

Impact of caregiver activities and social supports on multidimensional caregiver burden: analyses from nationally-representative surveys of cancer patients and their caregivers

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No funding was received for this research.

## Abstract

**Purpose:** Informal caregivers of individuals with cancer may experience substantial burdens. To develop interventions to support these caregivers, it is crucial to quantify and understand the domains of burdens potentially experienced by caregivers and factors contributing to each domain.

**Methods:** Using data from two national surveys, the National Survey of Caregiving (NSOC) linked to the National Health and Aging Trends Survey (NHATS), we identified all participants in the NHATS diagnosed with cancer who had a caregiver participating in the NSOC. Guided by a theoretical model, twenty-two items in the NSOC related to caregiver health, mood and outlook were included in factor analysis to develop scales capturing domains of burden. Multivariable regression analyses examined whether activities performed by caregivers and supports for caregivers were associated with these burden scales.

**Results:** Analysis of responses from 373 caregivers of cancer patients identified three scales: *emotional burden*; *psychological burden*; and *relationship with the patient*. Providing assistance managing medical care was associated with increased emotional and psychological burden, while assistance with non-medical issues increased psychological burden and worsened relationships with patients. Caregiver provision of direct patient care activities was also associated with increased burden but improved relationships with patients. Use of caregiver supports showed mixed associations with burden.

**Conclusions:** Using a nationally-representative sample of cancer patients and their caregivers and brief publicly-available survey questions, we present three scales addressing different aspects of caregiver burden that are responsive to caregiver activities and social supports. This may assist in developing and evaluating intervention to decrease caregiver burden.

**Key words:** cancer; caregivers; social support; factor analysis; interpersonal relations

## Background

In 2011, 18 million informal caregivers in the U.S. provided 1.3 billion hours of care monthly to more than 9 million older adults [1]. Informal caregivers (usually spouses, other relatives, or friends) may frequently experience caregiver burden. This refers to the potential negative physical, mental, emotional, financial, or social consequences associated with providing care [2]. Previous studies have indicated that increased caregiver burden may be associated with specific caregiver characteristics [3-5], although other studies have found that most caregiver characteristics are not directly associated with caregiver burden [6,7]. Patient characteristics and needs and patient-caregiver interactions are also associated with caregiver burden [1,3,8,9].

Some studies of caregiver burden have quantified this construct using a single measure or score such as the Caregiver Strain Index [3,7], the Zarit Burden Inventory [9], or the well-being score developed by Spillman et al. [1]. However, caregiver burden may be thought of as having multiple domains or components rather than being globally described by a single number. Other studies have used instruments that capture multiple dimensions of burden, such as the Caregiver Reaction Assessment Scale, which assesses five domains of burden (lack of family support, impact on health, impact on schedule, impact on finances, and caregivers esteem) [5,6] and the Supportive Care Needs Survey—Partners and Caregivers, which captures caregiver needs related to four domains (health care service needs, psychological and emotional needs, work and social needs, and information needs) [2]. As the magnitude of each of multiple burden components on caregiver outcomes is likely to vary based on the caregiver's and patient's characteristics and activities, expressing burden as a single score may obscure detailed impacts of caregiving. For example, in a study using the CRA, Burton et al. reported that caregivers' desire for more help from friends and family was significantly associated with burden only for the lack of family support and impact on health domains [6]. Varying impacts of separate domains of caregiver burden may highlight important unmet needs among caregivers and suggest tailored interventions to reduce burden.

In order to develop appropriate and effective interventions to decrease caregiver burden, particularly among individuals providing care for cancer patients, it is crucial to understand the types of burdens experienced by caregivers and the factors contributing to these burdens. Previous studies of exploring burden among caregivers of individuals with cancer have generally used information from smaller groups of caregivers, often from a single institution or geographic region. For example, the study reported by Burton et al. included 139 patients identified at two North Carolina medical centers and the local tumor registries; only 51 of these had cancer [6]. The National Survey of Caregiving (NSOC) is a survey administered by U.S. Dept. of Health and Human Services. The NSOC is a unique resource in that it collects a broad range of informal caregiver characteristics and measures, and links these data to a broader survey, the National Health and Aging Trends Survey (NHATS), which provides detailed information on patient clinical and sociodemographic characteristics. The linked NSOC and NHATS data form an ideal source for exploring the types of burdens experienced by caregivers of cancer patients and providing nationally-representative estimates of the factors and activities associated with these burdens. Initial analyses of the 2011 NSOC encompassing multiple patient types have been presented by Spillman et al. [1]. In this study, we used data from the 2011 NSOC and NHAT to assess the components of burden among caregivers of individuals with cancer

and assess factors that increased or decreased the caregiver-reported burden. The general aims of this study were to examine the characteristics of NHATS cancer patients and their caregivers, to explore factors to measure burden experienced by caregivers, and to determine the variables associated with burden among caregivers of patients with cancer.

## Methods

### Data source

This study used data from the National Health and Aging Trends Survey (NHATS) and the National Survey of Caregiving (NSOC). The NHATS is a publicly-available data set supported by the National Institute on Aging that collects information on a nationally representative sample of Medicare beneficiaries ages 65 and older [10]. NHATS is sponsored by the National Institute on Aging (grant number NIA U01AG32947) and was conducted by the Johns Hopkins University. The NSOC was conducted as a supplement to Round 1 (May-Oct. 2011) of the NHATS, to create a nationally representative sample of individuals providing informal assistance to older persons [11]. Eligibility for the NSOC was determined among NHATS respondents in the first round of the survey. NHATS respondents were eligible if they reported receiving help with mobility or self-care, help with household activities specifically for health/functioning-related reasons, or lived in residential care settings. Caregivers of eligible NHATS respondents, interviewed May-Nov. 2011, were eligible for the NSOC if they were family members or unpaid caregivers and helped with any activity identified during the NHATS interview. The NSOC telephone interview included questions about activities for which help was provided, duration and intensity of help, effects on helpers of providing assistance, support services used by helpers, and basic demographic information [11]. As the NSOC and NHATS do not include any protected health information (PHI) and cannot be readily linked to individuals, this study was classified as not being human subjects research and did not require review by the University of Arizona IRB.

### Participants and procedures

The sample for this study was drawn from participants in the NHATS with cancer and their caregiver who participated in the NSOC. All NHATS participants with a diagnosis of cancer who had at least one caregiver were included. If there were multiple caregivers per patient, we used the first caregiver listed in NSOC.

### Theoretical model and identification of NSOC items

We used the “Caregiving process and caregiver burden” theoretical model developed by Klassen et al. as the framework for developing scales quantifying domains of burdens experienced by caregivers [12]. In this model, *Caregiving Demands* affect caregiver’s *Intrapsychic Factors/Self-Perceptions*. *Caregiver Coping and Supportive Factors* moderate the impacts of *Intrapsychic Factors* on caregiver *Psychological Health* and *Physical Health*

outcomes. Based on this framework and a review of the prior literature, one author (MH) tentatively identified NSOC survey questions that corresponded to the Klassen model. The other authors reviewed the identified questions and all authors came to consensus regarding the survey questions to include. We identified 20 items from the NSOC that captured caregiver burden information corresponding to Klassen's *Intrapsychic Factors*. These items and their response ranges are listed in Table 1; all NSOC items corresponding to this theoretical model are presented in Figure 1. Seven of the 20 *Intrapsychic Factors* NSOC items were reversed scored so that higher numbers indicated higher burden/negative outcomes for all 20 items.

We also identified the 16 items on the NSOC associated with *Caregiving Demands*. These were grouped in three categories: *Management of Medical Care* (6 items); *Assistance with Non-Medical Issues* (3 items); and *Provision of Personal Care* (7 items) (Figure 1). Finally, we identified the seven items included in the NSOC corresponding to *Coping and Supportive Factors* (Figure 1).

### Statistical analysis

Patient and caregiver data were merged by patient ID. Descriptive analysis was performed for characteristics of the patients and their caregivers. A weighted (see below) factor analysis was used to explore the possible underlying factor structure of the 20 *Intrapsychic Factors* NSOC items as caregiver burden scales. Since item scorings were ordinal with few categories, factor analysis was based upon polychoric correlations. Factor analysis was performed with the varimax method for rotation; an *a priori* decision rule was to retain factors with eigenvalues over one. Internal consistency was estimated using Cronbach's alpha coefficient. Total factor scores for each caregiver were determined by summing the responses to the included NSOC items for that caregiver. Total scores for each factor were then standardized to a possible range of 0-100, with higher scores indicating greater burden.

Weighted multiple linear regression analyses (using weights provided with the NSOC) were performed to examine whether *Caregiving Demand* and *Coping and Supportive Factors* NSOC items were significantly associated with the caregiver burden scales (developed from the 20 NSOC *Intrapsychic Factors*, as discussed above). All of the *Caregiving Demand* and *Coping and Supportive Factors* NSOC items were reverse scored with higher scores indicating greater burden. Four *Caregiving Demand* items (help with personal care, help with getting around the home, shop for the patient, and help with chores) were scored 1-5 (1 = never, 5 = every day). The remaining *Caregiving Demand* items and all of the *Coping and Supportive Factors* NSOC items were scored 0-1 (no vs. yes). All models adjusted for patient age and gender, caregiver gender, and relationship of caregiver to patient (spouse, child, other). Caregiver age was not included in adjusted analyses because there were 145 observations missing (38.9% of observations). Sensitivity analyses (discussed below) explored the use of caregiver Medicare insurance status as a proxy for caregiver age. After calculating regression coefficients, standardized coefficients and their 95% confidence intervals were computed by multiplying the estimates by the ratio between the standard deviation of the independent variable and the standard deviation of the dependent variable. Thus, each standardized coefficient had a mean of zero and variance of one [13]. This allowed for easy comparison of estimated covariate coefficients measured on different scales.

For all analyses, we used the analytic weights provided with the NSOC to take into account differential probabilities of selection and non-response at the NHATS sample person and caregiver level and statistical software that adjusts standard errors for survey design [13]. As a sensitivity analysis we performed an un-weighted factor analysis; this did not result in substantial changes in results. We performed two sensitivity analyses of regressions examining the association of caregiver burden with the study outcomes. In the first, we included caregiver Medicare status (yes/no) as an independent variable; caregiver Medicare status served as a proxy for older caregiver age since this age variable was missing in almost 40% of observations. In the second sensitivity analysis, we included skin cancer diagnosis (yes/no) as a covariate to examine whether the presence of skin cancer versus other types of cancer was significantly associated with caregiver burden outcomes. Results for these sensitivity analyses are similar to the main analysis, and are presented in Supplemental Tables 2 and 3. For all analyses, we used SAS version 9.4. The standardized regression coefficient graph (Figure 2) was created with R version 3.2.2.

## Results

The characteristics of the 373 included cancer patients and their caregivers are displayed in Table 2. There were 128 (34%) cancer patients who had multiple caregivers; as discussed in the Methods section, only data from the first listed caregiver for these patients were included. Of the caregivers, 247 (66%) were females with an average age of 60 years. The majority of caregivers had Medicare insurance, but almost 30% had private health insurance and 10% were uninsured. The plurality of caregivers was spouses/partners (138, 37%), while a similar number (118, 32%) were daughters. A majority of patients were female with an average age of 82. More than 80% had Medicare coverage, although some also had private insurance. The most common type of cancer reported in this cohort was skin cancer, followed by breast, prostate, gynecologic (cervical, ovarian, or uterine) and colon cancer. No information was provided in the NSOC regarding cancer stage. Using the weights provided with the survey, the 373 observations corresponded to a population of 3,289,832 patient/caregiver dyads. Weighted caregiver and patient descriptive characteristics are presented in the Supplemental Table 1.

### *Exploratory factor analysis of NSOC caregiver burden items*

The factor analysis (using weights provided with the NSOC) with the 20 *Intrapsychic Factors* (caregiver burden) items identified three factors with eigenvalues greater than 1.0 and explained 50% of the variance (scree plot presented in Supplemental Figure 1). The percentage of missing item response was 0.01%. The first factor had 8 items and was termed *emotional burden*; the second factor had 7 items and was termed *psychological burden*; and the third factor termed *relationship with the patient*, had 5 items. The items comprising each factor and the loadings of these items for each factor are presented in Table 1. The highest value of Cronbach's  $\alpha$  (0.83) was for *emotional burden*, while *psychological burden* and *relationship with the patient* showed coefficients of 0.73, and 0.71, respectively. The weighted mean values (with high values indicating greater burden) for the three factors were 23.7 (factor 1), 27.8 (factor 2), and 19.3 (factor 3). As specified in the Methods section, all included items were scored or reversed scored as necessary so that higher factor scores correspond to negative outcomes (higher burden or worse relationship with the patient).

### *Caregiving Demand and Coping and Supportive Factors associated with caregiver burden scales*

Regression analysis results of the associations of the three caregiver burden scales with NSOC items assessing *Caregiving Demand* (management of medical care and assistance with non-medical issues) and *Coping and Supportive Factors* are presented in Table 3. For medical care management, significantly increased caregiver *emotional burden* was associated with providing help with keeping track of medications, help with special diet, help with making appointments, and speaking with medical providers. Increased caregiver *psychological burden* was associated with all of the medical care management activities, while none of these activities significantly affected scores for *relationship with the patient*.

For assistance with non-medical issues, help with bills/banking significantly increased caregiver *emotional burden*. All three non-medical activities (shopping, bills, and chores) were associated with significant increases in *psychological burden* and with better *relationship with the patient* (i.e., lower scores on the *relationship with the patient* scale).

Finally, use of *Coping and Supportive Factors* NSOC items had mixed associations with the scales. Having friends or family to talk to about important things and help with daily activities or help with taking care of the patient were associated with decreased *emotional burden*, *psychological burden*; having friends or family that help with daily activities was also associated with better *relationship with the patient*. In contrast, use of services that took care of the patient or finding financial help for patient were associated with significantly increased *emotional* and *psychological burden*. Having a paid helper and going to a support group were also associated with increased *psychological burden*. Finding financial help for the patient and having a paid helper were associated with a better *relationship with the patient*.

Standardized coefficients for the associations between the three scales and NSOC *Caregiving Demand* items assessing direct patient care activities are presented in Figure 2. In this figure, positive associations indicate that performing the specific patient care activity was associated with greater burden or worse patient relationship. Results indicate significantly higher *emotional burden* for caregivers who help with personal care ( $p < 0.0001$ ), getting around ( $p < 0.0001$ ), and teeth care ( $p = 0.03$ ). For *psychological burden*, significantly greater burden was found for caregivers who help with personal care ( $p < 0.0001$ ), getting around ( $p < 0.0001$ ), teeth care ( $p = 0.002$ ), skin care ( $p < 0.001$ ), shots/injections ( $p = 0.002$ ), and feet ( $p = 0.02$ ).

In contrast, significant negative standardized coefficients, indicating a better *relationship with the patient*, were observed for caregivers providing help with personal care ( $p = 0.004$ ), getting around ( $p < 0.001$ ), exercise ( $p = 0.01$ ), teeth ( $p = 0.02$ ), nails ( $p = 0.004$ ), and skin ( $p = 0.03$ ). These somewhat surprising results indicate that caregivers who help patients with personal care, getting around, and teeth care experience increased emotional and psychological burden but also experience better relationships with their patients.

### Conclusions

We used NHATS and NSOC data from 373 dyads of individuals with cancer and their caregivers (corresponding to a weighted sample of over 3.2 million dyads) to develop three caregiver burden scales: emotional burden, psychological burden, and relationship with patient. Our results indicate that caregivers involved in more personal care for the patient had significantly higher emotional and psychological burden according to several measures. Caregivers also had higher emotional and psychological burden when they were more involved in medical management. This is consistent with previous results indicating that more hours per week of providing care and greater duration of caregiving are also associated with greater burden [1,7], and that more patient unmet needs are predictive of greater unmet needs among caregivers [14].

As predicted by the Klassen et al. model [12], NSOC items measuring *Coping and Supportive Factors* were significantly associated with decreased caregiver burden. Specifically, having friends or family to discuss important things, help with daily activities, and help taking care of the patient were associated with decreased burden. This is similar to the results from previous studies. For example, Butow et al. and Hsu et al. reported that social support was associated with caregiver mental well-being and distress [3,8], and Burton et al. reported that greater desire among caregivers for help from friends and family (suggesting lack of social support) was associated with significantly higher odds of health burden [6]. These results suggest that strategies to increase interactions with and receipt of support from friends and family may substantially decrease burden among caregivers of individuals with cancer.

In contrast to these findings indicating greater burden associated with lack of social support, use of several *Coping and Supportive Factors* was associated with increased caregiver burden. That is, use of services that took care of the patient, financial help for the patient, having a paid caregiver, and going to a support group were associated with significantly increased psychological burden. It is important to note that due to the cross-sectional nature of the survey data, the temporal relationship of these results is unknown. For example, caregivers who experience greater burden may be more likely to use temporary care services and seek financial assistance, rather than use of these services leading to increased burden. This may be related to the finding reported by Burton et al. that caregivers who desired more help from friends and family (and were therefore potentially seeking supports) experienced greater burden [6]. In addition, a recently-published study using the NHATS and NSOC reported that caregivers providing substantial help with health care for older individuals with disabilities were more likely to experience burden; these caregivers were also more likely to use supports [15].

We also found that caregiver's relationship with the patient was improved when the caregiver helped with certain activities (e.g., getting around, feet, and exercise). While this study largely focused on caregiver burden, many caregivers also experience positive aspects of this role. For example, one study reported that 60% of caregiver identified positive aspects of being a caregiver [16]. Spillman et al. also found that two-thirds of caregivers report substantial gains from caregiving, including feeling closer to the recipient [1]. It is possible that improving the caregiver-patient relationship can, by itself, decrease caregiver burden. For example, Fried et al. found increased caregiver burden associated with a desire for more communications with patient [9]; improved communications may therefore be associated with decreased burden. Focusing on activities that involve positive experiences by

caregivers and that improve the caregiver-patient relationship may be important strategies for decreasing caregiver burden.

Wolff et al. [15] recently published a study examining burden among caregivers of older individuals with disabilities, using the same data sources as this study (i.e., the NHATS and NSOC). This study focused on differences in burden for caregivers that provided substantial help with health care versus those that provided some or no help. Similar to results presented in our study, Wolff et al. reported that caregivers providing substantial help were more likely to experience difficulties; these caregivers were also more likely to reduce participation in other activities and to have greater work productivity loss. The comparability of caregiver burden findings using two different patient populations further supports our results.

There are several limitations associated with this study. Data for this study, from the NHATS and NSOC, did not include clinical information such as time since cancer diagnosis and stage at diagnosis, so these factors could not be included in analyses. In addition, these data sets were collected at one time point. We are therefore unable to examine whether the three scales developed for this study change over time, and whether changes in these scales correspond to changes in caregiver activities or use of social supports. This relates to the limitation noted above, that the seemingly-contradictory relationship between use of social supports and increased caregiver burden may be that caregivers with higher levels of burden may be more likely to seek out social services. With the cross-sectional nature of data in the two surveys used, we are unable to clarify this. However, previous studies indicate that caregiver burden is relatively stable over time and is not specific to stage of illness [17]. Furthermore, the data provide in the NHATS and NSOC are based on self-report; no attempt was made to verify responses. However, it is unlikely that this would substantially bias the study's findings.

Despite these limitations, this study provides important new information on caregiver burden for individuals with cancer and offers three potential new scales, developed using a brief set of questions available in the public domain, to assess different aspects of caregiver burden. In addition, previous studies of caregiver burden generally used information from smaller groups of caregivers, often from a single institution or geographic region. This present study is one of the first to provide nationally-representative estimates for caregiver burden and associated predictors among caregivers of individuals with cancer. While further research is needed to develop the psychometric properties of these scales, they may be useful to assess burden among caregivers and to assist in developing and evaluating interventions to decrease caregiver burden.

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Table 1. Factor analysis loadings of the NSOC *Intrapsychic Factors* (caregiver burden) items

<i>Intrapsychic Factors</i> NSOC items	Response Scale (Score Range)	Mean (SD)	Factor 1	Factor 2	Factor 3
Factor 1: Emotional burden					
Thinking about the last month, how often did you feel cheerful?	Every day – never (1-5)	2.2 (1.0)	0.70		
Thinking about the last month, how often did you feel full of life?	Every day – never (1-5)	2.4 (1.0)	0.71		
Over the last month, how often have you felt down, depressed, or hopeless?	Not at all – nearly every day (1-4)	1.5 (0.8)	0.61		
My life has meaning and purpose.	Agree strongly – disagree strongly (1-4)	1.3 (0.6)	0.59		
In general, I feel confident and good about myself.	Agree strongly – disagree strongly (1-4)	1.4 (0.7)	0.72		
I like my living situation very much	Agree strongly – disagree strongly (1-4)	1.7 (1.0)	0.72		
I gave up trying to improve my life a long time ago.*	Agree strongly – disagree strongly (1-4)	1.5 (0.9)	0.45		
Thinking about the last month, how often did you feel lonely?*	Every day – never (1-5)	2.0 (1.2)	0.48		
Factor 2: Psychological burden					

You are exhausted when you go to bed at night.*	Very much – Not so much (1-3)	1.7 (0.8)		0.66	
You have more things to do than you can handle.*	Very much – Not so much (1-3)	1.6 (0.8)		0.71	
You don't have time for yourself.*	Very much – Not so much (1-3)	1.7 (0.8)		0.70	
How often does he/she get on your nerves?*	A lot – not at all (1-4)	2.2 (0.9)		0.39	
Thinking about the last month, how often did you feel upset?*	Every day – never (1-5)	2.4 (0.9)		0.44	
Over the last month, how often have you felt nervous, anxious, or on edge?	Not at all – nearly every day (1-4)	1.7 (0.8)		0.54	
How much enjoy being with patient?	A lot – not at all (1-4)	1.2 (0.7)		0.20	
Factor 3: Relationship with the patient					
How much does patient appreciate what you do for him/her?	A lot – not at all (1-4)	1.2 (0.5)			0.50
Helping has made you more confident about your abilities.	Very much – Not so much (1-3)	1.7 (0.7)			0.66
Helping has taught you to deal with difficult situations	Very much – Not so much (1-3)	1.6 (0.7)			0.63
Helping has brought you closer to him/her.	Very much – Not so much (1-3)	1.4 (0.6)			0.63

Helping gives you satisfaction that he/she is well cared for.	Very much – Not so much (1-3)	1.1 (0.4)			0.49
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\* Reverse scored

Table 2. Characteristics of the 373 caregivers and patients with cancer.

Characteristics	Caregiver (N=373)	Patient (N=373)
Age, median (Range) <sup>a</sup>	60 (19-88)	82 (65-101)
Female, N (%)	247 (66)	232 (62)
Education, N (%)		
None or missing	140 (38)	7 (2)
High school or less	78 (21)	213 (57)
Trade/Technical	19 (5)	27 (7)
Some university	136 (36)	126 (34)
Health insurance, N (%) <sup>b,c,d</sup>		
Medicare	143 (59)	316 (85)
Medicaid	21 (9)	67 (18)
Private health insurance (including TRICARE)	68 (28)	7 (2)
None	25 (10)	34 (9)
Married or partnered, N (%)	110 (29)	
Work for pay in last month, N (%)	118 (32)	
Relationship to patient, N (%)		
Spouse/partner	138 (37)	
Daughter	118 (32)	
Son	56 (15)	
Other relative	45 (12)	
Other nonrelative	15 (4)	
Type of cancer, N (%) <sup>b</sup>		
Skin		114 (31)
Breast		96 (26)
Prostate		64 (17)

Bladder		12 (3)
Cervical, ovarian, uterine		33 (9)
Colon		40 (11)
Kidney		9 (2)
Other		63 (17)

<sup>a</sup> N = 145 caregivers missing

<sup>b</sup> Categories do not add up to 100%. Some subjects may have indicated more than one category

<sup>c</sup> N = 6 caregivers missing

<sup>d</sup> N = 8 patients missing

Table 3. Coefficients and 95% confidence intervals (CI) of the association of medical care management, assistance with non-medical issues, and use of supports with caregiver burden and relationship with patient from adjusted linear regression models.<sup>a</sup>

NSOC <i>Caregiving Demands</i> and <i>Coping and Supportive Factors</i> items	Factor 1: Emotional burden Coefficient (95% CI)	Factor 2: Psychological burden Coefficient (95% CI)	Factor 3: Relationship with the patient Coefficient (95% CI)
<i>Caregiving Demands: Management of medical care</i>			
In the last month, help keeping track of medications	7.5 (4.0, 11.0)***	11.1 (7.6, 14.7)***	-3.4 (-7.4, 0.6)
In the last month, help with special diet	7.9 (3.8, 12.0)**	12.5 (8.4, 16.6) ***	-3.7 (-8.3, 0.9)
In the last year, help making medical appointments	4.7 (0.8, 8.6)*	10.8 (6.9, 14.7) ***	-4.1 (-8.4, 0.2)
In the last year, help speaking with medical provider	7.3 (3.5, 11.1)**	10.0 (6.2, 13.9) ***	-3.0 (-7.3, 1.3)
In the last year, help with other health insurance	3.4 (-0.2, 6.9)	8.8 (5.2, 12.4) ***	1.4 (-2.6, 5.3)
In the last month, help ordering prescribed medicines	-0.2 (-2.0, 1.7)	2.3 (5.2, 12.4) *	-1.3 (-3.3, 0.8)
<i>Caregiving Demands: Assistance with non-medical issues</i>			
In the last month, how often did you shop for patient	1.1 (-0.6, 2.8)	3.0 (1.3, 4.8)**	-3.6 (-5.5, -1.8)**
In the last month, help with bills/banking	4.8 (1.0, 8.7)*	8.6 (4.6, 12.5)***	-5.3 (-9.5, -1.0)*
In the last month, how often did you help with chores	0.7 (-0.5, 1.9)	2.4 (1.2, 3.7) **	-1.7 (-3.0, -0.4)*

NSOC <i>Caregiving Demands and Coping and Supportive Factors</i> items	Factor 1: Emotional burden Coefficient (95% CI)	Factor 2: Psychological burden Coefficient (95% CI)	Factor 3: Relationship with the patient Coefficient (95% CI)
<i>Coping and Supportive Factors</i>			
Do you have friends or family that you talk to about important things	-10.5 (-15.0, -6.1)***	-8.0 (-12.7, -3.3)**	-1.8 (-6.9, 3.3)
Do you have friends or family that help you with your daily activities	-2.0 (-15.0, -6.1)***	-4.6 (-8.3, -0.9)*	-4.2 (-8.2, -0.3)*
In the last year, used services that took care of patient so that you could take some time away from helping	7.4 (2.5, 12.3)*	12.3 (7.3, 17.4)***	-4.5 (-10.0, 1.0)
In the last year, found financial help for patient	6.0 (1.2, 10.9)*	10.1 (5.1, 15.1)***	-5.8 (-11.1, -0.4)*
Do you have friends or family that help you take care of patient	-3.9 (-7.7, -0.1)*	-6.3 (-10.3, -2.4)*	-3.9 (-8.1, 0.4)
In the last year, had a paid helper	4.4 (-0.3, 9.1)	8.6 (3.7, 13.4)**	-5.3 (-10.5, -0.04)*
In the last year, gone to a support group	4.6 (-2.8, 12.0)	15.2 (7.5, 22.8)**	-3.6 (-12.0, 4.8)

<sup>a</sup> All models adjusted for patient gender, caregiver age and gender, and relationship to patient (spouse, child, other).

\* P < 0.05

\*\* P < 0.001

\*\*\* P < 0.0001

## Figure Captions

**Fig. 1** Theoretical model for analyses developing scales quantifying domains of burdens experienced by caregivers, based on the framework of Klassen et al. [12]

**Fig. 2** Standardized coefficients and 95% confidence intervals of associations of burden among caregivers of cancer patients scales from adjusted linear regression models with NSOC *Caregiving Demands* items for direct “personal care” help