Understanding Stroke Survivorship
Expanding the Concept of Poststroke Disability

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Background and Purpose—Limitations in essential daily activities are common among older adults after stroke, but little is known about restrictions in their ability to participate in valued social activities. We sought to broaden our understanding of disability after stroke by characterizing poststroke participation restrictions and investigating the extent to which they are accounted for by differences in physical and cognitive capacity, aphasia/dysarthria, depressive, and anxiety symptoms.

Methods—Data from the 2011 National Health and Aging Trends Study (NHATS) were used to identify 892 self-reported stroke survivors aged ≥65 years. One-to-one propensity matching was performed on demographics and comorbidities to create a matched sample. Participation restrictions were defined as reductions/absence in social activities valued by respondents because of their health or functioning. Physical and cognitive capacity, depressive and anxiety symptoms were measured by validated scales and aphasia/dysarthria by a single question. Comparisons using survey-weighted χ² tests and logistic regression were made.

Results—Stroke survivors had more participation restrictions (32.8% versus 23.5%; odds ratio, 1.59; 95% confidence interval, 1.28–1.95; P<0.01) than controls. Differences between stroke survivors and controls in any participation restriction and several components (attending religious service, clubs/classes, and going out for enjoyment) were eliminated after adjusting for physical capacity. Depressive and anxiety symptoms and aphasia/dysarthria were independent predictors of participation restrictions.

Conclusions—Stroke survivors have more participation restrictions than can be accounted for by sociodemographic profiles and comorbidity burden. Future work aimed at improving physical capacity, reducing depressive and anxiety symptoms, and improving aphasia/dysarthria has potential to enhance participation. (Stroke. 2014;45:224-230.)

Key Words: disability evaluation ■ patient participation

The baby-boom generation, born from the mid-1940s to mid-1960s, currently comprises >25% of the US population. Because of the aging of this generation and declining stroke mortality, stroke survivors are expected to increase from 7 million to >10 million by 2030.1 Given the rising number of stroke survivors, understanding stroke’s effects on daily life to optimize stroke survivorship is an important goal.

In 2007, the Institute of Medicine recommended adopting a broader perspective on functioning and disability that recognizes both essential daily activities, for example, what is measured by Barthel Index, and participation in productive social and civic activities.2 Participation in social and civic activities is associated with decreased risk of dementia, institutionalization, and mortality.1,3–5 The few studies that have evaluated poststroke participation have been limited to inpatient rehabilitation facility patients,6,7 state stroke registry,8 working age hospitalized patients,9 small sizes6,7,9 and have not been nationally representative.

Using a national sample of older adults, we first sought to determine the extent to which stroke accounts for disability—broadly defined—above the normal aging process and comorbidities. We compared stroke survivors with demographic- and comorbidity-matched controls with respect to activity limitations and participation restrictions to determine whether stroke survivors have more or different disability. Our primary hypothesis was that stroke survivors would have greater activity limitations and participation restrictions than their matched controls. We then explored the extent to which differences in participation restrictions among stroke survivors and controls are accounted for by physical and cognitive capacity, aphasia/dysarthria, depressive and anxiety symptoms. We hypothesized that even after accounting for these variables that stroke survivors would have greater participation restrictions than controls. Finally, we explored whether these effects were different for strokes survivors and controls for our primary outcome (any...
participation restriction). These data may inform the design of interventions to improve poststroke participation, which require a clear understanding of the factors driving participation restrictions.

Methods

Data Source and Population

This evaluation is a cross-sectional study of stroke survivors and a cohort of nonstroke controls. Stroke survivors were identified in the National Health and Aging Trends Study (NHATS). NHATS is an annual face-to-face interview by trained study personnel of >8000 Medicare beneficiaries aged ≥65 years in their place of residence. If the selected Medicare beneficiary could not complete the interview, a proxy respondent was interviewed. The first round, which took place in 2011, oversampled blacks and people in older age groups. Response rates were 72% at baseline; analytic weights that take into account differential probabilities of selection and nonresponse allow generalization to the aged Medicare population. Nearly 900 stroke survivors living in the community (including residential care settings other than nursing homes) were identified (738 by self-report and 154 by proxy-report) on the basis of an affirmative response to: “Has a doctor has ever told you that you had a stroke?”

Matching Criteria

NHATS collected a variety of sociodemographic characteristics, including sex, age, race/ethnicity, marital status, and place of residence. Comorbidities included hypertension, myocardial infarction, coronary heart disease, diabetes mellitus, cancer, lung disease, dementia, smoking, osteoporosis, and arthritis.

Activity Limitations

Self-reported measures of activity limitations in the NHATS disability protocol have been validated.11 NHATS queried 7 self-care and mobility activities: eating, bathing/showering, toileting, dressing, getting out of bed, getting around within one’s home, and leaving one’s home. For each activity, questions elicited whether in the previous month the respondent had no difficulty and had difficulty but was able to perform activity or received help from another person with the activity. In addition, 5 household activities were assessed: performing own laundry, grocery shopping, making hot meals, handling bills/banking, and administering medications. For each activity, respondents were classified as receiving help or for them because of their health or functioning.

Participation Restrictions

Respondents were asked if in the previous month they had visited with friends/family not living with them either in their home or the home of their friends/family, attended religious services, participated in clubs/classes or other organized activities, and gone out for enjoyment (dinner, a movie, to gamble, listen to music, or see a play).11 Each activity had follow-up questions to elicit how important the activity some or a lot and that their health or functioning limited their participation. Respondents were considered to have a participation restriction if they reported that they valued the activity some or a lot and their health or functioning limited their participation. A previously validated dichotomous summary score to identify any participation restriction in a valued activity because of health was created.11

Physical and Cognitive Capacity

NHATS measures both self-reported and performance-based measures of capacity.11 The self-reported physical capacity measures queried if the stroke survivor could perform tasks independently and without the use of assistive devices in the previous month. Tasks were paired into less and more challenging functions. The 6 pairs were (1) walking 3 and 6 blocks; (2) going up 10 and 20 stairs; (3) lifting and carrying 10 and 20 pounds; (4) bending over and kneeling down; (5) reaching overhead and reaching overhead with a heavy object; and (6) open small objects and open sealed objects.11 Responses were divided into 3 options: can do harder task, can do easier but not harder task, and cannot do either task. A summary self-reported physical capacity measures was created with 1 point for every easy task and 2 points for every more challenging task performed (scores, 0–12).11

NHATS also measures physical capacity with a series of performance tests, including the short physical performance battery, a validated assessment tool for measuring lower extremity function consisting of a timed 4-m walk, repeated chair stands and a series of balance tests. Grip strength in the dominant hand and peak expiratory flow were also measured (see online-only Data Supplement).12 Cognitive capacity was summarized as the sum of correct immediate and delayed recall words scores (0–20) and the categorical

### Table 1. Characteristics of Stroke Survivors and Matched Controls

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Stroke (n=892, %)</th>
<th>Controls (n=892, %)</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Propensity-matched characteristics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>57.0</td>
<td>55.4</td>
<td>0.84</td>
</tr>
<tr>
<td>Married</td>
<td>46.5</td>
<td>50.9</td>
<td>0.12</td>
</tr>
<tr>
<td>Age, y</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>65–69</td>
<td>17.7</td>
<td>18</td>
<td></td>
</tr>
<tr>
<td>70–74</td>
<td>21.5</td>
<td>21.3</td>
<td></td>
</tr>
<tr>
<td>75–79</td>
<td>18.6</td>
<td>19.7</td>
<td></td>
</tr>
<tr>
<td>80–84</td>
<td>21</td>
<td>20.9</td>
<td></td>
</tr>
<tr>
<td>85–89</td>
<td>14.3</td>
<td>13.9</td>
<td></td>
</tr>
<tr>
<td>≥90</td>
<td>7</td>
<td>6.2</td>
<td></td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>78.9</td>
<td>80.1</td>
<td>0.75</td>
</tr>
<tr>
<td>Black</td>
<td>10.1</td>
<td>10.1</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>6.7</td>
<td>5.5</td>
<td></td>
</tr>
<tr>
<td>Place of residence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community</td>
<td>90.7</td>
<td>93.1</td>
<td>0.12</td>
</tr>
<tr>
<td>Comorbidities</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Myocardial infarction</td>
<td>31</td>
<td>30.9</td>
<td>0.99</td>
</tr>
<tr>
<td>Coronary artery disease</td>
<td>30.1</td>
<td>29.1</td>
<td>0.69</td>
</tr>
<tr>
<td>Hypertension</td>
<td>78.1</td>
<td>79.8</td>
<td>0.43</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>36.2</td>
<td>38.3</td>
<td>0.37</td>
</tr>
<tr>
<td>Cancer</td>
<td>27.9</td>
<td>27.6</td>
<td>0.91</td>
</tr>
<tr>
<td>Lung disease</td>
<td>21</td>
<td>18.9</td>
<td>0.40</td>
</tr>
<tr>
<td>Dementia</td>
<td>11.8</td>
<td>10.6</td>
<td>0.48</td>
</tr>
<tr>
<td>Smoking</td>
<td>11.3</td>
<td>7.9</td>
<td>0.18</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>27.8</td>
<td>27.5</td>
<td>0.92</td>
</tr>
<tr>
<td>Arthritis</td>
<td>35.6</td>
<td>24.0</td>
<td>0.56</td>
</tr>
<tr>
<td>Nonmatched characteristics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td>0.22</td>
</tr>
<tr>
<td>Did not graduate from high school</td>
<td>30.0</td>
<td>24.1</td>
<td></td>
</tr>
<tr>
<td>High-school graduate</td>
<td>28.1</td>
<td>29.8</td>
<td></td>
</tr>
<tr>
<td>Some post–high school</td>
<td>25.7</td>
<td>26.4</td>
<td></td>
</tr>
<tr>
<td>College graduate</td>
<td>8.2</td>
<td>9.4</td>
<td></td>
</tr>
<tr>
<td>Advanced degree</td>
<td>6.3</td>
<td>8.9</td>
<td></td>
</tr>
</tbody>
</table>

Cells represent survey-weighted percentages by group. Statistical comparisons were made using χ² tests.
Propensity matching was performed to create a matched sample of race/ethnicity, residence, and all individual NHATS comorbidities. To test our hypothesis that patients with stroke have greater activity limitations and participation restrictions compared with controls, we estimated the survey-weighted proportion of stroke survivors and 8% of controls), a large proportion did not have any proxy interview. For the proxy interviews (14% of cases/controls that completed the performance measures of physical capacity and anxiety symptoms) and stroke to determine whether these covariates predict differently in strokes and controls. A sensitivity analysis was completed with the performance measures of physical capacity for the 85% of cases/controls that completed the performance battery. Two-sided P < 0.05 were considered statistically significant, with no adjustments for multiple statistical testing. All analyses were performed using Stata 12 (Stata Statistical Software: Release 12; StataCorp LP, College Station, TX).

### Results

There were 892 stroke survivors representing 3.5 million American stroke survivors identified (Table 1). Seventy-nine percent of the stroke survivors were non-Hispanic white and 57% were women. Propensity score matching resulted in excellent balance of sociodemographic and comorbidities in the stroke survivors and the nonstroke controls.

The activity limitation measures are shown in Table 2 and in Table 1 in the online-only Data Supplement. Stroke survivors were 65% to 121% more likely to receive help with self-care activities. Cognitive capacity measures were completed for the vast majority of those without a proxy interview. For the proxy interviews (14% of stroke survivors and 8% of controls), a large proportion did not complete the cognitive measures (76% of stroke survivors and 81% of controls). To minimize missing data, we assigned the mean score of the respondents with proxies who completed the cognitive testing to those respondents with proxies who did not complete the cognitive testing separately in the stroke and control groups. Respondents were also queried about symptoms for the previous month and if this impairment limited their activities (see online-only Data Supplement). Aphasia/dysarthria was queried with 1 item: “In the last month because of your health, did you have any problems in speaking or in making yourself understood when you talk?”

### Depressive and Anxiety Symptoms

NHATS administered the Patient Health Questionnaire with scores ≥3, indicating the presence of depressive symptoms (yes versus no) and the Generalized Anxiety Disorder questionnaire with scores ≥3, indicating the presence of anxiety symptoms (yes versus no).  

### Statistical Analysis

To estimate the association between stroke and measures of interest independent of demographic and comorbidity influences, we developed a control group using one-to-one propensity matching on age, sex, race/ethnicity, residence, and all individual NHATS comorbidities. Propensity matching was performed to create a matched sample of stroke and nonstroke controls from observational data.  

### Table 2. Prevalence of Activity Limitations Among Stroke Survivors and Matched Controls

<table>
<thead>
<tr>
<th>Activity Limitations</th>
<th>Stroke n % (n=892)</th>
<th>Controls n % (n=892)</th>
<th>Difference, %</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self-care activities</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Receives help</td>
<td></td>
<td></td>
<td></td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Eating</td>
<td>484,404 (13.7%)</td>
<td>220,681 (6.2%)</td>
<td>121</td>
<td></td>
</tr>
<tr>
<td>Bathing/showering</td>
<td>752,411 (21.3%)</td>
<td>461,141 (12.9%)</td>
<td>65.1</td>
<td></td>
</tr>
<tr>
<td>Using toilet</td>
<td>329,941 (9.3%)</td>
<td>188,991 (5.3%)</td>
<td>75.5</td>
<td></td>
</tr>
<tr>
<td>Dressing</td>
<td>861,248 (24.4%)</td>
<td>521,021 (14.6%)</td>
<td>67.1</td>
<td></td>
</tr>
<tr>
<td><strong>Mobility activities</strong></td>
<td></td>
<td></td>
<td></td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Receives help</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Going outside</td>
<td>864,221 (24.4%)</td>
<td>528,730 (14.8%)</td>
<td>64.9</td>
<td></td>
</tr>
<tr>
<td>Getting around in home</td>
<td>616,340 (17.4%)</td>
<td>371,851 (10.4%)</td>
<td>67.3</td>
<td></td>
</tr>
<tr>
<td>Getting out of bed</td>
<td>501,056 (14.2%)</td>
<td>266,360 (7.4%)</td>
<td>91.9</td>
<td></td>
</tr>
<tr>
<td><strong>Household activities</strong></td>
<td></td>
<td></td>
<td></td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Receives help for health-related reason</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laundry</td>
<td>966,700 (27.3%)</td>
<td>602,391 (16.8%)</td>
<td>62.5</td>
<td></td>
</tr>
<tr>
<td>Shopping</td>
<td>1,268,102 (35.9%)</td>
<td>773,363 (21.6%)</td>
<td>66.2</td>
<td></td>
</tr>
<tr>
<td>Making hot meals</td>
<td>994,383 (28.1%)</td>
<td>553,833 (15.5%)</td>
<td>81.3</td>
<td></td>
</tr>
<tr>
<td>Handling bills/banking</td>
<td>969,420 (27.4%)</td>
<td>486,921 (13.6%)</td>
<td>101.5</td>
<td></td>
</tr>
<tr>
<td>Administer medications</td>
<td>906,210 (25.6%)</td>
<td>499,630 (14%)</td>
<td>82.9</td>
<td></td>
</tr>
</tbody>
</table>

Cells report the estimated number of Americans with stroke (or in the control group) with a given activity limitation and the percentage of all group-members with a given activity limitation. Statistical comparisons were made using χ² tests.
and mobility activities than controls. The household activities and medication administration followed a similar pattern. Stroke survivors were 62% to 102% more likely to have someone perform household activities with them or for them because of their health or functioning. Similar to prior international work on self-care activities, stroke survivors received the most help with bathing/showering (21.3%) and dressing (24.4%) although overall limitations in self-care activities were less common.

Stroke survivors had significantly lower short physical performance battery scores (walking speed, repeated chair stand, and balance tests) and self-reported physical capacity than controls (Table 3). Among the self-reported physical capacity measures, stroke survivors had lower physical capacity for every measure (Figure). Stroke survivors also had lower cognitive capacity than controls. Compared with the controls, stroke survivors had poorer performance on word recall (6.9 versus 7.4; \( P < 0.01 \)) and had lesser accurate clock drawing. Stroke survivors reported more aphasia/dysarthria (17.4% versus 8.5%; \( P < 0.01 \)) in the preceding month than controls. In addition, stroke survivors were more likely to report depressive symptoms (28% versus 17.2%; \( P < 0.01 \)) and anxiety (23.6% versus 16.4%; \( P < 0.01 \)) than controls.

Participation restrictions were higher among stroke survivors compared with controls (32.8% versus 23.5%; odds ratio, 1.59; 95% confidence interval, 1.28–1.98; \( P < 0.01 \)). Stroke survivors were 40% more likely to have restricted participation in an activity that they valued because of their health than controls. Extrapolating this to the US population, 1.6 million stroke survivors have restricted participation when compared with \( \approx 840,000 \) of the controls. Stroke survivors were 84% more likely to restrict visiting with family and friends, 32% more likely to restrict attending religious services, and 59% more likely to restrict going out for enjoyment than controls. There was no difference between stroke survivors and controls in participating in clubs/classes (9.2% versus 7.3%; odds ratio, 1.28; 95% confidence interval, 0.90–1.84; \( P = 0.16 \)).

### Table 3. Physical and Cognitive Capacity, Aphasia/Dysarthria, and Psychological Status Among Stroke Survivors and Matched Controls

<table>
<thead>
<tr>
<th>Measures</th>
<th>Stroke (n=892), %</th>
<th>Controls (n=892), %</th>
<th>( P ) Value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Short physical performance battery, %</strong></td>
<td></td>
<td></td>
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<tr>
<td>Missing/inapplicable</td>
<td>15.6</td>
<td>15.6</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>0–3 worst</td>
<td>37.6</td>
<td>24</td>
<td></td>
</tr>
<tr>
<td>4–6</td>
<td>23</td>
<td>22.2</td>
<td></td>
</tr>
<tr>
<td>7–8</td>
<td>13.6</td>
<td>17.6</td>
<td></td>
</tr>
<tr>
<td>≥9 best</td>
<td>10.3</td>
<td>20.6</td>
<td></td>
</tr>
<tr>
<td><strong>NHATS balance score, %</strong></td>
<td></td>
<td></td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Missing/inapplicable</td>
<td>5.2</td>
<td>5.8</td>
<td></td>
</tr>
<tr>
<td>0 worst</td>
<td>20.9</td>
<td>14.3</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>31.2</td>
<td>21.2</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>21</td>
<td>23.2</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>15.5</td>
<td>19.2</td>
<td></td>
</tr>
<tr>
<td>4 best</td>
<td>6.2</td>
<td>16.3</td>
<td></td>
</tr>
<tr>
<td><strong>NHATS walk score, %</strong></td>
<td></td>
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<td>&lt;0.01</td>
</tr>
<tr>
<td>Missing/inapplicable</td>
<td>7.9</td>
<td>8.8</td>
<td></td>
</tr>
<tr>
<td>0 worst</td>
<td>19.2</td>
<td>11.3</td>
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<tr>
<td>1</td>
<td>32</td>
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<td>3</td>
<td>11.5</td>
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<td>4 best</td>
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<tr>
<td><strong>NHATS chair stand score, %</strong></td>
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<td>&lt;0.01</td>
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<tr>
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<tr>
<td>0 worst</td>
<td>37.6</td>
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<td>1</td>
<td>22.7</td>
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<td>2</td>
<td>14.4</td>
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<td>3</td>
<td>8.5</td>
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<tr>
<td>4 best</td>
<td>8.1</td>
<td>13.5</td>
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</tr>
<tr>
<td><strong>NHATS best grip score, %</strong></td>
<td></td>
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<td>0.22</td>
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<tr>
<td>Missing/inapplicable</td>
<td>8</td>
<td>6.6</td>
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<tr>
<td>0 worst</td>
<td>15.7</td>
<td>15.5</td>
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<td>1</td>
<td>28.7</td>
<td>24.0</td>
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<td>17.8</td>
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</tr>
<tr>
<td>3</td>
<td>14.9</td>
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</tr>
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<td>4 best</td>
<td>14.9</td>
<td>17.9</td>
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<tr>
<td><strong>NHATS best peak airflow score, %</strong></td>
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<td>&lt;0.01</td>
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<td>9.5</td>
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</tr>
<tr>
<td>0 worst</td>
<td>3.7</td>
<td>2</td>
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<tr>
<td>1</td>
<td>35.3</td>
<td>26.5</td>
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<td>2</td>
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<tr>
<td>3</td>
<td>16.2</td>
<td>19.1</td>
<td></td>
</tr>
<tr>
<td>4 best</td>
<td>12.9</td>
<td>18.2</td>
<td></td>
</tr>
<tr>
<td><strong>Self-reported physical capacity index: mean (95% CI)</strong></td>
<td>12.5 (12.2–12.7)</td>
<td>13.8 (13.5–14.0)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Cognitive measures</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 word recall: mean (95% CI)*</td>
<td>6.9 (6.6–7.0)</td>
<td>7.4 (7.2–7.7)</td>
<td>&lt;0.01</td>
</tr>
</tbody>
</table>

(Continued)
There was no difference between stroke survivors and controls in any participation restriction after adjusting for self-reported physical capacity (adjusted odds ratio, 1.25; 95% confidence interval, 0.96–1.62; \(P=0.01\); Table 5). This overall pattern was relatively consistent across activities—after adjusting for physical capacity differences between stroke survivors and controls were eliminated for all activities except visiting with family and friends. A sensitivity analysis adjusting for performance-based measures of physical capacity was performed, and very similar results were obtained. Moreover, in the fully adjusted models, depressive and anxiety symptoms were predictors of any participation restrictions, restriction in visiting with family/friends and in attending religious services, and aphasia/dysarthria predicted restrictions in clubs/classes and going out for enjoyment. Finally, there were no significant interactions between predictor variables and stroke in the model predicting any participation restriction.

**Discussion**

In this nationally representative sample of older adults enrolled in Medicare, we found that stroke survivors have lower physical capacity and a greater prevalence of activity limitations and physical symptoms than expected given their sociodemographic profile and comorbidities. We also found that stroke survivors were less likely to go out for enjoyment, visit with family, and participate in religious services than nonstroke controls. Therefore, standard measures of poststroke disability, such as the Barthel Index that do not measure participation or the modified Rankin Scale, where participation is coarsely measured, are only describing part of the true effect of strokes on the daily life of survivors. Increased use of the participation measures analyzed here or other patient-centered assessments that measure both activities and participation would capture a more complete picture of poststroke disability.

Our study provides population-based estimates for late-life activity limitations and participation restrictions among community-based Medicare-enrolled stroke survivors. Currently in the United States, there are 1.6 million older stroke survivors with participation restrictions in activities they value because of their health. In addition, >500,000 stroke survivors need help getting out of bed and >900,000 do not administer their medications by themselves for health reasons. The prevalence and greater disability among stroke survivors compared with their sociodemographic- and comorbidity-matched controls suggest the need for stroke survivorship research, possibly modeled after cancer research, which has been at the forefront of survivorship research. Currently, there are >70 cancer survivorship research projects for the estimated 2.4 million American breast cancer survivors.17

<table>
<thead>
<tr>
<th>Type of Participation Restriction</th>
<th>Stroke (95% CI)</th>
<th>Controls (95% CI)</th>
<th>(P) Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Summary measure: any participation restriction (primary outcome)</td>
<td>32.8% (29.7%–36.1%)</td>
<td>23.5% (20.7%–26.5%)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Components of summary measure</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visiting with family/friends</td>
<td>13.8% (11.3%–16.8%)</td>
<td>7.5% (5.5%–10.2%)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Attending religious services</td>
<td>19.1% (16.4%–22.1%)</td>
<td>14.5% (12.4%–16.9%)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Participating in clubs or classes</td>
<td>9.2% (7.1%–11.9%)</td>
<td>7.3% (5.7%–9.3%)</td>
<td>0.16</td>
</tr>
<tr>
<td>Going out for enjoyment</td>
<td>14.0% (11.6%–16.7%)</td>
<td>8.8% (6.9%–11.1%)</td>
<td>&lt;0.01</td>
</tr>
</tbody>
</table>

Cells represent the survey-weighted percentage by group. Statistical comparisons were made using Wald tests.
Table 5. Logistic Regression Models of Predictors of Participation Restrictions Among Stroke Survivors and Matched Controls

<table>
<thead>
<tr>
<th>Variable</th>
<th>Any Participation Restriction</th>
<th>Restriction Visiting With Family/Friends</th>
<th>Restriction Attending Religious Services</th>
<th>Restriction Participating in Clubs or Classes</th>
<th>Restriction Going Out for Enjoyment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(Primary Outcome)</td>
<td>(Primary Outcome)</td>
<td>(Primary Outcome)</td>
<td>(Primary Outcome)</td>
<td>(Primary Outcome)</td>
</tr>
<tr>
<td></td>
<td>Unadjusted OR (95% CI)</td>
<td>Unadjusted OR (95% CI)</td>
<td>Unadjusted OR (95% CI)</td>
<td>Unadjusted OR (95% CI)</td>
<td>Unadjusted OR (95% CI)</td>
</tr>
<tr>
<td></td>
<td>Adjusted for Physical Capacity AOR (95% CI)</td>
<td>Adjusted for Physical Capacity AOR (95% CI)</td>
<td>Adjusted for Physical Capacity AOR (95% CI)</td>
<td>Adjusted for Physical Capacity AOR (95% CI)</td>
<td>Adjusted for Physical Capacity AOR (95% CI)</td>
</tr>
<tr>
<td></td>
<td>Fully Adjusted AOR (95% CI)</td>
<td>Fully Adjusted AOR (95% CI)</td>
<td>Fully Adjusted AOR (95% CI)</td>
<td>Fully Adjusted AOR (95% CI)</td>
<td>Fully Adjusted AOR (95% CI)</td>
</tr>
<tr>
<td>Controls vs stroke</td>
<td>1.59 (1.28–1.98)</td>
<td>1.98 (1.32–2.98)</td>
<td>1.39 (1.07–1.80)</td>
<td>1.28 (0.90–1.84)</td>
<td>1.69 (1.16–2.47)</td>
</tr>
<tr>
<td>Stroke (yes vs no)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical capacity (0–12 best)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Word recall (0–10)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(0–10 best)</td>
<td>1.02 (1.00–1.05)</td>
<td>1.02 (0.97–1.06)</td>
<td>1.01 (0.98–1.04)</td>
<td>1.01 (0.98–1.04)</td>
<td>1.03 (1.00–1.06)</td>
</tr>
<tr>
<td>Clock draw (0–5 best)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(0–5 best)</td>
<td>0.95 (0.88–1.03)</td>
<td>0.91 (0.85–1.03)</td>
<td>1.13 (0.87–1.01)</td>
<td>0.97 (0.88–1.06)</td>
<td>1.00 (0.92–1.08)</td>
</tr>
<tr>
<td>Aphasia/dysarthria (yes vs no)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(yes vs no)</td>
<td>0.69 (0.46–1.04)</td>
<td>0.69 (0.58–1.41)</td>
<td>1.60 (0.73–1.76)</td>
<td>1.60 (0.25–0.64)</td>
<td>1.60 (0.27–0.78)</td>
</tr>
<tr>
<td>Depressive symptoms (yes vs no)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(yes vs no)</td>
<td>1.60 (1.11–2.32)</td>
<td>1.58 (1.08–2.31)</td>
<td>1.51 (1.03–2.22)</td>
<td>1.43 (0.87–2.34)</td>
<td>1.18 (0.73–1.92)</td>
</tr>
<tr>
<td>Anxiety symptoms (yes vs no)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(yes vs no)</td>
<td>1.89 (1.39–2.55)</td>
<td>2.25 (1.49–3.40)</td>
<td>2.14 (1.47–3.14)</td>
<td>1.29 (0.77–2.14)</td>
<td>1.52 (0.95–2.42)</td>
</tr>
</tbody>
</table>

AOR indicates adjusted odds ratio; and CI, confidence interval.
Understanding participation restrictions and the role of capacity are important for optimizing stroke survivorship. We found that after adjusting for physical capacity, the difference in participation restrictions between stroke survivors and their controls became nonsignificant for all social/civic activities except visiting with family and friends. These results are supported by smaller studies of selected stroke population.\textsuperscript{6,9} Research to investigate the causal link between physical capacity and participation restrictions and whether improving capacity among stroke survivors leads to increased participation among stroke survivors is needed.

Consistent with prior in work in smaller and more selected populations,\textsuperscript{6,9} we found that depressive and anxiety symptoms are independently associated with participation restrictions involving family, friends, and religious ties, and aphasia/dysarthria seems to restrict other activities (eg, clubs/groups, going out for enjoyment). These data underscore the importance of diagnosing and treating depression and anxiety and improving aphasia/dysarthria, which may optimize stroke survivorship.

Several limitations of this study are worth noting. Our study relies on self-reported stroke and we cannot be sure that all transient ischemic attacks are excluded. However, data suggest high accuracy of self-reported stroke, including in the elderly.\textsuperscript{18} We cannot determine the duration because stroke that we expect to be variable, or the temporal order of onset of capacity declines, mood symptoms, and disability. Aphasia/dysarthria was measured with a single question (yes versus no) and thus inclusion of a scale may improve the precision of this measure. We cannot rule out that cognitive impairment, higher level cortical deficits (eg, anosognosia), and mood disorders may lead to less accurate reporting of limitations and participation restrictions. In addition, proxy measures of self-reported measures may be biased. However, our results did not change with the use of performance-based measures of physical capacity. To the extent that we have introduced matched controls, our conclusions about differences between the stroke cohort and controls may be overly conservative. Finally, NHATS does not interview older adults living in nursing home facilities and does not include those aged <65 years; thus, these results may only be generalized to community-based older adults.

In summary, stroke survivors have participation restrictions above that which would be expected for sociodemographic- and comorbidity-matched controls. A broader conceptual framework of poststroke disability with attention to both activity limitations and participation restrictions is consistent with the Institute of Medicine recommendations and is feasible with increased use of both activity and participation measures. Improving physical capacity, decreasing depressive and anxiety symptoms, and improving aphasia/dysarthria may reduce many of the participation restriction among stroke survivors and controls although this requires further study.

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Disclosures
None.

References
Understanding Stroke Survivorship: Expanding the Concept of Poststroke Disability
Lesli E. Skolarus, James F. Burke, Devin L. Brown and Vicki A. Freedman

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**Supplemental table I:** Prevalence of activity limitations among stroke survivors and matched controls. Cells report the estimated number of Americans with stroke (or in the control group) with a given activity limitation and the percentage of all group-members with a given activity limitation. Statistical comparisons were made using chi-squared tests.

<table>
<thead>
<tr>
<th></th>
<th>Stroke N%</th>
<th>Controls N%</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Eating</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uses assistive devices</td>
<td>42,565 (1.2%)</td>
<td>23,616 (0.7%)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Level of Difficulty</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing/NA</td>
<td>2,890 (0.1%)</td>
<td>24,187 (0.7%)</td>
<td></td>
</tr>
<tr>
<td>No difficulty by yourself</td>
<td>2,872,404 (81.2%)</td>
<td>3,228,579 (90.2%)</td>
<td></td>
</tr>
<tr>
<td>Difficulty by yourself, but able to perform without help</td>
<td>177,160 (5%)</td>
<td>106,231 (3%)</td>
<td></td>
</tr>
<tr>
<td>Requires help</td>
<td>484,404 (13.7%)</td>
<td>220,681 (6.2%)</td>
<td></td>
</tr>
<tr>
<td><strong>Cleaned up</strong></td>
<td></td>
<td></td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Uses assistive devices</td>
<td>1,771,334 (50.1%)</td>
<td>1,610,203 (45%)</td>
<td></td>
</tr>
<tr>
<td>Level of Difficulty</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing/NA</td>
<td>8,806 (0.2%)</td>
<td>14,548 (0.4%)</td>
<td></td>
</tr>
<tr>
<td>No difficulty by yourself</td>
<td>2,322,998 (65.7%)</td>
<td>2,726,729 (76.2%)</td>
<td></td>
</tr>
<tr>
<td>Difficulty by yourself, but able to perform without help</td>
<td>452,645 (12.8%)</td>
<td>377,260 (10.5%)</td>
<td></td>
</tr>
<tr>
<td>Requires help</td>
<td>752,411 (21.3%)</td>
<td>461,141 (12.9%)</td>
<td></td>
</tr>
<tr>
<td><strong>Using Toilet</strong></td>
<td></td>
<td></td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Uses assistive devices</td>
<td>1,986,069 (56.2%)</td>
<td>1,643,161 (45.9%)</td>
<td></td>
</tr>
<tr>
<td>Level of Difficulty</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing/NA</td>
<td>(0%)</td>
<td>19,968 (0.6%)</td>
<td></td>
</tr>
<tr>
<td>No difficulty by yourself</td>
<td>2,886,818 (81.6%)</td>
<td>3,090,193 (86.3%)</td>
<td></td>
</tr>
<tr>
<td>Difficulty by yourself, but able to perform without help</td>
<td>320,100 (9.1%)</td>
<td>280,526 (7.8%)</td>
<td></td>
</tr>
<tr>
<td>Requires help</td>
<td>329,941 (9.3%)</td>
<td>188,991 (5.3%)</td>
<td></td>
</tr>
<tr>
<td><strong>Dressing</strong></td>
<td></td>
<td></td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Uses assistive devices</td>
<td>213,466 (6%)</td>
<td>158,931 (4.4%)</td>
<td></td>
</tr>
<tr>
<td>Level of Difficulty</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing/NA</td>
<td>31,438 (0.9%)</td>
<td>50,140 (1.4%)</td>
<td></td>
</tr>
<tr>
<td>No difficulty by yourself</td>
<td>2,269,016 (64.2%)</td>
<td>2,583,326 (72.2%)</td>
<td></td>
</tr>
<tr>
<td>Difficulty by yourself, but able to perform without help</td>
<td>375,156 (10.6%)</td>
<td>425,192 (11.9%)</td>
<td></td>
</tr>
<tr>
<td>Requires help</td>
<td>861,248 (24.4%)</td>
<td>521,021 (14.6%)</td>
<td></td>
</tr>
<tr>
<td><strong>Mobility measures</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Going Outside</strong></td>
<td></td>
<td></td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Uses assistive devices</td>
<td>1,523,534 (43.1%)</td>
<td>1,099,466 (30.7%)</td>
<td></td>
</tr>
<tr>
<td>Level of Difficulty</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Activity</td>
<td>Missing/NA</td>
<td>No or little difficulty</td>
<td>Some or a lot of difficulty, but able to do without help</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>------------</td>
<td>-------------------------</td>
<td>----------------------------------------------------------</td>
</tr>
<tr>
<td>Missing/NA</td>
<td>78,824 (2.2%)</td>
<td>112,003 (3.1%)</td>
<td>174,902 (4.9%)</td>
</tr>
<tr>
<td>No or little difficulty</td>
<td>2,418,912 (68.4%)</td>
<td>2,747,105 (76.7%)</td>
<td>191,841 (5.4%)</td>
</tr>
<tr>
<td>Some or a lot of difficulty, but able to do without help</td>
<td>174,902 (4.9%)</td>
<td>191,841 (5.4%)</td>
<td>864,221 (24.4%)</td>
</tr>
<tr>
<td>Requires help</td>
<td>2,747,105 (76.7%)</td>
<td>191,841 (5.4%)</td>
<td>864,221 (24.4%)</td>
</tr>
<tr>
<td>Getting around in Home</td>
<td>&lt;0.01</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uses assistive devices</td>
<td>1,380,863 (39%)</td>
<td>940,637 (26.3%)</td>
<td></td>
</tr>
<tr>
<td>Level of Difficulty</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing/NA</td>
<td>20,633 (0.6%)</td>
<td>25,881 (0.7%)</td>
<td></td>
</tr>
<tr>
<td>No or little difficulty</td>
<td>2,673,344 (75.6%)</td>
<td>2,997,193 (83.7%)</td>
<td></td>
</tr>
<tr>
<td>Some or a lot of difficulty, but able to do without help</td>
<td>226,543 (6.4%)</td>
<td>184,753 (5.2%)</td>
<td></td>
</tr>
<tr>
<td>Requires help</td>
<td>616,340 (17.4%)</td>
<td>371,851 (10.4%)</td>
<td></td>
</tr>
<tr>
<td>Getting out of Bed</td>
<td>&lt;0.01</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uses assistive devices</td>
<td>757,936 (21.4%)</td>
<td>523,197 (14.6%)</td>
<td></td>
</tr>
<tr>
<td>Level of Difficulty</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing/NA</td>
<td>4,005 (0.1%)</td>
<td>21,571 (0.6%)</td>
<td></td>
</tr>
<tr>
<td>No or little difficulty</td>
<td>2,717,441 (76.8%)</td>
<td>3,078,811 (86%)</td>
<td></td>
</tr>
<tr>
<td>Some or a lot of difficulty, but able to do without help</td>
<td>314,358 (8.9%)</td>
<td>212,938 (5.9%)</td>
<td></td>
</tr>
<tr>
<td>Requires help</td>
<td>501,056 (14.2%)</td>
<td>266,360 (7.4%)</td>
<td></td>
</tr>
<tr>
<td>Household Activities</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laundry</td>
<td>&lt;0.01</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing/NA</td>
<td>11,709 (0.3%)</td>
<td>21,068 (0.6%)</td>
<td></td>
</tr>
<tr>
<td>Done by self with little or no difficulty</td>
<td>1,469,568 (41.6%)</td>
<td>1,724,335 (48.2%)</td>
<td></td>
</tr>
<tr>
<td>Done by self with some or a lot of difficulty</td>
<td>254,829 (7.2%)</td>
<td>248,381 (6.9%)</td>
<td></td>
</tr>
<tr>
<td>Not done by self for non-health reason</td>
<td>834,053 (23.6%)</td>
<td>983,503 (27.5%)</td>
<td></td>
</tr>
<tr>
<td>Not done by self for health reason</td>
<td>966,700 (27.3%)</td>
<td>602,391 (16.8%)</td>
<td></td>
</tr>
<tr>
<td>Shopping</td>
<td>&lt;0.01</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing/NA</td>
<td>38,956 (1.1%)</td>
<td>56,345 (1.6%)</td>
<td></td>
</tr>
<tr>
<td>Done by self with little or no difficulty</td>
<td>1,093,849 (30.9%)</td>
<td>1,574,109 (44%)</td>
<td></td>
</tr>
<tr>
<td>Done by self with some or a lot of difficulty</td>
<td>347,162 (9.8%)</td>
<td>287,244 (8%)</td>
<td></td>
</tr>
<tr>
<td>Not done by self for non-health reason</td>
<td>788,789 (22.3%)</td>
<td>888,618 (24.8%)</td>
<td></td>
</tr>
<tr>
<td>Not done by self for health reason</td>
<td>1,268,102 (35.9%)</td>
<td>773,363 (21.6%)</td>
<td></td>
</tr>
<tr>
<td>Making Hot Meals</td>
<td>&lt;0.01</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing/NA</td>
<td>28,960 (0.8%)</td>
<td>43,162 (1.2%)</td>
<td></td>
</tr>
<tr>
<td>Done by self with little or no difficulty</td>
<td>1,450,534 (41%)</td>
<td>1,883,933 (52.6%)</td>
<td></td>
</tr>
<tr>
<td>Done by self with some or a lot of difficulty</td>
<td>333,087 (9.4%)</td>
<td>348,214 (9.7%)</td>
<td></td>
</tr>
<tr>
<td>Activity</td>
<td>2021 Q4</td>
<td>2020 Q4</td>
<td></td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>---------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td><strong>Handling Bills/Banking</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing/NA</td>
<td>64,413</td>
<td>32,795</td>
<td></td>
</tr>
<tr>
<td>Done by self with little or no difficulty</td>
<td>1,477,058</td>
<td>2,009,961</td>
<td></td>
</tr>
<tr>
<td>Done by self with some or a lot of difficulty</td>
<td>268,238</td>
<td>203,326</td>
<td></td>
</tr>
<tr>
<td>Not done by self for non-health reason</td>
<td>757,731</td>
<td>846,675</td>
<td></td>
</tr>
<tr>
<td>Not done by self for health reason</td>
<td>969,420</td>
<td>486,921</td>
<td></td>
</tr>
<tr>
<td><strong>Self-Administer Medications</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing/NA</td>
<td>95,878</td>
<td>157,686</td>
<td></td>
</tr>
<tr>
<td>Done by self with little or no difficulty</td>
<td>1,982,381</td>
<td>2,511,003</td>
<td></td>
</tr>
<tr>
<td>Done by self with some or a lot of difficulty</td>
<td>295,433</td>
<td>273,301</td>
<td></td>
</tr>
<tr>
<td>Not done by self for non-health reason</td>
<td>256,957</td>
<td>138,058</td>
<td></td>
</tr>
<tr>
<td>Not done by self for health reason</td>
<td>906,210</td>
<td>499,630</td>
<td></td>
</tr>
</tbody>
</table>
Supplemental table II. Prevalence of self-reported symptoms in the last month among stroke survivors and matched controls. Cells represent the survey-weighted percentage by group. Statistical comparisons made using chi-squared tests.

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Stroke %</th>
<th>Controls %</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problems chewing/swallowing</td>
<td>18.4%</td>
<td>10.9%</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Upper body strength limits activity</td>
<td>32.4%</td>
<td>23.5%</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Lower body strength limits activity</td>
<td>44.8%</td>
<td>33.6%</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Low energy limits activity</td>
<td>49.6%</td>
<td>38.0%</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Balance/coordination problems limit activity</td>
<td>35.2%</td>
<td>22.5%</td>
<td>&lt;0.01</td>
</tr>
</tbody>
</table>

Supplemental Methods:

The performance measures of physical capacity include the short physical performance battery (SPPB), a validated assessment tool for measuring lower extremity function consisting of a timed 4 meter walk, repeated chair stands, and series of balance tests. NHATS made adjustments to the standard balance test to allow for greater discrimination at the higher end of the scale. Scores range from 0 (most impaired) to 4 (least impaired) for each measure and thus 0-12 on the combined measure. NHATS also measured grip strength in the dominant hand (which is most likely the non-paretic hand in stroke survivors) and peak expiratory flow (a non-specific measure of cardiopulmonary function).

Respondents were also queried about symptoms over the last month and if this impairment limited their activities. Impairments included chewing/swallowing, speaking (aphasia/dysarthria), limited strength or movement in upper body (shoulder, elbow, hand), lower body (hips, knees, legs, feet) and balance/coordination.