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## Needs of Older Caregivers of Patients with Advanced Cancer

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### Abstract

**OBJECTIVES**—To determine whether age or stage of cancer can be used to identify caregivers at high risk for excessive burden or distress.

**DESIGN**—Descriptive data collected as part of a psychosocial research registry, comparing younger caregivers with older and caregivers of early-stage patients with those of later stage.

**PARTICIPANTS**—Caregivers of newly diagnosed adult cancer patients.

**MEASUREMENTS**—Caregiver Reaction Assessment (CRA), the Profile of Mood States (POMS), single-item indicators from the Patient Reported Outcome Measurement Information System set, and the Medical Outcomes Study Social Support (MOS-SS) Scale. Patient information was obtained from the medical record.

**RESULTS**—Younger caregivers and caregivers of patients with Stage I and II cancer identified a greater lack of family support than older caregivers and caregivers of patients with Stage III and IV cancer. Significant regression models were found for three CRA subscales (Disrupted Schedule, Lack of Family Support, and Health Problems), as well as for the POMS depression and fatigue scales. Caregiver social support (MOS-SS) made the only significant contribution to the models. There were significant differences between caregivers with high and low levels of social support on almost all measures of well-being.

**CONCLUSION**—Incorporating formal assessment of social support may be useful in identifying at-risk caregivers. In addition, there is a need to further investigate which dimensions of social support are most strongly related to measures of well-being.

### Keywords

caregiver burden; caregiver distress; social support

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**Author Contributions:** B. Daly: principal investigator; directed all aspects and drafted major portion of manuscript. S. Douglas: co-investigator; responsible for statistical analysis and editing manuscript. A. Lipson: project manager; supervised data acquisition and entry; edited manuscript. H. Foley: research nurse, participated in design and evaluation meetings; contributed to outline and editing of manuscript.

All disciplines involved in cancer care (e.g., oncologists, nurses, social workers, clergy) have formally recognized the importance of addressing quality of life as an outcome of cancer treatment.<sup>1,2</sup> There has been considerable foundational work in examining the influence of age on the clinical pattern and treatment of cancers in older patients, but there has been almost no exploration of the needs and burdens of family caregivers of older patients.

The Ireland Cancer Center (ICC) at University Hospitals Case Medical Center initiated a patient and family psychosocial research registry for adults newly diagnosed with cancer and their family caregivers in 2006.<sup>3</sup> The availability of data from the registry has enabled questions related to the psychosocial components of the cancer experience to be explored. Specifically, the objective was to determine whether age or stage of cancer could be used to identify caregivers at high risk for excessive burden or distress. It was hypothesized that older caregivers might be more vulnerable to the burdens of caregiving because of their own physical health problems or more-limited resources. Previous research has shown that some measures of caregiver well-being are related to patient physical condition; therefore, the objective was also to explore whether the patient's cancer stage might be helpful in identifying caregivers who were more likely to exhibit negative reactions or distress.<sup>4</sup>

## METHOD

Registered nurse research assistants (RAs) reviewed the daily schedule of appointments at the ICC and identified new patients scheduled for their first chemotherapy or radiation appointment. After explaining the purpose of the registry and obtaining written consent, the RA interviewed the patient and caregiver separately while they waited for their appointment or during the treatment. "Caregiver" was defined as the person who the patient identified as providing the greatest amount of care and support. The interview consisted of a variety of questions about quality of life and psychosocial matters.<sup>3</sup> For this report, the caregiver outcomes on the Caregiver Reaction Assessment (CRA), the Profile of Mood States (POMS), single item indicators from the Patient Reported Outcome Measurement Information System (PROMIS) set, and the Medical Outcomes Study Social Support (MOS-SS) Scale were examined.<sup>5-8</sup> Patients and their family caregivers were interviewed at baseline and 3 and 12 months.

## RESULTS

Table 1 shows the demographic characteristics of the total sample of patients and caregivers. Although 411 patients were enrolled, only 230 (55.9%) had caregivers willing and able to participate. The most common reasons for lack of caregiver data were absence of any identified person as a "caregiver," reluctance of patients to burden their family member by inviting them to participate in the registry, and inability to contact the family members who did not accompany the patients to appointments.

To explore the influence of caregiver age on caregiver well-being, caregivers were first categorized into three groups: 65 and younger, 66 to 75, and 76 and older. There were no significant differences between the groups on caregiver outcomes on any subscale of the

CRA, the POMS, or the MOS-SS, although the oldest caregiver group had the lowest scores on all measures of distress and burden. Because there were only 17 subjects in the oldest group, the comparison was repeated after recategorizing subjects into those younger than 65 (n = 163) and those aged 65 and older (n = 67). Again there were no statistically significant differences, but the older group demonstrated lower scores on all distress measures and higher or better scores on social support.

The influence of patient cancer stage on caregiver outcomes was next examined. Patients with early-stage cancers (Stage I, II, or local) were first compared with patients with late-stage (III, IV, or advanced) in terms of patient well-being variables, including their Karnofsky score, Functional Assessment of Cancer Therapy—General (FACT-G) total, FACT-Spirituality, POMS subscales, the single-item quality-of-life question from the PROMIS series, and the MOS-SS Scale. There were no significant differences on any of the measures. As might be expected, given this finding, there were also no differences between caregivers of patients with early- and late-stage cancer on caregiver outcomes except for the CRA subscale Lack of Family Support, which was higher in the early-stage group. This indicated that caregivers of patients with Stage I and II cancers identified a greater lack of family support than caregivers of patients with Stage III and IV cancers. Given that most patients were in reasonably good overall physical and emotional condition when initially diagnosed, one would not expect to see much difference between caregiver outcomes at this time. The comparison was repeated at the second data collection point, 3 months after the beginning of treatment. Again, the only difference was in the Lack of Family Support subscale, but the advanced cancer group at this time had the higher score. From baseline to 3 months, caregivers of patients with early-stage cancer reported lower scores on this subscale, and caregivers of later-stage patients reported higher scores. The opposing direction of change may reflect growing needs of caregivers of later-stage patients for support as the patients' physical conditions began to deteriorate, in contrast to a gradual reduction in the anxiety of caregivers of early-stage patients.

Because it appeared that neither age nor cancer stage was a strong influence on caregiver outcomes, a number of linear regressions were performed, with patient age, cancer stage, Karnofsky score, total FACT-G score, and caregiver age and social support as independent variables and care-giver scores on the CRA, POMS, and PROMIS quality-of-life question as dependent variables. Significant predictive models were found for the outcomes of three CRA subscales (Disrupted Schedule, Lack of Family Support, and Health Problems), as well as for the POMS depression and fatigue scales. In each of these five models, caregiver social support (MOS-SS) made the only significant contribution to the model.

Given these results, which suggest that social support may play the most significant role in caregiver outcomes, caregivers were compared according to their level of social support. The group was divided using the MOS-SS Study sample mean of 4.2 into those with a score of 4 or below and those with a score above 4. As can be seen on Table 2, there were significant differences between the groups on almost all caregiver measures of well-being.

Finally, an additional linear regression analysis was performed to determine whether there were significant predictors of the level of social support. Regressing the MOS-SS score on caregiver age, sex, employment status, and income did not produce a significant model.

## DISCUSSION

These results suggest that neither age nor patient cancer stage is an important predictor of measures of caregiver distress, although social support was shown to be influential in identifying caregivers likely to experience more emotional distress and burden of caregiving. In particular, the high scores on the POMS total mood disturbance point to the importance of continuing to work toward reliable and efficient ways to identify caregivers who can benefit from formal interventions. Incorporating formal assessment of social support may be an important starting point, and the change in perceived lack of support for late-stage patients, comparing the first time point with the second, indicates the need for repeated assessment. In addition, there is a need to further investigate which dimensions of social support are most strongly related to measures of well-being as part of the necessary effort to design and test interventions to improve caregiver outcomes.

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**Table 1**

Patient (n = 411) and Caregiver (n = 230) Characteristics

<b>Variable</b>	<b>Patient</b>	<b>Caregiver</b>
Age, mean $\pm$ standard deviation	59.6 $\pm$ 12.5	56.9 $\pm$ 11.6
Female, n (%)	234 (56.9)	144 (62.6)
Caucasian, n (%)	310 (75.4)	199 (86.5)
Type of cancer, n (%)		
Blood	70 (17.0)	
Lung	69 (16.8)	
Gyn	49 (11.9)	
Breast	44 (10.7)	
Other	178 (43.3)	
Stage, n (%)		
I or II or local	113 (33.4)	
III or IV or advanced	225 (66.6)	
Relationship of caregiver to patient, n (%)		
Spouse		152 (66.1)
Daughter		33 (14.3)
Son		8 (3.5)
Sibling		7 (3.0)
Other		30 (13.0)

Gyn = gynecological.

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**Table 2**

Differences in Outcome Measures Between Caregivers with Low (&lt; 4) and High (&gt; 4) Social Support Scores\*

Variable	Low Social Support (<4)	High Social Support (>4)	P-Value
Patient Reported Outcome Measurement Information System Quality of Life item	3.79	4.31	.03
Profile of Mood State			
Angry	4.64	2.98	.04
Depressed	4.21	2.69	.02
Total mood disturbance	14.42	6.57	.03
Caregiver Reaction Assessment			
Disrupted schedule	3.53	3.07	.02
Financial concerns	2.65	2.04	.08
Lack of family support	2.30	1.64	<.001
Health problems	2.27	1.77	.001

\* Total score on Medical Outcomes Social Support Scale used to categorize subjects.

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