Published in final edited form as:
Cancer. 2014 September 15; 120(18): 2927–2935. doi:10.1002/cncr.28765.

Factors Associated with High Burden in Caregivers of Older Adults with Cancer

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Abstract

Background—Older adults with cancer are vulnerable to functional decline, placing greater onus on caregivers. Few studies have prospectively examined burden in caregivers of older cancer patients. We sought to determine factors associated with high caregiver burden.

Methods—100 caregivers of patients age ≥65 with cancer, recruited at a single-institution, completed questionnaires gauging their perception of the patient's physical, emotional, and social health. The association between these items, cancer-related factors, sociodemographic factors, and caregiver burden [measured by the Caregiver Strain Index (CSI)] was determined through multivariate analysis.

Results—Patients were a median age of 70 (range 65–91), 70% had advanced disease, and 98% were receiving treatment. Caregivers were mostly female (73%), spouses (68%), and lived with the patient (79%). Median hours of care provided was 10 hours/week. Mean CSI score was 3.1±3.2. Most caregivers (75%) reported some burden, with 15% reporting high caregiver burden (CSI ≥7). In multivariate analysis, employed caregivers (OR 4.5; 95% CI 1.1–18.4, $p=0.04$) and those who cared for patients requiring more help with instrumental activities of daily living (OARS-IADL score <12 of 14) (OR 12.4; 95% CI 2.4–62.5, $p<0.001$) were more likely to experience high caregiver burden (CSI ≥7).

Conclusions—Caregiver burden is common in those who care for older cancer patients. High burden is more likely in employed caregivers and those who care for patients who require increased functional assistance. Further studies are needed to determine unique challenges experienced by caregivers of older adults with cancer and potential interventions to alleviate burden in these caregivers.

Keywords

aged; caregivers; neoplasms; prospective studies; stress; psychological

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Financial Disclosures:
Matthew Loscalzo: Novartis, Lilly
Karen Clark: Novartis, Lilly
Arti Hurria: Seattle Genetics, GTX, Celegene, GSK

Introduction

Cancer treatment is increasingly administered as an outpatient resulting in reliance on informal caregivers, predominantly family, to assist with day-to-day activities[1, 2]. Caregiver responsibilities can include bathing, transportation, medication management, and monitoring for and managing treatment side effects[1, 3, 4]. This can place burden on caregivers, many of whom feel inadequately prepared for this role[5–7].

Caring for a loved one can be rewarding, but can also be associated with significant caregiver burden. Caregiver burden is a "subjective experience that is perceived as stressful"[6] and occurs when an imbalance exists between caregiving demands and caregiver resources to cope with those demands[8]. Caregivers are at higher risk of depressive symptoms[9–11], more likely to experience difficulties with sleep and fatigue[11–13], and are less likely to practice preventive health than non-caregivers[14]. Older caregivers experiencing burden may also be at higher risk of death than non-caregivers[15].

Caring for older adults with cancer may involve additional challenges, which may put these caregivers at particularly high risk of burden. Increasing age is associated with a decline in physiologic reserve, which can result in increased need for functional assistance at baseline and during periods of stress, such as during treatment[16]. Furthermore, comorbidities, frailty, and geriatric syndromes are more common in older adults with cancer[16–18]. Given the aging population and increasing prevalence of cancer[19], a better understanding of the unique challenges that face this population of patients and caregivers is needed. Unfortunately, few studies have examined burden specifically in caregivers of older adults with cancer. We sought to determine factors associated with high burden in caregivers of older adults with cancer in this hypothesis-generating pilot study.

Methods

Patients, age 65 and older with a diagnosis of cancer, and their primary caregiver, as identified by the patient, were approached in clinic. Patients without a caregiver were excluded. One hundred patient-caregiver dyads were enrolled (50 solid tumor malignancies, 50 hematologic malignances). Non-English speaking patients and caregivers were excluded as some measures have only been validated in English. Approval from the institution's ethics and research board and attending physician was obtained. Informed consent was obtained from patients and caregivers.

Sample characteristics

Caregiver sociodemographics, relationship to the patient, cohabitation with the patient, and time spent caring for the patient were assessed through a structured interview with the caregiver. Patient sociodemographics and cognitive function was obtained via patient interview. Details about cancer diagnosis and treatments were gathered via chart review.

Geriatric Assessment Measures

A geriatric assessment serves to provide a comprehensive picture of a patient's health, encompassing several domains including cognition, functional status, comorbidity, nutrition, psychological state, and social activity and support. The validated instruments utilized (Table 1) were chosen based on the feasibility and acceptability of a self-administered geriatric assessment developed in a prior study[20] and have been fully described previously[20].

All domains were obtained via a self-administered questionnaire completed by the caregiver utilizing a touch-screen interface, with the exception of cognition, which was administered to the patient by the research team. Caregivers' responded based on their assessment of the patient. Responses were obtained independently from the patient. We used the caregiver's assessment of the patient's health rather than the patient's as we hypothesized that the caregiver's perception of the patient's health may differ from patient's self-assessment but may be more important to caregiver burden than the patient's perception of these domains.

Caregiver Burden

Caregiver burden was assessed using the Caregiver Strain Index (CSI), a validated 13-item self-administered measure that evaluates five domains of caregiving: employment, financial, physical, social, and time[21]. It has a reliability coefficient alpha of 0.86 and has good construct validity[21]. Answers are dichotomous (yes/no). Higher values indicate more burden (range 0–13). A score ≥7 is considered high caregiver burden[21] and this threshold for caregiver burden has been used in other studies of cancer caregivers[12, 22].

Statistical Analyses

Descriptive statistics were used to summarize patient and caregiver demographics, clinical characteristics, caregiver strain scores, and geriatric assessment measures.

The association between caregiver burden and patient, caregiver, and caregiving factors, as well as the geriatric assessment was evaluated. A model for caregiver burden was developed using unconditional logistic regression. The caregiver strain score was dichotomized (≥ 7 vs. <7) to identify those caregivers experiencing high levels of caregiver burden. The mean was used to dichotomize all quantitative variables that were normally distributed. Median values were utilized to dichotomize variables that were not normally distributed (caregiver age, hours of caregiving per week, caregiver-reported Karnofsky Performance Status (KPS), Blessed Orientation-Memory-Cognition (BOMC)). Variables that reached a p-value <0.1 (Supplemental Table 1) in bivariate analysis were considered in the multivariate analysis using the stepwise method. Two variables were included in the final model [caregiver employment status and caring for patients needing more help with instrumental activities of daily living (IADLs)]. The likelihood ratio test was used to check for possible interaction terms between factors. The calibration of the final model was checked using the Hosmer-Lemeshow test and the discrimination of the model was checked by the area under the receiver operating characteristics (ROC) curve.

Statistical analyses were done using SAS 9.2 (SAS Institute, Cary, NC) and STATA SE 12.0 (StataCorp, College Station, Texas).

Results

Patient and Caregiver Characteristics

One hundred patient-caregiver pairs were included (see Supplemental Figure 1 for non-participants). Median patient age was 70 (range 65–91) (Table 2). Patients with a variety of tumors types were included: lymphoma (26%), breast cancer (19%), gastrointestinal malignancies (15%), and myeloma (10%). Most patients (70%) had advanced disease and were on treatment (62% chemotherapy, 34% targeted therapy alone).

Caregivers were a median age of 66 (range 28–85) (Table 2). Most caregivers were female (73%) and almost a quarter (23%) were employed. Spouses and children comprised the majority of caregivers (68% and 18% respectively) with other relatives and friends making up the remainder. Almost 80% of caregivers lived with the patient.

Caregiver assessment of Patient

Patients had an average of 2.4±1.8 comorbid conditions and 26% had at least 1 fall in the past 6 months, as reported by caregivers (Table 3). Caregivers reported that patients had a mean Medical Outcomes Study (MOS) physical function of 53.7±27.9 and mean KPS of 80.5±16 (indicating the average patient was able to do “normal activity with effort, some symptoms of disease”). Sixty-four percent of individuals required some assistance with IADLs [Older American Resources and Services-IADL (OARS-IADL<14)] and the mean OARS-IADL score was 11.9±2.3, meaning that on average patients were either completely dependent for one IADL or required some help with two IADLs.

The mean patient mental health inventory score as assessed by the caregiver was 76.9±16.3. Five percent of patients scored above the threshold for possible cognitive impairment (BOMC≥11).

Caregivers reported patients were well supported (mean MOS-social support survey (MOS-SSS) 90.6±12.7), but that patients’ social activities were limited by their health (mean MOS-social activity 54.7±19.4).

More than a third (35%) of patients were assessed to have ≥5% of unintentional weight loss.

Caregiver burden

Caregivers reported providing a median of 10 hours of care per week. The highest quartile provided ≥35 hours/week (Table 4). Most caregivers (61%) had provided care for at least one year. The mean caregiver burden score, as measured by the CSI, was 3.1±3.2 (range 0–13). Seventy-five percent endorsed some level of caregiver burden with 15% reporting high levels of burden (CSI ≥7).

On bivariate analysis, high levels of burden was more likely in caregivers that were non-Caucasian (OR 4.76, p=0.033), employed (OR 3.77, p=0.024), and age <66 years old (OR

5.56, p=0.011), as well as those who cared for patients with a ≥5% unintentional weight loss (OR 3.88, p=0.025) and solid tumors (OR 8.67, p=0.01). Caregivers who provided care for at least 10 hours/week (median) and 35 hours/week (highest quartile) were more likely to experience high caregiver burden (OR 3.11, p=0.07 and OR 4.0, p=0.017 respectively). The caregiver's perception of the patient's physical and social function also correlated with caregiver burden. High levels of burden were seen in those caring for patients with a KPS <90 (OR 5.56, p=0.011), requiring more assistance with IADLs (OARS-IADL <12) (OR 20.0, p<0.001), lower perceived physical function (MOS-physical function <53.7) (OR 6.25, p=0.007), more limitations in social activities due to their health (MOS-social activity <54.7) (OR 6.25, p=0.007) and less social support (MOS-SSS <90.6) (OR 2.94, p=0.073). Of caregivers who reported the patient to be completely independent (KPS 100% or OARS-IADL 14), none experienced high levels of caregiver burden. Full results of the bivariate analysis are in Supplemental Table 1.

On multivariate analysis, employed caregivers (OR 4.5, 95% CI 1.1–18.4, p=0.04) and those caring for patients who required more help with IADLs (OARS-IADL <12) (OR 12.5, 95% CI 2.4–62.5, p<0.001) remained significantly associated with high caregiver burden (Table 5). There was no interaction between employment status and IADL dependency. There was good calibration (Hosmer-Lemeshow test, p=0.85) and discrimination (ROC=0.85).

Discussion

Our study demonstrates that most caregivers in this cohort experienced some level of caregiver burden, with 15% reporting high levels of burden. Screening for caregiver burden is not routine and caregiver burden is rarely addressed in the clinical setting[23, 24]. Given the exponential growth of older adults with cancer, prevalence of caregiving burden, and the potential for higher mortality in caregivers expressing caregiver burden[15], identifying factors associated with high caregiver burden is important in order to target interventions at those caregivers most in need. Though many factors were associated with caregiver burden, caregivers who were employed and those caring for patients requiring help with IADLs, as assessed by the caregiver, had a higher risk of high caregiver burden on multivariate analysis.

Compared to studies of caregivers of cancer patients of all ages, caregiver burden in our study was lower (mean CSI 3.1 vs. 4.2 to 6.3[6, 12, 22, 25–27]), suggesting that caregivers of older adults with cancer may potentially experience less burden than other caregivers of cancer patients. Caregiver burden may have been lower in our study as caregivers were generally older than those in other studies (mean 63.1 vs. 43.8–63.1 years old). This is consistent with studies that have shown that older caregivers have better mental health and experience less psychological distress due to caregiving[28, 29]. This may be because older caregivers perceive caregiving to be less overwhelming and their activities less restricted than younger caregivers do[29, 30]. We recognize, however, that caregiving may have a greater physical impact on older caregivers, especially on those who are already vulnerable (i.e. those with serious health conditions, poor health, and disability)[31, 32].

Caregivers who perceived care recipients as being more dependent with their IADLs were more likely to experience high caregiver burden. This is consistent with prior studies which also found that caregivers of patients who require more daily assistance had higher caregiver burden[33–35]. One possible explanation for this is that caregiving restricts the caregiver's ability to socialize and participate in valued activities[36].

In our study, caregivers who were employed were more likely to have high levels of caregiver burden, likely due to competing demands from caregiving and work. This association is consistent with some studies[3, 37, 38], but not others[39, 40]. Research suggests that employment can be either protective or detrimental to caregivers[41]. While work can be a source of additional stress and demands, it can also be an important source of income, social support and respite from caregiving[41]. Differential effects of employment on caregiver burden may depend on age,[42] since younger caregivers may be less well-established in their careers and less financially secure[30, 42].

Many studies have explored factors associated with burden in caregivers of cancer patients in general. Fewer studies have looked at factors associated with caregiver burden solely in those who care for older adults with cancer. Other studies of caregivers of older adults with cancer also identified higher caregiver burden in employed caregivers[43] and those whose care recipients are more dependent[43, 44]. One study, however, did not find an association between IADL dependency and caregiver burden[35]. Other factors associated with burden and/or mental health in caregivers of older cancer patients include patient symptoms or distress[35, 43, 45], cancer type[45], proximity to surgical treatment[35], patient physical function[45], trajectory of illness (eventual death or survival)[43], caregiver age[35], caregiver gender (husbands > wives)[35], caregiver health status[43], and relationship of the caregiver to the patient (spouse > non-spousal)[43, 44]. Many of these factors were also identified in our study at the bivariate level, though no significant association between caregiver burden and caregiver gender, relationship to the patient, and the patient's emotional state were seen in our study. Differences may be due to differences in methodology, instruments utilized, cultural norms surrounding caregiving[46], and the population of caregivers and patients studied. In addition, several of these studies included only patients with early-stage disease[35] or included pre-specified groups of caregivers (e.g. all spouses ≥65 years)[35, 44].

We acknowledge the limitations of our study. First, we did not differentiate between physical and psychological caregiver burden, which may have demonstrated a differential pattern in caregiver burden in this cohort of caregivers. We also did not capture potentially important information about caregivers, such as their health status and the presence of informal and formal social supports. Our study included all caregivers and patients of all stages in order to allow wider applicability of these results to the clinical setting. However, as in previous studies, the majority of caregivers in our cohort were female and either spouses or children and we acknowledge specific subgroups of caregivers may have unique needs. In addition, although we used the caregiver assessment of the patient as an indicator of high caregiver burden, we recognize that high caregiver burden itself may impact negatively on caregiver perception of the caregiving tasks and the caregiver recipient's health. Although this is one of the largest studies to our knowledge to investigate factors associated with high burden in caregivers of older adults with cancer, given the modest sample size and small number of caregivers with high caregiver burden, the confidence intervals are wide and the model may be 'overfit'. Furthermore, only two factors were identified in the final model and given our modest sample size some factors may not have been identified. As a single institution, hypothesis-generating study we acknowledge the need to validate these findings.

Hopefully by identifying caregivers of older adults at high risk of caregiver burden, this will allow researchers and clinicians to target interventions at those most in need. Interventions have included psychological counseling, teaching caregivers skills, support groups, and respite care. Two large meta-analyses, one on caregivers of patients with cancer and another on caregivers of older adults (predominantly those with dementia), found that most interventions had a small to moderate positive effect on a variety of outcomes including caregiver perception of caregiving[2, 47], knowledge[47], coping and self-efficacy[2, 47], quality of life[2], and ultimately caregiver burden[2, 47]. Few studies have tested interventions specifically in caregivers of older adults with cancer[1]. More studies are needed to determine whether these interventions produce similar results in caregivers of older adults with cancer or whether tailored interventions are needed to target the unique needs of these patients and caregivers.

In conclusion, although most caregivers of older adults with cancer do experience some caregiver burden, only a small proportion report high levels of burden. Caregivers who care for patients who require help with IADLs and who are employed are most likely to experience high levels of caregiver burden. These risk factors can help identify those caregivers at highest risk of burden and serve as a platform to test interventions to help alleviate this burden.

Acknowledgments

Funding: Supported by a National Institute of Health R21 AGO41489 grant and a City of Hope Excellence Award.

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Table 1

Geriatric Assessment Domains and Measures

Domain and Measures Used	No. of Items	Description	Range of scores
Functional Status			
MOS Physical Function sub scale[48]	10	Measures limitations in physical activities due to health, using 3-point Likert scale	0–100 ↑
OARS-Instrumental Activities of Daily (OARS-IADL) sub scale[49]	7	Evaluates ability to perform tasks needed to live independently (i.e. transportation, shopping) using 3-point Likert scale	0–14 ↑
Caregiver-assessed Karnofsky performance status (KPS)[50]	1	Caregiver-rated performance status using 8-point descriptive scale (“normal” to “severely disabled”)	0–100% ↑
Number of falls in prior 6 months	1		
Comorbidity			
OARS-Physical health sub scale[49]	15	Presence of 15 medical conditions	
Cognition *			
Blessed Orientation-Memory-Concentration (BOMC)[51]	6	Cognitive screen; Score of 11+ indicates potential cognitive impairment	0–28↓
Nutrition			
% unintentional weight loss	1	Indicator of nutritional status over prior 6-month period	
Psychological State			
Mental Health Index (MHI)[52]	17	Evaluation of anxiety, depression, loss of behavioral/emotional control, and positive affect using 6-point Likert scale	0–100 ↑
Social activity and support			
MOS-Social Activity[48]	4	Measures social activity limitations due to health using 5-point Likert scale	0–100 ↑
MOS-Social Support Survey[48]	12	Measures perceived social supports using 5-point Likert scale	0–100↑

OARS: Older American Resources and Services; MOS: Medical Outcomes Study

* Administered by the research team to the patient; all other measures completed by caregiver

↑= higher scores indicate better function and/or outcomes

↓= lower scores indicate better function and/or outcomes

Table 2

Caregiver and patient demographics

Variable	Caregiver (n=100)	Patient (n=100)
Median age (range)	66 (28–85)	70 (65–91)
	%	%
Ethnicity		
Hispanic	14	12
Non-Hispanic	84	86
Unknown	--	2
Missing	2	--
Race		
White	88	89
Black	10	10
Other	--	1
Missing	2	--
Gender		
Male	27	53
Female	73	47
Marital Status		
Single (never married)	12	6
Married	81	76
Divorced	3	8
Widowed	4	10
Education		
Less than high school graduate	2	5
High school graduate	13	17
College	70	55
Greater than college	15	23
Employment Status		
Employed	23	17
Retired, homemaker, unemployed	75	80
Disabled, medical leave	1	3
Student	1	--
Household income		
<100,000	63	71
≥100,000	27	24
Missing	10	5

Variable	Caregiver (n=100)	Patient (n=100)
Tumor type		
Breast	N/A	19
Lung		4
Gastrointestinal		15
Genitourinary		5
Other solid tumors		8
Lymphoma		26
Myeloma		10
Leukemia		
Acute		8
Chronic		4
Other hematologic malignancies		1
Stage		
Early	N/A	29
Advanced		70
Missing		1
Current Treatment		
Chemotherapy	N/A	62
Targeted therapy alone		34
Chemo-radiation		2
No treatment		2
Relationship to patient		
Spouse	68	N/A
Child	18	
Other	14	
Live with patient		
No	21	N/A
Yes	79	

Table 3

Caregiver assessment of the patient (n=100)

Measurement	Descriptive statistics
Comorbid conditions	
Mean±SD	2.4±1.8
Median	2
Range	0–8
MOS physical function	
Mean±SD	53.7±27.9
Median	55.6
Range	0–100
OARS-IADL	
Mean±SD	11.9±2.3
Median	13
Range	0–4
% completely independent (score 14)	36%
Caregiver-assessed KPS	
Mean±SD	80.5±16.0
Median	90
Range	30–100
Falls	
Mean±SD	0.5±0.9
Median	0
Range	0–4
% 1+ falls in past 6 months	26%
MOS social activity	
Mean±SD	54.7±19.4
Median	56.3
Range	0–93.8
MOS social support	
Mean±SD	90.6±12.7
Median	95.8
Range	43.8–100
Mental health inventory	
Mean±SD	76.9±16.3
Median	81.5
Range	12.5–98.8
Blessed Orientation-Memory-Concentration	

Measurement	**Descriptive statistics**
Mean±SD	3.0±3.4
Median	2
Range	0–14
% ≥11	5%
	%
Unintentional weight loss	
<5%	61
≥5%	35
Missing	4

Table 4

Caregiver burden

Measurement	**Descriptive statistics**
Caregiver strain index (n=100)	
Mean±SD	3.1±3.2
Median	2
Range	0–13
Score (%)	
0	25%
1–3	43%
4–6	17%
7+ (high burden)	15%
Hours (n=98)	
Mean±SD	21.7±30.5
Median	10
Range	0–168
	% (n=100)
Duration of caregiving	
<1 year	39
≥1 year	61

Table 5

Multivariate model of factors associated with high caregiver burden

Variables	**OR (95% Confidence interval)**	**p-value**
Caregiver employed vs. not employed	4.5 (1.1–18.4)	0.04
Caregiver perspective of patient IADL dependence: OARS IADL <12 vs. ≥12	12.5 (2.4–62.5)	<0.001