Are Disagreements in Caregiver and Patient Assessment of Patient Health Associated with Increased Caregiver Burden in Caregivers of Older Adults with Cancer?

TINA HSU, MATTHEW LOSCALZO, RUPAL RAMANI, STEPHEN FORMAN, LESLIE POPPLEWELL, KAREN CLARK, VANI KATHERIA, REX STROWBRIDGE, REDMOND RINEHART, DAN SMITH, KEITH MATTHEWS, JEFF DILLEHUNT, TAO FENG, DAVID SMITH, CANLAN SUN, ARTI HURRIA
City of Hope National Medical Center, Duarte, California, USA

Disclosures of potential conflicts of interest may be found at the end of this article.

Key Words. Aged • Caregivers • Neoplasms • Patient-caregiver assessment

ABSTRACT

Background. As patients age, caregivers increasingly provide essential support and patient information. We sought to determine if patient-caregiver assessments of patient health differ and if differences contribute to burden in caregivers of older adults with cancer.

Materials and Methods. One hundred patients, aged ≥65, and their caregivers independently assessed patient function, comorbidity, nutrition, social activity, social support, and mental health. Caregivers completed the Caregiver Strain Index (CSI). Patient-caregiver assessments were compared using the Wilcoxon signed rank test and paired t test. Association between caregiver burden and differences between patient-caregiver assessments was examined using generalized linear regression.

Results. Median patient age was 70 (range 65–91) and 70% had advanced disease. Sixty percent of patients reported requiring help with instrumental activities of daily living (IADLs); most had good social support (median Medical Outcomes Study [MOS]-Social Support Survey score 92) and mental health (median Mental Health Inventory score 85).

Caregivers were a median age of 66 (range 28–85), 73% female, 68% spousal caregivers, and 79% lived with the patient. Caregivers rated patients as having poorer physical function (more IADLs dependency \( p = .008 \), lower Karnofsky Performance Status \( p = .02 \), lower MOS-Physical Function \( p < .0001 \)), poorer mental health \( ( p = .0002 ) \), and having more social support \( ( p = .03 ) \) than patients themselves. Three-quarters of caregivers experienced some caregiver burden (mean CSI score 3.1). Only differences in patient-caregiver assessment of the patient's need for help with IADLs were associated with increased caregiver burden \( ( p = .03 ) \).

Conclusion. Patient-caregiver assessments of patient function, mental health, and social support differ. However, only differences in assessment of IADLs dependency were associated with increased caregiver burden. The Oncologist 2017;22:1383–1391

Implications for Practice: As patients age, there is a higher incidence of frailty and cognitive impairments. As a result, caregivers play an increasingly vital role in providing information about patient health to healthcare providers, which is used to help healthcare providers tailor treatments and optimize patient health. These findings highlight that caregiver reporting in older adults with cancer may not replace patient reporting in those older adults who are otherwise able to self-report. Furthermore, clinicians should check for caregiver burden in caregivers who report providing more help with instrumental activities of daily living than patients themselves report and provide appropriate support as needed.

INTRODUCTION

Cancer-related therapy is increasingly administered in the outpatient setting, resulting in increased dependence on caregivers to help with daily activities, such as dressing, bathing, and meal preparation, and to help with cancer-related tasks such as transportation to appointments and managing treatment-related side effects. Older adults in particular, who may have decreased physiologic reserve, may require increased assistance from caregivers during periods of stress, such as during treatment. This can place significant strain on caregivers [1].

Caregiver burden is a subjective feeling of stress that occurs when the demands of caregiving overwhelm caregiver resources to cope with those demands [2, 3]. Patient factors (such as advanced cancer stage [4], health status [5], increased symptom burden, and decreased quality of life [QOL] [6–8]), caregiver factors (such as female gender [6, 7, 9–11], age [5, 10,
12–14], comorbidity [5], relationship to patient [15], education [14], and employment status [10]), and caregiving characteris-
tics (such as increased duration of caregiving [7] and more help
required by the patient [6, 10, 14]) are associated with
increased caregiver burden. This information is typically
obtained from patients or their caregivers. Some of these fac-
tors are subjective and differences can exist between patient
and caregiver perceptions.

A comprehensive geriatric assessment evaluates older
patients on multiple domains (including physical, psychological,
and social) and helps clinicians optimize patient health and tai-
lor treatments appropriately [16, 17]. The accuracy of proxy-
provided information within the context of a geriatric assess-
ment in older patients with cancer has not been studied.
Because these patients are more likely to be frail and have geri-
artic syndromes, such as falls and incontinence, than older
adults without cancer [18], this may represent a population in
which proxy reporting is especially important. In the general
population, differences in patient and proxy assessments of
patient health, distress, and QOL have been associated with
caregiver burden in some studies [19–23], but not in others
[24, 25]. Most studies assessing patient-proxy discrepancies
and caregiver burden have been predominantly in patients
with Alzheimer’s disease or community-dwelling older adults.
However, several key factors are unique to older adults with
cancer, including a higher likelihood of comorbidities, limita-
tions in performing activities of daily living, and poor health,
which may affect assessment results as well as caregiver bur-
den [18]. Given the complexity of this patient population,
assessment may be challenging and caregivers may be at par-
ticularly high risk of caregiver burden. Furthermore, differences
in what the caregiver perceives the patient can do compared
with what the patient can or is doing can potentially lead to
caregiver strain due to the dissonance from the conflicting
perceptions.

We hypothesized that the dissonance caused by a mis-
mash between caregiver and patient assessments may place
these caregivers at higher risk of caregiver burden. We sought
to describe if differences exist in patient and caregiver
assessment of patient health and function, in the form of a
geriatric assessment in older adults with cancer, and describe if
this difference is associated with a higher risk of caregiver
burden.

METHODS
One hundred patient-caregiver dyads were recruited from 134
eligible consecutive patients from the outpatient clinic (50
from the hematology-oncology clinic and 50 from the solid
tumor oncology clinic), representing a participation rate of
75%. Patients aged 65 and older with cancer, who had a pri-
mary caregiver who was also willing to participate, were eligi-
ble. Patients were asked to identify their primary caregiver,
declared as the person who provided the most assistance to the
patient in their health care and daily needs. This was con-
firmed by the caregivers. Caregivers who were <18 years were
excluded. Patients and caregivers who did not speak English
were excluded because some measures have only been vali-
dated in English. Approval from the institutional research and
ethics board and the patient’s oncologist was obtained. A
trained member of the research team recruited and obtained
informed consent from patients and caregivers.

Patient and caregiver sociodemographics and employment
status were obtained via in-person interviews by a member of
the research team. In addition, the caregiver’s relationship to
the patient, cohabitation with the patient, and duration and
time spent caring for the patient were obtained via interview
with the caregiver. Patient and caregiver cognition were
assessed using the Blessed-Orientation-Memory-Concentration
(BOMC) test (Table 1), but patients and caregivers were not
excluded on the basis of their score. The patient’s cancer diag-
nosis, stage, and treatments were gathered via chart review.

Geriatric Assessment Measures
Caregivers and patients completed a self-administered geriatric
assessment, which seeks to identify factors that place the
patient at higher risk of morbidity and mortality and subse-
quently implement potential interventions to decrease this
risk. The domains evaluated included patient functional status,
comorbidities, psychological state, nutrition, social activity,
and social support (Table 1). Caregivers were asked to complete
the questionnaire based on their assessment of the patient. The
measures utilized in this geriatric assessment were chosen
based on the feasibility of obtaining this information through
self-report and their psychometric properties have been fully
described previously [26]. The geriatric assessment was admin-
istered independently to patients and caregivers via a
touchscreen interface.

Caregiver Burden
Caregivers completed the Caregiver Strain Index (CSI), a 13-
item measure of caregiver burden, via the touchscreen inter-
face [27]. This instrument targets the following domains of
caregiver burden: employment, time, financial, physical health,
and social health. The caregiver’s responses establish the presence
of sleep disturbance; inconvenience; physical effort; confine-
ment; family, personal, emotional, and employment disruption;
time pressures; feeling upset from changes in patient behavior
and personality; financial stress; and emotional and psychologi-
cal overload. Answers to each question were dichotomized to
yes = 1 and no = 0, and the sum of all the answers constitutes
the CSI score. Scores range from 0–13, with scores ≥7 indicat-
ing high caregiver burden. This tool was chosen because it is
short and easy to administer and is validated with good con-
struct validity and a reliability coefficient alpha of 0.86.

Patient-Caregiver Agreement
Each pair of patient and caregiver assessments were compared.
There is no standard definition of what constitutes a significant
difference in responses between patients and caregivers. Some
studies have utilized exact agreement [28], whereas others use
exact agreement ± 25% of the scale [29], exact agreement half
standard deviation (SD) [30], or agreement within one category
of choice [28]. We utilized exact agreement for our analysis
(defined as cases in which patient-caregiver total scores on
the assessment tools were identical) but also analyzed the results,
defining differences as those whose scores differed by ± one
SD of the measure.
## Table 1. Composition of geriatric assessment

| Domain and measures used | No. of items | Description | Range of scores |
|--------------------------|--------------|-------------|-----------------|
| **Functional status**    |              |             |                 |
| MOS Physical Function subscale [33] | 10 | Measures limitations in physical activities due to health conditions using 3-point Likert scale | 0–100 ↑ |
| OARS-IADL subscale [34] | 7 | Evaluation of ability to perform tasks needed to live independently at home (i.e., transportation, shopping, medications) using 3-point Likert scale | 0–14 ↑ |
| Self-rated Karnofsky Performance Status | 1 | Self-rated performance status rated on 8-point descriptive scale (“normal” to “severely disabled”) | 0–100 ↑ |
| Number of falls in prior 6 months | 1 | Indicator of the patient’s mobility, gait, and balance |                |
| **Comorbidity** |              |             |                 |
| OARS-Physical health subscale [34] | 15 | Presence of 15 medical conditions and if the condition interferes with the patient’s daily activities | 0–15 |
| **Cognition** |              |             |                 |
| BOMC [36] | 6 | Screen for cognitive impairment; 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** |              |             |                 |
| MHI-17 [37] | 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 [33] | 4 | Measure of social activity limitations due to health conditions using 5-point Likert scale | 0–100 ↑ |
| MOS Social Support Survey [33] | 12 | Measure of perceived social supports using 5-point Likert scale | 0–100 ↑ |

*Administered by the research team to the patient and the caregiver; all other measures completed by caregiver.  
† = higher scores indicate better function and/or outcomes.  
↓ = lower scores indicate better function and/or outcomes.  
Abbreviations: BOMC, Blessed-Orientation-Memory-Concentration; IADL, instrumental activities of daily living; MHI-17, Mental Health Inventory-17; MOS: Medical Outcomes Study; OARS: Older American Resources and Services.

### Statistical Analysis

Patient and caregiver demographics, caregiver burden, and results of the geriatric assessment were summarized using descriptive statistics. Differences between patient and caregiver assessments were calculated as caregiver assessment minus patient assessment. All variables in the geriatric assessment, as assessed by patients and caregivers, were compared, except for patient cognition, which was objectively assessed through testung by the research team rather than by the caregiver. Wilcoxon signed rank test was used for geriatric assessments and paired t test for weight change were used to examine the significance of differences between patient-caregiver assessments. Except for the BOMC tool, we did not utilize any cut-points for evaluation of the tools used in the geriatric assessment because these have not been clearly identified and because normative values for these instruments were established in the general population and may not be applicable to patients with cancer.

The outcome variable, CSI, was analyzed as a continuous variable. For all the geriatric assessments, patient-caregiver agreement variables were considered as categorical variables (agreement, caregivers rated patients as doing worse, or patients rated themselves as doing worse). Generalized linear model (GLM) was used to examine the association between patient-caregiver agreement variables and CSI. The association between CSI and patient/caregiver demographics, cancer characteristics, and caregiver characteristics were also examined univariately to select for potential confounding factors for the multivariate GLM model. Variables with an association of p value <.05 with CSI on univariate analysis were considered to be included in the multivariate model. The final model only retained variables with p value <.05.

Statistical analyses were done using SAS 9.3 (SAS Institute, Cary, NC, https://www.sas.com/en_us/home.html).

### Results

One hundred patient-caregiver pairs were included (Fig. 1). Patient and caregiver characteristics are presented in Table 2. Median patient age was 70 (range 65–91) and median caregiver age was 66 (range 28–85). Most patients had lymphoma (26%), breast cancer (19%), or gastrointestinal cancers (15%). Most patients had advanced disease (70%) and were on treatment (62% chemotherapy). The majority of caregivers were female (73%), 79% lived with the patient, and 68% were spousal caregivers. Five percent of caregivers scored above the threshold for possible cognitive impairment (BOMC ≥11).

### Geriatric Assessment—Patient-reported Assessments

A summary of the results of the patients’ geriatric assessment is shown in Table 3. These are the average scores of assessments done by all caregivers and all patients in the study.
Patients reported a median of 2 comorbid conditions and 39% reported at least 5% unintentional weight loss over the preceding 6 months. Patients reported a median KPS of 90. Despite this, 60% of patients reported needing assistance with at least one of their instrumental activities of daily living (IADL). Patients reported that their social activity was affected by their health (mean Medical Outcomes Study [MOS]-Social Activity score 50.8). Patients generally perceived themselves to be well supported and had high mean scores on assessments of social support and psychological health (mean MOS-Social Support

Table 2. Caregiver and patient demographics

| Variable                        | Caregiver (n = 100), n (%) | Patient (n = 100), n (%) |
|---------------------------------|----------------------------|--------------------------|
| **Age, years**                  |                            |                          |
| Median (range)                  | 66 (28–85)                 | 70 (65–91)               |
| **Ethnicity**                   |                            |                          |
| Hispanic                        | 14 (14.0)                  | 12 (12.0)                |
| Non-Hispanic                    | 84 (84.0)                  | 86 (86.0)                |
| Unknown/Missing                 | 2 (2.0)                    | 2 (2.0)                  |
| **Race**                        |                            |                          |
| White                           | 88 (88.0)                  | 89 (89.0)                |
| Black                           | 10 (10.0)                  | 10 (10.0)                |
| Other                           | 0 (0.0)                    | 1 (1.0)                  |
| Missing                         | 2 (2.0)                    | 2 (2.0)                  |
| **Gender**                      |                            |                          |
| Male                            | 27 (27.0)                  | 53 (53.0)                |
| Female                          | 73 (73.0)                  | 47 (47.0)                |
| **Marital status**              |                            |                          |
| Single (never married)          | 12 (12.0)                  | 6 (6.0)                  |
| Married                         | 81 (81.0)                  | 76 (76.0)                |
| Divorced                        | 3 (3.0)                    | 8 (8.0)                  |
| Widowed                         | 4 (4.0)                    | 10 (10.0)                |
| **Education**                   |                            |                          |
| Less than high school graduate  | 2 (2.0)                    | 5 (5.0)                  |
| High school graduate            | 13 (13.0)                  | 17 (17.0)                |
| College                         | 70 (70.0)                  | 55 (55.0)                |
| Advanced                        | 15 (15.0)                  | 23 (23.0)                |

(continued)

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Table 2. (continued)

| Variable                        | Caregiver (n = 100), n (%) | Patient (n = 100), n (%) |
|---------------------------------|----------------------------|--------------------------|
| **Employment status**           |                            |                          |
| Full or part time               | 23 (23.0)                  | 17 (17.0)                |
| Retired, homemaker, unemployed  | 75 (75.0)                  | 80 (80.0)                |
| Disabled, medical leave         | 1 (1.0)                    | 3 (3.0)                  |
| Student, full or part time      | 1 (1.0)                    | 0 (0.0)                  |
| **Household income**            |                            |                          |
| <$100,000                       | 63 (63.0)                  | 71 (71.0)                |
| ≥$100,000                       | 27 (27.0)                  | 24 (24.0)                |
| Missing                         | 10 (10.0)                  | 5 (5.0)                  |
| **Tumor type**                  |                            |                          |
| Breast                          | NA                         | 19 (19.0)                |
| Lung                            | 4 (4.0)                    | 4 (4.0)                  |
| Gastrointestinal                | 15 (15.0)                  | 15 (15.0)                |
| Genitourinary                   | 5 (5.0)                    | 5 (5.0)                  |
| Other solid tumors              | 8 (8.0)                    | 8 (8.0)                  |
| Lymphoma                        | 26 (26.0)                  | 26 (26.0)                |
| Myeloma                         | 10 (10.0)                  | 10 (10.0)                |
| Leukemia                        | 8 (8.0)                    | 8 (8.0)                  |
| Acute                           | 4 (4.0)                    | 4 (4.0)                  |
| Chronic                         | 2 (2.0)                    | 2 (2.0)                  |
| Other hematologic malignancies  | 1 (1.0)                    | 1 (1.0)                  |
| **Stage**                       |                            |                          |
| Early (curable)                 | NA                         | 29 (29.0)                |
| Advanced (noncurable)           | 70 (70.0)                  | 70 (70.0)                |
| Missing                         | 1 (1.0)                    | 1 (1.0)                  |
| **Treatment**                   |                            |                          |
| Chemotherapy                    | NA                         | 62 (62.0)                |
| Targeted therapy alone          | 34 (34.0)                  | 34 (34.0)                |
| Chemoradiation                  | 2 (2.0)                    | 2 (2.0)                  |
| No treatment                    | 2 (2.0)                    | 2 (2.0)                  |
| **Relationship to patient**     |                            |                          |
| Spouse                          | 68 (68.0)                  | NA                       |
| Adult child                     | 18 (18.0)                  | 18 (18.0)                |
| Other                           | 14 (14.0)                  | 14 (14.0)                |
| **Live with patient**           |                            |                          |
| No                              | 21 (21.0)                  | NA                       |
| Yes                             | 79 (79.0)                  | 79 (79.0)                |

Abbreviation: NA, not applicable.
### Table 3. Geriatric assessment of patient as assessed by patient and caregiver

| Measurement                                 | Patient assessment of self | Caregiver assessment of patient |
|---------------------------------------------|---------------------------|---------------------------------|
| Measurement                                | Mean (SD); Median (range) | Mean (SD); Median (range)       |
| Number of comorbid conditions              | 2.4 (1.6); 2 (0–6)        | 2.4 (1.8); 2 (0–8)              |
| Number of falls                            | 0.4 (0.9); 0 (0–4)        | 0.5 (0.9); 0 (0–4)              |
| Weight change (%)                          | −3.7 (8); −2.7 (−24 to 18) | −2.5 (6.9); 0 (−20 to 15)       |
| % wt loss >5%: 39%                         |                           | % wt loss >5%: 39%, 35%         |
| MOS Physical Function                      | 63 (25); 67 (6–100)       | 54 (28); 56 (0–100)             |
| OARS-IADL                                   | 13 (2.0); 13 (6–14)       | 12 (2.3); 13 (5–14)             |
| Karnofsky Performance Status               | 84 (16); 90 (30–100)      | 81 (16); 90 (30–100)            |
| MOS Social Activity                        | 51 (15); 50 (13–81)       | 55 (19); 56 (0–94)              |
| MOS Social Support                         | 87 (15); 92 (29–100)      | 91 (13); 96 (44–100)            |
| Mental Health Inventory                    | 82 (12); 85 (45–100)      | 77 (16); 82 (13–99)             |
| BOMC                                        | 3.0 (3.4); 2.0 (0–14)     | Not done                        |

*Negative values represent weight loss and positive values represent weight gain.

Abbreviations: BOMC, Blessed-Orientation-Memory Concentration; IADL, instrumental activities of daily living; MOS, Medical Outcomes Study; OARS, Older American Resources and Services; wt, weight.

### Table 4. Caregiver-patient paired assessment differences

| Measurement                                | Number of dyads | Difference in caregiver-patient assessments (caregiver score–patient score) | p value |
|---------------------------------------------|-----------------|---------------------------------------------------------------------------|---------|
| Comorbid conditions                         |                 | Med (range)                                                               |         |
| Total                                       | 100             | 0.00 (−5.00 to 1.00)                                                     | .68     |
| Exact agreement                             | 36              |                                                                           |         |
| Caregiver rates worse                       | 29              | 2.00 (1.00 to 3.00)                                                      |         |
| Patients rates worse                        | 35              | −1.00 (−5.00 to −1.00)                                                   |         |
| Falls                                       |                 |                                                                           |         |
| Total                                       | 91              | 0.00 (−3.00 to 3.00)                                                     | .71     |
| Exact agreement                             | 69              |                                                                           |         |
| Caregiver rates worse                       | 11              | 1.00 (1.00 to 3.00)                                                      |         |
| Patients rates worse                        | 11              | −1.00 (−3.00 to −1.00)                                                   |         |
| Percent weight change                       |                 |                                                                           |         |
| Total                                       | 95              | 0.00 (−18.06 to 20.00)                                                   | .21     |
| Exact agreement                             | 22              |                                                                           |         |
| Caregiver rates worse                       | 27              | 2.61 (0.09 to 20.00)                                                     |         |
| Patient rates worse                         | 46              | −2.91 (−18.06 to −0.08)                                                  |         |
| MOS Physical Function                       |                 | −11.11 (−66.67 to 54.86)                                                 | <.001   |
| Total                                       | 100             |                                                                           |         |
| Exact agreement                             | 10              |                                                                           |         |
| Caregiver rates worse                       | 67              | −16.67 (−66.67 to −5.56)                                                 |         |
| Patients rates worse                        | 23              | 16.67 (3.17 to 54.86)                                                    |         |
| OARS-IADL                                   |                 |                                                                           | .008    |
| Total                                       | 100             | 0.00 (−5.00 to 3.00)                                                     |         |
| Exact agreement                             | 37              |                                                                           |         |
| Caregiver rates worse                       | 43              | −2.00 (−5.00 to −1.00)                                                   |         |
| Patient rates worse                         | 20              | 2.00 (1.00 to 3.00)                                                      |         |
| Karnofsky Performance Status                |                 |                                                                           | .02     |
| Total                                       | 99              | 0.00 (−40.00 to 30.00)                                                   |         |
| Exact agreement                             | 37              |                                                                           |         |
| Caregiver rates worse                       | 39              | −10.00 (−40.00 to −10.00)                                                |         |
| Patient rates worse                         | 23              | 10.00 (10.00 to 30.00)                                                   |         |

(continued)
score of 87.1 and MHI of 82.0, respectively). Four percent of patients scored above the threshold for possible cognitive impairment (BOMC >11). This paper focuses on the results comparing patient and caregiver assessments.

### Geriatric Assessment—Caregiver-Patient Differences

Patient and caregiver assessments were compared for each patient-caregiver dyad (Table 4). Several differences were noted between caregiver and patient assessments of the patient. Similar results were seen whether “agreement” was defined as identical responses or as responses that differed by ± one SD, with the exception of social support, which was no longer significantly different (data not shown). Caregivers were more likely to rate patients as having poorer physical function (lower MOS-Physical Function \( p < .0001 \), requiring more help with IADLs \( p = .008 \), and lower KPS \( p = .02 \)). Caregivers also reported patients having more social support (MOS-Social Support survey, \( p = .03 \)) and having poorer mental health (lower MHI, \( p = .0002 \)). There were no significant differences between the patient and caregiver assessments of the patient’s comorbid conditions, falls, weight change, and social activity (\( p > .05 \)).

### Caregiver Burden

Most caregivers (75%) experienced some degree of caregiver burden (CSI ≥1), with a mean caregiver burden score as measured by the CSI of 3.1 (range 0–13). Fifteen percent of caregivers reported high caregiver burden (CSI ≥7; Table 5) [22]. Caregivers also reported providing a median of 10 hours per week of care and most (61%) had been a caregiver for at least 1 year.

Mean CSI scores by whether patient-caregiver assessments agreed or not are presented in Table 6. Those caregivers who assessed the patient to require more help with their IADLs (Older American Resources and Services [OARS]-IADL) than reported by the patient reported higher caregiver burden (CSI 4.71 vs. 1.89, \( p < .001 \); Table 6). Similar results were found utilizing disagreement as differences ± one SD in assessments (CSI 5.73 vs. 2.23, \( p < .001 \)). There was no significant association between caregiver burden and caregiver-patient assessments for other geriatric assessment measures.

For patient-related variables (demographics, cancer characteristics, and patient-reported geriatric assessment results), patient-reported KPS and weight change were negatively.

### Table 4. (continued)

| Measurement                  | Number of dyads | Difference in caregiver-patient assessments (caregiver score–patient score) | \( p \) value |
|------------------------------|-----------------|------------------------------------------------------------------------------|--------------|
| MOS Social Activity          |                 |                                                                              |              |
| Total                        | 98              | 6.25 (−75.00 to 50.00)                                                      | .08          |
| Exact agreement              | 5               |                                                                             |              |
| Caregiver rates worse        | 37              | −18.75 (−75.00 to −6.25)                                                    |              |
| Patient rates worse          | 56              | 18.75 (6.25 to 50.00)                                                       |              |
| MOS Social Support Survey    |                 |                                                                              |              |
| Total                        | 98              | 0.00 (−33.33 to 54.55)                                                      | .04          |
| Exact agreement              | 17              |                                                                             |              |
| Caregiver rates worse        | 34              | −6.67 (−33.33 to −2.08)                                                     |              |
| Patient rates worse          | 47              | 10.42 (2.08 to 54.55)                                                       |              |
| Mental Health Inventory      |                 | −5.00 (−54.41 to 38.12)                                                     | .002         |
| Total                        | 97              |                                                                             |              |
| Exact agreement              | 0               |                                                                             |              |
| Caregiver rates worse        | 59              | −10.51 (−54.41 to −0.88)                                                    |              |
| Patient rates worse          | 38              | 6.63 (0.22 to 38.12)                                                        |              |

Abbreviations: IADL, instrumental activities of daily living; MOS, Medical Outcomes Study; OARS, Older American Resources and Services.

### Table 5. Caregiver burden summary

| Measurement                  | Descriptive statistics |
|------------------------------|------------------------|
| Caregiver Strain Index       | Mean 3.05              |
|                              | Median 2               |
|                              | SD 3.2                 |
|                              | Range 0–13             |
|                              | % 25%                  |
|                              | 1–3 43%                |
|                              | 4–6 17%                |
|                              | 7+ 15%                 |
| Hours/week                   | Mean 21.7              |
|                              | Median 10              |
|                              | SD 30.5                |
|                              | Range 0–168            |

\( n = 100, n (\%) \)

### Table 6. Caregiver burden by agreement

| Measurement                  | \( p \) value |
|------------------------------|--------------|
| MOS Social Activity          |              |
| Exact agreement              |              |
| Caregiver rates worse        |              |
| Patient rates worse          |              |
| MOS Social Support Survey    |              |
| Exact agreement              |              |
| Caregiver rates worse        |              |
| Patient rates worse          |              |
| Mental Health Inventory      |              |
| Exact agreement              |              |
| Caregiver rates worse        |              |
| Patient rates worse          |              |

Abbreviation: SD, standard deviation.
associated with CSI on univariate analysis (p < .05). Among caregiver-related variables (demographics, caregiving characteristics, and results from the caregiver’s assessment of the patient), caregiver age, race and/or ethnicity, employment status, and caregiver-reported measures of patient physical function (OARS-IADL, MOS-Physical Function, and KPS) were negatively associated with CSI (p < .05). After adjustment for these variables, caregivers who reported patients as requiring more help with IADLs continued to experience increased caregiver burden (CSI 4.04 vs. 2.51, p = .026) compared with caregivers whose assessment agreed with the patient.

**DISCUSSION**

Caregivers and older adults with cancer differed in their assessment of the patient’s physical function, with caregivers reporting that patients needed more help with their IADLs and had poorer physical function than patients reported. As caregivers of older adults often provide information about patient health and function to clinicians, particularly as cognitive impairment and frailty are more common with increasing age, this is important to consider and may have significant implications as to how clinicians interpret patient performance status, which may influence treatments offered to the patient. Moreover, these

| Measurement                        | Number of dyads | Mean Caregiver Strain Index | p value |
|-----------------------------------|----------------|-----------------------------|---------|
| **Comorbid conditions**           |                |                             |         |
| Exact agreement                   | 36             | 3.06                        | Ref     |
| Caregiver rates worse             | 29             | 3.83                        | .33     |
| Patient rates worse               | 35             | 2.40                        | .39     |
| **Falls**                         |                |                             |         |
| Exact agreement                   | 69             | 2.84                        | Ref     |
| Caregiver rates worse             | 11             | 4.45                        | .40     |
| Patient rates worse               | 11             | 3.72                        | .13     |
| **Percent weight change**         |                |                             |         |
| Exact agreement                   | 22             | 2.59                        | Ref     |
| Caregiver rates worse             | 27             | 2.85                        | .78     |
| Patient rates worse               | 46             | 3.17                        | .48     |
| **MOS Physical Function**         |                |                             |         |
| Exact agreement                   | 10             | 3.00                        | Ref     |
| Caregiver rates worse             | 67             | 3.34                        | .75     |
| Patient rates worse               | 23             | 2.22                        | .52     |
| **OARS-IADL**                     |                |                             |         |
| Exact agreement                   | 37             | 1.89                        | Ref     |
| Caregiver rates worse             | 43             | 4.70                        | <.001*  |
| Patient rates worse               | 20             | 1.65                        | .76     |
| **Karnofsky Performance Status** |                |                             |         |
| Exact agreement                   | 37             | 3.27                        | Ref     |
| Caregiver rates worse             | 39             | 3.33                        | .93     |
| Patient rates worse               | 23             | 2.22                        | .22     |
| **MOS Social Activity**           |                |                             |         |
| Exact agreement                   | 5              | 3.80                        | Ref     |
| Caregiver rates worse             | 37             | 4.70                        | .51     |
| Patient rates worse               | 56             | 1.77                        | .13     |
| **MOS Social Support Survey**     |                |                             |         |
| Exact agreement                   | 17             | 2.35                        | Ref     |
| Caregiver rates worse             | 34             | 3.44                        | .25     |
| Patient rates worse               | 47             | 2.83                        | .60     |
| **Mental Health Inventory**       |                |                             |         |
| Exact agreement                   | 0              |                             |         |
| Caregiver rates worse             | 59             | 3.36                        | Ref     |
| Patient rates worse               | 38             | 2.47                        | .19     |

*p < .05.

Abbreviations: IADL, instrumental activities of daily living; MOS, Medical Outcomes Study; OARS, Older American Resources and Services; Ref, Reference group.
differences in assessments between caregivers and patients were associated with an increased likelihood of greater caregiver burden, which has important implications given the growing number of caregivers caring for an aging cancer population.

We found that caregiver and patient assessments differ in some but not all domains of patient health and function. Patient and caregiver assessments were more likely to differ with respect to subjective health, such as the patient’s mental health and social support, with no differences seen in more observable areas such as number of falls and weight loss, which has also been described in prior studies [20, 21, 24, 31–36]. Unlike prior studies, however, caregiver-patient assessments differed with respect to physical health and function. This may be because patients in this study were of intermediate physical health, as evidenced by the fact that although patients reported a median KPS of 90, 60% reported needing assistance with at least one of their IADLs, a finding consistent with prior studies [37]. These patients may be harder for caregivers to assess accurately compared with patients who were in either perfect health or very poor health (e.g., completely dependent) [24].

Most caregivers experienced some level of caregiver burden. However, caregivers who reported that patients required more help with their IADLs than patients themselves reported were more likely to experience higher levels of caregiver burden. This was true even after taking into account factors associated with caregiver burden in other studies, such as poor physical function and functional dependence [6, 10, 14]. It is unclear how much of a difference in patient-caregiver assessment of IADLs is clinically significant. Further research is required to evaluate this. At this time, clinicians should consider screening for caregiver burden in those caregivers who report the patient as being more dependent than patients themselves do.

There are few other studies that have looked at differences in patient-caregiver assessments in older adults with cancer and their association with caregiver burden, but similar findings have been seen in both the general cancer literature and geriatric studies. Several studies of cancer patients have suggested an association between caregiver burden and differences in caregiver-patient assessments [31, 38–40], although none have looked specifically at patient function and health within the context of a geriatric assessment. However, the association between caregiver burden and differences in patient and caregiver assessments about the need for help with IADLs has been seen in a study of community-dwelling adults aged 65 and over [21]. The patients’ lack of awareness of impairments in their IADLs may be a source of stress for caregivers [41]. This may be due to concern about patient safety and/or conflict with the patient about their independence [42].

There are several limitations to our study. Because three-quarters of caregivers were women and the majority of participants were non-Hispanic, these results may not generalize to all caregivers. Additional research in males and patients of ethnic diversity is needed. Importantly, because all patients were fit enough to complete the geriatric assessment, it is unclear whether the results would be applicable to assessment of those patients who are too unwell to respond, a situation in which the accuracy of a caregiver response would be most relevant. Because we did not include an objective assessment of patient health or function, it is difficult to determine whether caregivers experience more burden because there is a discrepancy in assessments, or whether the presence of caregiver burden itself influences caregiver perception of patient function and health. Prior studies have posited that differences in assessments may be due to the tendency of patients to underestimate the level of support and help they require [43]. On the other hand, a study of patients with dementia found that although caregiver report was strongly associated with some aspects of patient function (walking, dressing), it correlated less strongly for others (toileting, shopping), suggesting that caregiver assessments are not always correct either [44]. It is likely that both are important factors to consider, with a bidirectional relationship as suggested by another study [38]. Lastly, due to the modest sample size, our analysis focused on the association between caregiver burden and patient-caregiver assessments for each measure as a whole, rather than on differences in assessment for individual components of each measure.

CONCLUSION

Discrepancies were observed between patient and caregiver assessments in patient physical function, and these discrepancies were associated with increased caregiver burden. Caregivers who perceived patients to be more dependent for their IADLs than patients did were more likely to experience caregiver burden. Based on our results, we suggest that assessing both patients and caregivers is important when utilizing caregivers as proxies for understanding patient function and when assessing for burden in caregivers of older adults with cancer. Further research investigating caregiver burden and caregiver-patient assessment, with the addition of an objective marker of patient health and function, would be helpful to better understand whether caregiver burden is the cause or consequence of differences in caregiver-patient perception of patient health.

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AUTHOR CONTRIBUTIONS

Conception/design: Matthew Loscalzo, Stephen Forman, Leslie Popplewell, Karen Clark, Tao Feng, David Smith, Arti Hurria

Provision of study material or patients: Tina Hsu, Stephen Forman, Leslie Popplewell, Rex Strowbridge, Redmond Rinehart, Dan Smith, Keith Matthews, Jeff Dillehunt, Arti Hurria

Collection and/or assembly of data: Tina Hsu, Rupal Ramani, Stephen Forman, Leslie Popplewell, Vani Katheria, Rex Strowbridge, Redmond Rinehart, Dan Smith, Keith Matthews, Jeff Dillehunt, Arti Hurria

Data analysis and interpretation: Tina Hsu, Matthew Loscalzo, Karen Clark, Tao Feng, David Smith, Canlan Sun, Arti Hurria

Manuscript writing: Tina Hsu, Matthew Loscalzo, Karen Clark, Tao Feng, David Smith, Canlan Sun, Arti Hurria

Final approval of manuscript: Tina Hsu, Matthew Loscalzo, Rupal Ramani, Stephen Forman, Leslie Popplewell, Karen Clark, Vani Katheria, Rex Strowbridge, Redmond Rinehart, Dan Smith, Keith Matthews, Jeff Dillehunt, Tao Feng, David Smith, Canlan Sun, Arti Hurria

DISCLOSURES

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