



Original Research

Perceived Community Participation and Associated Factors in People With Stroke



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KEYWORDS

Stroke;
Community
Participation;
Rehabilitation

Abstract Objective: To examine individual- and environmental-level factors associated with perceived participation performance and satisfaction in people with chronic stroke.

Design: Cross-sectional study using secondary data analysis of baseline data from a randomized controlled trial.

Setting: Community-based setting.

Participants: Community-dwelling adults with mild to moderate stroke (N=113; mean age=57 years; 58 males).

Interventions: Not applicable.

Main Outcome Measures: Main outcomes were measured with the Reintegration to Normal Living Index (perceived participation performance) and Patient-Reported Outcome Measure Information System satisfaction with participation in social roles (perceived participation satisfaction). Other variables collected included personal (eg, age, perceived recovery), health-related (eg, time since stroke, number of comorbidities), body function-related (eg, Stroke Impact Scale, Center for Epidemiologic Studies Depression Scale), and environmental (eg, World Health Organization Quality of Life Short Form Environmental subscale) data.

Results: Depression, fatigue, mobility, and environmental support showed moderate to strong, statistically significant associations with participation performance and satisfaction in people with stroke. Perceived recovery was moderately associated with participation performance but not with participation satisfaction.

List of abbreviations: ICF, *International Classification of Functioning, Disability and Health*; NIHSS, NIH Stroke Scale; PROMIS, Patient-Reported Outcome Measure Information System; RNLI, Reintegration to Normal Living Index; SIS, Stroke Impact Scale; WHOQOL-BREF, World Health Organization Quality of Life Short Form.

Original data were collected in a study supported by the National Institute on Disability Independent Living and Rehabilitation Research (NIDILRR) within the Rehabilitation Research and Training Center on enhancing the functional and employment outcomes of individuals who experience a stroke (#H133B08003)

Disclosures: none.

Cite this article as: Arch Rehabil Res Clin Transl. 2022;4:100210

<https://doi.org/10.1016/j.arrct.2022.100210>

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Conclusions: Returning to participation is a complex process after stroke. Results suggest that various personal, body function-related, and environmental factors are associated with participation performance and satisfaction.

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Stroke is a common global health problem that frequently results in a complex matrix of physical, communication, cognitive, and emotional impairments.¹ This chronic effect of stroke on body and mind, in conjunction with environmental barriers, makes it difficult for many people with stroke to pursue participation in life roles. People with stroke experience participation restrictions in daily activities, social roles, employment, mobility, and economic self-sufficiency.²⁻⁶ They constantly show lower levels of community participation when compared to a control group without a stroke or when compared to prestroke participation.^{5,7}

A recent systematic review used the *International Classification of Functioning, Disability and Health* (ICF) as a framework to identify factors associated with participation outcomes for community-dwelling adults with stroke.⁸ The ICF highlights that participation dynamically interacts with environmental factors in addition to one's health condition, body functions and structures, and personal factors.^{9,10} Based on 92 articles, they identified stroke severity, number of comorbidities (health condition), lower limb function and balance, cognition, affect, pain and fatigue (body functions), age (personal factor), and social support (environmental factor) as significant factors associated with community participation outcomes.⁷ The review revealed that most factors investigated for association with participation outcomes were related to body functions and that there was insufficient evidence to draw conclusions about the effect of environmental factors other than social support. This further emphasized the need for future research to develop understanding on how environment enables or restricts stroke survivors' participation.

As seen in the systematic review, there has been much research on factors influencing community participation outcomes poststroke. However, to our knowledge, literature on comprehensively evaluating the association of multiple factors with participation within 1 study is less common. In addition, most studies tend to focus on 1 side of community participation, either participation performance (eg, frequency of engagement or perceived restriction to activities) or the subjective meaning of participation (eg, satisfaction with participation), though literature has consistently pointed to the distinctive importance of measuring both.¹¹⁻¹⁴ Using the ICF as a framework, the aim of this study was to examine personal, medical, and environmental factors associated with participation performance and satisfaction among people with stroke.

Methods

This cross-sectional study analyzed secondary data collected at baseline of a randomized controlled trial. The Human Subject Division at the University of Washington determined

that the study did not involve human subjects and thus did not require approval.

Data source and participants

Data included baseline data from a randomized controlled trial evaluating the efficacy of a stroke specific self-management intervention called the Improving Participation After Stroke Self-Management Program.¹⁴ The recruitment for the original study occurred between November 2010 and June 2013. Participants were recruited using convenience sampling through existing stroke registries and flyers at 2 major urban rehabilitation hospitals in Chicago, Illinois, and St. Louis, Missouri. The inclusion criteria included (1) be over 18 years old; (2) have a mild (ie, NIH [National Institutes of Health] Stroke Scale [NIHSS] score<5) or moderate stroke (ie, NIHSS score<16); (3) be at least 3 months post-stroke; (4) reside in a community-based setting; and (5) have completed initial acute/rehabilitation care. Individuals were excluded if they were not medically stable, had moderate or severe cognitive impairment (ie, Short Blessed Cognitive Test score>8), or had severe aphasia (ie, Boston Diagnostic Aphasia Examination score<9; 15-item Boston Naming Test<10). All participants provided informed consent to participate in this study.

Outcomes of interest

The outcome measures included perceived level of participation and satisfaction with participation. Using the ICF as a guiding framework, other variables included in the analysis were data related to personal factors, health conditions, body structure and functions, and social and environmental factors.

Perceived performance of participation (participation performance)

The Reintegration to Normal Living Index (RNLI) captures participation in areas such as recreational and social participation, community mobility, family roles, and other relationships.¹⁵ It consists of 11 items with a Likert scale of 0-10 (0=minimal integration; 10=complete integration) in which higher score indicates higher level of community participation.¹⁵ The RNLI has been extensively used in people with stroke and has shown to have good psychometric properties.^{16,17}

Perceived satisfaction of participation (participation satisfaction)

The Patient-Reported Outcome Measure Information System (PROMIS) Satisfaction With Participation in Social Roles –Short Form assesses satisfaction with performing one's usual social roles and activities, such as satisfaction in ability

to participate in family activities.^{18,19} Its items were developed using item response theory and it consists of 14 questions with a maximum total score of 70 points and has been found to be responsive to changes in social roles.¹⁸

Personal factors

Variables included sociodemographic characteristics such as sex (male or female), age (in years), marital status (married or unmarried/divorced/widowed), household income (in dollars), community living situation (living independently or with assistance), and employment status (working or not working). Perceived recovery was measured using a single item from the Stroke Impact Scale (SIS),²⁰ which has been validated with people with acute and chronic stroke.²¹

Health conditions

Variables included time since stroke (in months) and number of past medical conditions, calculated as a sum of medical conditions reported by participants.

Body functions and structures

Depression symptoms were measured using the Center for Epidemiologic Studies Depression Scale, which has been shown to have good psychometric properties.^{22,23} The score ranges from 0 to 60, with higher numbers meaning greater depressive symptoms.^{22,23} Fatigue was measured using a single question asking the severity of fatigue on a scale of 1 (mild) to 10 (severe). The effects of stroke on mobility, strength, hand function, communication, and cognition were assessed using the SIS, which was validated in people with acute and chronic stroke. Scores of each domain range from 0 to 100, with higher scores indicating less impairment.²⁰

Environmental factors

Environmental factors were measured using the environment subdomain of the World Health Organization Quality of Life Short Form (WHOQOL-BREF), a cross-cultural quality of life measure.²⁴ The environment domain includes items on finances, freedom, safety, health and social care, home environment, access to opportunities, physical environment, and transportation, all of which collectively measure various aspects of one's physical, social, and attitudinal environments.²⁵ The score ranges from 0 to 100, with a higher score indicating a more supportive environment.

Statistical analyses

Characteristics of the participants were described by means, standard deviations, medians, and interquartile range for numeric variables and by frequency and percentages for categorical variables. The association between the 2 participation measures (RNLI and PROMIS Satisfaction With Social Roles) and numeric personal, health- and function-related, and environmental factors was assessed by the Spearman correlation. For categorical factors, we calculated the means of the outcome measures by category and compared them using analysis of variance. Significance level was kept at .05 for all tests, without correction for multiple comparison, because of the exploratory nature of the study, which was taken into consideration when interpreting the results. Strength of correlation was defined as weak if $0.2 \leq |r| < 0.4$, moderate if $0.4 \leq |r| < 0.6$, and strong if $|r| \geq 0.6$.²⁶

Results

All 113 participants from the original data set were included in this study. Demographic characteristics including personal, social, and health-related and environmental factors are presented in table 1. Approximately half of the participants (51%) were males, were married/divorced/widowed (63%), were living without assistance (56%), and were retired or unemployed (55%). The mean age of the sample was 57 years (SD=10), and mean time since stroke was 51 months (SD=61). The mean NIHSS was 4.9 (SD=3.0), with a majority having a mild stroke (56%) Mean depression score at baseline was 12 (SD=12), and mean number of medical conditions was 6 (SD=4).

The mean of RNLI (participation performance) was 83.5 (SD=21.6) and the mean of the PROMIS Satisfaction with Social Roles and Activities Scale (participation satisfaction) was 47.8 (SD=15.7). Table 2 shows the Spearman correlation between the 2 outcome variables (ie, participation performance and participation satisfaction) and numeric measures. Participation performance was positively correlated with perceived recovery ($r=0.41$, $P<.001$). Body functions such as fewer symptoms of depression ($r=-0.40$, $P<.001$; $r=-0.50$, $P<.001$), lesser severity of fatigue ($r=-0.46$, $P<.001$; $r=-0.42$, $P<.001$), and better mobility ($r=0.43$, $P<.001$; $r=0.45$, $P<.001$) showed significantly moderate correlations with participation performance and satisfaction respectively. Environmental factors such as having more environmental resources ($r=0.62$, $P<.001$; $r=0.70$, $P<.001$) also strongly correlated with higher participation performance and satisfaction. Other factors were not statistically correlated or showed weak correlations with participation performance or satisfaction. There were no statistical differences between groups defined by sex, marital status, employment status, and living situation for either participation performance or satisfaction scores.

Discussion

The goal of this study was to assess factors associated with participation outcomes among community-dwelling people who had a mild or moderate stroke. The study found that higher participation performance and satisfaction were moderately to strongly associated with having fewer depressive symptoms and fatigue, having more mobility, and having more environmental supports. Higher participation performance was also moderately associated with better perceived recovery. Increased age weakly correlated with increased participation performance and satisfaction. Previous reports often state that increased age correlates with reduced participation performance.^{27,28} Additionally, reaching a stage of acceptance or content with participation after stroke takes about 7-8 years.²⁹ This incongruity in results could be because our sample was relatively younger in age and less time had passed since their stroke (median=23 months, table 1) compared to the other studies.

The body function-related variables (ie, depression, fatigue, and mobility) moderately associated with participation outcomes were consistent with factors found to be associated with participation outcomes in a previous systematic

Table 1 Demographic characteristics and descriptive statistics of the participants

Factors	Descriptive Statistic
Personal factors	
Age, years, mean±SD; min-max	57.2 (10.0); 32-93
Median (IQR)	56 (52, 63)
Monthly income (\$), mean±SD; min-max	6255 (1627); 0-150,000
Median (IQR)	2720 (1190, 5333)
Sex, n (% males)	58 (51.3)
Marital status, n (% single [never married])	42 (37.2)
Community living status, n (% living without assistance)	63 (55.8)
Employment status, n (%)	
Unemployed; retired	38 (33.6); 24 (21.2)
Long-term disability status	33 (29.2)
On formal leave	7 (6.2)
Part-time	7 (6.2)
Full-time	3 (2.7)
Missing	1 (0.9)
Health conditions	
Time since stroke (months), mean±SD; min-max	51 (61); 3-295
Median (IQR)	23 (9, 25)
Number of medical conditions, mean±SD; min-max	6.3 (3.5); 1-15
Median (IQR)	6 (4, 8)
Stroke severity (NIHSS); min-max	4.9 (3.0); 1-12
Median (IQR)	4 (2, 7)
Body functions and structures	
Depression (CES-D), mean±SD; min-max	12.0 (11.7); 0-55
Median (IQR)	11.0 (5, 21)
Fatigue severity, mean±SD; min-max	3.7 (2.9); 1-10
Median (IQR)	3.0 (0.0, 10.0)
Mobility (SIS), mean±SD; min-max	79.9 (16.5); 35-100
Median (IQR)	84.4 (68.9, 93.3)
Strength (SIS), mean±SD; min-max	59.5 (19.2); 20-100
Median (IQR)	60.0 (40.0, 75.0)
Hand function (SIS), mean±SD; min-max	54.9 (28.8); 20-100
Median (IQR)	56.0 (22.0, 80.0)
Communication (SIS), mean±SD; min-max	89.3 (12.8); 45-100
Median (IQR)	94.3 (80.0, 100.0)
Cognition (SIS), mean±SD; min-max	81.4 (15.6); 31-100
Median (IQR)	85.7 (72.9, 94.3)
Environmental factors	
Environmental support (WHOQOL-BREF), mean±SD; min-max	72.2 (18.1); 25-100
Median (IQR)	75.0 (59.5, 88.0)
Participation	
RNLI (participation performance), mean±SD	83.5 (21.6)
Total score	100
PROMIS satisfaction (participation satisfaction), mean±SD	47.8 (15.7)
Total score	100

Abbreviations: CES-D, Center for Epidemiologic Studies Depression Scale; IQR, interquartile range.

review.⁸ Unlike our study, this systematic review also identified number of comorbidities and cognition as associated factors.⁷ In our study, these variables were significantly associated with community participation outcomes, although the strengths of the associations were weak. Weak associations with cognition scores could be explained by the fact that participants in this study only had mild cognitive impairments, and the correlation was calculated with a subgroup of a cognitively impaired population. Most of the identified variables may be modifiable with targeted

interventions. Though mobility is already a focus of rehabilitation, the findings suggest that rehabilitation should focus more on building participants' self-management skills for managing the chronic effects of stroke such as fatigue and depression. Integration of the chronic care model into stroke rehabilitation with trainings for health care providers to provide self-management support (eg, goal setting, problem solving, mastery experience) with traditional rehabilitation could help build stroke survivors' self-management skills early on while in rehabilitation.^{30,31}

Table 2 Spearman correlations

Variable Name	Participation Performance (RNLI) Spearman Correlation Coefficient (r)	P Value	Participation Satisfaction (PROMIS) Spearman Correlation Coefficient (r)	P Value
Personal factors				
Age	0.22	.02	0.24	<.001
Monthly income	0.01	.89	0.03	.73
Perceived recovery	0.41	<.001	0.37	<.001
Health conditions				
Months since stroke	0.17	.07	0.28	.003
No. of medical conditions	−0.24	.01	−0.28	.003
Body functions and structures				
Depression (CES-D)	−0.40	<.001	−0.50	<.001
Fatigue severity	−0.46	<.001	−0.42	<.001
Mobility (SIS)	0.43	<.001	0.45	<.001
Strength (SIS)	0.38	<.001	0.31	<.001
Hand function (SIS)	0.27	.004	0.20	.034
Communication (SIS)	0.29	.002	0.28	.003
Cognition (SIS)	0.32	<.001	0.23	.013
Environmental factors				
Environmental support (WHOQOL BREF)	0.61	<.001	0.69	<.001

NOTE. Higher scores are better for all variables, except for number of medical conditions, depression, and fatigue severity. Abbreviation: CES-D, Center for Epidemiological Studies Depression Scale.

The finding that perceived recovery showed moderate correlations with participation performance is consistent with previous literature that identified perceived recovery as a predictor of participation in leisure and outdoor activities.^{32,33} This highlights the importance of considering nonneurologic clinical assessments that include patients' self-evaluations. Given that perceived recovery is a modifiable psychological construct, future research may consider whether interventions directed at increasing self-efficacy, resilience, and perceived recovery may improve participation outcomes.³⁴ Interventions focusing on the social model of disabilities³⁵ highlighting that the environment and system, rather than the bodily impairment, disable individuals (eg, reframing disability, facilitating positive disability identity through peer support) could positively influence patients' perceptions of their recovery after a stroke.

Moderate to strong correlations between the environment with both participation performance and satisfaction highlight the well-documented effect of environment on participation.³⁶⁻³⁹ It is noteworthy that environmental factors were the only variable showing strong significant correlations. Though the data from this study are dated, the findings are consistent with recent literature exploring the effect of environmental factors. Miller et al found that the physical, socioeconomic, and social environments contributed to significant differences in real-world walking among stroke survivors.⁴⁰ A recent systematic review on contextual determinants of poststroke participation also identified social support, people's attitudes, physical environment, access to health and social services, policies, and environmental factors assessed in our study with the WHOQOL Environment subdomain as major facilitators in poststroke participation.⁴¹ The findings of our study align well with documented lived experience of people with stroke and the disability community in general, suggesting the importance

of rehabilitation interventions focusing on navigating environmental barriers (eg, use of community resources and services, peer navigators, advocacy training).⁴²⁻⁴⁴ More research is needed to understand how environmental factors enable or restrict poststroke participation over time, which environmental factors in particular have stronger effects on participation, and what interventions can mediate the environmental influence on participation.^{43,45,46}

We did not find differences in the results between performance and satisfaction except for perceived recovery. This may be because the chosen outcomes were the participants' perceptions of participation performance and satisfaction. Future evaluation using objective participation performance data such as use of Global Positioning Systems, ecological momentary assessments, and accelerometers for measuring community integration will allow us to explore whether and how participation performance and satisfaction differ from each other and how different factors relate to these 2 aspects of participation.

Limitations

The study has several limitations. The study used a small sample of individuals with mild to moderate stroke recruited from 2 Midwest urban areas, which limits the generalizability of the findings. Patient-reported measures were used that have limitations inherent to self-report data. The cross-sectional data only allowed for an analysis of associations without an investigation of the direction of associations. Finally, the study utilized data collected over 10 years ago. Future studies should collect long-term data, particularly data related to environmental factors, with a larger sample size to better understand predictors of participation outcomes.

Conclusions

This study shows that participation, which is known to be a complex construct, is associated with a variety of personal, body function–related, and environmental factors, as the ICF suggests. It particularly establishes evidence supporting the strong association of environmental factors and participation and supports the importance of paying attention to the nonneurologic effects of stroke (eg, support system, depression, fatigue). The finding stresses the need for more research in stroke rehabilitation to develop interventions that use thorough evaluations and address the various biopsychosocial effects of stroke from both micro- and macrolevels.

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