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The Epidemiology of the Homebound in the United States

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Abstract

Importance—An increasing number of older, community-dwelling adults have functional impairments that prevent them from leaving their homes. It is uncertain how many people who live in the United States (U.S.) are homebound.

Objective—To develop measures of the frequency of and ability to leave the home, and to use these measures to estimate the homebound population in the U.S. population.

Design—Cross-sectional data from the National Health and Aging Trends Study, collected in 2011.

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Dr. Ornstein had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study concept and design: Ornstein, Szanton
Acquisition, analysis, or interpretation of data: Ornstein, Szanton, Roberts, Leff
Drafting of the manuscript: Ornstein
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Setting—Contiguous U.S.

Participants—Nationally representative sample of non-institutionalized Medicare beneficiaries, ages 65 and older (n=7609)

Exposure(s) for observational studies—We defined homebound persons as those who never (completely homebound) or rarely (mostly homebound) left the home in the past month. We defined semi-homebound persons as those who only left the home with assistance, or had difficulty or needed help leaving the home.

Main Outcome(s) and Measure(s)—We compared demographic, clinical, and healthcare utilization characteristics across different homebound status categories.

Results—In 2011, the prevalence of the homebound was 5.6% (95% CI= 5.09%–6.14%), including an estimated 395,422 people who were completely homebound and 1,578,984 who were mostly homebound. Among the semi-homebound, the prevalence of those who never left home without personal assistance was 3.3% (95% CI=2.82%–3.77%) and the prevalence of those who required help and/or had difficulty was 11.7% (95% CI=10.89%–12.6%). Completely homebound individuals were more likely to be older, female, non-White and have less education and income than the non-homebound population (all $p<0.05$), to have more chronic conditions (4.9 vs. 2.5, $p<0.001$), and to have been hospitalized in the last 12 months (52.1% vs. 16.2%, $p<0.001$). Only 11.9 % of completely homebound individuals reported receiving primary care services at home.

Conclusions and relevance—In 2011, 5.6% of the elderly, community-dwelling Medicare population, about 2 million people, were completely or mostly homebound. Our findings can inform improvements in clinical and social services for these individuals.

BACKGROUND

An increasing number of older, community-dwelling adults have functional impairments that prevent them from leaving their homes.[1] The homebound have high disease and symptom burden, substantial functional limitations, and higher mortality than the non-homebound. [1–3] The homebound also use healthcare services at high rates. [4,5,6]

The Patient Protection and Affordable Care Act has spurred the development of new health service delivery models to serve the homebound, including the Independence at Home demonstration program[7,8] and multidisciplinary home-based primary care programs that deliver medical and social services.[9,10,11] There is evidence of cost savings.[12]

It is uncertain how many people who live in the United States (U.S.) are homebound. Medicare defines homebound status in the context of reimbursement for Part A skilled home health care services.[13] Although receipt of home care services is often used to define the homebound population,[1] this measure may not reflect the actual number of people who are homebound. Home health care recipients may only have a temporary need for home care services, and most people who are homebound do not receive Medicare home health care services. Disability has been used to estimate the homebound population.[14,15] This approach, however, has focused on the need for personal assistance rather than whether the individual is limited to their home.[16]

We developed measures of the frequency of and ability to leave the home, and used these measures to more accurately estimate the homebound population in the U.S.

METHODS

Study sample

Data are from the first round of the National Health and Aging Trends Study (NHATS), a population-based survey of late-life disability trends and trajectories. [15,17,18] NHATS drew a random sample of individuals ages 65 years and older living in the contiguous U.S. from the Medicare enrollment file on September 30, 2010 with oversampling of those over age 90 and non-Hispanic blacks. Interviews were completed in 2011 and yielded a sample of 8,245 persons, and a 71% response rate. Two-hour in-person interviews were conducted to collect detailed self-reported information on participants' physical capacity, activities of daily life, chronic health conditions and economic status. Physical and cognitive performance batteries were also conducted. Our sample included all participants in settings other than nursing homes (n=7609). Proxy respondents were interviewed when the sample person could not respond (6%).[19] The Johns Hopkins University Institutional Review Board approved the NHATS protocol, and all participants provided informed consent.

Measures

The NHATS has no pre-defined measure of homebound status. We used gerontological conceptual frameworks to develop measures in which the impact of disability is based on the confluence of personal capacity and the ability of social support to compensate for limitations in capacity. [15,20,21] Thus, many older adults may be unable to leave their homes without assistance or have difficulty doing so, but this lack of capacity may be partially or fully remediated by the availability of personal assistance. We created measures based on (1) the frequency that individuals leave home; (2) whether the individual had difficulty leaving the home; and (3) whether help was required to leave the home. We used a series of questions that respondents were asked as part of a mobility questionnaire (Figure). First, we determined the frequency of activity by respondents' reports of how often they left the home to go outside in the last month. Response options were: every day, most days (5–6 days per week), some days (2–4 days per week), rarely (once a week or less), and never. Respondents who reported that they ever went outside were asked whether they needed assistance. Those that reported needing help were asked if they were ever able to go outside by themselves. Respondents who ever went outside without help then reported whether they had difficulty doing the activity alone (regardless of use of assistive devices) in the last month.

We categorized individuals across three main measures: (1) homebound, (2) semi-homebound and (3) not homebound (Table 1). Homebound individuals never or rarely left the home; we divided them into the "completely homebound," who never went out in the last month, and the "mostly homebound," who went out once a week or less. Semi-homebound individuals left the home, but were at risk of becoming homebound either because getting out of the home was difficult, or they needed personal assistance to do so. Thus, we divided them into individuals who never left the home without personal assistance

and those who needed help or had difficulty leaving the home. The remainder of the population was considered non-homebound.

Our analyses included demographic data: age, gender, race, education, marital status, income, language and living arrangements. Clinical data were based on self-report and included whether a doctor had ever told a subject that they had individual health conditions. We created a count of 13 self-reported chronic conditions to reflect multimorbidity: heart attack, heart disease (including angina, congestive heart failure), high blood pressure, arthritis, osteoporosis, diabetes, lung disease, stroke, dementia/Alzheimer's disease, cancer, depression, anxiety and broken or fractured hip. Depression was defined as a score of 3 or greater on the two item ("feeling down, depressed, or hopeless" and "having little interest or pleasure in doing things") Patient Health Questionnaire.[22] Dementia was classified as probable, possible, or none based on report of diagnosis and/or cognitive testing.[23] We recorded data on self-reported visits to a 'regular' doctor and hospital stays in last 12 months.

Analysis

We applied analytic survey weights, [24] to adjust for differential nonresponse based on individual variables (e.g., race/ethnicity, age) and county and census-tract level data and produced count and national prevalence estimates, with 95% confidence intervals (CI), of community dwelling homebound Medicare beneficiaries ages 65 and over. We report descriptive statistics for the entire NHATS sample and homebound categories (homebound, semi-homebound and not homebound), including demographic, clinical, and health care utilization characteristics. We compared differences between each sub-group and the completely homebound population using t-tests and chi-square analyses. All analyses accounted for complex survey design and were performed with Stata version 12 (College Station, Texas).

RESULTS

As shown in Table 1, the prevalence of the completely homebound was 1.1% (95% CI= 0.93%–1.34%), an estimated 395,422 people. The prevalence of the mostly homebound was 4.5% (95% CI=4.02%–4.97%), an estimated 1,578,984 people. Among the semi-homebound, the prevalence of those who never left home without personal assistance was 3.3% (95% CI=2.82%–3.77%) and the prevalence of those who required help and/or had difficulty was 11.7% (95% CI=10.89%–12.6%). About 80% of the population was classified as non-homebound.

Completely homebound individuals were older (83.2 vs. 74.3 years, $p<0.001$), and more likely to be women (67.9% vs 53.4%, $p=0.006$) and non-White (34.1% vs. 17.6%, $p<0.001$) than those who were not homebound (Table 2). Completely homebound individuals had significantly less education and lower income than those who were not homebound or the semi-homebound individuals who needed help and/or had difficulty leaving the home. The completely homebound and the mostly homebound had similar demographic characteristics, except the mostly homebound were more likely to live alone.

Of the completely homebound, 70% reported that they were in fair or poor health (Table 3). The completely homebound had on average twice as many chronic conditions as those who were not homebound (4.9 vs. 2.5, $p<0.001$) and were significantly more likely to be depressed or to have possible or probable dementia. The completely homebound and the semi-homebound who require personal assistance had similar needs for help with self-care activities.

The homebound and semi-homebound were more likely to have been hospitalized in the past year (rates ranging from 38%–52% across categories) than the non-homebound (16%). Of the completely homebound, 11.9% reported that they received primary care at home, significantly more than the comparable percentage for the semi-homebound or non-homebound groups ($p<0.001$).

DISCUSSION

We found that about 5.6% of the elderly, community-dwelling Medicare population, about 2 million people, were completely or mostly homebound in the U.S. in 2011. By comparison, the U.S. nursing home population was 1.4 million in 2012.[25] The homebound included about 400,000 people who were completely homebound and about 1.6 million who only left the home with another person, or had difficulty leaving the home alone.

Medicare defines homebound status in the context of determining patient eligibility to receive services under the Part A skilled home health care benefit. Such patients must (1) be under a doctor's care, (2) need skilled services, (3) receive services from a Medicare-approved home health agency, and (4) because of illness or injury, need the aid of supportive devices, special transportation, or assistance from another person to leave their home or have a condition for which leaving the home is medically contraindicated.[13] Our conceptual approach to defining homebound status focused on the individual's ability to leave the home. A measure based on eligibility for Medicare services may not reflect the number of people who are, in fact, unable to leave the home.

Consistent with previous research[26] we found that homebound or semi-homebound status are associated with markers of greater socioeconomic vulnerability, such as advanced age, low income, and higher prevalence of hospitalization. Although these individuals often are disabled or have chronic illness, being homebound or semi-homebound might also result from social, psychological, and environmental phenomena. Semi-homebound individuals who never leave home without personal assistance are similar in terms of disease burden and functional capacity to the completely homebound. This finding suggests that social support may be as important as medical factors in determining whether a person is completely homebound.[27] An individual who may be homebound because they have limited disability but live in an apartment or house with entrance stairs exemplifies the potential role of environmental factors. Research should examine whether adaptations to disability,[15] such as home accommodations (e.g., stair lifts or grab bars) and the use of assistive devices (e.g., canes or wheelchairs), modify homebound status.

Of the completely homebound, we found that only 11.9% reported that they received primary medical care services at home. Our measures of homebound status may be helpful for targeting patients for programs that serve the homebound, and for developing new programs. As Medicare considers home health payment reform[28] and changes in the methods of paying for medical care, the development and dissemination of home-based primary care and associated quality frameworks is essential.[29] Much of what we know about the homebound is based on studies of those who receive home health care services[30,31,32] or home-based primary care.[33–35] Combining survey data with administrative data on service use may inform the development of improved clinical services for homebound individuals.

Our study has limitations. This study was cross-sectional and therefore cannot account for the variable nature of disability, such as when individuals experience disabilities, and then recover. As longitudinal data become available from the NHATS, the stability of homebound status can be examined. There also may be seasonal variations in homebound status- depending on the local climate some individuals may be more likely to be homebound in winter months. Our measures of homebound status were constrained by the items and skip patterns within the NHATS mobility questionnaire. For example, the mobility questions were limited to activities within the last month and no information was collected about reasons why individuals did not leave the home. We were also unable to determine how much difficulty those who are completely homebound or reliant on personal assistance would have leaving the home independently. Additionally, the 6% of instances where interviews were with a proxy may contribute to measurement error. Finally, it is possible that the homebound were overrepresented among study non-responders; if so, the number of homebound in the U.S. would be higher than our estimates. These limitations notwithstanding, our findings provide an estimate of the homebound population in the U.S, which can inform improvements in clinical and social services for these individuals.

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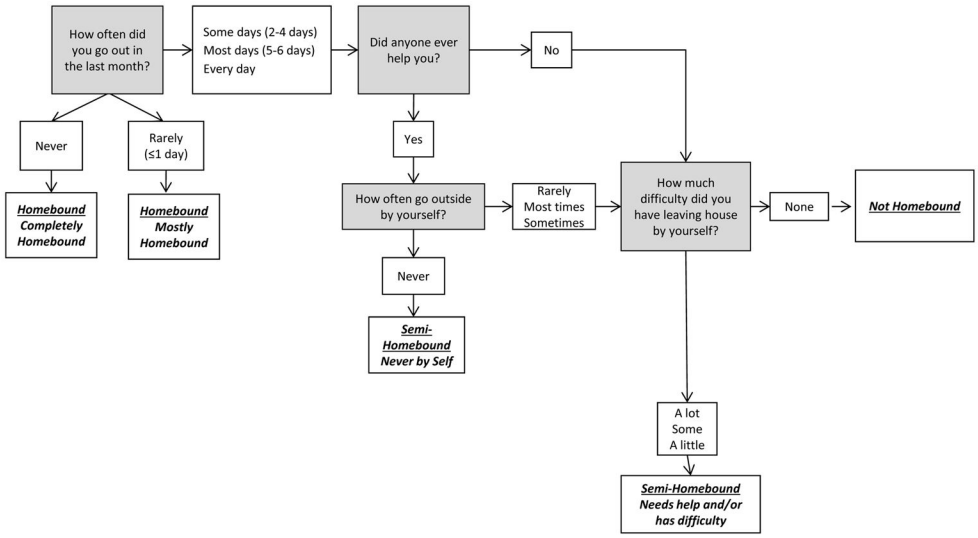

Figure 1.

Determining homebound status using the National Health and Aging Trends Study (NHATS)

Table 1

Prevalence and number of community-dwelling Medicare beneficiaries age 65 by frequency and ability to leave the home using the National Health and Aging Trends Study (NHATS), United States, 2011 (n=7609).

Level	Subgroup	Definition	Unweighted % (95% CI)	Number	Weighted % (95% CI)	Number
1. Homebound	A. Completely	Never went out in the last month	1.75% (1.48%, 2.07%)	133	1.12% (0.93%, 1.34%)	395,422
	B. Mostly	Rarely (once a week or less) went out in the last month	5.62% (5.13%, 6.17%)	428	4.47% (4.02%, 4.97%)	1,578,984
2. Semi-homebound	A. Never by self	Go out at least sometimes (twice per week), but never by themselves	4.49% (4.05%, 4.98%)	342	3.26% (2.82%, 3.77%)	1,151,389
	B. Needs help and/or has difficulty	Go out at least sometimes (twice per week), but needs help and/or has difficulty	13.39% (12.65%, 14.18%)	1,019	11.74% (10.89%, 12.64%)	4,143,579
3. Not Homebound		Go out at least twice per week without help and/or difficulty	74.66% (73.67%, 75.63%)	5,681	79.33% (78.26, 80.36%)	28,008,54

Table 2

Demographics characteristics of community-dwelling homebound Medicare beneficiaries by homebound status using the National Health and Aging Trends Study (NHATS), United States, 2011.

	Total NHATS	Homebound			Semi-homebound				Not homebound	
		Completely	Mostly	p-value	Never by self	p-value	Needs help and/or has difficulty	p-value		p-value
Age (Mean(SD))	75.3 (7.17)	83.2 (10.64)	80.9 (9.29)	.06	82.2 (9.23)	.37	77.1 (8.05)	<.001	74.3 (6.36)	<.001
Gender										
Female	56.6%	67.9%	77.1%	.12	79.2%	.06	63%	.37	53.4%	.006
Race										
White, non-Hispanic	80.5%	65.9%	68.9%	.19	72.3%	.23	75.9%	.10	82.4%	.001
Black, non-Hispanic	8.1%	15.6%	10.8%		10.7%		10.3%		7.4%	
Hispanic	6.8%	10.7%	15.5%		12.7%		9.2%		5.6%	
Other	4.6%	7.8%	74.8%		4.3%		4.6%		4.6%	
Education										
Less than High School	21.5%	35.1%	41.6%	.57	32.9%	.63	34%	.006	17.9%	<.001
High School/GED	27.3%	30.4%	27.1%		30.3%		25.3%		27.4%	
>High School	49.9%	29.9%	28.7%		34.3%		39.5%		53.7%	
Marital Status										
Married or Live w/Partner	58.0%	39.5%	31.2%	.25	37.1%	.55	43.7%	.31	61.5%	<.001
Not Married	11.9%	9.2%	15.7%		8.2%		10.9%		12.4%	
Widowed	27.0%	45.8%	45.8%		50.1%		39.6%		22.9%	
Never Married	42.0%	60.5%	68.8%		62.9%		56.3%		3.1%38.5%	
Income										
< $15,000	23.8%	42.3%	46.5%	.49	39.3%	.17	36.9%	.008	19.7%	<.001
$15,000 – $29,999	24.3%	39.0%	33%		30.2%		28.2%		22.8%	
$30,000 – $59,999	26.7%	11.9%	15.7%		22.2%		21.1%		28.6%	
≥ 60,000	25.1%	6.8%	4.8%		8.3%		13.8%		28.9%	
Covered by Medicaid										

	Total NHATS	Homebound			Semi-homebound				Not homebound	
		Completely	Mostly	p-value	Never by self	p-value	Needs help and/or has difficulty	p-value		p-value
Yes	12.0%	29.8%	29.9%	.78	23.2%	.46	22.0%	.003	8.7%	<.001
Language other than English										
Yes	19.7%	23.2%	28.1%	.12	25.6%	.62	22.6%	.09	18.4%	.05
Living Arrangement										
Alone	30%	27%	41.2%	.02	32.2%	.39	36.2%	.09	28.4%	.77
With Others	70%	73%	58.8%		67.8%		63.8%		71.6%	

Note: SD = standard deviation

Table 3

Clinical and health care utilization characteristics of community-dwelling homebound Medicare beneficiaries by homebound status using the National Health and Aging Trends Study (NHATS), United States, 2011.

	Total NHATS	Homebound			Semi-homebound				Not homebound	
		Completely	Mostly	p-value	Never by self	p-value	Needs help and/or has difficulty	p-value		p-value
Self-Reported Health										
Fair or Poor	25%	70.1%	62.9%	.22	58.6%	.04	52.9%	.003	16.8%	<.001
Self-Reported Diseases										
Heart Attack	14%	23.6%	23.0%	.90	23.4%	.98	21.5%	.66	11.9%	.002
Heart Disease	17.4%	33.5%	26.3%	.17	30.9%	.66	26.9%	.18	14.7%	<.001
Arthritis	53.7%	71.4%	71.3%	.97	67.3%	.44	71.3%	.98	49.3%	<.001
Diabetes	23.9%	25.0%	32.9%	.22	34.6%	.09	32.7%	.17	21.6%	.47
Lung Disease	15.4%	29.6%	27.0%	.65	17.7%	.03	23.9%	.27	13.2%	<.001
Stroke	10%	19.9%	23.3%	.52	25.7%	.30	17.4%	.54	7.4%	<.001
Cancer	25.8%	31.2%	21.0%	.06	26.1%	.30	28.1%	<.001	25.7%	.21
Depression (PHQ2) (range 0–6)										
0–2	84.8%	36.6%	58.6%	.002	65.7%	<.001	72.4%	<.001	89.6%	<.001
≥ 3	14.4%	59.3%	38.1%		31.9%		26.5%		10%	
Dementia Classification										
Possible/Probable Dem.	21%	80.1%	55.7%	<.001	57.5%	.001	33.5%	<.001	14.8%	<.001
Number of Conditions (range 0–13)										
Mean (SD)	2.8 (1.81)	4.9 (2.41)	4.5 (2.34)	.09	4.4 (2.37)	.02	3.9 (2.14)	<.001	2.5 (1.53)	<.001
Fall past Month										
Yes	10.4%	25.1%	24.6%	.93	24.3%	.89	22.6%	.62	7.0%	<.001
Physical capacity										
Walk at least 6 blocks	64.8%	1.7%	11.2%	<.001	3.7%	.23	20.9%	<.001	77.7%	<.001
Self-care Activities										

	Total NHATS	Homebound			Semi-homebound				Not homebound	
		Completely	Mostly	p-value	Never by self	p-value	Needs help and/or has difficulty	p-value		p-value
Help Eating	4.1%	47.5%	22.8%	<.001	36.3%	.09	6.5%	<.001	0.7%	<.001
Help Bathing	27.8%	65.2%	44.2%	.001	61.9%	.61	16.4%	<.001	1.5%	<.001
Help Toileting	3.2%	45.1%	15.5%	<.001	36.6%	.14	4.9%	<.001	0.3%	<.001
Help Dressing	9.8%	54.8%	43.2%	.06	63%	.22	21.6%	<.001	3.3%	<.001
Seen regular doctor last year										
Yes	93%	90%	95.5%	.02	98.4%	<.001	96.1%	.002	92.3%	.33
Regular doctor was a home visit										
Yes	0.75%	11.9%	4.9%	.006	3.1%	<.001	0.4%	<.001	0.32%	<.001
Hospital stay in last 12 months										
Yes	21%	52.1%	38.8%	.01	50.6%	.77	36.0%	.001	16.2%	<.001
Number of hospital stays										
Mean(SD)	1.7 (1.79)	1.8 (2.24)	2.2 (2.61)	.03	2.3 (2.19)	.05	1.8 (1.48)	.92	1.6 (1.64)	.08

Note: PHQ2= 2 item Patient Health Questionnaire; SD = standard deviation