

Net Worth Predicts Symptom Burden at the End of Life

MARIA J. SILVEIRA, M.D., M.A., M.P.H.,^{1,2} MOHAMMED U. KABETO, M.D.,² and
KENNETH M. LANGA, M.D., Ph.D.¹⁻⁵

ABSTRACT

Objectives: To explore the predictors of symptom burden at the end of life.

Design: Observational, secondary analysis of Health and Retirement Study (HRS) data.

Setting: USA.

Participants: Two thousand six hundred four deceased, older adults.

Methods: Multivariate Poisson and logistic regression to explore the relationship between sociodemographic and clinical factors with symptoms.

Results: Fatigue, pain, dyspnea, depression, and anorexia were common and severe; 58% of participants experienced more than 3 of these during their last year of life. Sociodemographic and clinical factors were associated with the number of symptoms as well as the presence of pain, depression, and dyspnea alone. Decedents in the highest quartile of net worth had fewer symptoms (incident rate ratio [IRR] 0.90, confidence interval [CI] 0.85–0.96) and less pain (odds ratio [OR] 0.66, CI 0.51–0.85) than comparisons did. Patients with cancer experienced more pain (OR 2.02, CI 1.62–2.53) and depression (OR 1.31, CI 1.07–1.61). Patients experienced more depression (OR 2.37, CI 1.85–3.03) and dyspnea (OR 1.40, CI 1.09–1.78).

Limitation: Use of proxy reports for primary data.

Conclusion: Older Americans experience a large symptom burden in the last year of life, largely with treatable symptoms such as pain, dyspnea, and depression. The adequacy of symptom control relates to clinical factors as well as net worth. This association between symptoms and wealth suggests that access to health care and other social services beyond those covered by Medicare may be important in decreasing symptom burden at the end of life.

INTRODUCTION

IT IS A SAD REALITY that for most Americans access to good palliative and hospice care is limited. A recent national survey on the status of end-of-life care reported that among all U.S. hos-

pitals only 14% offer palliative care, 23% offer hospice care, and 42% have comprehensive pain services.¹ While these numbers motivate improving end-of-life care for all, there is good reason to focus special attention upon the plight of older adults.

¹VA Health Services Research & Development Center of Excellence, VA Ann Arbor Healthcare System, Ann Arbor, Michigan.

²Division of General Medicine, University of Michigan Medical School, Ann Arbor, Michigan.

³Survey Research Center, Institute for Social Research, Ann Arbor, Michigan.

⁴Patient Safety Enhancement Program, University of Michigan Health System, Ann Arbor, Michigan.

⁵SGIM Collaborative Center for Research and Education in the Care of Older Adults, Ann Arbor, Michigan.

Not only do older adults represent the fastest growing segment of the U.S. population,² but they carry an especially high symptom burden. Desbiens et al.³ showed that among seriously ill, hospitalized elders, 50% experience pain in the year after their hospitalization. Among elders in nursing homes, the estimates are even higher.⁴⁻⁹ Lynn et al.¹⁰ showed that in the last 3 days of life, 40% of elders experience severe pain, 80% severe fatigue, and 25% moderate dysphoria—higher levels than those reported among equally sick, younger patients.¹¹

To date, no study has thoroughly explored the determinants of symptom burden among older adults. Studies of predictors of symptom burden among seriously ill, younger patients have shown that clinical (e.g., comorbidities, age, cognitive status, and depression), sociodemographic (e.g., caregiver support, gender, and ethnicity), and systemic factors (e.g., hospital and region) are important^{3,12,13} patients' wishes for comfort care and their wealth appear not to matter.¹⁴ It is unclear if these factors would be the same for older adults. Some factors, such as wealth and caregiver status, may be more salient to older adults than to younger ones. To improve the end-of-life care of the older adults, we need to understand which mutable factors are associated with the extent of symptom burden. Thus, we decided to explore the determinants of symptom burden among older adults using a large, national database of deceased individuals which included clinical, sociodemographic, and geographic information.

MATERIALS AND METHODS

Study population

We used data from the Health and Retirement Study (HRS), a biennial longitudinal survey of a nationally representative cohort of U.S. adults aged 50 or older.¹⁵ The HRS interviewed a cohort of individuals aged 70 or older in 1993, 1995, and 1998. For those respondents who died after these interviews, data were collected from a proxy when possible during the HRS 1995, 1998, or 2000 exit interview. A total of 2832 HRS respondents died between 1993 and 1998. After excluding decedents who were younger than 70 at the time of death (29; 1%), lacked age data (35; 1%), or lacked a proxy interview (164; 6%), we were left

with a study population of 2604 (92%) representing 7.9 million elderly U.S. residents.

The Health and Retirement Study

The HRS, funded by the National Institute on Aging and performed by the Institute for Social Research at the University of Michigan, is designed to provide representative data on the aging of the U.S. population. HRS questionnaire topics include: health, cognitive status, retirement planning, subjective probabilities, family structure, caregiving, employment status, job demands, disability, and demographics, housing, income, net worth, health insurance and pension plans. For more details about HRS sampling and response rates, data collection procedures, and measures, see Juster and Suzman,¹⁵ and the HRS web site at (www.hrsonline.isr.umich.edu/).

Dependent variables

The HRS asked proxies to report on the decedent's pain, depression, delirium, dyspnea, fatigue, and anorexia. For pain, proxies were asked if the decedent, "was often troubled with pain between the last interview and when he died." For all other symptoms, proxies were asked, "Was there a period of at least 1 month during the last year of life when he had (this symptom)?" Answers to these questions were dichotomized and used as our outcomes of interest. We took particular interest in pain, depression, and dyspnea, because in comparison to other symptoms experienced at the end of life, they are treatable and not an inevitable part of the dying process (as fatigue, anorexia, or delirium might be).

In addition, we explored overall symptom burden, defined as the total number of symptoms. Symptom burden was determined by summing the number of affirmative answers to the 6 symptom questions. Hence, symptom burden could range from 0 to 6.

Independent variables

We explored clinical, sociodemographic, and economic factors. Clinical factors that we considered included: age (categorized as 70-79, 80-89, and 90 or older), gender (categorized as male or female), smoking status (categorized as yes or no), history of alcohol abuse (categorized as yes or no), history of cognitive impairment (defined by "fair" or "poor" memory 1 month prior to

death as assessed by the proxy respondent), and chronic conditions (presence of cancer, lung, heart, or cerebrovascular disease). Sociodemographic factors that we explored included: ethnicity (categorized as white, black, or other), living arrangement (categorized as married, unmarried cohabitating, and unmarried living alone), and educational attainment (categorized as no education, less than high school, and high school and above). Economic variables included household net worth¹⁶ (categorized into quartiles: less than \$10,400, \$10,400–\$70,000, \$70,000–\$182,000, and more than \$182,000) and Medicare coverage (categorized as yes or no). Other variables we considered were geographic region (categorized as Northeast, Midwest, Southeast, and West), year of death, and any visit for health care (defined as any overnight stay at a hospital, nursing home, or hospice) during the last year of life (categorized as yes or no).

Analyses

We used Poisson regression to explore the association between these factors and total symptom burden (categorized into four mutually exclusive categories: 0, 1–2, 3–4, and 5–6). We used logistic regression to explore the association between the independent variables (i.e. clinical, sociodemographic, and economic factors) and the presence of pain, depression and dyspnea. We accounted for the complex sampling design of the HRS in our analyses.^{15,16} All statistical analyses were performed using STATA 7.0 software (Stata Corporation, College Station, TX).

Ethical considerations

This study was approved by the Health Sciences Institutional Review Board at the University of Michigan. At the time this study was done, Drs. Silveira and Langa had no conflicts of interest that may have influenced this work; neither currently receives industry funding.

RESULTS

Study population

Our final study population consisted of 2604 older adults in the HRS who died between 1993 and 2000 and whose proxies had responded to exit surveys administered in 1995, 1998, or 2000

(2604 represents 94% of the HRS subjects who died during our study period). The characteristics of our study population are summarized in Table 1. Subjects' ages at the time of death ranged from 70 to 108, with a median age of 84. The population was mostly female (56%), white (89%), and married (40%). Subjects came from throughout the United States: 38% from the Southeast, 25% from the Midwest, 20% from the Northeast, and 17% from the West. Most, 85%, suffered from at least one chronic condition including: heart disease (55%), cognitive impairment (42%), cancer (34%), stroke (32%), and lung disease (22%).

Proxies reported that the majority of subjects had died expectedly (59%) and in hospital (39%) as opposed to home (29%), nursing home (25%), or hospice (3%). Most subjects (66%) had visited a hospital, hospice, or nursing facility sometime in the last year. Proxy data was obtained an average of 27 months (standard deviation [SD]3) after the subject's death.

Proxy population

Descriptive data on proxies was available only for 700 proxies who themselves were enrolled in the study (as spouses). Similar to our subjects, most proxies were white (89%) and married. Proxies' ages ranged from 49 to 94 (with a median of 70) prior to the death of the subject. Most were male (73%) and high school educated (67%). Proxies were interviewed a median of 13 months after the decedent's death (SD 8; range, 1–39).

Symptom prevalence and burden

Symptoms were widely prevalent within the study population (Table 1). Approximately half of the study population was often troubled by pain (52%), depression (45%), or dyspnea (47%) from the time of their last interview and when he/she died. Among those with pain, proxies reported that most (59%) experienced pain at severe levels. Most subjects experienced one or more symptoms (90%) with 58% experiencing at least 3.

Pain was most common among individuals with cancer (63%), lung disease (58%), and cardiovascular disease (56%). Depression was most common among individuals with cognitive impairment (57%). Dyspnea was most common among those with pulmonary disease (83%).

In a Poisson regression adjusting for the sociodemographic, clinical, and economic variables

TABLE 1. CHARACTERISTICS OF STUDY POPULATION ($n = 2604$)

Variable	n (%) ^a	Variable	n (%) ^a
Age		Symptoms	
70–79	742 (28)	Fatigue	1450 (57)
80–89	1245 (48)	Pain	1333 (52)
>89	617 (24)	Dyspnea	1215 (47)
Gender		Anorexia	1206 (47)
Female	1465 (56)	Depression	1164 (45)
Male	1139 (44)	Confusion	1152 (44)
Ethnicity		Total number of symptoms	
White	2165 (89)	None	261 (10)
Black	385 (9)	1–2	826 (32)
Other	54 (2)	3–4	991 (38)
U. region		5–6	525 (20)
Southeast	1110 (38)	Visited a hospital in the last year	1651 (64)
North Central	607 (25)	Visited a healthcare facility in last year	1706 (66)
Northeast	494 (20)	Place of death	
West	380 (17)	Hospital	1061 (39)
Educational attainment		Home	722 (29)
High school and above	1207 (51)	Skilled nursing facility	624 (25)
No high school diploma	1118 (43)	Other	118 (5)
No formal education	208 (7)	Hospice	79 (3)
Living arrangement		Medicare	2524 (97)
Married	1040 (40)	Alcohol use	659 (26)
Unmarried, living alone	968 (38)	Tobacco use	304 (12)
Unmarried, living with someone	593 (22)	Year of death	
Net worth		1993 and 1994	322 (12)
<\$10,400	612 (22)	1995	431 (16)
\$10,400–\$70,000	618 (25)	1996	401 (17)
\$70,001–\$182,000	596 (26)	1997	400 (18)
>\$182,000	607 (27)	1998	415 (16)
Chronic conditions		1999	449 (15)
Heart problem	1389 (55)	2000	174 (7)
Cognitive impairment	1098 (42)		
Cancer	856 (34)		
Stroke	816 (32)		
Lung disease	554 (22)		

^aThis number represents a weighted percentage.

listed above, there was a statistically significant association between the number of symptoms and age, net worth, chronic conditions (cancer, lung disease, heart disease, stroke, and cognitive impairment), visit for health care, place of death, alcohol abuse, smoking status, and year of death (Table 2). Age was inversely related to symptom burden in a dose-response fashion; subjects in the 80–89 and 90 and older age categories had incrementally fewer symptoms (incident rate ratio [IRR] 0.94 and 0.83, respectively) relative to those in the reference age category of 70–79. Similar to age, net worth was inversely related to symptom burden; subjects in the two highest quartiles of net worth had fewer symptoms (IRR 0.91 and 0.90, respectively) relative to those in the lowest quartile. For example, 25% of those in the lowest quartile experienced 5–6 symptoms while only

18% and 15% of those in the two highest quartiles did (unadjusted, weighted percentage, $p = 0.004$). Individuals with each of the five chronic conditions experienced more symptoms compared to those free of the chronic condition. Notably, cognitive impairment had the strongest association with symptom burden; those with cognitive impairment had 43% more symptoms (IRR 1.43, confidence interval [CI] 1.36–1.50) than those without. Thirty-one percent of those with cognitive impairment had 5–6 symptoms, while only 13% of those with normal cognition did (unadjusted, weighted percentage, $p < .001$)

Pain, depression, and dyspnea

In three multivariate logistic regressions examining factors associated with pain, depression,

TABLE 2. FACTORS RELATING TO TOTAL SYMPTOM BURDEN AMONG THE OLDER ADULTS: RESULTS OF A MULTIVARIATE POISSON REGRESSION

<i>Factor</i>		<i>Incident rate ratio (IRR)</i>	<i>95% CI</i>
Age	70–79	—	—
	80–89	0.94	0.89–1.00
	≥90	0.83	0.76–0.90
Gender	Female	1.02	0.94–1.01
Ethnicity	White	—	—
	Black	0.92	0.84–1.00
	Other	1.01	0.84–1.20
Region	Northeast	—	—
	Southeast	1.03	0.94–1.16
	West	1.04	0.94–1.13
	Midwest	1.05	0.95–1.21
Education	No formal education	—	—
	Less than high school	1.02	0.90–1.16
	High school and above	1.01	0.88–1.16
Living arrangement	Living alone	—	—
	Unmarried, cohabitating	1.02	0.95–1.09
	Married	0.94	0.89–0.96
Net worth	<\$10,400	—	—
	\$10,400–\$70,000	0.98	0.92–1.06
	\$70,001–\$182,000	0.91	0.85–0.98
	>\$182,000	0.90	0.85–0.96
Chronic conditions	Cancer	1.21	1.16–1.26
	Lung disease	1.23	1.16–1.30
	Stroke	1.04	1.00–1.09
	Heart disease	1.17	1.11–1.24
	Cognitive impairment	1.43	1.36–1.50
Healthcare visit		1.29	1.23–1.35
Alcohol use		1.02	1.00–1.04
Tobacco use		0.97	0.95–0.99
Medicare		0.97	0.87–1.09
Year of death	1993/1994	—	—
	1995	1.00	0.91–1.11
	1996	1.18	1.10–1.28
	1997	1.15	1.04–1.26
	1998	1.16	1.05–1.29
	1999	1.13	1.03–1.24
	2000	1.10	0.98–1.23

CI, confidence interval.

or dyspnea, there was an inverse and dose-related relationship between age and presence of these symptoms (Table 3). For example, the oldest-old (90 or older) had lower risk for pain (OR 0.69, CI 0.51–0.93), depression (OR 0.48, CI 0.35–0.65), and dyspnea (OR 0.50, CI 0.35–0.70) compared to younger subjects.

Net worth was associated with pain but not depression or dyspnea. This relationship was inverse and dose related as well; decedents in the highest quartile of net worth had lower risk of pain (OR 0.66, CI 0.51–0.85) compared to those in the lowest quartile. The relationship between net worth and depression and dyspnea followed the

same pattern (inverse and dose related), but was not statistically significant.

Chronic conditions were associated with all three symptoms after adjusting for other factors. Pain was most likely among those with cancer (OR 2.02, CI 1.62–2.53) and heart disease (OR 1.50, CI 1.18–1.91). Depression was ubiquitously associated with all five chronic conditions; however, those with cognitive impairment seemed to carry the greatest risk (OR 2.37, CI 1.85–3.03). Dyspnea was most likely among subjects with lung disease (OR 7.66, CI 5.93–9.90), heart disease (OR 2.28, CI 1.86–2.79), and cognitive impairment (OR 1.40, CI 1.09–1.78).

TABLE 3. FACTORS RELATING TO PAIN, DEPRESSION, AND DYSPNEA AMONG THE OLDER ADULTS: RESULTS OF MULTIVARIATE POISSON REGRESSION

Factor		OR (95% CI)		
		Pain	Depression	Dyspnea
Age	70–79	—	—	—
	80–89	0.94 (0.72–1.21)	0.81 (0.61–1.04)	0.86 (0.69–1.06)
	≥90	0.69 (0.51–0.93)	0.48 (0.35–0.65)	0.50 (0.35–0.70)
Gender	Female	1.29 (0.98–1.71)	0.88 (0.67–1.16)	0.99 (0.83–1.18)
Ethnicity	White	—	—	—
	Black	0.85 (0.60–1.21)	0.86 (0.62–1.19)	0.85 (0.62–1.17)
	Other	1.20 (0.61–2.38)	0.89 (0.41–1.92)	0.83 (0.40–1.73)
Region	Northeast	—	—	—
	Southeast	1.05 (0.81–1.36)	1.02 (0.75–1.38)	1.10 (0.81–1.51)
	West	1.08 (0.80–1.46)	1.12 (0.79–1.59)	0.96 (0.56–1.64)
	Midwest	1.12 (0.80–1.55)	0.97 (0.69–1.35)	1.02 (0.70–1.48)
Education	No formal education	—	—	—
	Less than high school	1.00 (0.61–1.63)	1.03 (0.64–1.65)	0.86 (0.55–1.32)
	High school and above	0.76 (0.46–1.23)	1.07 (0.68–1.66)	1.02 (0.67–1.76)
Living arrangement	Living alone	—	—	—
	Unmarried, co-habiting	1.16 (0.90–1.48)	0.92 (0.72–1.18)	1.06 (0.78–1.45)
	Married	1.10 (0.61–1.63)	0.76 (0.59–0.97)	0.78 (0.58–1.03)
Net worth	<\$10,400	—	—	—
	\$10,400–\$70,000	0.99 (0.73–1.34)	0.87 (0.66–1.16)	0.85 (0.63–1.14)
	\$70,000–\$182,000	0.70 (0.53–0.93)	0.75 (0.56–1.00)	0.74 (0.50–1.08)
	>\$182,000	0.66 (0.51–0.85)	0.84 (0.63–1.12)	0.76 (0.55–1.05)
Chronic conditions	Cancer	2.02 (1.62–2.53)	1.31 (1.07–1.61)	1.08 (0.89–1.32)
	Lung disease	1.12 (0.87–1.45)	1.33 (1.04–1.69)	7.66 (5.93–9.90)
	Stroke	1.05 (0.85–1.30)	1.42 (1.13–1.77)	0.94 (0.77–1.15)
	Heart disease	1.50 (1.18–1.91)	1.52 (1.21–1.93)	2.28 (1.86–2.79)
	Cognitive impairment	0.97 (0.79–1.17)	2.37 (1.85–3.03)	1.40 (1.09–1.78)
Healthcare visit		1.79 (1.47–2.18)	1.47 (1.21–1.79)	1.64 (1.35–2.00)
Alcohol use		1.04 (0.98–1.09)	1.02 (0.96–1.09)	1.01 (0.95–1.08)
Tobacco use		0.88 (0.81–0.95)	0.94 (0.86–1.02)	0.85 (0.79–0.92)

^aYear of death and Medicare status were adjusted for and are not shown (neither had a statistically significant relationship to the outcome of interest).

OR, odds ratio; CI, confidence interval.

DISCUSSION

In this nationally representative sample of more than 2000 older individuals, we found that older adults carry a great symptom burden in their last year of life, largely with symptoms that are amenable to treatment. Fatigue was the most prevalent symptom, followed by pain, dyspnea, anorexia, depression and delirium—at frequencies greater than those observed among hospice patients.¹⁷ Most older adults experienced multiple symptoms, with over half experiencing at least 3—at levels similar to those reported for seriously, ill hospitalized patients.^{3,10,11,14} Our findings suggest that a general population of older adults in their last year of life suffer as much as do patients whom we traditionally consider for palliative care, that is, patients with life-limiting conditions and patients who are severely ill and hospitalized. Because our current health system provides pallia-

tive care mostly through hospice and inpatient palliative care services, our health care providers' radar may be set to miss older adults unless they carry a life-limiting condition or become hospitalized with organ failure. This is concerning because older adults do not die in patterns that would identify them for palliative care. Indeed, Lunney et al.¹⁸ showed that 47% of older adults Medicare decedents die of frailty (defined as a slow decline that allows the patient to return home between stays in the hospital), rather than cancer (22%) or organ system failure (16%). This may explain why studies have consistently shown undertreatment of pain among the older adults.^{4,13} To provide such patients with palliative care, we would need to either consider advanced age a life-limiting condition or trigger palliative care not by condition or prognosis, but by the presence of symptoms.

It appears that clinical, sociodemographic, and local health system factors all may play a role in

symptom burden. In our study, age, comorbidities (cancer, pulmonary disease, cardiovascular disease, and cognitive impairment), visits to a health care provider, alcohol use, tobacco use, and net worth were all associated with symptom burden. Of these relationships, three are unique to the older adults and worthy of discussion.

We found that the oldest-old had the lowest risk for overall symptom burden as well as pain, depression, and dyspnea individually. Other studies have reported that very advanced age is associated with less pain^{19–22}; we are the first to show that this is true for other symptoms as well. Why is this so? It may be that those who survive into their 90s are a healthier group overall, one with a lower disease burden and better functional status than those who are chronically ill and die before reaching 90. This phenomenon is unlikely to be due to a birth cohort effect because it has been observed across birth cohorts since the 1970s.²² There is the possibility that this finding is the result of an ascertainment bias, in that proxies may not interpret problems such as depression and dyspnea in the oldest-old as “symptoms” because they assume that these problems are “part of old age.” Further research is necessary to determine if there are systematic differences in how proxies interpret and report symptoms for the oldest-old, as compared to younger individuals. Regardless of the explanation, finding that the oldest-old have fewer symptoms means that using age as a criterion for palliative care would require that the cut-off be set low, at age 70 for example, where the specificity might be poor.

Seniors with cognitive impairment had the greatest symptom burden, more than seniors with cancer, pulmonary disease or cardiovascular disease. This finding is not surprising given the lower rates of enrollment in hospice for patients with dementia.²³ Another possible explanation is that proxies may over-report symptoms experienced by cognitively impaired patients; however, studies show that proxies can accurately report the symptoms of patients with mild to moderate cognitive impairment—this is not so when patients have advanced dementia.²⁴

Individuals with cognitive impairment had greater relative risks for depression and dyspnea, but not pain. The relationship between depression and cognitive impairment is well known;²⁵ early stages of Alzheimer’s disease and other dementias frequently involve depressive symp-

oms. Why elders with cognitive impairment might experience more dyspnea, however, is unclear; perhaps the functional decline, deconditioning, and aspiration associated with cognitive decline increase the risk of dyspnea. That cognitive impairment was not associated with pain may be due to our method of pain assessment (i.e., by proxy); however, it is known that cognitively impaired older adults do experience a moderate decrease in pain in comparison to older adults who are cognitively intact, even after accounting for the method of assessment.²⁶

Our most unique and sobering finding is that wealth was a strong predictor of symptom burden in older adults during the last year of life, even after adjusting for other sociodemographic variables. Older adults belonging to the two highest quartiles of net worth (\$70,000–182,000 and more than \$182,000) had 9% and 10% lower risk (respectively) of high symptom burden (i.e., a higher number of total symptoms) than did older adults in the lowest quartile of wealth. When we examined the relationship between wealth and pain, older adults belonging to the two highest quartiles of net worth had 30% and 36% lower odds of experiencing pain. While the relationships between net worth and depression and dyspnea were in the same direction (i.e., wealthier elders experienced less depression and dyspnea) these relationships were not statistically significant.

How might wealth affect the level symptom burden among older Americans? Most of our study population was insured (97% had Medicare) and most, 66%, saw a healthcare provider at some point during their last year of life. What is it about their care that may explain why symptoms persisted among the less privileged? We offer some potential explanations: elders of higher socioeconomic status may (1) express their symptoms more assertively and demand better care, (2) have more ready access to goods and services above and beyond what insurance provides, (3) have greater access to social capital (e.g., social support from family and friends), or (4) reside in settings with better quality of care.

Medicare-dependent older adults bear much financial responsibility for their care. Many outpatient services, supplies, and medications are not covered by Medicare and must be paid for out of pocket, leaving some older adults to prioritize and limit treatments. Indeed, Steinman et al.²⁷ showed that many older adults, especially those

with low income, self-limit their medications because of the high cost of medication. When given the choice between medications that may prolong life, devices or services that may prolong independence, and those that might make the quality of life better, some older adults may choose to sacrifice their comfort. Alternatively, physicians might make the choice for them when writing prescriptions. Patients' general reluctance to take certain medications with negative stigma, such as opiates or antidepressants, may make the decision even clearer.

To break the connection between wealth and symptom burden we might consider expanding Medicare's services to include medications or expanding the criteria for hospice to include older adults with significant symptom burden, regardless of their prognosis. This would enable older adults to access medications regardless of ability to pay and would be consistent with CMS's mission to "improve access to services for underserved and vulnerable beneficiary populations, including eliminating health disparities."

This study has a number of potential limitations relating to data collection. We relied on retrospective proxy reports for our outcomes of interest, and this raises several concerns: It is unclear how accurately proxy reports reflect subjects' actual experiences. Proxy-subject concordance is known to depend on demographics, relationship, caregiver burden, expectations, hopes, emotions, and coping skills.²⁴ Moreover, prospective proxy reports are generally more reliable than retrospective ones, as memories change with time, and reports of objective symptoms (e.g., vomiting and cough) are more reliable than those of subjective ones (e.g. pain and depression).²⁴ However, our findings are consistent with those of others who have explored similar questions but collected data differently.^{10,13,17,19,20} In addition, our findings have face validity, that is, patients with cardiovascular disease experienced pain and dyspnea, and those with pulmonary disease experienced dyspnea. Proxy reports of chronic conditions may not reflect true diagnoses. When proxies were asked if patients were depressed, it is unclear if an affirmative answer means the subject felt blue or carried a *DSM IV* diagnosis of depression. Except for pain, symptoms were measured in only one realm—their presence, not their severity or their timing. Moreover, we could not ascertain whether and how symptoms were treated.

These findings demonstrate the need for widespread institution of symptom assessment and management for older adults throughout all the health care settings they frequent—hospitals, clinics, and nursing homes. However, the ultimate success of such programs may be limited by elders' ability to pay for goods and services that are not covered by Medicare. Further research into the relationship between wealth and symptom burden is necessary to better identify possible causal mechanisms leading from poverty to poor symptom control, and appropriate clinical and public policy interventions to decrease symptom burden at the end of life.

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Address reprint requests:

Maria J. Silveira, M.D., M.A., M.P.H.
300 North Ingalls Building, Room 7C27
Ann Arbor, MI 48109-0429

E-mail: mariaajs@umich.edu

APPENDIX A.
RELATIONSHIP OF PROXIES TO DECEASED SUBJECTS

<i>Proxy relationship to deceased</i>	<i>Weighted N (%)</i>
Daughter/stepdaughter	1377 (51.6)
Spouse	700 (28.2)
Friend	96 (3.8)
Sibling	89 (3.6)
Grandchild	102 (3.5)
Other relative	209 (8.1)
Paid helper/professional	31 (1.2)

APPENDIX B.
HEALTH AND RETIREMENT STUDY EXIT INTERVIEW QUESTIONS

*To assess the subject's **pain**, proxies were asked:*

"Was (he/she) often troubled with pain between the last interview and when (he/she) died"?

- 0 Not applicable
- 1 Yes
- 5 No
- 8 Don't know
- 9 Refused to answer

We used answers to classify pain into two mutually exclusive categories. A subject was classified as having "no pain" if the proxy responded with a 5 and "pain" if the proxy responded 1. Other answers were treated as missing values.

*To assess the subject's **depression**, proxies were asked:*

"Was there a period of at least one month during the last year of (his/her) life when (he/she) had depression?"

- 0 Not applicable
- 1 Yes
- 5 No
- 8 Don't know
- 9 Refused to answer

A subject was classified as having "No Depression" if the proxy responded with a 5 or "Depression" if the proxy responded with a 1. Other answers were treated as missing values.

To assess the subject's **difficulty breathing**, proxies were asked:

"Was there a period of at least one month during the last year of (his/her) life when (he/she) had the difficulty breathing?"

- 0 Not applicable
- 1 Yes
- 3 ON RESPIRATOR
- 5 NO
- 8 Don't know
- 9 Refused to answer

A subject was classified as having "No difficulty" if the proxy responded with a 5 and "Difficulty" if the proxy responded with a 1 or 3. Other answers were treated as missing values.

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