

Activity limitations and subjective well-being after stroke

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ABSTRACT

Objective: As limitations in activities of daily living are major components of many stroke outcome scales, we examined how well activity limitations predicted subjective well-being among stroke survivors in a nationally representative survey.

Methods: Individuals with a self-reported history of stroke were identified from the National Health and Aging Trends Study. Subjective well-being (primary outcome) was assessed with a validated 7-item measure (higher = greater well-being) assessing emotions (cheerful, bored, full of life, and upset) and self-realization (purpose in life, self-acceptance, and environmental mastery). Activity limitations were defined by the receipt of help in any of 11 activities of daily living/instrumental activities of daily living. Multivariable linear regression assessed predictors of well-being including medical, physical, cognitive, psychological, and environmental factors.

Results: A total of 738 stroke survivors age 65 or older were included (57% female, 9% African American, 6% Hispanic). Activity limitations were modestly associated with well-being after adjusting for demographic characteristics and availability of assistance (estimate -0.49 , 95% confidence interval -0.61 to -0.37). However, in the fully adjusted model ($R^2 = 0.28$), neither activity limitations nor physical capacity was associated with subjective well-being. Predictors of lower well-being in the final model included depressive symptoms, chewing/swallowing problems, pain that limited activity, and restricted participation in valued life activities. Income and executive function were modestly associated with improved well-being, while comorbidities and communication technology access were not associated.

Conclusions: Activity limitations were not associated with stroke survivors' subjective well-being after adjustment for other factors. While some predictors of well-being after stroke were identified, the determinants of well-being remained largely unexplained. *Neurology*® 2017;89:944-950

GLOSSARY

NHATS = National Health and Aging Trends Study.

Stroke outcomes reported in clinical trials typically focus on functional impairments or activity limitations as measured by scales such as the NIH Stroke Scale, modified Rankin Scale, Barthel Index, or Glasgow Outcome Scale.^{1,2} This focus is entirely appropriate when testing therapies designed to reduce neurologic disability. However, this focus does not fully capture the breadth of stroke outcomes, as patients with similar activity limitations may have different outcomes in other domains. Obtaining a more complete picture of stroke outcomes can help to better inform patients and families about what to expect and assist in developing interventions to improve stroke survivorship.

Although depressive symptomology among stroke survivors has been well-described,³ subjective well-being, defined as “optimal psychological functioning and experience,”⁴ has received only limited attention in the stroke literature. The concept of subjective well-being includes both hedonic (pleasurable emotions) and eudaimonic (self-actualization) components. Recognizing the potential for mismatch between overall well-being and functional or activity limitations is important regardless of the direction of mismatch: whether a patient has relatively mild

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functional impairment but severe psychological sequelae, or a patient may be unable to ambulate but has otherwise adapted and reports high well-being.

We therefore investigated the relationship between activity limitations and well-being in a cohort of community-dwelling stroke survivors in a nationally representative sample. Project goals were to (1) determine the association between activity limitations and subjective well-being after stroke and (2) determine other predictors of subjective well-being and the degree to which these attenuate or strengthen the relationship between activity limitations and well-being.

METHODS Study population and eligibility. We performed a cross-sectional analysis using data from the National Health and Aging Trends Study (NHATS). NHATS is a longitudinal study of a nationally representative sample of community-dwelling Medicare beneficiaries age 65 and older in the United States with intentional oversampling of non-Hispanic black individuals and the oldest old.⁵ Participants for this study were identified from NHATS (wave 1, year 2011) as eligible for the current study if they responded “yes” to the question: “Please tell me if a doctor ever told you that you had a stroke.” Individuals who could not complete the interviews (for example, due to dementia or speech/hearing impairments) had a proxy complete the surveys, although these individuals were not eligible for the current study as they did not undergo the well-being assessment.

Primary outcome measure: Subjective well-being. The primary outcome measure was a previously validated scale of subjective well-being.⁶ This 7-item measure is based on established hedonic and eudaimonic domains of well-being,⁷ and includes measure of both emotions (2 positive and 2 negative items) and self-realization (3 items). The 4 emotional domain questions were “During the last month, how often did you feel (cheerful/full of life/upset/bored),” with 5 response options ranging from never (0 points) to every day (4 points). Similarly, 3 items addressing self-realization were asked (“My life has meaning and purpose”; “I feel confident and good about myself”; and “I like my living situation

very much”), with response options scored on a scale ranging from agree not at all (0) to agree a lot (2). Negative items were reverse coded such that higher numeric scores indicated greater well-being, with the total possible well-being score ranging from 0 to 22. While there has been debate about the number of dimensions of well-being,^{4,7} factor analysis of this scale has confirmed a unidimensional construct.^{6,8}

Primary independent variable: Activity limitations. Our primary analysis relied on a summary activity limitations index generated by summing the number of self-care, mobility, and household activities (table 1) where help from another person was required due to health or functioning (range 0–11). The included activities were based on a previously validated multiple-category assessment of activity limitations.^{6,9} Scenarios where an individual received help with a household activity, but did not require help due to health or functioning (for example, if a respondent’s spouse always did the laundry), would not have been considered an activity limitation. Since the relationship between the activity index and well-being could be confounded by availability of assistance from friends and family, we also assessed the availability of help with 3 indicators: (1) marital status (married or living with a partner vs not), (2) number of adult children living in the household, and (3) social network size. Social network size was assessed by counting the number of individuals (other than the spouse/partner and coresiding adult children) who were adult children, who lived with the respondent, or who were a confidant of the respondent (that is, the respondent named them as one of the people they talked with most often about important things over the last year).

Other symptoms or indicators of functional status. Using self-reported measures of physical capacity, a validated summary physical capacity index (range 0–12) was generated, with included domains shown in table 1.^{6,9} Cognition was assessed with a word recall task (scored 0–20, analyzed as continuous variable) and executive function as measured by a clock-drawing task (scored 0–5, analyzed as a continuous variable), with higher scores indicating better cognition for each measure. Swallowing difficulties were assessed with a question to determine if a participant had chewing or swallowing difficulties in the last month that led to difficulty eating. Hearing or vision difficulties were assessed with questions about difficulty carrying on a conversation in a quiet room or seeing well enough to read newspaper print. Speech difficulties were assessed with a question about whether the participant had difficulty making himself or herself understood when talking. Pain was classified into 3 levels: (1)

Table 1 Definition of key measures

Construct	Description	Scale items	Range
Well-being, primary outcome measure	Based on established domains of well-being, validated as unidimensional construct	Self-realization: My life has meaning and purpose; I feel confident and good about myself; I like my living situation very much; Emotions: How often do you feel...cheerful, full of life, upset (reverse coded), bored (reverse coded)	0–22, Higher indicates greater well-being
Activity limitations, primary independent variable	Sum of the number of activities where help was required from another person due to health or functioning	Eating, bathing/showering, using toilet, dressing, going outside, getting around in home, getting out of bed, laundry, shopping, making hot meals, handling bills/banking	0–11, Higher indicates more limitations
Physical capacity	Self-reported ability to complete selected tasks; for each pair of tasks, participants received 1 point if able to perform the 1st task or 2 points if able to perform the 2nd task	Walk at least 3 blocks/6 blocks, walk up at least 10 stairs/20 stairs, lift and carry at least 10 pounds/20 pounds, reach up over head/put heavy object on shelf overhead, grasp small objects/open sealed jar, bend over/kneel	0–12, Higher indicates better function
Restricted participation	Sum of the number of activities that a participant found valuable, but was unable to participate in due to health or functioning	Visiting family, attending religious services, going out for enjoyment, participating in clubs, classes, or activities	0–4, Higher indicates greater participation restrictions

never bothered by pain in the last month; (2) bothered by pain that did not limit activities; and (3) bothered by pain that limited activities.

Other potential predictors of well-being. A restricted participation index was created by summing the number of activities that an individual valued as somewhat or very important, but were unable to participate in due to health or functioning, from the following list of 4 items: visiting in person with friends or family; attending religious services; participating in clubs, classes, or other organized activities; and going out for enjoyment.¹⁰ A comorbidity index was generated as the sum of NHATS reported comorbidities (range 0–8). Depressive symptoms were assessed with the Patient Health Questionnaire-2, with individuals scoring ≥ 3 out of a possible 6 points classified as having depressive symptoms.¹¹ Income was self-reported and categorized into income quintiles. For individuals with missing data, the mean of 5 NHATS imputed values was used to assign income quintile. Access to communication technology was assessed by summing the response of questions about whether respondents (1) had a working cell phone; (2) had one phone other than cell phone; (3) communicated by e-mail or text in the last month; or (4) went online for any other reason besides e-mail or texting in the last month.

Statistical analysis. Characteristics of the study population were described with mean and SD for continuous variables and proportions for categorical variables. A series of linear regression models were generated to allow an understanding of how the relationship between activity limitations (linear) and well-being changed as additional factors were added. Model 1, the demographics/availability model, included activity limitations and demographics including age (categorical), sex (male as reference), and race-ethnicity (white as reference). Availability of help was also included to account for possible confounding using 3 separate variables: married or living with a partner (yes vs no), number of adult children living in the household (linear), and social network size (linear). Model 2, the symptoms/capacity model, incorporated a broader definition of symptoms or functional limitations, and therefore physical capacity index, cognition, pain, and measures assessing difficulty with swallowing/chewing, speech, hearing, or vision were added to the variables present in model 1. Model 3, the fully adjusted model, included other prespecified potential predictors of well-being, including income, number of comorbid illnesses, restricted participation in valued activities, technology access, and depressive symptoms. Models were adjusted for NHATS survey design using analytic weights and strata to produce nationally representative estimates. Non-linear forms were explored for activity limitations, physical capacity index, and restricted participation with quadratic terms or quantiles. In addition, to explore whether a more nuanced definition of activity limitations may change our understanding of the relationship between activities and well-being, we explored modeling activity limitations as 11 separate multiple-category variables.^{6,9} There was no major improvement in model fit and no change in the primary conclusions with these alternative modeling strategies compared to treating the primary variables of interest as linear. Post hoc sensitivity analyses were conducted to address possible overlap between depressive symptoms and subjective well-being, including (1) model 3 excluding depressive symptoms as a predictor; and (2) model 3 restricted to individuals without depressive symptoms. Statistical analysis was performed using Stata Statistical Software, Release 14 (StataCorp., College Station, TX).

Standard protocol approvals, registrations, and participant consents. The study protocol was reviewed by the

University of Michigan Medical Institutional Review Board and was deemed to be not regulated as it relied on a publicly available, deidentified dataset.

RESULTS A total of 892 NHATS participants self-reported a history of stroke; 154 of those were ineligible due to interview completion by proxy, leaving 738 participants in the current analysis. Descriptive characteristics of the population are shown in table 2. The mean well-being score was 16.0 (SD 3.9), and the mean number of activity limitations was 2.0 (SD 2.9).

Table 3 shows the results from the linear regression models examining predictors of well-being. Increasing activity limitations were associated with a modest decrease in well-being when adjusted for demographics and availability of assistance in model 1, with about a one-half point decrease in the well-being score for each additional activity limitation ($\beta = -0.49$, 95% confidence interval $-0.61, -0.37$, $p < 0.001$). However, model 1 (demographics/availability) explained very little of the overall variability in well-being based on an R^2 value of 0.14.

When additional measures of symptoms and physical and cognitive capacity were added in model 2 (symptoms/capacity model), the association of activity limitations with well-being was attenuated (table 3). Other predictors of better well-being in model 2 included greater physical capacity and better clock drawing scores, while chewing/swallowing problems and pain that limited activity were associated with decreased well-being.

In the final fully adjusted model (model 3, table 3), activity limitations were not associated with well-being. The model R^2 remained modest at 0.28, indicating that less than a third of the variability in well-being was explained by the included covariates. Chewing/swallowing difficulties and pain that limited activity remained associated with a large decrease in well-being, with each of these factors having a more than 1-point decrease in well-being when present. Better clock drawing score was associated with higher well-being—more than 2 points on the well-being score separated those whose drawing was unrecognizable as a clock from those who produced an accurate clock depiction. Similarly, higher incomes were also associated with greater well-being. An individual in the top income quintile had a well-being score almost 2 points higher than those in the lowest income quintile, on average. Restricted participation in valued activities was also associated with decreased well-being but physical capacity score was not. Depressive symptoms were associated with an almost 2-point decline in well-being. Sensitivity analyses addressing possible overlap between depressive symptoms and well-being indicated no change in the conclusions about the relationship between well-being and

Characteristics	% or mean (SD)
Age, y	
65-69	18.7
70-74	22.6
75-79	18.7
80-84	21.9
85-89	12.9
90+	5.2
Female	56.5
Race	
White	80.7
Black	9.2
Hispanic	5.8
Others	4.3
Income	
Missing	20.1
Less than \$12,100	23.0
\$12,101-\$21,000	20.8
\$21,001-\$34,409	21.7
More than \$34,410	14.5
Activity limitations (help received from another person)	
Eating	8.1
Bathing/showering	14.1
Using toilet	5
Dressing	18
Going outside	18.9
Getting around in home	11.5
Getting out of bed	9.1
Laundry	18.0
Shopping	28.1
Making hot meals	18.9
Handling bills/banking	19.7
Activity index	2.0 (2.9)
Availability of help	
Married or living with a partner	48.5
No. of adult children in household	0.25 (0.60)
No. of social network supports	3.7 (2.3)
Physical capacity	3.9 (2.0)
Cognitive measures	
Word recall	6.7 (3.2)
Clock drawing moderate to severely impaired	18.8
Pain	
Bothered by pain without activity limitation	19.7
Bothered by pain with activity limitation	40.3

Continued

Characteristics	% or mean (SD)
Chewing or swallowing difficulties	16.7
Hearing difficulties	1.2
Vision difficulties	7.5
Speech difficulties	12.7
Depressive Symptoms (PHQ-2 \geq 3)	24.6
Technology access index (e.g., cell phone or computer)	2.0 (1.0)
Restricted participation in valued activities	0.6 (0.9)
Well-being (primary outcome)	16.0 (3.9)

Abbreviation: PHQ-2 = Patient Health Questionnaire-2.

activity limitations, physical capacity, or restricted participation (table e-1 at Neurology.org).

DISCUSSION In this large nationwide sample of older stroke survivors, we found that activity limitations were not predictive of subjective well-being after adjustment for other factors such as pain, depressive symptoms, and restricted participation in valued activities. This finding is important, given that the most commonly used stroke outcome measures largely focus on activity limitations, and it suggests that these outcome measures may be insensitive to important drivers of self-reported well-being.

Recent efforts have sought to address this conceptual problem by developing scales that assess more global stroke outcomes. However, many of these measures, including Stroke-Specific Quality of Life Scale¹² and the Stroke Impact Scale,^{13,14} are still fairly heavily weighted toward domains assessing physical impairments or functional abilities.¹ Considerable effort has also gone into development and validation of patient-reported outcomes including the NIH Patient-Reported Outcome Measurement Information System (PROMIS)¹⁵ and Neuro-QoL measures.^{16,17} Hopefully, increased use of these and other patient-reported outcomes will allow a more comprehensive assessment of stroke outcomes beyond just functional status in future clinical trials and epidemiologic studies. However, a critical challenge in efforts to optimize outcome assessment after stroke is the fact that much of the variability in well-being remained unexplained despite the extensive list of predictors we examined. More work will be needed in the future to better understand predictors of subjective well-being in stroke survivors.

One potential explanation for the lack of association between activity limitations and subjective well-being is the possibility that stroke survivors have adapted to their activity limitations. The process of resetting one's expectations after disability,

Table 3 Predictors of well-being after stroke

Characteristic	Model 1, demographics/ availability		Model 2, symptoms/capacity		Model 3, fully adjusted	
	Estimate	95% CI	Estimate	95% CI	Estimate	95% CI
Model R ²	0.14	—	0.21	—	0.28	—
Intercept	15.8	14.7 to 16.9	13.8	11.5 to 16.0	14.5	12.1 to 16.8
Activity limitations index ^a	-0.49 ^b	-0.61 to -0.37	-0.19 ^c	-0.36 to -0.01	-0.09	-0.26 to 0.08
NHATS physical capacity scale ^d			0.25 ^c	0.004 to 0.51	0.17	-0.08 to 0.43
Cognitive measures						
Words recall			0.03	-0.09 to 0.15	0.03	-0.07 to 0.13
Clock drawing			0.35 ^c	0.04 to 0.66	0.36 ^c	0.09 to 0.64
Chewing or swallowing difficulties			-1.38 ^e	-2.35 to -0.41	-1.24 ^c	-2.24 to -0.24
Speech difficulties			0.14	-0.99 to 1.26	0.52	-0.63 to 1.67
Hearing difficulties			-1.35	-3.44 to 0.72	-1.02	-3.38 to 1.35
Vision difficulties			-0.89	-2.35 to 0.56	-1.00	-2.44 to 0.44
Pain ("never bothered by pain" as reference)						
Bothered by pain without activity limitation			-0.56	-1.21 to 0.09	-0.45	-1.01 to 0.10
Bothered by pain with activity limitation			-1.56 ^b	-2.30 to -0.81	-1.16 ^e	-1.83 to -0.48
Income (per quintile of income category)					0.32 ^c	0.07 to 0.57
No. of comorbid illnesses					0.06	-0.12 to 0.24
Depressive symptoms (PHQ-2 ≥3)					-1.91 ^b	-2.56 to -1.26
Restricted participation in valued activities ^f					-0.51 ^c	-0.91 to -0.11
Technology access index (e.g., cell phone or computer)					-0.24	-0.54 to 0.06

Abbreviations: CI = confidence interval; NHATS = National Health and Aging Trends Study; PHQ-2 = Patient Health Questionnaire-2.

All models were also adjusted for age, sex, race-ethnicity, and availability of help (marital status, number of adult children living in the home, and social network size). Other model covariates are defined by the left-hand column.

^aSum of number of activities where help was needed from another person from list of eating, bathing/showering, using toilet, dressing, going outside, getting around in home, getting out of bed. Laundry, shopping, making hot meals, handling bills/banking activities were only included if help was needed due to health/functioning (range 0-11).

^b $p < 0.001$.

^c $p < 0.05$.

^dSelf-reported physical capacity to complete tasks such as walking at least 6 blocks, walking up at least 10 stairs, lifting and carrying at least 10 pounds, reaching up over head, grasping small objects (range 0-12).

^e $p < 0.01$.

^fNumber of activities that a person found valuable, but was unable to participate in due to health (options were visiting family; attending religious services; going out for enjoyment; participation in clubs, classes, or organized activities; range 0-4).

which is termed a response shift,^{18,19} is important to consider when examining patient-reported outcomes. Awareness of this possibility of response shift could also be an important target in rehabilitative efforts in order to maximize self-perceived well-being or quality of life.¹⁸ If response shift is common in stroke survivors, it may be important to account for this phenomenon when counseling patients and families early after stroke. We were not able to assess whether response shift occurred directly in this study, as our data collection occurred at a single time point and we did not have data available on time from stroke to well-being assessment. Future longitudinal studies exploring well-being before and after stroke will be better positioned to assess response shift in stroke survivors.

We identified several predictors of well-being that could serve as future intervention targets. Pain that limited activity and depressive symptoms were both strongly associated with reduced well-being, while better performance on the clock drawing task was associated with improved well-being. Although the evidence for specific therapies for executive dysfunction after stroke is currently limited,²⁰ the association of the clock drawing task with well-being would support ongoing efforts to further develop rehabilitation strategies that target cognitive function.²¹ The magnitude of effect we observed for pain and depressive symptoms was on the order of one-fourth to one-half of an SD in the well-being measure, commonly considered to be a small to medium effect size.²² The importance of pain and depression after stroke has

been increasingly recognized,^{3,23,24} and additional efforts are needed to optimize treatment. While some overlap between symptoms of depression and the psychological construct of subjective well-being is possible, sensitivity analyses (table e-1) confirmed that our conclusions about the relationship between activity limitations and subjective well-being were robust regardless of how depressive symptoms were analyzed.

Restricted participation in valued activities was also an important predictor of reduced well-being. The importance of assessing community and social participation in addition to function or activity limitations is emphasized in the 2002 WHO International Classification of Functioning Disability and Health.²⁵ There is a growing literature on the importance of participation after stroke,^{26–29} and continued focus on maximizing participation in valued activities as a goal of rehabilitation is warranted. Studies in nonstroke populations have used various methods of rating the relative importance of different valued life activities.^{30,31} A list of most-valued activities could serve as a roadmap for where to focus rehabilitative efforts or adaptive technology for stroke survivors. Reviewing such a list with patients and families also has potential use in advance care planning,³² or when making values-sensitive treatment decisions such as use of life-sustaining treatments after stroke. More work would be needed on how best to integrate such a list of valued activities into routine clinical care of stroke patients, but there is the potential for such an approach to improve the patient-centeredness of care.

A prior analysis of from the Canadian Study on Health and Aging also assessed well-being among community-dwelling stroke survivors, though they separately analyzed 6 distinct dimensions of well-being rather than treating well-being as a single construct.³³ Similar to our findings, they found that restrictions in basic self-care activities of daily living (e.g., dressing, grooming) were largely not associated with well-being, and the amount of variability explained by their models was relatively low for the majority of domains of well-being.

This work has limitations. As stroke diagnosis was by self-report, we were unable to verify the stroke diagnosis and had no detailed data on stroke characteristics such as subtype, severity, or time between stroke and the well-being assessment. Because this was a community-dwelling stroke population and individuals requiring a proxy were excluded, this study population may represent a milder subset of the overall population of stroke survivors. We are also uncertain if the reported functional limitations are due to direct effects of the stroke or other health conditions. The use of the activity index is limited by greater

relative emphasis on activities of daily living rather than instrumental activities of daily living, though this is a common limitation of many stroke outcome scales. The activity index may be confounded by the availability of help, as the items are defined by receiving help from another person. We accounted for this by adjusting for the availability of help in all models, though this assessment was limited to counts of the number of people available, which may not reflect the quality of social support. While income was modestly associated with well-being, this finding should be interpreted with caution due to the amount of missing income data (20%) and the fact that income may not be the best marker of available financial resources in this population of older adults.

We found that limitations in daily activities had only modest association with subjective well-being among stroke survivors and this association was no longer significant after consideration of other factors. Addressing pain, depressive symptoms, and inability to participate in valued activities may be targets to improve well-being among survivors. Importantly, much of what determined well-being remained unexplained despite inclusion of multiple factors, and more research is needed on determinants of well-being after stroke and how to best address discrepancies among physical impairments, activity limitations, and well-being.

AUTHOR CONTRIBUTIONS

Dr. Zahuranec: study concept and design, wrote initial draft of manuscript, interpretation of data. Dr. Skolarus: study concept and design, interpretation of data, drafting/revising the manuscript for content, obtaining funding. Dr. Feng: statistical analysis, drafting/revising manuscript for content. Dr. Freedman: study concept/design, analysis/interpretation of data, revision of manuscript for important content, obtained funding, study supervision. Dr. Burke: study concept and design, analysis/interpretation of data, drafting/revising the manuscript for content, obtaining funding.

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