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Symptom Burden in Chronically Ill Homebound Individuals

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Abstract

Objectives—To document the degree of symptom burden in an urban homebound population.

Design—Cross-sectional survey.

Setting—The Mount Sinai Visiting Doctors Program (MSVD).

Participants—All individuals newly enrolled in the MSVD.

Measurements—Edmonton Symptom Assessment Scale (ESAS), which consists of 10 visual analogue scales scored from 0 to 10; symptoms include pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, shortness of breath, and other.

Results—ESAS scores were completed for 318 participants. Most participants were aged 80 and older (68%) and female (75%); 36% were white, 22% black, and 32% Hispanic. Forty-three percent had Medicaid, and 32% lived alone. Ninety-one percent required assistance with one or more activities of daily living, 45% had a Karnofsky Performance Scale score between 0 and 40 (unable to care for self), and 43% reported severe burden on one or more symptoms. The most commonly reported symptoms were loss of appetite, lack of well-being, tiredness, and pain; the symptoms with the highest scores were depression, pain, appetite, and shortness of breath. Participants were more likely to have severe symptom burden if they self-reported their ESAS, had chronic obstructive pulmonary disease or diabetes mellitus with end organ damage, or had a Charlson Comorbidity Index greater than 3 and less likely to have severe burden if they had dementia.

Conclusion—In chronically ill homebound adults, symptom burden is a serious problem that needs to be addressed alongside primary and specialty care needs.

Keywords

home-based primary care; palliative care; symptom management; Edmonton Symptom Assessment Scale

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Increasing numbers of elderly adults are living with multiple chronic medical conditions.[1] The prevalence of chronic conditions rises with age,[2] and by 2030, almost 20% of the U.S. population will be aged 65 and older, with a more than 50% increase in those aged 85 and older.[3] A large portion of these elderly, chronically ill individuals have significant functional impairment that leaves them homebound and unable to access routine medical care. The number of these homebound seniors already exceeds 2 million and is expected to exceed 3 million by the end of the decade.[4]

Homebound individuals often have medical conditions associated with substantial palliative symptom burden, such as dementia, congestive heart failure, depression, and cancer.[5] Common symptoms related to chronic illness include pain, nausea, shortness of breath, fatigue, and depression. Short-term mortality rates in the homebound are high—nearly one in five die each year.[6–9] Poverty, poor health literacy, and limited social support complicate timely access to quality care.[5–9] Even those who are able to access outpatient care may not be able to find appropriately trained and experienced providers to manage their complex primary care needs and substantial symptom burden.

It has been increasingly recognized that high-quality outpatient care includes palliative care,[10] but the symptom management, skilled communication, and psychosocial and spiritual support that palliative care specialists offer continue to be available mostly in the inpatient or outpatient hospice setting, despite evidence showing that in-home palliative care for vulnerable elderly adults increases satisfaction and cuts costs.[11] The current reimbursement incentives and the lack of a sufficient number of trained providers are two barriers contributing to this gap. Given these realities, cohorts with high symptom burden who would benefit most from the limited palliative care resources available in the outpatient setting must be identified.

A cross-sectional survey of individuals newly enrolled in an urban home-based primary care (HBPC) program was conducted to document the degree of symptom burden in a chronically ill homebound population that may benefit from in-home palliative care. The severity of common symptoms in the homebound, whether the presence of various diseases and level of comorbidity predicted ESAS score severity, and whether reporting bias exists between self-scored ESAS and ESAS scored by informal caregivers was examined.

METHODS

Setting

This study was conducted at the Mount Sinai Visiting Doctors (MSVD) program, a large HBPC program based in New York City. Previously described in detail,[12] the program employs 14 physicians (8 FTE), two nurse practitioners (NPs), two nurses, three social workers, and four clerical staff to serve more than 1,000 homebound individuals annually. Approximately 300 individuals are admitted to the program annually. Individuals are referred from a variety of sources, including the inpatient setting, outpatient clinics, community agencies, nursing agencies, and word of mouth. A primary care physician (PCP) performs a comprehensive initial visit for all newly enrolled individuals using standardized assessments measuring functional status, cognition, and symptom burden.

PCPs visit participants on average once every 2 months, and physicians are able to make urgent home visits if clinical need arises. Participants and their families are able to contact a physician 24 hours per day, 7 days per week by telephone. High priority is placed on quality of life, comfort, and minimizing unnecessary emergency department visits and hospitalizations.

Subjects

Between September 2008 and February 2010, data were collected on all individuals newly enrolled in the MSVD program. Eligibility criteria for the MSVD program include living in Manhattan above 59th Street, aged 18 and older, and meeting the Medicare homebound definition: able to leave home only with great difficulty and for absences that are infrequent or of short duration. Individuals are enrolled regardless of insurance status, comorbidities, or cognitive status. The Mount Sinai School of Medicine institutional review board approved this study protocol.

Measures

The Edmonton Symptom Assessment Scale (ESAS), which consists of 10 visual analogue scales scored from 0, indicating no symptoms, to 10, the worst possible symptom burden, was administered to all study participants. The symptoms assessed include pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, shortness of breath, and other (to be filled out by the provider).[13] The ESAS was chosen because it has been validated in a number of care settings[14] and is validated for participant and caregiver report. Severe burden is defined as a score greater than 6 on one or more individual symptoms, moderate burden as a score greater than 3 on one or more individual symptoms, and mild burden as a score of 1 to 3 on one or more individual symptoms.[15]

The Karnofsky Performance Scale (KPS) allows individuals to be classified according to their functional impairment, with an overall score given that reflects their ability to perform normal activities and care for themselves. The lower the score, the worse the individuals' prognosis. Scores range from 100 (normal, no evidence of disease) to 0 (dead).[16]

The Palliative Performance Scale (PPS) also classifies individuals according to their functional status, assessing ambulation, evidence of disease, self-care, oral intake, and consciousness level. The lower the score, the worse the prognosis; scores range from 100% (normal) to 0% (death).[17]

Activities of daily living (ADLs) assessed were bathing, dressing, toileting, transferring, continence, and feeding.[18] Instrumental ADLs assessed were shopping, food preparation, housekeeping, laundry, medication administration, transportation, ability to use the telephone, and ability to handle finances.[19]

The Charlson Comorbidity Index (CCI), a composite score that includes 16 diagnoses (acquired immunodeficiency syndrome, myocardial infarction, congestive heart failure, peripheral vascular disease, dementia, chronic obstructive pulmonary disease (COPD), connective tissue disease, peptic ulcer disease (PUD), leukemia, lymphoma, tumor without metastasis, metastatic solid tumor, moderate to severe renal disease, cerebrovascular disease, liver disease, and diabetes mellitus with or without end organ damage (retinopathy, neuropathy, nephropathy, or brittle diabetes mellitus)) and assigns individuals a weighted score if the diagnosis is present, was used to measure comorbidity. Prior studies have shown that 1-year mortality in individuals with a CCI of 0 is 12%, 1 to 2 is 26%, 3 to 4 is 52%, and 5 or more is 85%.[20] The current analysis dichotomized CCI as less than 3 versus 3 or greater, because a score of less than 3 is associated with a greater than 50% likelihood of death within one year.

Data Collection

Participants' PCPs administered the ESAS as a routine part of the comprehensive initial home visit. PCPs received a one-page summary handout about the ESAS and a 1-hour training in ESAS administration before the start of the study. The participant or the caregiver completed the ESAS alone, or the caregiver assisted the participant. The MSVD provider also collected information on participant demographics, healthcare proxy completion, comorbidities, PPS score, KPS score, and functional status (ADLs and IADLs) at the initial visit. CCI was calculated using the comorbidities that each participant's MSVD provider listed in their problem list.

Analysis

Participant ESAS scores were stratified into none, mild, moderate, or severe burden. Investigators completed bivariate analyses looking for associations between severe ESAS symptom burden and disease state, CCI score, and reporter (participant or caregiver) using the Pearson chi-square test. Severe ESAS symptom burden was defined as a score greater than 6 on any one or more ESAS symptoms. All analyses were completed using SAS version 9.1 (SAS Institute, Inc., Cary, NC).

RESULTS

Between September 2008 and February 2010, 475 individuals were newly enrolled in the MSVD program. Providers recorded ESAS scores for 318 individuals (67%). Reasons for missing were 59 (12%) participants or caregivers were unable to complete the survey, 16 (3%) refused, and 82 (17%) had no reason recorded but included insufficient time during the initial provider visit, inability of participant and lack of familiar informal caregiver to report scores, and language barrier (ESAS was available only in English and Spanish). There were no statistically significant differences in age, sex, median ADL or IADL score, or living status between those with completed ESAS scores and those with missing scores. Participants with missing scores were more likely to be white ($p=.03$). The majority of participants with ESAS scores were aged 80 and older (68%) and female (75%). Thirty-six percent of these participants were white, 22% were black, and 32% were Hispanic. Forty-three percent had Medicaid, and 32% lived alone. On admission to MSVD, 39% of participants already had a healthcare proxy (HCP) completed, and another 35% completed a HCP during their initial visit; 28 participants (9%) had capacity but did not wish to complete a HCP after a discussion with their PCP at the initial visit. The remaining participants did not have capacity to complete a HCP (13%) or had no HCP with no reason recorded (4%).

Disease burden was considerable; 49% had dementia, 33% had diabetes mellitus, 26% had depression, 18% had coronary heart disease, 18% had congestive heart failure, 17% had chronic lung disease, and 13% had cancer. Ninety-one percent of participants required assistance with one or more ADLs and 99% with one or more IADLs. Forty-nine percent of participants had a KPS score between 0 and 40 (unable to care for self) and 50% between 50 and 70 (unable to work, able to live at home). Ten percent of participants had a PPS score between 0 and 30 (end of life) and 81% between 40 to 60 (transitional phase) (Table 1).

The most commonly reported symptoms were loss of appetite, lack of well-being, tiredness, and pain (Table 2). Forty-three percent reported severe burden on one or more symptoms, 33% had at least one moderately troubling symptom, and 14% reported no symptoms. The symptoms that had the highest average score were tiredness, depression, and anxiety. The median score for all symptoms for participants who scored greater than 0 was 5. Participants reported difficulty with a median of three symptoms at baseline, two of which were moderate to severe.

Participants completed 54% of ESAS surveys, 12% were caregiver assisted, and caregivers completed 27% (7% were missing data on who completed the survey). Participants who self reported ESAS scores (n=172) were compared with those who had caregiver-assisted or -reported ESAS scores (n=124). In this analysis, participants were more likely to have severe symptom burden if they self-reported their ESAS (47% vs 35%, p=.03).

Thirty-one participants (10%) had a CCI score of 0, 120 (38%) of 1 or 2, 109 (34%) of 3 or 4, and 58 (18%) of 5 or greater. Participants with severe symptom burden were analyzed according to individual diagnosis and CCI score (Table 3). Participants with a CCI score greater than 3 (>50% of these individuals have a life expectancy of less than 1 year[16]) were statistically significantly more likely to report severe symptom burden than participants with scores of 0 to 2 (p=.003). Participants with chronic lung disease (p=.006), diabetes mellitus with end organ damage (p=.009), and PUD (p=.04) were statistically significantly more likely to report severe symptom burden according to their ESAS score. Participants with dementia were statistically less likely to report severe symptom burden (p<.001). This association remained when participants with dementia who were able to self-report ESAS were included alone (without caregiver-reported ESAS); participants with dementia were still less likely to have severe burden (p<.001).

DISCUSSION

This study demonstrated a significant symptom burden in a previously uninvestigated population of elderly homebound adults with multiple comorbidities and functional impairment. Few studies have measured symptom burden in chronically ill individuals and even fewer in homebound elderly adults. Studies of chronically ill individuals have been largely disease specific and have found that most individuals with CHF, COPD, or cancer have at least one moderate to severe symptom and that many have two or more symptoms, even if they are not yet at the end of life.[21,22] Some studies have correlated worse ESAS scores with worse outcomes in CHF and cancer.[23,24] One study of home-based primary and palliative care services[25] found that the most commonly reported symptoms in homebound elderly adults were nausea and shortness of breath, differing from the most frequently reported symptoms of loss of appetite, lack of well-being, tiredness, and pain in the current study. Another study showed that the specific symptoms of shortness of breath, depression, and physical discomfort were associated with poorer quality of life, self-rated health, and functional status.[26]

The findings of the current study show that symptom burden in chronically ill homebound individuals is similar in severity and scope to that in individuals referred to hospice or who are hospitalized. A 2003 study found that individuals referred to hospice had high burden (7.21 median ESAS score), with the most common symptoms being pain (64%), anorexia (34%), and constipation (32%).[27] Similarly, in individuals with cancer attending an outpatient palliative care clinic, the most-frequent and most-severe self-reported symptoms were fatigue (77%, median ESAS score 7), pain (75%, median ESAS score 7), and lack of appetite (66%, median ESAS 5).[28] In a group of 500 individuals undergoing hemodialysis, ESAS administration revealed a mean of 7.5±2.5 symptoms, with tiredness, well-being, appetite, and pain being the most severe.[29]

Examining predictors of ESAS burden, greater CCI scores were statistically significantly associated with greater symptom burden. Chronic lung disease, PUD, and diabetes mellitus with end-organ damage were each associated with higher symptom scores, whereas dementia was associated with lower symptom scores. It was hypothesized that this might be due to reporting bias, because individuals with dementia may be less able to report symptoms to their caregivers, but further analysis revealed that this lower symptom score persisted in participants with dementia who were able to self-report ESAS scores. It may be that individuals with dementia are less reliably able to report their symptoms over time than those without and that alternative scoring tools more specific to individuals with dementia (Pain Assessment in Advanced Dementia or Abbey Scale) would yield different results.[30,31] In addition, it is possible that, because of the neurological derangements associated with dementia, individuals with dementia and few other chronic conditions have less symptom burden than those with chronic illnesses without dementia.

The data were also examined to compare all participants who had self-reported ESAS scores with those who had caregiver-assisted or -reported ESAS scores. In this analysis, participants were more likely to have severe burden if they self-reported, indicating that caregivers may underreport symptoms in homebound individuals. Prior studies examining proxy reporting of ESAS scores suggest that nonclinical, informal primary caregivers for individuals in hospice or with cancer tend to overestimate symptom intensity, especially for pain, insomnia, and dyspnea.[32–36] In the current study, primary caregivers underreported symptom severity overall. It is likely that this is because of the difference between this cohort, the majority of whom were not in the terminal phase of illness or receiving hospice care but have multiple chronic illnesses, and that of the previous study. It also may be related to the higher percentage of participants in the current cohort with dementia and, as above, may have been less able to report or express symptoms to their caregivers.

There were a number of limitations to this study. The ESAS was available only in English and Spanish. Although it has been well validated in the inpatient setting, less information is available on its use in the homebound population or in outpatients with dementia. Individuals with advanced dementia pose a particular challenge in terms of symptom assessment and recognition, and other scales may be more appropriate in this population.

Although the ESAS allowed for better symptom identification, it remains unclear whether administering the ESAS to all new patients led to more PCP interventions or better symptom treatment. Additionally, the data collection plan of using individuals' PCPs to assess symptom burden meant that different providers, many of whom were not trained researchers, collected data.

The high symptom burden in the homebound population underscores the importance of symptom recognition and management for those with advanced illness from chronic medical conditions. This should be considered as the United States healthcare system restructures itself to meet the needs of its most vulnerable groups. Finding new ways to address their healthcare needs is a growing need because the number of homebound individuals will increase by millions in the coming decades. Furthermore, the cost of caring for elderly adults with multiple chronic medical problems is becoming an increasing burden on the healthcare system, with 10% of Medicare beneficiaries accounting for approximately two-thirds of Medicare costs.[37] Emergency department and hospital use of individuals seeking relief for untreated symptoms may be driving some of this high cost. In the current climate of healthcare reform, a variety of initiatives have been proposed to prevent unnecessary emergency department visits, hospitalizations, and institutionalizations. To this end, as well as to improve quality of life, symptom burden must be addressed alongside disease burden in individuals with chronic illness. With 76% of participants in the current cohort reporting moderate to severe burden, the need for the incorporation of palliative care into models of care for homebound individuals is evident. Palliative care should be integrated into primary care for chronically ill individuals to lessen symptom burden, alleviate suffering, and help individuals and families define and articulate their goals of care.

CONCLUSION

Prior studies have shown that palliative care services increase satisfaction and well-being, and the authors believe that this can be extended into the community. This study demonstrates that, in a population of chronically ill homebound adults, most of whom do not meet hospice criteria, ESAS is a feasible tool to assess symptom burden, which is a serious problem that needs to be addressed alongside their primary and specialty care needs. Timely symptom burden assessment and aggressive intervention may prevent unnecessary healthcare use, improve quality of life, reduce caregiver burden, and improve satisfaction. Further study will investigate whether ESAS scores in this population are predictive of hospitalization and mortality and whether follow-up ESAS assessments serve as a useful tool to monitor symptom burden over time.

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Table 1

Characteristics of the Study Sample (N=318)

Characteristic	n (%)
Sex	
Female	238 (75)
Male	80 (25)
Race and ethnicity	
White	115 (36)
Latino	101 (32)
Black	70 (22)
Asian	7 (2)
Other	7 (2)
Diagnosis	
Dementia	155 (49)
Congestive heart failure	56 (18)
Chronic obstructive pulmonary disease	12 (4)
Depression	83 (26)
Cancer	42 (13)
Insurance	
Medicaid	136 (43)
Non Medicaid	182 (57)
Age	
<60	10 (3)
60–69	29 (9)
70–79	60 (19)
80–89	107 (34)
90–99	99 (31)
≥100	13 (4)
Living situation	
Alone	101 (32)
With family member	121 (38)
With paid caregiver	58 (18)
With family and paid caregiver	20 (6)
Unknown	18 (6)
Activities of daily living (0 (dependent)–16 (independent))	
0–3	82 (26)
4–7	51 (16)
8–11	47 (15)
12–15	63 (20)
16	60 (19)
Missing	15 (5)
Instrumental activities of daily living (0 (dependent)–8 (independent))	

Characteristic	**n (%)**
7–8	9 (3)
5–6	26 (8)
3–4	57 (18)
0–2	190 (60)
Missing	36 (11)

Table 2

Symptom Burden According to the Edmonton Symptom Assessment Scale (ESAS) (N=318)

Symptom	Symptom Present, n (%)[a]	Mean Score (for Patients with Scores >0 in Each Symptom)
Pain	150 (47)	5.09
Tiredness	155 (49)	5.79
Nausea	33 (10)	4.27
Depression	103 (33)	5.27
Anxiety	85 (27)	5.32
Drowsiness	117 (37)	5.18
Loss of appetite	167 (53)	4.77
Feeling of well-being	152 (48)	5.24
Shortness of breath	86 (27)	4.91

[*] ESAS Score >0

Table 3

Severe Symptom Burden According to Diagnosis and Charlson Comorbidity Index (CCI)

Diagnosis and CCI	Participants with High Symptom Burden (>6 on ≥1 Edmonton Symptom Assessment Scale Symptoms), %
Diagnosis	
Cancer	61
Moderate to severe chronic kidney disease	42
Dementia	31
Peptic ulcer disease	58
Coronary artery disease	48
Cerebrovascular accident	48
Chronic lung disease	62
Diabetes mellitus	58
CCI >3	54

Patients may have had multiple diagnoses.