The Burden of Symptoms Among Community-Dwelling Older Persons With Advanced Chronic Disease

Lisa M. Walke, MD; William T. Gallo, PhD; Mary E. Tinetti, MD; Terri R. Fried, MD

Background: Little is known about the frequency and range of symptoms experienced by community-dwelling older persons with advanced chronic disease who are not enrolled in hospice. The objectives of our study were to determine (1) the prevalence of a range of symptoms among older persons with advanced chronic disease and (2) whether the prevalence of symptoms is similar across diagnoses.

Methods: This was a cross-sectional study of the symptoms reported by 226 community-dwelling persons 60 years or older with advanced chronic obstructive pulmonary disease (COPD), cancer, or congestive heart failure (CHF). Symptoms were assessed using the Edmonton Symptom Assessment System.

Results: Virtually all participants (86%) experienced at least 1 symptom that rated moderate or severe, and most (69%) experienced 2 or more symptoms. The symptoms reported by the greatest proportion of participants were limited activity (61%), fatigue (47%), and physical discomfort (38%). Participants with COPD had a higher unadjusted mean ± SD number of moderate or severe symptoms (3.3 ± 2.1) than did participants with cancer (2.6 ± 1.8; P = .03) or CHF (2.0 ± 1.7; P < .001). After we adjusted for sociodemographic factors, compared with participants with CHF, participants with cancer experienced 38% (95% confidence interval, 9%-75%) more moderate or severe symptoms and participants with COPD experienced 71% (95% confidence interval, 37%-114%) more moderate or severe symptoms.

Conclusions: Most community-dwelling older persons with advanced COPD, cancer, or CHF experienced multiple moderate or severe symptoms. The clinical care of community-dwelling older persons with advanced chronic illnesses would be enhanced by the identification and alleviation of the range of symptoms they experience.

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ure (CHF) and (2) whether the prevalence of symptoms is similar across diagnoses.

**METHODS**

**PARTICIPANTS**

Sequential medical charts of community-dwelling persons 60 years or older with a primary diagnosis of COPD, cancer, or CHF receiving outpatient care in 3 pulmonary, 4 oncology, and 6 cardiology practices in southern Connecticut, in addition to 2 Veterans Affairs (VA) clinics, were screened for eligibility. We chose to focus on COPD, cancer, and CHF because they are common and important causes of morbidity and mortality in the older population. Sequential medical charts of inpatients at 3 hospitals—a university teaching hospital, a community hospital, and a VA hospital—were also screened for eligibility. Participants were selected according to objective criteria for advanced disease, defined by the clinical criteria established by the Connecticut Hospice for those screened while they were inpatients or the criteria used in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) for those screened during hospitalization. The criteria used to define advanced disease were based on objective measures such as disease status, medication use, and physiological status. The complete diagnosis-specific entry criteria are listed here.

- **Chronic Obstructive Pulmonary Disease**
  1. Two of the following: PCO₂ of ≥45 mm Hg or greater or oxygen saturation of 90% or lower when breathing room air; cor pulmonale; respiratory failure episode (with intubation) prior year; FEV₁ (forced expiratory volume in 1 second) of lower than 0.5 L; polycythemia (hematocrit >53%); or
  2. Hospitalization within the past 6 months with breathlessness, respiratory failure, or mental status change as the main reason for hospital admission and PO₂ of ≤60 mm Hg or lower and PCO₂ of 50 mm Hg or greater if patient is receiving supplemental oxygen.

- **Congestive Heart Failure**
  1. New York Heart Association class III or IV and use of 2 of the following 4 classes of medications: diuretics; inotropics; angiotensin-converting enzyme inhibitors; other vasodilators; or
  2. Left ventricular ejection fraction of 20% or lower and use of 2 of the following 4 classes of medications: diuretics; inotropics; angiotensin-converting enzyme inhibitors; other vasodilators; or
  3. Hospitalized and use of 2 of the following 4 classes of medications: diuretics; inotropics; angiotensin-converting enzyme inhibitors; other vasodilators.

- **Cancer**
  1. All patients with brain cancer, liver cancer, inoperable non–small cell lung carcinoma lung cancer, pancreatic cancer, or gallbladder cancer; or
  2. Patients with these cancers if they have had 1 hospitalization or more for their cancer: metastatic colon cancer or stage III or IV non–small cell lung cancer (involvement of mediastinum, hilum, peribronchial nodes, pleural space, or distant metastases); or
  3. Patients with these cancers if first-line therapy has failed and limited response expected to second-line therapy: breast cancer, colorectal cancer, head and neck cancer, stomach cancer, esophageal cancer, melanoma, leukemia, ovarian cancer, prostate cancer, renal cancer, sarcoma, lung cancer, myeloma, or lymphoma.

Screening was stratified by diagnosis to identify approximately equal numbers of participants with each of the 3 diagnoses. Persons enrolled in hospice prior to screening were excluded. The human investigations committee of each hospital approved the study protocol. All participants provided written informed consent.

After the medical chart review process, 548 potential participants were identified and received a telephone screen to determine whether they were dependent in at least 1 instrumental activity of daily living (eg, using the telephone or taking medications), an additional inclusion criterion chosen to confirm the selection of persons with advanced disease, and to determine whether they met any exclusion criteria. Telephone screens were not conducted for 30 persons because of physician refusal; 24 persons who died before telephone screening; 6 persons who could not be reached; and 19 persons who declined screening. Of the 469 potential participants who received a telephone screen, 108 persons did not require assistance with at least 1 instrumental activity of daily living. Of the remaining 361, we excluded 76 persons with cognitive impairment by the Short Portable Mental Status questionnaire and/or the Executive Interview (EXIT) and 6 persons who were not full time Connecticut residents. Of the 279 eligible participants, 2 died before enrollment and 51 declined participation. Participants and nonparticipants did not differ according to age or sex. A greater proportion of eligible participants with COPD (25%) declined participation compared with eligible CHF (8%) or cancer (19%) participants (P = .02).

To permit time for recovery from their acute illness or chronic illness exacerbation, participants identified during hospitalization were interviewed 2 months after discharge.

**MEASURES**

**Outcome Variables**

The outcome variables, Edmonton Symptom Assessment System (ESAS) responses, were obtained during in-home interviews. Participants rated the severity of 10 symptoms—limited activity, fatigue, physical discomfort, shortness of breath, pain, anxiety, problems with appetite, feelings of depression, lack of well-being, and nausea—in the prior 24 hours. The ESAS has been validated in a population of older persons with advanced disease. We modified the original visual analog scale, so that symptoms were rated on a 4-point scale (not present, mild, moderate, and severe), which allowed participants to provide verbal rather than written responses. Participants provided completely subjective responses; their symptoms were not framed by comparisons with either objective signs or their premorbid status. To provide a conservative estimate of symptom burden, we only examined symptoms rated as moderate or severe.

**Descriptive Variables/Covariates**

Participants provided information regarding their sociodemographic characteristics (age, race, educational background, marital status, housing situation, and income level), functional status (measured using the activities of daily living scale) and health care utilization (number of hospitalizations) in the prior 12 months.

**STATISTICAL ANALYSIS**

We described participant characteristics using univariate statistics. To obtain a measure of symptom burden, we created a
### Table 1. Description of 226 Participants

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>COPD† (n = 81)</th>
<th>Cancer† (n = 79)</th>
<th>CHF (n = 66)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean ± SD, y</td>
<td>72 ± 7</td>
<td>72 ± 7</td>
<td>75 ± 8</td>
</tr>
<tr>
<td>Female</td>
<td>41 (50)</td>
<td>34 (43)</td>
<td>22 (33)</td>
</tr>
<tr>
<td>VA recruitment site</td>
<td>28 (35)</td>
<td>28 (35)</td>
<td>27 (41)</td>
</tr>
<tr>
<td>White</td>
<td>75 (93)</td>
<td>72 (92)</td>
<td>58 (88)</td>
</tr>
<tr>
<td>Education, mean ± SD, y</td>
<td>12 ± 3</td>
<td>12 ± 3</td>
<td>12 ± 3</td>
</tr>
<tr>
<td>Married</td>
<td>44 (54)</td>
<td>49 (62)</td>
<td>37 (56)</td>
</tr>
<tr>
<td>Lives alone</td>
<td>21 (26)</td>
<td>13 (16)</td>
<td>20 (30)</td>
</tr>
<tr>
<td>Not enough money</td>
<td>6 (8)</td>
<td>4 (5)</td>
<td>9 (15)</td>
</tr>
<tr>
<td>at the end of the month</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥1 ADL disability</td>
<td>38 (47)</td>
<td>24 (30)</td>
<td>23 (35)</td>
</tr>
<tr>
<td>≥2 Hospitalizations</td>
<td>40 (49)</td>
<td>25 (32)</td>
<td>41 (62)</td>
</tr>
</tbody>
</table>

*Abbreviations: ADL, activities of daily living; CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease; VA, Veterans Affairs.

†Data are given as number (percentages [rounded to the nearest whole number]) of participants per diagnosis unless otherwise specified.

‡Reference group is CHF.

### Table 2. Symptom Prevalence in 226 Participants

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Overall</th>
<th>COPD† (n = 81)</th>
<th>Cancer† (n = 79)</th>
<th>CHF (n = 66)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limited activity</td>
<td>138 (61)</td>
<td>49 (61)</td>
<td>44 (56)</td>
<td>45 (68)</td>
</tr>
<tr>
<td>Fatigue</td>
<td>106 (47)</td>
<td>40 (49)</td>
<td>38 (48)</td>
<td>28 (42)</td>
</tr>
<tr>
<td>Physical discomfort</td>
<td>85 (38)</td>
<td>36 (44)†</td>
<td>31 (39)</td>
<td>18 (27)</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>80 (35)</td>
<td>53 (65)§</td>
<td>15 (19)</td>
<td>12 (18)</td>
</tr>
<tr>
<td>Pain</td>
<td>62 (27)</td>
<td>23 (28)</td>
<td>26 (33)</td>
<td>13 (20)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>42 (19)</td>
<td>26 (32)§</td>
<td>15 (19)</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Problems with appetite</td>
<td>30 (13)</td>
<td>9 (11)</td>
<td>14 (18)</td>
<td>7 (11)</td>
</tr>
<tr>
<td>Feelings of depression</td>
<td>25 (11)</td>
<td>14 (17)</td>
<td>7 (9)</td>
<td>4 (6)</td>
</tr>
<tr>
<td>Lack of well-being</td>
<td>22 (10)</td>
<td>11 (14)</td>
<td>8 (10)</td>
<td>3 (5)</td>
</tr>
<tr>
<td>Nausea</td>
<td>9 (4)</td>
<td>3 (4)</td>
<td>5 (6)</td>
<td>1 (2)</td>
</tr>
</tbody>
</table>

*Abbreviations: CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease.

†Data are given as number (percentages [rounded to the nearest whole number]) of participants per diagnosis unless otherwise specified.

‡Reference group is CHF.

### RESULTS

**PARTICIPANT CHARACTERISTICS**

Participants’ sociodemographic characteristics, functional status and health care utilization in the prior 12 months are described in Table 1. Compared with participants with CHF, participants with COPD were more likely to be female (P = .04). Participants with cancer were less likely to either live alone (P = .05) or report 2 or more hospitalizations in the prior 12 months (P < .001) compared with participants with CHF.

**OVERALL SYMPTOM PREVALENCE**

Among the 226 participants, 195 (86%) experienced at least 1 moderate or severe symptom. The symptoms reported by the greatest proportion of participants were limited activity (61%), fatigue (47%), and physical discomfort (38%) (Table 2). Among the 195 participants who experienced symptoms, 39 (20%) had 1 symptom, 51 (26%) had 2 symptoms, 33 (17%) had 3 symptoms, 32 (16%) had 4 symptoms, and 40 (21%) had 5 or more symptoms.

**SYMPTOM PREVALENCE BY DIAGNOSIS**

Participants with COPD had a significantly higher unadjusted mean ± SD number of moderate or severe symptoms (3.2 ± 2.1) than did participants with cancer (2.6 ± 1.8; P = .03) or CHF (2.0 ± 1.7; P < .001). After adjusting for age, income, sex, site of recruitment (VA vs non-VA), and number of hospitalizations in the past year, participants with cancer had 38% (95% confidence interval, 9%-75%) more moderate or severe symptoms (P < .01) than did participants with CHF. Participants with COPD had 71% (95% confidence interval, 37%-114%) more moderate or severe symptoms than did participants with CHF (P < .001).

To understand how individual symptoms contributed to the difference in number of symptoms experienced across diagnoses, we examined the prevalence of individual symptoms among participants according to diagnosis. Compared with CHF participants, a larger proportion of COPD participants experienced anxiety (2% vs 32%; P < .001), shortness of breath (18% vs 65%; P < .001), and physical discomfort (27% vs 44%; P = .03). There was no difference in the proportion of participants who had pain, limited activity, nausea, feelings of depression, fatigue, problems with appetite, or lack of well-being across diagnoses.

**COMMENT**

Most persons in our study of community-dwelling older persons with advanced COPD, cancer, or CHF experienced multiple symptoms. The prevalence of moderate or severe symptoms was high across diagnoses although participants with COPD reported the greatest number of symptoms over-
all. Indeed, the percentage of our participants reporting pain, dyspnea, anxiety, feelings of depression, and nausea was similar to that reported in a previously studied group of hospitalized individuals with terminal disease.2

Even though most prior studies of symptoms have focused on persons with cancer,3,7,12,13,23 our study indicates that symptom burden, demonstrated by the high prevalence rates of several symptoms, is a characteristic shared among various populations with chronic disease. Our participants with advanced COPD, cancer, or CHF reported similar levels of several symptoms. Moreover, although most prior studies have focused on a limited number of individual symptoms such as pain, dyspnea, or fatigue,3,6,12,13,15 our results in community-dwelling older persons with advanced chronic disease revealed high prevalence rates of additional symptoms that have been investigated less often, such as limited activity and physical discomfort.

This study has several limitations. First, the study population was racially homogeneous. Thus, the low percentage of minority participants may limit the generalizability of our findings. However, our proportion of minority participants was similar to the proportion among the population of older persons in Connecticut,27 and the high participation rate (81%) reduces the likelihood of nonresponse bias. Second, cognitively impaired older persons were not included. Similar studies in racially and cognitively diverse populations are needed to confirm our findings for other populations. Third, we cannot be certain that the ESAS includes all the symptoms relevant to community-dwelling older persons with advanced chronic disease because there is no standard regarding the most important symptoms for this or any other population. Although scales exist that include more symptoms compared with the ESAS, given the advanced status of our participants, we chose to use a scale that was inclusive without being overly time consuming or cumbersome to the participants. Finally, although there is biological plausibility for some of the symptom-disease relationships demonstrated in our investigation, such as dyspnea with COPD, we cannot ascribe all the symptoms reported by our participants to a specific disease.

In summary, community-dwelling older persons with advanced chronic diseases including COPD, cancer, and CHF experience multiple moderate or severe symptoms. Systematic symptom assessment and aggressive symptom management are warranted for all older persons with advanced chronic disease.

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REFERENCES