

Original Investigation

Epidemiology of the Homebound Population in the United States

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IMPORTANCE Increasing numbers 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 are homebound.

OBJECTIVES To develop measures of the frequency of leaving and ability to leave the home and to use these measures to estimate the size of the homebound population in the US population.

DESIGN, SETTING, AND PARTICIPANTS Cross-sectional data from the National Health and Aging Trends Study collected in 2011 in the contiguous United States. Participants were a nationally representative sample of 7603 noninstitutionalized Medicare beneficiaries 65 years and older.

MAIN OUTCOMES AND MEASURES We defined homebound persons as those who never (completely homebound) or rarely (mostly homebound) left the home in the last month. We defined semihomebound persons as those who only left the home with assistance or had difficulty or needed help leaving the home. We compared demographic, clinical, and health care utilization characteristics across different homebound status categories.

RESULTS In 2011, the prevalence of homebound individuals was 5.6% (95% CI, 5.1%-6.2%), including an estimated 395 422 people who were completely homebound and 1 578 984 people who were mostly homebound. Among semihomebound individuals, the prevalence of those who never left home without personal assistance was 3.3% (95% CI, 2.8%-3.8%), and the prevalence of those who required help or had difficulty was 11.7% (95% CI, 10.9%-12.6%). Completely homebound individuals were more likely to be older (83.2 vs 74.3 years, $P < .001$), female (67.9% vs 53.4%, $P < .006$), and of nonwhite race (34.1% vs 17.6%, $P < .001$) and have less education and income than nonhomebound individuals. They also had more chronic conditions (4.9 vs 2.5) and were more likely to have been hospitalized in the last 12 months (52.1% vs 16.2%) ($P < .001$ for both). Only 11.9% of completely homebound individuals reported receiving primary care services at home.

CONCLUSIONS AND RELEVANCE In total, 5.6% of the elderly, community-dwelling Medicare population (approximately 2 million people) were completely or mostly homebound in 2011. Our findings can inform improvements in clinical and social services for these individuals.

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An increasing number of older, community-dwelling adults have functional impairments that prevent them from leaving their homes.¹ The homebound population has high disease and symptom burden, substantial functional limitations, and higher mortality than the nonhomebound population.¹⁻³ Homebound individuals also use health care services at high rates.⁴⁻⁶

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

It is uncertain how many people who live in the United States 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} However, this approach has focused on the need for personal assistance rather than whether the individual is limited to his or her home.¹⁶

We developed measures of the frequency of leaving and ability to leave the home. We used these measures to more accurately estimate the homebound population in the United States.

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} The NHATS drew a random sample of individuals 65 years and older living in the contiguous United States from the Medicare enrollment file on September 30, 2010, with oversampling of those 90 years and older and non-Hispanic blacks. Interviews were completed in October 2011 and yielded a sample of 8245 persons and a 70.9% 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 7603 participants in settings other than nursing homes with complete data on frequency and ability to leave the home (99.9%). Proxy respondents were interviewed when the sample person could not respond (5.8%).¹⁹ The Johns Hopkins University Institutional Review Board approved the NHATS protocol, and all participants provided written informed consent.

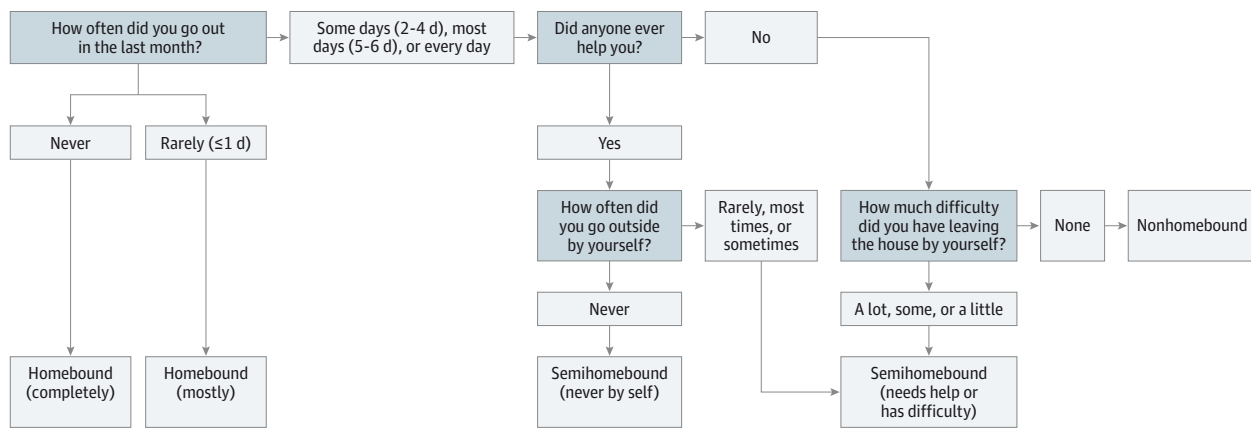
Measures

The NHATS has no predefined 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 ability of social support to compensate for limitations in capacity.^{15,20,21} Therefore, 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 with which 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 who 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 the use of assistive devices) in the last month.

We categorized individuals across the following 3 main measures: (1) homebound, (2) semihomebound, and (3) nonhomebound (Table 1). Homebound individuals never or rarely left the home. We divided them into a completely homebound group, who never went out in the last month, and a mostly homebound group, who went out once a week or less. Semihomebound individuals left the home but were at risk of becoming homebound because getting out of the home was difficult or they needed personal assistance to do so. Therefore, 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 nonhomebound.

Our analyses included the following demographic data: age, sex, race, education, marital status, income, language, and living arrangement. Clinical data were based on self-report and included whether a physician had ever told an individual that he or she had specific health conditions. We created a count of the following 13 self-reported chronic conditions to reflect multimorbidity: heart attack, heart disease (including angina and congestive heart failure), high blood pressure, arthritis, osteoporosis, diabetes mellitus, lung disease, stroke, dementia or Alzheimer disease, cancer, depression, anxiety, and broken or fractured hip. Depression was defined as a score of 3 or higher on the 2-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 or cognitive testing.²³ Data on self-reported visits to a regular physician and hospital stays in the last 12 months were also collected.

Figure. Determining Homebound Status Using the National Health and Aging Trends Study



Respondents were asked a series of questions as part of a Mobility Questionnaire found in the National Health and Aging Trends Study.

Table 1. Prevalence and Number of 7603 Community-Dwelling Medicare Beneficiaries 65 Years and Older by the Frequency of Leaving and Ability to Leave the Home Using the National Health and Aging Trends Study, United States, 2011

Level and Subgroup	Definition	Unweighted % (95% CI)	No.	Weighted % (95% CI)	No.
Homebound					
Completely	Never went out in the last month	1.75 (1.48-2.07)	133	1.12 (0.93-1.34)	395 422
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
Semihomebound					
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
Needs help or has difficulty	Go out at least sometimes (twice per week) but needs help or has difficulty	13.39 (12.65-14.18)	1019	11.74 (10.89-12.64)	4 143 579
Nonhomebound	Go out at least twice per week without help or difficulty	74.66 (73.67-75.63)	5681	79.33 (78.26-80.36)	28 008 542

Statistical Analysis

We applied analytic survey weights²⁴ to adjust for differential nonresponse based on individual variables (eg, race and age) and county and census tract-level data and produced count and national prevalence estimates (with 95% CIs) of community-dwelling homebound Medicare beneficiaries 65 years and older. We report descriptive statistics for the entire NHATS sample and for homebound categories (homebound, semihomebound, and nonhomebound), including demographic, clinical, and health care utilization characteristics. We compared differences between each subgroup and the completely homebound population using *t* tests and χ^2 analyses. All analyses accounted for complex survey design and were performed with statistical software (STATA, version 12; StataCorp LP).

Results

As summarized in Table 1, the prevalence of completely homebound individuals was 1.12% (95% CI, 0.93%-1.34%), an estimated 395 422 people. The prevalence of mostly homebound individuals was 4.5% (95% CI, 4.0%-5.0%), an estimated 1 578 984 people. Among semihomebound individuals, the prevalence of those who never left home without personal as-

sistance was 3.3% (95% CI, 2.8%-3.8%), and the prevalence of those who required help or had difficulty was 11.7% (95% CI, 10.9%-12.6%). Approximately 80% of the population were classified as nonhomebound.

Completely homebound individuals were older (83.2 vs 74.3 years, *P* < .001) and more likely to be female (67.9% vs 53.4%, *P* = .006) and of nonwhite race (34.1% vs 17.6%, *P* < .001) than nonhomebound individuals (Table 2). Completely homebound individuals had significantly less education and lower income than nonhomebound individuals or semihomebound individuals who needed help or had difficulty leaving the home. The completely homebound group and the mostly homebound group had similar demographic characteristics, except that the mostly homebound group was more likely to live alone.

Of the completely homebound individuals, 70.1% reported that they were in fair or poor health (Table 3). Those who were completely homebound had on average twice as many chronic conditions as those who were nonhomebound (4.9 vs 2.5, *P* < .001) and were significantly more likely to be depressed or have possible or probable dementia. The completely homebound group and the semihomebound group who require personal assistance had similar needs for help with self-care activities.

Table 2. Demographic Characteristics of Community-Dwelling Medicare Beneficiaries by Homebound Status Using the National Health and Aging Trends Study (NHATS), United States, 2011

Variable	NHATS Total	Homebound			Semihomebound			Nonhomebound		
		Completely	Mostly	P Value	Never by Self	P Value	Needs Help or Has Difficulty	P Value	Value	P Value
Age, mean (SD), y	75.3 (7.2)	83.2 (10.6)	80.9 (9.3)	.06	82.2 (9.2)	.37	77.1 (8.1)	<.001	74.3 (6.4)	<.001
Female sex, %	56.6	67.9	77.1	.12	79.2	.06	63.0	.37	53.4	.006
Race				.19		.23		.10		<.001
Non-Hispanic white	80.5	65.9	68.9		72.3		75.9		82.4	
Non-Hispanic black	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, %				.57		.63		.006		<.001
<High school	21.5	35.1	41.6		32.9		34.0		17.9	
High school or 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, %				.25		.55		.31		<.001
Married or live with partner	57.0	39.5	31.2		37.1		43.8		61.5	
Not married	12.2	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	3.7	4.8	7.1		4.6		5.7		3.2	
Income, %				.49		.17		.008		<.001
<\$15 000	23.8	42.3	46.5		39.3		36.9		19.7	
\$15 000-\$29 999	24.3	39.0	33.0		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	
Medicaid beneficiary, %	12.0	29.8	29.9	.78	23.2	.46	22.0	.003	8.7	<.001
Language other than English, %	19.7	23.2	28.1	.12	25.6	.62	22.6	.09	18.4	.05
Living arrangement, %				.02		.39		.09		.77
Alone	30.0	27.0	41.2		32.2		36.2		28.4	
With others	70.0	73.0	58.8		67.8		63.8		71.6	

Abbreviation: GED, General Educational Development.

Homebound individuals and semihomebound individuals were more likely to have been hospitalized in the last year (range, 36.0%-52.1% across categories) than nonhomebound individuals (16.2%). Of the completely homebound group, 11.9% reported that they received primary care at home, significantly more than the comparable percentage for the semihomebound group or nonhomebound group ($P < .001$).

Discussion

We found that approximately 5.6% of the elderly, community-dwelling Medicare population (approximately 2 million people) were completely or mostly homebound in the United States in 2011. By comparison, the US nursing home population in 2012 was 1.4 million.²⁵ The homebound population included approximately 400 000 people who were completely homebound and approximately 1.6 million people who rarely went out.

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 (1) must be under a physician's care, (2) must need skilled services, (3) must receive services from a Medicare-approved home health agency, and (4) because of illness or injury must 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 semihomebound status is 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 semihomebound might also result from social, psychological, and environmental phenomena. Semihomebound individuals who never leave home without personal assistance are similar to completely homebound individuals in terms of disease bur-

Table 3. Clinical and Health Care Utilization Characteristics of Community-Dwelling Medicare Beneficiaries by Homebound Status Using the National Health and Aging Trends Study (NHATS), United States, 2011

Variable	NHATS Total	Homebound			Semihomebound			Nonhomebound		
		Completely	Mostly	P Value	Never by Self	P Value	Needs Help or Has Difficulty	P Value	Value	P Value
Self-reported health fair or poor, %	25.0	70.1	62.9	.22	58.6	.04	52.9	.003	16.8	<.001
Self-reported diseases, %										
Heart attack	14.0	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 mellitus	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	10.0	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	.51	25.7	.21
Depression PHQ2 score on PHQ2, %				.002		<.001		<.001		<.001
0-2	84.8	36.6	58.6		65.7		72.4		89.6	
≥3	14.4	59.3	38.1		31.9		26.5		10.0	
Dementia classification possible or probable, %	21.0	80.1	55.7	<.001	57.5	.001	33.5	<.001	14.8	<.001
No. of chronic conditions, mean (SD) ^a	2.8 (1.8)	4.9 (2.4)	4.5 (2.3)	.09	4.4 (2.4)	.02	3.9 (2.1)	<.001	2.5 (1.5)	<.001
Fall in the last month, %	10.4	25.1	24.6	.93	24.3	.89	22.6	.62	7.0	<.001
Physical capacity to walk ≥6 blocks, %	64.8	1.7	11.2	<.001	3.7	.23	20.9	<.001	77.7	<.001
Self-care activities, %										
Help eating	4.1	47.5	22.8	<.001	36.3	.09	6.5	<.001	0.7	<.001
Help bathing	7.8	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	63.0	.22	21.6	<.001	3.3	<.001
Saw regular physician in the last year, %	93.0	90.0	95.5	.02	98.4	<.001	96.1	.002	92.3	.33
Regular physician visit was a home visit, %	0.8	11.9	4.9	.006	3.1	<.001	0.4	<.001	0.3	<.001
Hospital stay in the last 12 mo, %	21.0	52.1	38.8	.01	50.6	.77	36.0	.001	16.2	<.001
No. of hospital stays, mean (SD)	1.7 (1.8)	1.8 (2.2)	2.2 (2.6)	.03	2.3 (2.2)	.05	1.8 (1.5)	.92	1.6 (1.6)	.08

Abbreviation: PHQ2, 2-item Patient Health Questionnaire (score range, 0-6).

^a Range of 0 to 13.

den and functional capacity. 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 he or she has limited disability but lives in an apartment or house with entrance stairs exemplifies the potential role of environmental factors. Research should examine whether adaptations to disability¹⁵ such as home accommodations (eg, stair lifts or grab bars) and the use of assistive devices (eg, canes or wheelchairs) modify homebound status.

Of the completely homebound individuals, we found that only 11.9% reported that they received primary care services at home. Our measures of homebound status may be helpful for targeting patients for programs that serve the homebound population and for developing new programs. As Medicare considers home health payment reform²⁸ and changes in the methods of paying for medical care, the

development and dissemination of home-based primary care and associated quality frameworks are essential.²⁹ Much of what we know about homebound individuals is based on studies of those who receive home health care services³⁰⁻³² 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: some individuals may be more likely to be homebound in winter months, depending on the local climate. 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. In addition, the 5.8% of instances where interviews were with a proxy may have contributed to measurement error. Finally, it is possible that homebound individuals were overrepresented

among study nonresponders. If so, the number of homebound individuals in the United States would be higher than our estimates.

Conclusions

These limitations notwithstanding, our findings provide an estimate of the homebound population in the United States. This information can inform improvements in clinical and social services for these individuals.

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Author Contributions: Dr Ornstein had full access to all 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.

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