health-related quality of life metrics such as the SF36, but do not include such a comprehensive assessment allowing for broader understanding of the impact of phase I study enrollment on the caregiver. A significant proportion (38 %) of caregivers in this study scored above the threshold for depressive symptomatology on the CES-D (>16). In other studies of cancer caregivers, depressive symptoms have been identified; the caregivers in this study exceeded previously described prevalence of such symptoms. In a study of spouses of lung cancer patients [37], the mean score on the CES-D was 11.3 (SD 9.1) with 30 % scoring above 16. Two other studies of cancer caregivers found that the mean CES-D score was approximately 3 points lower than in our population and that approximately 25 % scored >16 [38, 39]. The relatively low SF-36 mental health scores among study participants provide further evidence of the mental health impact of caregiving in this setting.

The caregiver experience of phase I trial participants has unique features in comparison to other caregiver populations. The study population reported less impact on health and support system via the Caregiver Reaction Assessment (CRA) subscales, compared to populations of family caregivers of early stage cancer patients [39]. The phase I caregivers reported a notably greater (>0.5 SD) impact on finances and schedule than the population norms on the CRA. It should be noted that these norms were obtained from a group of students during the validation of the tool, and the age and experiences of that population may influence the values. Yet overall, these responses support the argument that while our caregiving population is physically healthy and supported, enrollment on phase I trials places a considerable burden on caregivers in scheduling and accessing health care.

Study participants also reported lower coping scores on the PAC scale than other caregiver populations, which suggests a less positive assessment of caregiving. Both a population of caregivers of patients with dementia and a cancer caregiving population scored higher on the PAC than caregivers of phase I trial participants [43, 44]. The impact of caregiving on emotional health was studied through the ERQ, and the care-givers of phase I oncology trial participants scored similar to caregivers of phase II–IV oncology trial participants [40] and higher than the population norms for this scale. Like the CRA, the ERQ was validated in a



younger population, and this may influence the reappraisal abilities of respondents. These comparisons further support the emotional impact of caregiving in our study population.

While respondents identified availability of social support and some positive aspects of caregiving, which is consistent with the literature [41], of particular concern are the responses on the distress scales. Notably, respondents exhibited more anxiety and perceived stress than population norms, a high prevalence of depressive symptoms, as well as impaired emotion regulation. These findings are consistent with a recent meta-analysis of anxiety in cancer patients and their caregivers [42]. Such findings increase the likelihood of caregiver burnout, with potential adverse physical and emotional health consequences for both the caregiver and the patient.

The observed greater caregiver burden and higher levels of perceived stress among respondents with poor health is consistent with previously reported findings [45, 46]. Given the physical and emotional demands of caregiving, it is not surprising that caregivers with better self-reported personal health status reported lower caregiver burden and less stress. The finding that younger caregivers exhibited greater stress compared to older caregivers may be explained by the common scenario of younger caregivers who are juggling the demands of caring for children and maintaining employment with the demands of caregiving [47], oftentimes requiring an adjustment of their workload [48, 49].

This study has identified a caregiver population with increased distress compared to population norms, with the reported distress similar to that found in a study of caregivers of patients undergoing bone marrow transplant [50]. Previous studies evaluating quality of life in phase I trials have identified the importance of family in a patient's perception of quality of life, placing importance on the supportive network [51, 52]. Identifying baseline characteristics of emotional coping in caregivers is important in helping to guide them through this transition period in cancer care. The prevalence of anxiety and depression has been identified in multiple caregiver studies and at times has been shown to exceed patient rates [53]. Thus, our findings of high anxiety and depressive symptoms are in keeping with previous reports. While previous longitudinal studies have found that overall caregiver burden does not necessarily increase as illness progresses, fatigue and energy level are adversely affected as the patient becomes more reliant on help for functioning [54].

The unifying experience for the caregivers in this study is the experience with phase I oncologic trial enrollment. Currently, there are few data to inform the most effective mechanism and approach to supporting the needs of these caregivers throughout the caregiving experience and across the trajectory of cancer treatment [50, 55–57]. Given the identification of distress in this population, an intervention focused on the unique needs of this population has the potential to enhance the quality of life of caregivers and, potentially, that of patients.

This study had a few notable strengths and weaknesses. The strengths include a high response rate with the study population representing the phase I trial population seen at the University of Colorado Cancer Center. Although study participants appear to be rather homogenous, the study population was representative of the phase I clinic: primarily well

educated, women, from households with a comfortable income. While representative of this clinic, this lack of diversity may offer less insight into how caregivers from other racial/ethnic and socioeconomic groups cope with the demands of caregiving [58, 59]. This was a cross-sectional analysis; a longitudinal analysis would allow for more in-depth assessment of the caregiving experience over the course of illness and treatment, particularly with regard to the transition to a phase I trial with all its implications.

This study reveals that the time of enrollment in a phase I trial is a time of significant stress and fatigue for caregivers, indicating the need for future interventions to enhance the caregiver experience. It is hypothesized that the mental and physical health of the caregiver may impact the mental and physical health of the patient; this is supported in other populations [60, 61]. Addressing the interplay between the health of each member of the caregiver-patient dyad is important in future exploration. Future research should also focus on how best to support caregivers at the time of phase I trial enrollment and throughout trial participation in order to reduce the toll on caregivers, decreasing the probability of caregiver burnout and future caregiver morbidity [62]. As oncology continues to focus on developmental therapeutics and patients increasingly seek access to novel agents earlier in the drug development pipeline, this population is expected to expand, increasingly including patients earlier in their disease trajectory. Cognitive and behavioral interventions to support caregivers are in development [50], but neither traditional nor self-directed approaches have been studied in the phase I caregiver population.

## Conclusion

These data suggest that an evidence-based approach to decreasing distress among caregivers of patients enrolling in phase I trials is needed, particularly as the prevalence and duration of treatment on phase I trials increases.

## Acknowledgments

**Funding:** The funding of this study is provided through the following: 1K07AG030337 (JK), 3R01CA126971 (MLL), 2P30CA046934 (SGE, JK), and PCORI Contract CE-1304-6208 (MLL).

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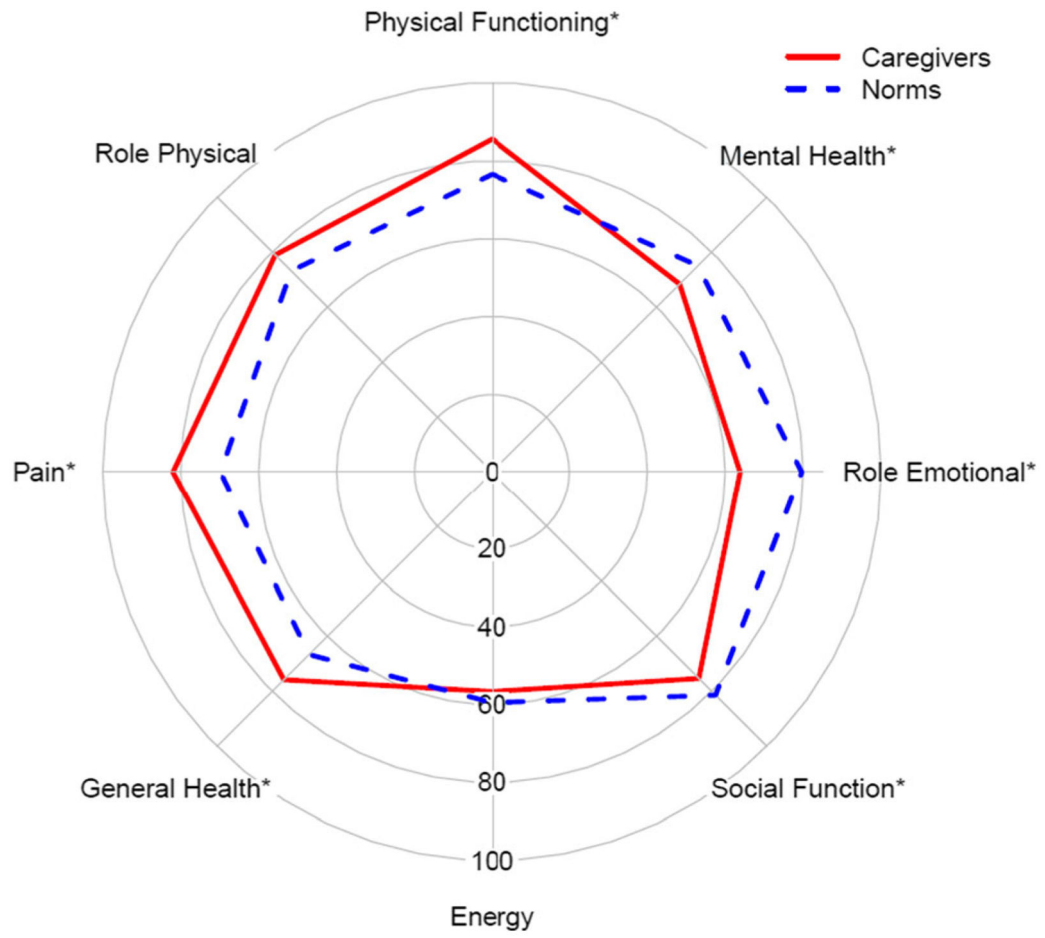
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**Fig. 1.** Scores on the SF36 in comparison with reported norms



Table 1

## Caregiver and patient demographics

Category	Caregiver characteristics (N=88) <sup>a</sup> mean (min, max) or N (%)	Patient characteristics (N=88) <sup>a</sup> N (%)
Age (years)	56.46 (mean) range (23, -76)	<17: 1 (1.2 %) 18–29: 3 (3.5 %) 30–45: 11 (12.8 %) 46–65: 49 (57 %) >65: 22 (25.9 %)
	Number of responses (percentage)	Number of responses (percentage)
Gender		
Female	53 (62.4)	40 (46.5)
Male	32 (37.7)	46 (53.5)
Race		
Asian	1 (1.1)	1 (1.2)
African American	3 (3.4)	4 (4.8)
Caucasian	74 (84.1)	74 (89.2)
Hispanic	8 (2.3)	0
Other	2 (2.2)	4 (4.8)
Current living situation		
Alone	4 (4.7)	5 (5.9)
With partner + children	23 (27.1)	20 (23.5)
With partner, no children	51 (60)	51 (60)
Parents	3 (3.5)	1 (1.2)
Family	2 (2.4)	3 (3.5)
Other	2 (2.4)	5 (5.9)
Education		
<High school	1 (1.2)	0
Some high school	1 (1.2)	3 (3.5)
High school	16 (18.8)	17 (19.8)
Some college	22 (25.9)	20 (23.3)
Associate degree	10 (11.8)	4 (4.6)
College degree	16 (18.8)	25 (29.1)
Post graduate degree	19 (22.4)	17 (19.8)
Household income		
<\$25,000	12 (15.6)	22 (25.9)
\$25,001–\$50,000	14 (18.2)	18 (23.4)
\$50,001–\$75,000	14 (18.2)	9 (11.7)
\$75,001–\$100,000	10 (13.0)	7 (9.1)
\$100,001–\$200,000	20 (26)	15 (19.5)
>\$200,000	7 (9.1)	6 (7.8)
Additional caregiver demographics		
Marital status		
Married	70 (82.4)	
Divorced	6 (7.1)	

Category	Caregiver characteristics (N=88) <sup>a</sup> mean (min, max) or N (%)	Patient characteristics (N=88) <sup>a</sup> N (%)
Committed relationship	7 (8.2)	
Single	2 (2.4)	
Also provide child care		
Yes	17 (20)	
No	68 (80)	
Occupation		
Non-health care	60 (83.3)	
Clinical health care	12 (16.7)	
Relationship to patient		
Spouse	67 (76.1)	
Sibling	4 (4.6)	
Child	8 (9.1)	
Parent	5 (5.7)	
Friend	2 (2.3)	
Other	2 (2.3)	
Years involved helping patient		
<1	6 (7.4)	
1–5	43 (56.8)	
6–10	6 (7.4)	
11–15	6 (7.4)	
16–20	2 (2.5)	
>20	15 (18.5)	
Average hours/week caregiving		
0–9	6 (6.9)	
10–29	11 (12.6)	
30–49	7 (8.1)	
50+	63 (72.4)	
Resided with patient		
Prior to illness	74 (85.1)	
After illness	13 (15)	
Additional patient demographics		
Patient cancer type		
Lung	10 (11.6)	
Musculoskeletal	6 (7)	
Liver	7 (8.1)	
Ovarian	11 (12.8)	
Pancreatic	6 (7)	
Melanoma	2 (2.3)	
Gastrointestinal	14 (16.3)	
Bladder	5 (5.8)	
Thyroid	1 (1.2)	
Neuroendocrine	4 (4.6)	

Category	Caregiver characteristics (N=88) <sup>a</sup> mean (min, max) or N (%)	Patient characteristics (N=88) <sup>a</sup> N (%)
Non-melanoma skin cancer	1 (1.2)	
Salivary gland/parotid	2 (2.3)	
Prostate	1 (1.2)	
Kidney	2 (2.3)	
Head and neck	6 (7)	
Brain	1 (1.2)	
Breast	2 (2.3)	
Gynecologic	4 (4.6)	
Hematologic	1 (1.2)	
Years since diagnosis		
<2	33 (38.4)	
2-5	38 (44.2)	
>5	15 (17.4)	

<sup>a</sup>Where sum is less than 88, data are missing

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**Table 2**

Mean values and comparisons for measures of distress and caregiver experience

Measure	Caregiver mean (SD)	Range	Population mean (SD)
Distress			
PSS	23.49 (8.42)	3–40	19.1 (7.1)
PANAS-positive	34.48 (7.1)	15–47	35 (6.4)
PANAS-negative	21.50 (7.8)	10–44	18.1 (5.9)
STAI trait	37.82 (10.26)	24–64.21	35.96 (1.1)
CESD total	13.58 (9.55)	0–42	>16=threshold for depression
CESD distress	0.38 (0.49)	0–1	
Caregiver experience			
CRA total	9.97 (2.56)	5.40–20.98	
CRA Lack of family support	1.67 (0.65)	1–3.80	2.1 (0.6)
CRA impact on finances	2.29 (1.13)	1–5	1.87 (0.57)
CRA impact on schedule	2.61 (0.81)	1.20–5	2.44 (0.84)
CRA impact on health	1.69 (0.54)	1–3.75	1.98 (0.62)
CRA self-esteem	1.69 (0.65)	1–3.43	4.19 (0.41)
BFS total	3.73 (0.68)	2–5	N/A

*PSS* Perceived Stress Scale [22], *PANAS* Positive and Negative Affect Scale [24], *STAI* State-Trait Anxiety Inventory [25], *CES-D* Center for Epidemiologic Studies Depression Scale [26], *CRA* Caregiver Reaction Assessment [27], *BFS* Benefit Finding Scale [29]

**Table 3**

Mean values and comparisons for measures of emotion regulation and coping

Measure	Caregiver mean (SD)	Range	Reference value mean (SD)
Emotion regulation			
ERQ reappraisal	4.99 (1.12)	1.67–7	4.6 (0.98)
ERQ suppression	3.64 (1.08)	1–6	3.39 (1.15)
DERS total	70.37 (14.88)	43–113	79.33 (20.22)
DERS nonacceptance	11.15 (4.25)	6–25	11.60 (4.59)
DERS goals	11.22 (3.68)	5–22	14.38 (5.01)
DERS impulse	9.84 (3.08)	6–18	11.19 (4.46)
DERS awareness	15.67 (2.92)	10–25	15.30 (4.60)
DERS strategies	13.07 (4.84)	8–34	16.20 (6.21)
DERS clarity	7.22 (2.55)	4–15	10.68 (3.77)
Support and coping			
Normative data not available			
PAC total	36.23 (6.74)	13–45	
ESSI total	33.11 (6.54)	12.86–43.71	
COPE self distraction	4.73 (1.63)	2–8	
COPE active coping	5.56 (1.61)	2–8	
COPE denial	2.80 (1.24)	2–8	
COPE substance use	2.39 (0.84)	2–6	
COPE use of emotional support	5.84 (1.54)	2.5–8	
COPE use of instrumental support	5.32 (1.51)	2–8	
COPE behavioral disengagement	2.28 (0.71)	2–5	
COPE venting	3.18 (1.07)	2–6	
COPE positive reframing	5.05 (1.81)	2–8	
COPE planning	5.70 (1.5)	2–8	
COPE humor	3.10 (1.45)	2–8	
COPE acceptance	6.51 (1.25)	4–8	
COPE religion	5.49 (1.87)	2–8	

*ERQ* Emotion Regulation Questionnaire [20] full + subscales, *DERS* Difficulties in Emotion Regulation Scale [30] full + sub-scales, *PAC* Positive Aspects of Caregiving [31], *ESSI* ENRICH Social Support Inventory [32], *COPE* Brief COPE Inventory [33]