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Poor Patient Health is associated with Higher Caregiver Burden for Older Adults with Advanced Cancer

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Abstract

Objectives: Family caregiver burden among older adults with advanced cancer remains poorly understood. We sought to (1) identify patient factors associated with caregiver burden and (2) examine how amount of time caregiving modifies these relationships.

Methods: Cross-sectional analysis of baseline data from a cluster-randomized palliative care intervention trial including patients with advanced cancer and their family caregivers, recruited from 17 oncology practices in Pennsylvania. Caregiver burden was measured using Zarit Burden Interview (ZBI-12; range 0–48). Patient factors included functional status (Eastern Cooperative Oncology Group), symptom burden (Edmonton Symptom Assessment Scale), anxiety and depression (Hospital Anxiety and Depression Scale), and quality of life (Functional Assessment of

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Author Contributions

Study concept and design: Schenker, White, Arnold, Chu, Smith; Acquisition of subjects and/or data: Schenker, Althouse, White, Arnold, Chu, Smith; Analysis and interpretation of data: Althouse, Semere, Schenker; Preparation of the manuscript: Semere, Althouse, Rosland, White, Arnold, Chu, Smith, Schenker.

Conflict of Interest

The authors have no conflicts of interest to disclose.

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Chronic Illness Therapy – Palliative Care). Using adjusted multivariable regression, we analyzed (1) independent associations between patient factors and caregiver burden and (2) how weekly caregiving hours modified these relationships.

Results: Among 441 patient-caregiver dyads, mean patient age was 70 ± 10 and caregiver age was 62 ± 13 years. Most caregivers (59%) were patients' partners. Caregivers reported 44.5 ± 53.5 average hours spent caregiving weekly; mean ZBI-12 scores were 10.3 ± 7.3 . Worse patient functional status ($\beta = 4.20, p < 0.01$), poorer quality of life ($\beta = -0.07, p < 0.01$), more anxiety ($\beta = 0.33, p < 0.01$) and depression ($\beta = 0.33, p < 0.01$) were associated with higher caregiver burden; caregiving hours did not affect these relationships.

Conclusions: In advanced cancer, poor patient physical and mental health is associated with higher caregiver burden regardless of hours caregiving; future studies should examine interventions tailored to alleviate caregiver burden for this group.

Keywords

Caregiving; Caregiver Burden; Advanced Cancer; Older Adults

Introduction

Burden associated with caring for patients with advanced cancer has been associated with worse physical and mental health for caregivers, as well as the patients they care for.¹⁻⁶ Older adults with advanced cancer have comorbidities and frailty that can further challenge caregiving and contribute to caregiver burden.⁷⁻⁹ When compared to caregivers for patients with other medical conditions, caregivers for patients with cancer report higher total number of hours providing care, more time spent assisting with activities of daily living (ADL) and independent activities of daily living (IADL), and more involvement with complex medical/nursing tasks.^{10,11} This increased responsibility, often coupled with a lack of preparation for caregiving roles, contributes to high levels of stress among caregivers for patients with cancer.^{12,13} For caregivers of patients with advanced cancer, who navigate patients' deteriorating physical function, increasing symptom distress, and anticipatory grief associated with the end of life, the consequences and risks associated with caregiver burden are heightened.¹⁴

Despite growing evidence that caregivers for patients with advanced cancer experience significant burden, little is currently known about factors associated with caregiver burden in this population. A few studies suggest that patients' physical and emotional health may be important contributors.^{15,16} For example, Wood et al found that caregivers of patients with advanced non-small cell lung cancer experiencing functional status decline reported increased caregiver burden.¹⁵ However, this study was restricted to patients with a single cancer type and did not consider additional patient factors such as symptom burden and emotional well-being. It also remains unclear how the amount of time caregivers spend caring for patients with advanced cancer influences potential relationships between patient factors and caregiver burden. While some studies suggest that more time spent providing care and the effects of caregiving on a caregiver's daily schedule are key factors in the trajectory of burden, this relationship has not been explored in the context of patient factors.

^{17,18} By better characterizing the relationship between patient factors, time spent caregiving, and caregiver burden, we can target existing interventions to mitigate caregiver burden among those at highest risk while optimizing outcomes for both patients and caregivers.

In this study, we sought to (1) determine the relationship between patient factors (functional status, symptom burden, mood, and quality of life) and caregiver burden, and (2) examine how the relationships between these factors is influenced by the amount of time spent caregiving for patients with advanced cancer. We hypothesized that worse patient functional status, greater symptom burden, higher levels of anxiety and depressive symptoms, and worse quality of life would be associated with higher levels of caregiver burden. We also hypothesized that, for caregivers spending more time caregiving, these patient factors would be associated with even higher levels of burden.

Methods

Study Overview and Design

This cross-sectional study draws from baseline data collected as part of the CONNECT cluster-randomized trial. The complete details of the study protocol have been published previously.¹⁹ The University of Pittsburgh Institutional Review Board (PRO15120154) approved the study protocol, and the trial is registered on [clinicaltrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT02712229) (NCT02712229).

Study Setting

Patients and their caregivers were recruited from seventeen oncology practices within the University of Pittsburgh Medical Center (UPMC) Hillman Cancer Center Network in Western Pennsylvania. Over 30,000 patients receive care in this network each year, approximately 8% of whom are racial/ethnic minorities.

Study Participants

Eligible patient participants were adults (≥ 21 years) with metastatic solid tumors receiving ongoing oncologic care at a participating study site for whom their oncologist “would not be surprised” if the patient died within a year.^{20,21} Patients were excluded if they had an Eastern Cooperative Oncology Group (ECOG) performance status of 3 (capable of only limited selfcare; confined to bed or chair more than 50% of waking hours) or 4 (completely disabled; totally confined to bed or chair).²² Additional patient exclusion criteria were (1) cognitive impairment or inability to consent to study participation, as determined by the patient’s oncologist, (2) patient’s inability to read and respond to questions in English, and (3) inability to complete the baseline interview. All patients completed written informed consent prior to study enrollment.

Patients eligible for the parent study were encouraged but not required to identify an adult caregiver (≥ 21 years). For this analysis, only patients with an enrolled caregiver were included. Caregivers were defined as the “family member or friend most likely to accompany you to clinic visits or help with your care should you need it.” Caregivers were excluded if they were unable to read and respond to questions in English or were unable to

complete the baseline interview. Caregivers were required to provide written or verbal informed consent.

Study Measures

Caregiver burden.—Caregiver burden was assessed using the validated Zarit Burden Interview (ZBI) short version (ZBI-12). The ZBI is the most widely used instrument to assess subjective caregiver burden; it was first validated in caregivers of patients with dementia and has since been examined extensively in caregivers of patients with cancer.²³ The shorter version, ZBI-12, has been shown to correlate well with the full ZBI in patients with advanced cancer.²⁴ Caregivers subjectively answer questions that probe the impact of caregiving on their physical, emotional, and social well-being. Responses are given on a 5-point Likert scale (0=Never to 4=Nearly Always) and total scores range from 0 to 48, with higher scores indicating more burden.

Time spent caregiving.—Caregivers were asked “on average how many hours per week do you provide care?” Care was defined as “attention to any of the needs of the person, including hands-on care, overnight care, respite, shopping, help with medications, taking to appointments, emotional support, bathing, etc.” Some caregivers reported providing full-time, 24–7 care, which was considered equal to 168 hours per week for the purposes of this analysis.

Additional caregiver characteristics.—In addition, we collected caregiver sociodemographic characteristics, including age, gender, race/ethnicity, partner status, and education level. We also asked caregivers about their relationship to the patient and whether they lived with the patient.

Patient Factors

Functional status.—Oncologists assessed patients’ functional status using the ECOG performance score, which is used to determine how a patient’s disease impacts their ability to carry out daily activities. ECOG 0 refers to patients with normal activity. ECOG 1 refers to patients able to carry out work of a light or sedentary nature, but restricted in physically strenuous activities. ECOG 2 refers to patients capable of all selfcare, but unable to carry out any work activities.

Symptom burden.—We evaluated patient symptom burden using the Edmonton Symptom Assessment Scale (ESAS). The ESAS questionnaire is a validated tool that has been used in cancer patients to rate the intensity of nine commonly experienced symptoms. Each symptom is scored from 0 (not present) to 10 (worst possible). Single symptom item scores are summed to calculate a total ESAS score (range, 0–90), with higher scores indicating greater symptom burden.^{25,26}

Depression and anxiety.—We assessed patients’ symptoms of anxiety and depression using the Hospital Anxiety and Depression Score (HADS), a widely used instrument that has been extensively validated for measuring symptoms of emotional distress among advanced cancer patients. The HADS consists of 14 items, divided into two 7-item subscales

that measure symptoms of anxiety (HADS-A) and depression (HADS-D); respondents rate each symptom on a scale from 0 (absence) to 3 (extreme presence). Higher scores (HADS-A, range 0–21; HADS-D, range 0–21) indicate greater levels of anxiety or depression.^{27,28}

Quality of Life.—We determined patients' health-related quality of life using the Functional Assessment of Chronic Illness Therapy- Palliative care (FACIT-Pal), which is a validated self-reported instrument. The FACIT-Pal consists of 46 items, that include statements regarding 4 domains of well-being (physical 7 items, social 7 items, emotional 6 items, functional 7 items) and a palliative care supplement (19 items). For each item, patients report on a five-point Likert scale (“not at all,” “a little bit,” “somewhat,” “quite a bit,” and “very much”) whether, as it relates to the last seven days, they agree with the statement. The score for the total FACIT-Pal ranges from 0 to 184, with higher scores indicating better quality of life.²⁹

Clinical and sociodemographic factors.—We collected information related to each patient's cancer diagnosis, including type of cancer and whether they were currently receiving chemotherapy treatment. During patient baseline interviews, we also obtained sociodemographic information. We collected patient age, gender, race/ethnicity, partner status, education level, and current living situation. Patients also reported their current employment status and ability to manage with their current income.

Statistical Analysis

We used descriptive statistics (frequency, mean, standard deviation) to summarize sociodemographic and cancer-related characteristics for patients and caregivers. Using unadjusted linear regression models, we examined the relationship between these characteristics and caregiver burden. To test our first hypothesis, we used multivariable linear regression models to assess relationships between five patient factors of interest (functional status, symptom burden, depression, anxiety, and quality of life), and caregiver burden. We adjusted our models for patient covariates (age, education, income) and caregiver covariates (age, gender, education, and income) shown to be associated with caregiver burden in our univariate analyses and in prior literature.^{7,17,30–34} We tested the independent relationship between each patient factor of interest and caregiver burden in these adjusted models.

To test our second hypothesis, we added an interaction term for each patient factor and caregiving hours to multivariable regression models examining whether the number of caregiving hours influenced the relationship between each patient factor of interest and caregiver burden. We adjusted for the same patient and caregiver covariates as in models testing our first hypothesis. We performed a complete case analysis, only including those caregivers who reported caregiving hours. A significant result for one of the interaction terms would suggest that the number of caregiving hours modified the relationship between that respective patient factor and caregiver burden; the lack of evidence for an interaction term would suggest that the relationship between a given patient factor and caregiver burden was not modified by the amount of caregiver hours. Interactions were considered statistically significant at the $p < 0.05$ significance level.

We conducted a sensitivity analysis, removing all full-time, 24–7 caregivers from our multivariable regression models to account for uncertainty in the caregiver hours response question. We also used descriptive statistics to compare characteristics (patient and caregiver) for caregivers who did not respond to the caregiver hours question to caregivers who did respond.

We performed all statistical analyses using SAS version 9.4 (SAS Institute, Cary, NC).

Results

A total of 441 patient-caregiver dyads were enrolled in the CONNECT trial and included in this analysis.

Patients were 70 years old on average, and half (50%) were men. Nearly two-thirds of patients were married, and most (85%) lived with someone else. Thirty-three percent of patients had a college degree or more education. Approximately 75% of patients reported being unemployed or retired. More than one-third of patients reported that they “just manage to get by” (31%) or “can’t make ends meet” (6%) with their income (Table 1).

Lung cancer was the most common (38%) cancer diagnosis among patients. Approximately 70% of patients were currently undergoing chemotherapy, and most had some restriction in functional status, as indicated by their ECOG score of 1 or 2. The average ESAS score was 25.2 ± 16.0 and the average total FACIT-Pal score was 129 ± 25.6 . The mean depression (HADS-D) score was 5.4 ± 3.7 and anxiety (HADS-A) score was 5.9 ± 4.0 (Table 1).

Caregivers were 62 years old on average, and the majority (73%) were women. Most caregivers (59%) were spouses or partners to patients; 25% were adult children of patients. Over two-thirds lived with the patient. Eighty two percent (N=362) of caregivers completed the caregiving hours question. Caregivers reported spending on average $44.5 (\pm 53.5)$ hours per week caring for patients, with 12% identifying as full-time (24–7) caregivers. Thirty-six percent of caregivers had a part-time or full-time job outside of caregiving. The mean caregiver Zarit Burden Interview score was 10.3 ± 7.3 (Table 1).

In unadjusted linear regression models, patient sociodemographic characteristics including younger age ($\beta=-0.09$, $p=0.01$) and having a high school diploma or more ($p<0.05$) were associated with higher caregiver burden. Patients who reported that they were “just managing to get by” ($\beta=-3.76$, $p=0.01$) or were “having enough with a little extra” ($\beta=-4.26$, $p<0.01$) with their income, were more likely to have lower caregiver burden compared to those who reported they “can’t make ends meet.” Caregivers who had difficulty managing on their income were also more likely to have higher caregiver burden ($p<0.01$) than those who did not have difficulty (Table 2).

The Figure shows the distribution of Zarit scores by each patient factor of interest; all five patient factors were correlated with higher caregiver burden (higher levels of depression $r=0.21$, $p<0.001$; higher levels of anxiety $r=0.20$, $p<0.001$; poorer quality of life $r=-0.299$, $p<0.001$; higher symptom burden $r=0.125$, $p=0.009$; worse functional status $p<0.001$). In fully adjusted models, patient functional status, anxiety and depression, and quality of life

remained independently associated with caregiver burden ($p < 0.01$); patient symptom burden did not retain significant association ($p = 0.23$). For example, a one-point increase in patient FACIT-Pal score was associated with an estimated decrease of 0.07 points in Zarit Burden score, meaning that caregivers for patients with higher quality of life had lower observed burden (Table 3).

We found little evidence that any relationship between patient factors of interest and caregiver burden were influenced by caregiving hours (Table 4). There was no significant interaction term for caregiving hours and patient functional status, symptom burden, anxiety, depression, or quality of life on the outcome of caregiver burden. When we excluded full-time 24–7 caregivers from analyses, we similarly found no significant interaction terms for caregiving hours and any of the patient factors of interest on caregiver burden (Supplement Table 1). When we compared caregivers who responded to the caregiver hours question to those who did not, we found that the groups had largely similar sociodemographic and caregiving characteristics. The patients they cared for also had similar sociodemographic and clinical characteristics.

Discussion

In this study of older patients with advanced cancer and their caregivers, we found that caregivers for patients with worse functional status, higher levels of depression and anxiety, and poorer quality of life experienced greater levels of caregiver burden, irrespective of the amount of time caregiving. To our knowledge, this is the first study to examine the effect of time spent caregiving on the relationship between patient factors and caregiver burden in advanced cancer. Our findings highlight the importance of considering patient factors as contributors to caregiver burden independent of caregiving hours.

We found caregivers for patients with ECOG scores of 2 (ambulatory and capable of all selfcare but unable to carry out any work activities) were more likely than those caring for patients with fewer physical activity restrictions to experience burden. In another study of older patients with newly diagnosed cancer, patient ECOG scores of 3 (capable of only limited selfcare) and 4 (completely disabled) were associated with increased risk of mild to severe caregiver burden.³⁵ Our findings suggest that caring for patients with milder physical restrictions still places caregivers at risk for burden. This may reflect more demanding functional needs or burden related to a longer duration of support for patients with advanced cancer, even with milder physical constraints.

Higher levels of patient depression and anxiety were also associated with higher caregiver burden in our sample. While previous studies have found that cancer caregiver mental health is associated with caregiver burden, few studies have examined the relationship between patient mental health and caregiver burden.^{36,37} Caring for patients with advanced cancer and psychological distress may place additional strain on caregivers.¹⁶

Caregiver burden can negatively impact both caregiver health and patient well-being.^{38–41} While a number of caregiver burden assessments exist, screening can be a time consuming and resource intensive process.⁴² Furthermore, inconsistent contact with caregivers in

oncology practices may make routine screening for caregiver burden impractical. However, providers routinely assess patient performance status and mental health in the process of providing cancer care and determining treatment approaches.^{43,44} Recognizing some of the patient characteristics that may be associated with greater risk of caregiver burden can offer an opportunity to identify caregivers most in need of screening and subsequent intervention.

Caregiver burden scores in our population were low on average, indicating mild overall burden. This is consistent with previous work finding low levels of burden among older caregivers^{7,45,46} and higher levels of burden among younger caregivers for patients with cancer.⁴⁷ Older caregivers may have fewer responsibilities for other family members and be less likely to work outside the home, which could contribute to overall lower burden compared to younger caregivers. It is also important to note that older caregivers for patients with cancer have been found to experience certain aspects of caregiver burden, such as growing isolation or feelings of missing out on life, at higher levels than younger caregivers.³⁰ Additional work is needed to explore unique experiences of burden among caregivers of patients with advanced cancer that may differ based on caregiver age and be beneficial in informing tailored interventions.

We did not find that time spent caregiving influenced relationships between patient factors and caregiver burden. Previous studies have not firmly established the degree to which time spent caregiving affects the relationship between patient factors and caregiver burden.^{17,18} Caregivers in our study reported spending, on average, 44 hours per week providing care, the equivalent of a full-time job; 12% identified as full-time (24–7) caregivers. In other studies, cancer caregivers have reported spending less time caregiving on average (20 to over 40 hours a week) when compared to our cohort.^{7,10} However, these studies did not focus on caregivers for patients with advanced cancer, who may have more time-consuming roles. Our findings suggest that the demands of caregiving for patients with impairments in physical function and mental health may outweigh any difference in time spent providing care. This is consistent with prior research suggesting that caregivers providing fewer hours of care take on similar roles on behalf of patients as caregivers providing more hours of care.⁴⁸ The support roles themselves, such as assistance with patient physical impairments or emotional needs, rather than the amount of time in these roles, may be most relevant to caregiver burden.

Our study has several important limitations. First, this is a cross-sectional analysis, and as such, we cannot make causal conclusions. The relationships between patient factors and caregiver burden could be considered bi-directional. For example, higher levels of patient anxiety may lead to higher levels of caregiver burden; alternatively, higher caregiver burden levels may lead to higher levels of patient anxiety. Given the cross-sectional design of this study, we were unable to measure the trajectory of caregiver burden over time. Prior studies examining the trajectory of caregiver burden in advanced cancer have had mixed findings, with some showing no change and others an increase in caregiver burden as patient functional status declines.^{18,43} Second, we excluded patients with very poor performance status (ECOG 3 and 4) from the parent trial given our prior pilot work demonstrating this group's limited ability to engage in palliative care interventions.⁴⁹ Our study is also geographically restricted and includes a predominantly Caucasian population. These

findings may not generalize to caregivers of patients with worse performance status or more diverse populations. Third, 18% of caregivers did not report the number of hours that they spend caregiving and this missingness may not have been random. However, when comparing caregivers who did and did not report caregiving hours we found that these groups had generally similar measured characteristics as did the patients that they cared for. Finally, we did not measure caregiver supports (i.e. respite care, home services) or caregiver health which can influence caregiver burden. While our primary focus was elucidating patient factors associated with caregiver burden, additional work is needed to better understand relationships between caregiver factors and caregiver burden when caring for older patients with advanced cancer.

Despite these limitations, this study adds to an emerging body of work examining patient factors contributing to caregiver burden among those caring for older populations with cancer. We identified patient functional impairment, higher depression and anxiety levels, and poor quality of life as associated with higher caregiver burden. To our knowledge, this is also the first study demonstrating a lack of influence of time spent caregiving on the relationship between patient factors and burden in caregivers of older patients with advanced cancer. Our findings have important implications for identifying caregivers at risk for burden and targeting existing interventions to mitigate this risk. By leveraging accessible knowledge of patient factors that place caregivers at risk for burden, we can direct limited resources to support caregivers and patients most in need, with potential benefits for both caregiver and patient outcomes.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Highlights

- Worse patient functional status is associated with higher caregiver burden in advanced cancer
- Poor patient quality of life is associated with higher caregiver burden in advanced cancer
- More patient anxiety and depression is associated with higher caregiver burden in advanced cancer
- Hours caregiving do not affect relationships between patient health factors and caregiver burden

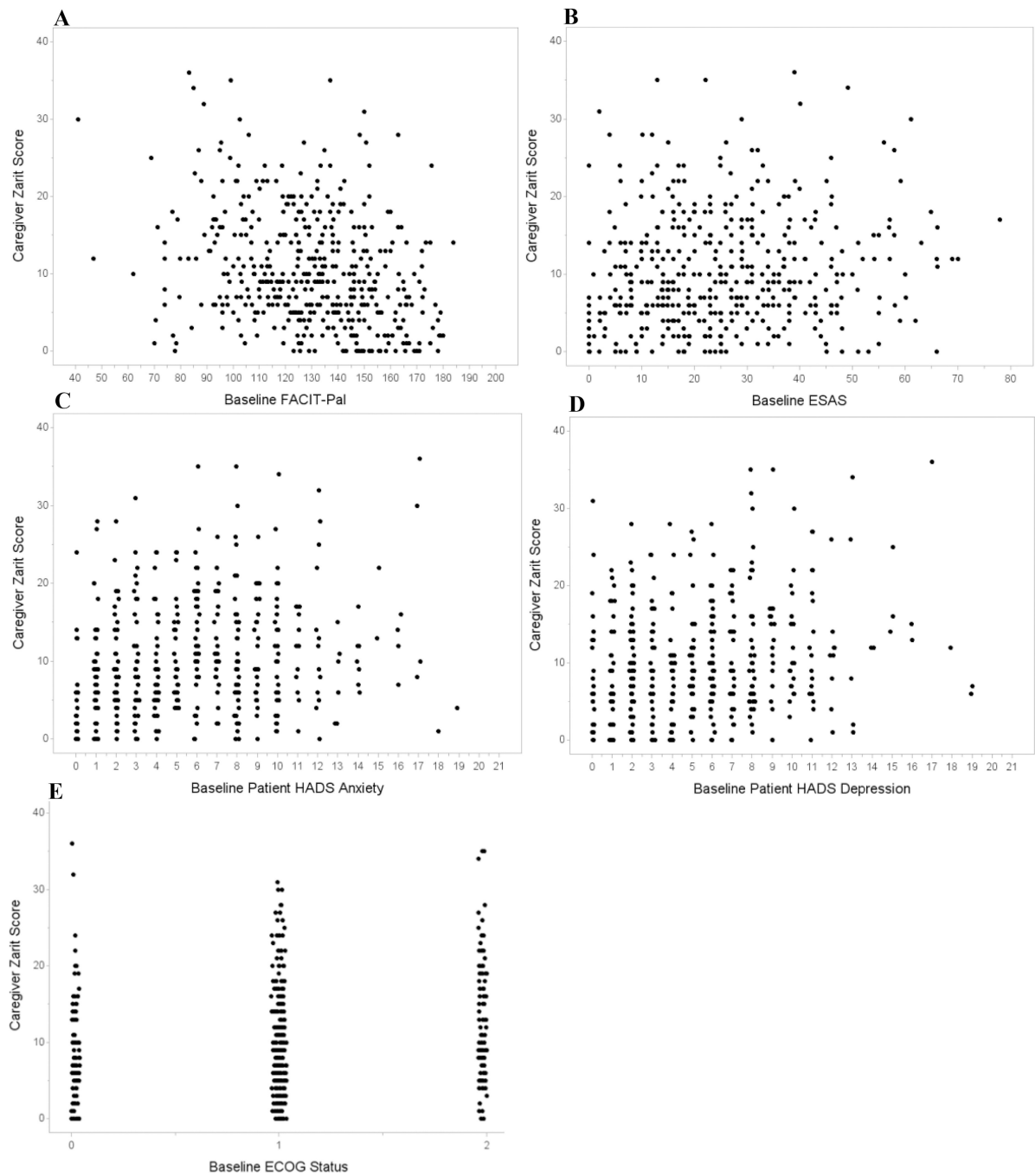


Figure 1.

The figure shows the distribution of caregiver Zarit burden scores by each patient factor of interest: A. Zarit score vs FACIT-Pal ($r = -0.299$, $p < 0.001$); B. Zarit score vs ESAS ($r = 0.125$, $p = 0.009$); C. Zarit score vs HADS-A ($r = 0.20$, $p < 0.001$); D. Zarit score vs HADS-D ($r = 0.21$, $p < 0.001$); E. Zarit score vs ECOG ($p < 0.001$)

Table 1.

Patient (N=441) and Caregiver (N=441) Characteristics

Characteristics	No. (%)
Patient	
Age, mean \pm SD	69.9 \pm 10.0
Female	221 (50.1)
Race	
Caucasian/White	419 (95.0)
African-American/Black	18 (4.1)
Asian	3 (0.7)
Other	1 (0.2)
Ethnicity	
Non-Hispanic	436 (98.9)
Hispanic	5 (1.1)
Married	295 (66.9)
Lives alone	65 (14.7)
Highest level of education	
Less than high school	37 (8.4)
High school diploma or GED	181(41.0)
Some college, no degree	72 (16.3)
College degree or more	147 (33.4)
Current Employment Status	
Retired or unemployed	331 (75.1)
Working full-time or part-time	32 (7.3)
Homemaker	12 (2.7)
Other	63 (14.3)
How well are you able to manage on your income?	
Can't make ends meet	28 (6.3)
Just manage to get by	137 (31.1)
Have enough with a little extra	174 (39.5)
Money is not a problem	70 (15.9)
Cancer Type	
Breast	46 (10.4)
Lung	166 (37.6)
Gastrointestinal	139 (31.5)
Gynecologic	18 (4.1)
Genitourinary	38 (8.6)
Other cancers specified	33 (7.5)
Other cancer unspecified	1 (0.2)
Currently Receiving Chemotherapy	305 (69.2)
Performance Status (ECOG)	
0=Fully Active	89 (20.2)

Characteristics	No. (%)
1=Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature	260 (59.0)
2=Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours	92 (20.9)
Symptom burden (ESAS), mean \pm SD	25.2 \pm 16.0
Quality of life (FACIT-PAL), mean \pm SD	129 \pm 25.6
Depressive symptoms (HADS-D), mean \pm SD	5.43 \pm 3.74
Anxiety symptoms (HADS-A), mean \pm SD	5.90 \pm 3.97
Caregiver	
Age, mean \pm SD	61.5 \pm 13.3
Female	322 (73.0)
Highest level of education	
Less than high school	15 (3.4)
High school diploma or GED	157 (35.6)
Some college, no degree	65 (14.7)
College degree or more	200 (45.4)
Current Employment Status	
Retired or unemployed	217 (49.2)
Working full-time or part-time	161 (36.5)
Homemaker	25 (5.7)
Other	34 (7.7)
How well are you able to manage on your income?	
Can't make ends meet	20 (4.5)
Just manage to get by	112 (25.4)
Have enough with a little extra	189 (42.9)
Money is not a problem	82 (18.6)
Relationship to Patient	
Spouse/Partner	261 (59.2)
Adult Child	111 (25.2)
Parent	4 (0.9)
Sibling	27 (6.1)
Friend	15 (3.4)
Other	20 (4.5)
Lives with patient	305 (69.2)
Average hours per week spent caregiving, mean \pm SD *	44.5 \pm 53.5
24-7 Caregivers	44 (10.0)
Caregiver burden (Zarit Burden Score), mean \pm SD	10.3 \pm 7.3

Percentages based on non-missing values.

* N=362 Caregivers responded to the caregiving hours question and were included in this analysis.

Abbreviations: ECOG, Eastern Cooperative Oncology Group performance status; ESAS, Edmonton Symptom Assessment System; FACIT-Pal, Functional Assessment of Chronic Illness Therapy – Palliative care scale; HADS-D, Hospital Anxiety and Depression Score – Depression subscale; HADS-A, Hospital Anxiety and Depression Score – Anxiety subscale; SD, Standard Deviation

Table 2.

Association of Patient (N=441) and Caregiver (N=441) Factors with Caregiver Burden

Characteristics	β [95% CI]	p-value
Patient		
Age	-0.09 (-0.15, -0.02)	0.01
Female	0.08 (-1.29, 1.45)	0.91
Married	-0.70 (-2.16, 0.75)	0.34
Lives alone	-0.10 (-2.04, 1.83)	0.92
Highest level of education		
Less than high school	ref	ref
High school diploma or GED	3.77 (1.19, 6.35)	<0.01
Some college, no degree	3.00 (0.10, 5.90)	0.04
College degree or more	3.58 (0.94, 6.21)	<0.01
Current Employment Status		
Retired or unemployed	ref	ref
Working full-time or part-time	-1.25 (-3.91, 1.41)	0.36
Homemaker	-1.83 (-6.05, 2.38)	0.39
Other	1.18 (-0.77, 3.13)	0.23
How well are you able to manage on your income?		
Can't make ends meet	ref	ref
Just manage to get by	-3.76 (-6.72, -0.80)	0.01
Have enough with a little extra	-4.26 (-7.17, -1.35)	<0.01
Money is not a problem	-2.55 (-5.74, 0.64)	0.12
<i>Cancer-related characteristics</i>		
Cancer Type		
Breast	ref	ref
Lung	0.13 (-2.27, 2.52)	0.92
Gastrointestinal	-0.78 (-3.23, 1.66)	0.53
Gynecologic	-2.29 (-6.29, 1.71)	0.26
Genitourinary	-2.16 (-5.32, 0.99)	0.18
Other cancers specified	-0.82 (-4.10, 2.46)	0.62
Other cancers unspecified	-1.85 (-16.4, 12.69)	0.80
Currently receiving chemotherapy	0.81 (-0.67, 2.29)	0.28
Caregiver		
Age	-0.09 (-0.14, -0.04)	<0.01
Female	0.27 (-1.28, 1.81)	0.73
Highest level of education		
Less than high school	ref	ref
High school diploma or GED	1.75 (-2.08, 5.58)	0.37
Some college, no degree	3.39 (-0.67, 7.46)	0.10
College degree or more	4.29 (0.50, 8.09)	0.03
Current Employment Status		

Characteristics	β [95% CI]	p-value
Retired or unemployed	ref	ref
Working full-time or part-time	1.82 (0.34, 3.30)	0.02
Homemaker	-2.46 (-5.47, 0.55)	0.11
Other	2.53 (-0.03, 5.09)	0.05
How well are you able to manage on your income?		
Can't make ends meet	ref	ref
Just manage to get by	-5.36 (-8.83, -1.89)	<0.01
Have enough with a little extra	-6.33 (-9.70, -2.97)	<0.01
Money is not a problem	-6.35 (-9.91, -2.78)	<0.01
Average hours per week spent caregiving *	0.01 (-0.01, 0.02)	0.33

*N=362 Caregivers responded to the caregiving hours question and were included in the analyses.

Table 3.

Relationship Between Patient Factors and Caregiver Burden (N=441)

Patient factor	Unadjusted		Adjusted	
	β [95% CI]	p-value	β [95% CI]	p-value
ECOG (reference=0)				
1	1.07 (-0.66, 2.79)	0.23	1.11 (-0.73, 2.95)	0.24
2	4.64 (2.55, 6.73)	<0.01	4.20 (1.93, 6.46)	<0.01
ESAS	0.06 (0.01, 0.10)	<0.01	0.03 (-0.02, 0.08)	0.23
HADS-D	0.41 (0.23, 0.59)	<0.01	0.33 (0.13, 0.553)	<0.01
HADS-A	0.37 (0.20, 0.54)	<0.01	0.33 (0.15, 0.51)	<0.01
FACIT-Pal	-0.09 (-0.11, -0.06)	<0.01	-0.07 (-0.10, -0.04)	<0.01

Adjusted regression models assessing the relationship between each patient factor and caregiver burden, include patient (age, education, and income) and caregiver (age, gender, education, and income) covariates.

Abbreviations: ECOG, Eastern Cooperative Oncology Group performance status; ESAS, Edmonton Symptom Assessment System; FACIT-Pal, Functional Assessment of Chronic Illness Therapy – Palliative care scale; HADS-D, Hospital Anxiety and Depression Score – Depression subscale; HADS-A, Hospital Anxiety and Depression Score – Anxiety subscale

Table 4.

Effect of Caregiving Hours on the Relationship Between Patient Factors and Caregiver Burden (N=362) *

	Unadjusted		Adjusted	
	β [95% CI]	p-value	β [95% CI]	p-value
Caregiver Hours	0.012 (-0.042, 0.067)	0.656	0.018 (-0.049, 0.085)	0.603
ECOG (ref=0)				
1	1.358 (-1.181, 3.896)	0.293	1.197 (-1.420, 3.815)	0.368
2	4.049 (0.949, 7.149)	0.011	3.639 (0.344, 6.934)	0.030
Caregiver Hours *ECOG				
1	-0.017 (-0.075, 0.039)	0.541	-0.016 (-0.086, 0.053)	0.645
2	0.0016 (-0.061, 0.063)	0.957	-0.0005 (-0.074, 0.073)	0.989
Caregiver Hours	0.020 (-0.008, 0.048)	0.154	0.023 (-0.006, 0.053)	0.119
ESAS	0.075 (0.014, 0.134)	0.016	0.024 (-0.039, 0.086)	0.462
Caregiver hours *ESAS	-0.0006 (-0.0015, 0.0002)	0.145	-0.0004 (-0.001, 0.0004)	0.361
Caregiver Hours	0.002 (-0.023, 0.028)	0.855	0.006 (-0.021, 0.034)	0.636
HADS-D	0.349 (0.085, 0.613)	0.009	0.207 (-0.075, 0.489)	0.151
Caregiver hours *HADS-D	0.000 (-0.003, 0.003)	0.980	0.0006 (-0.003, 0.005)	0.758
Caregiver Hours	0.001 (-0.024, 0.026)	0.928	0.019 (-0.009, 0.046)	0.191
HADS-A	0.312 (0.057, 0.566)	0.016	0.284 (0.019, 0.549)	0.035
Caregiver hours *HADS-A	0.000 (-0.003, 0.003)	0.997	-0.001 (-0.005, 0.002)	0.417
Caregiver Hours	-0.0046 (-0.073, 0.063)	0.893	-0.199 (-0.091, 0.051)	0.581
FACIT-Pal	-0.082 (-0.119, -0.046)	<0.001	-0.067 (-0.107, -0.028)	<0.001
Caregiver Hours *FACIT-Pal	0.00003 (-0.0005, 0.005)	0.893	0.0002 (-0.0003, 0.0008)	0.439

* N=362 Caregivers responded to the caregiving hours question and were included in the analyses.

Adjusted regression models assessing the combined effect of each patient-related factor and caregiving hours on caregiver burden, including patient (age, education, and income) and caregiver (age, gender, education, and income) covariates