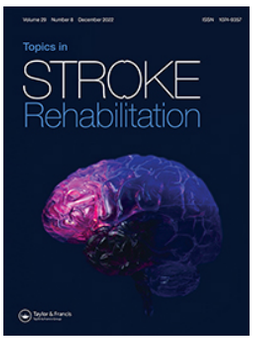

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Self-reported emotional health and social support but not executive function are associated with participation after stroke

Corinne Ianni[a], Laura Magee[a], Chaitali Dagli[b], Marjorie L. Nicholas[c], and Lisa Tabor Connor[b,d]

[a]Department of Occupational Therapy, MGH Institute of Health Professions, Boston, MA, USA; [b]Program in Occupational Therapy, Washington University School of Medicine, St. Louis, MO, USA; [c]Department of Communication Sciences and Disorders, MGH Institute of Health Professions, Boston, MA, USA; [d]Department of Neurology, Washington University School of Medicine, St. Louis, MO, USA

ABSTRACT

Background: Participation restrictions continue to be prevalent for community-dwelling stroke survivors. Research is needed to understand the associated post-stroke factors that limit or facilitate optimal participation and quality of life.

Objectives: To investigate emotional health, executive functioning (EF), and social support as predictors of participation restrictions post-stroke.

Methods: Cross-sectional data collected from participants ≥ 6 months after mild stroke with and without aphasia (N = 114) were analyzed using three participation outcome measures: Reintegration to Normal Living Index (RNL), Activity Card Sort (ACS), and the Stroke Impact Scale (SIS) Version 2.0 Participation/Role Function domain. Predictor variables investigated were emotional health (SIS Emotion domain scores), EF (Delis Kaplan Executive Function System Trail Making Condition 4: DKEFS), social support (Medical Outcomes Study Social Support Survey: MOS-SSS), stroke severity (National Institutes of Health Stroke Scale: NIHSS), and education level.

Results: Using multiple regression, these predictors accounted for 26.4% to 40% of the variance for the three participation outcomes. Emotional health was a significant independent predictor across all three measures. Social support was a significant predictor of participation as measured on the RNL. Executive function was not a significant predictor of participation when controlling for the other predictor variables.

Conclusions: Emotional health and social support should be considered as modifiable factors that could optimize meaningful participation and quality of life.

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stroke; participation; social support; emotional health; executive function

An alarming 65% of stroke survivors struggle with returning to participation in meaningful social roles and desired activities.[1] Participation, or engagement in intrinsically motivating activities, is crucial to stroke survivors as it contributes to higher reported quality of life.[2,3] Many current stroke rehabilitation interventions, regardless of stroke severity, exclusively focus on enabling participation in basic activities of daily living (ADLs).[4–6] Yet, evidence reveals that mild stroke survivors, despite capacity for ADL independence, report poorer quality of life and primarily encounter restrictions in returning to instrumental activities of daily living (IADLs) and activities of leisure, social, work/vocational, and a communication-dependent nature.[1,4–10] These limitations indicate a need for stroke rehabilitation to encompass complex and meaningful activity participation.

This study aimed to identify some of the personal and environmental factors associated with participation restrictions. Common post-stroke factors linked to participation restrictions in the literature, include: poor overall emotional health which encompasses anxiety, depression and apathy as well as emotional lability[4,5,11,12] impaired executive functions or higher-level cognitive abilities such as "cognitive flexibility, problem solving, conceptual reasoning, inhibition, multi-tasking, and nonverbal and verbal creativity"[13–18] and reduced social support, namely the capacity to access emotional, physical and/or spiritual benefits through social connections with other individuals or groups.[8,9,19–22]

Aphasia is another common barrier occurring in one-third of stroke survivors.[23] Although there is conflicting evidence relating aphasia to participa-

CONTACT Lisa Tabor Connor lconnor@wustl.edu Program in Occupational Therapy, Washington University School of Medicine, St. Louis MO, USA
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tion restrictions, aphasia may limit one's capacity to participate in communication-dependent life activities[24,25,26]. The post-stroke aphasia population is frequently underrepresented in the literature due to criteria that disqualify their participation in studies[27,24]. By including persons with aphasia, this study aims to represent the total stroke survivor population more accurately. Further, we investigate if aphasia status independently predicts participation.

There are several gaps in the literature that this study aims to address, including a lack of research about participation as a construct and inconsistencies in participation measures used across the literature. This presents a major barrier to comprehensively understanding participation outcomes. No operational definition of participation has yet been adopted to support measurement development[7,28,29,10,18] though participation has been defined by the World Health Organization's International Classification of Functioning, Disability and Health[30] [pg 10], as "involvement in a life situation." Complimentary to the WHO-ICF definition, Hammel and colleagues[2] identified the personal values and qualities that more holistically define participation, including: meaningful engagement, autonomous choice, intrinsic and extrinsic control, social roles, personal causation, social connection and societal inclusion. We have adopted this expanded definition of participation delineated aboveand have included measures of participation in this study that fit within it.

Worse participation outcomes after stroke have been reported across various participation measures-[12, 29, 31–33]. Tse et al. (2018), however, advised caution when comparing across studies due to the variability of constructs and the multidimensional nature of participation. This study aims to support cross-comparison of post-stroke participation outcome studies by employing three commonly used measures of participation revealing whether influences on participation are common across measures or are specific to individual measures.

Executive dysfunction, emotional health status, and social support have been investigated independently in relation to post-stroke participation. However, it is imperative that these factors be included in a single study to further understand the extent to which the relative impacts of each common post-stroke factor predicts participation outcomes in survivors with and without aphasia. A secondary aim of this study is to understand differences in the extent to which these factors predict participation outcomes across three commonly used measures.

Methods

Research design

This study is a prospective cross-sectional, correlational study exploring the relative influence of executive function abilities, self-reported emotional health, and social support on three different measures of participation in people with and without aphasia after stroke. This study conforms to STROBE guidelines.

Participants

Participants were community-dwelling, first-time stroke survivors with and without aphasia who completed a large comprehensive assessment battery from which the measures included in this study were drawn. Participants were recruited from the Washington University Stroke Research Database in St. Louis Missouri and from outpatient centers and stroke support groups located at the MGH Institute of Health Professions in Boston, Massachusetts or in the surrounding community. Inclusion criteria were: at least 18 years old, had a stroke more than 6 months prior, and were able to endure up to 3 hours of testing in a session. People with aphasia (PWA) demonstrated the ability to accurately respond to an aphasia-adapted screening questionnaire about their consent. People with aphasia either had a score on the National Institutes of Health (NIH) Stroke Scale higher than 0 on the aphasia item at the acute hospitalization or had a diagnosis of aphasia within the past year. There were no restrictions on inclusion with regard to aphasia severity or aphasia classification and a variety of people with aphasia were able to successfully complete the study using aphasia-adapted measures and a hierarchy of examiner support[34]. Participants were excluded if they had major, non-stroke related physical, cognitive, neurological, or psychological disorders.

All data were collected in person in an interview format; assessments were delivered in a fixed order for all participants. All participants provided written informed consent. Institutional Review Boards at the two locations approved this research. Data collection for this study occurred between December 2010 and March of 2020. No participants dropped out of the study after being consented.

Assessments were administered by trained lab personnel, both research coordinators and occupational therapy graduate students. Training was conducted by the principal investigator of the study and by research coordinators through a series of lessons on each assessment followed by observation of administration of each of the measures prior to data collection. All measures were cross-scored by other trained lab members prior to being entered into the master dataset.

Measures

Participation

As there is no single gold standard assessment of participation in the literature, three assessments commonly administered as outcome measures were included. The measures were: 1) the Activity Card Sort[35]; 2) the Stroke Impact Scale (SIS) Version 2.0 Participation / Role Function domain score[36]; and 3) the Reintegration to Normal Living Index.[37]

Activity Card Sort [ACS[35]] measures self-reported activity participation across instrumental, social, low-physical demand and high-physical demand leisure domains using 89 activity-specific color photo cards. This assessment requires participants to group activity cards to indicate prior and current participation levels. The outcome measure used in this study was the percentage retained of pre-stroke activities. The ACS has high internal consistency,[38] high test-retest reliability, and satisfactory construct, content, and predictive validity.[35]

The SIS 2.0 Participation/Role Function domain [SIS-PR[36]] is a self-perception measure that includes 8-items assessing participation with lower scores indicating greater difficulty, and scores ranging from 0 to 100. The SIS-PR has good reliability (Cronbach alpha >0.80), high discriminant validity, and modest criterion and construct validity.[36]

The Reintegration to Normal Living Index [RNL[37]] uses an 11-item questionnaire to measure perceived abilities in activity reintegration across 5 domains [mobility, self- care, daily activity, recreational activity, and family roles). In the version used for this study, participants rated their agreement with statements about activities on a 5-point Likert scale, with higher scores indicating greater satisfaction with return to normal activity levels. Possible scores range from 11 to 55. The measure has good test-retest reliability and internal consistency (ICC = 0.83–0.87, Cronbach *a*: 0.73–0.97], good content validity, acceptable discriminant validity, and moderate to good criterion validity when compared to other participation measures (0.54–0.77).[39]

Aphasia severity

Boston Diagnostic Aphasia Examination 3rd-edition Short Form [BDAE-3[40]] was used to characterize the language abilities of people with aphasia in our sample. Subtests of the BDAE-3 that contribute to the Language Competency Index scores were collected. Language competency domains are scored from 0 to 100, with higher scores demonstrating better language performance. The BDAE-3 was found to have high internal consistency (average alpha 0.81).[40]

Stroke severity

The National Institutes of Health Stroke Scale [NIHSS[41]] was used to measure the level of residual neurological impairment. This measure indicates the level of persistent neurological impairment and is heavily weighted to reflect motor impairment with 21 of 42 possible points being derived from motor items on the scale. The resulting score ranges from 0–42, with higher scores indicating more severe stroke impairments. The NIHSS has good to excellent reliability and high validity.[42] This performance-based scale was administered at the time of study by trained staff.

Emotional health status

The Stroke Impact Scale (SIS) Version 2.0 Emotion domain[36] measures self-reported emotional health status post stroke, covering a wide range of emotions. The measure includes reports of depressive, anxious, and/or positive mood states in the past week. Lower scores indicate greater difficulty with emotional health.[36] The SIS Emotion subscale demonstrates excellent item discrimination (89–98%), poor to moderate

reliability when measured across subject groups based on the intraclass correlation coefficient of 0.527 (though higher than other mental health measures), and high intra-rater reliability (Cronbach's alpha = 0.83 to 0.90).[36,43]

Executive function

The Delis Kaplan Executive Function System [D-KEFS[44]] was used to test participants' executive functioning abilities. Specifically, the fourth condition of the trail-making subtest was used as it requires the highest level of executive functioning. The paper-pencil test requires participants to switch between letters and numbers, integrating both visual and motor functions, while maintaining the correct sequence. The score demonstrates sequencing, staying on task, and cognitive flexibility. It has high internal consistency and moderate test-retest reliability.[44]

Social support

The Medical Outcomes Study Social Support Survey [MOS-SSS[45]] is a 19-item questionnaire to measure perceived availability of social support across 4 domains: emotional/informational, tangible, affectionate, and positive interaction social support. Participants rate the extent to which various forms of social support are available to them using a 5-point Likert Scale, with higher scores indicating greater perceived social support.[45]MOS-SSS has satisfactory convergent and discriminant validity and high internal consistency.

Data analysis

With a sample size of 114 participants, the power to detect associations between independent and dependent variables was deemed adequate based on the heuristic that 10–15 participants are necessary for each independent variable included in a linear regression analysis.[46] Data analysis followed a three-phase procedure. All analyses were conducted using IBM Statistical Packages for the Social Sciences [SPSS- Version 27.0[47]]. In the first phase, a between-groups independent *t*-test established if PWA and without aphasia (PWOA) differed on the three primary participation outcome variables in this study. This initial step determined whether the group variable (aphasia/no-aphasia) was necessary to include in the later regression model.

During the second phase, Pearson correlation analyses examined zero-order correlations between proposed predictor variables: demographic variables of age, months post stroke, stroke severity, education level, and the participation outcome variables[1,48,49]. The threshold for inclusion in the regression analysis was a correlation that was significant at the $p < .05$ level.

In the third phase, the significant independent variables from the preceding two phases were included in a multiple regression analysis as potential predictors for each of the three participation outcome measures. The total variance in the dependent measures accounted for by the independent variables was examined via the *R*-squared statistic. Additionally, the standardized regression coefficients, or beta weights, were examined to determine the relative importance of the predictors for each of the participation outcomes.

Results

Data from 114 community-dwelling participants were included in this study; 56 participants had aphasia. Participant demographics are detailed in Table 1.

Between-groups independent *t*-tests found no statistically significant differences between PWA and PWOA on any of the three measured participation outcomes (see Table 1). Therefore, data were treated collectively as a single stroke group in all subsequent analyses. Overall, participants reported that they retained 70% of their pre-stroke activities on the ACS. On the RNL mean scores on the measure indicated that participants were moderately satisfied with their reintegration to normal living; means scores on the SIS-PR indicated that they were participating in activities and roles at about 70% of their pre-stroke capabilities.

Next, Pearson correlations identified which predictor and demographic variables were significantly correlated with the participation outcome measures and would, therefore, be included in the regression analyses (see Table 2). Significant correlations were obtained between participation outcome variables and education, NIH Stroke Scale Total, SIS

Table 1. Demographics and assessment scores with standard deviations in parentheses.

	All participants (N = 114)	PWA (N = 58)	PWOA (N = 56)
Self-Identified Gender			
Male	51		
Female	63		
Self-Identified Race/Ethnicity			
White	59		
Black	53		
Asian	1		
Hispanic/Latinx	1		
Age in years	59.4 (10.9)	59.7 (10.1)	59.1 (11.9)
Education in years (N = 111)	14.7 (3.0)	15.2 (3.2)	14.2 (2.7)
Months post stroke ***	45.3 (65)	64.6 (76)	24.7 (41)
NIH Stroke Scale Total	2.89 (2.4)	3.0 (2.3)	2.8 (2.4)
BDAE-3			
LCI – Expression		67.8 (24)	
LCI – Compr ehension		68.4 (23)	
LCI – Total		68.1 (22)	
ACS Total percent retained	71.1 (18.7)	73.0 (18.6)	69.0 (22.0)
RNL Total	45.1 (7.9)	45.3 (7.9)	44.9 (8.0)
SIS Participation/Role Function Scaled Score	70.5 (22.2)	69.9 (23.6)	71.2 (22.0)
SIS Emotion Scaled Score	76.1 (19.7)	74.7 (19.8)	77.6 (19.7)
MOS Social Support Total Score *	78.9 (17.0)	75.6 (17.4)	82.3 (15.9)
DKEFS Trail Making Condition 4 Scaled Score**	6.0 (4.2)	5.1 (4.0)	7.1 (4.4)

*p < .05; **p < .01; **p < .001; PWA = People with aphasia; PWOA = People without aphasia; NIH = National Institutes of Health; BDAE = Boston Diagnostic Aphasia Examination; LCI = Language Competency Index; ACS = Activity Card Sort; RNL = Reintegration to Normal Living Index; SIS = Stroke Impact Scale; MOS = Medical Outcome Survey; DKEFS = Delis-Kaplan Executive Function System

Emotion, MOS Social Support, and D-KEFS Trail Making scores. In all cases, these predictor variables correlated with all three participation outcome measures to a significant degree, ranging in magnitude from $r = 0.22$ to $r = 0.54$, with higher participation outcomes associated with higher education, less residual neurological impairment, greater self-reported emotional health, more social support and greater cognitive ability. Participation outcomes did not correlate significantly with months post-stroke or age.

Three separate regression analyses were then conducted to ascertain the percent of variance accounted for by these predictors for each of the three participation outcome measures (see Table 3). For the ACS, a moderate proportion of the variance (26.4%) was accounted for by the predictor variables, $F(5,110) = 7.88$, $p = .0001$. Significant independent predictors of activity retention on the ACS included education, residual neurological impairment (NIHSS), and emotional health. Social support and executive function were not independent contributors to ACS scores.

For the RNL, the R^2 statistic revealed that predictor variables contributed a moderate amount (40.2%) of the total variance, $F(5,107) = 14.376$, $p = .0001$. As seen in Table 3, significant independent predictors of RNL participation included education, residual neurological impairment, perceived emotional health, and social support. Executive function was not a significant independent contributor to RNL participation outcomes.

Table 2. Pearson correlations of potential predictor variables with participation outcomes.

Potential Predictor Variables	% Retained ACS	RNL	SIS-PR
Months post-stroke at test	0.141	−0.075	−0.157
Age in years	−0.115	0.064	0.116
Education in years	0.316**	0.262**	0.223*
NIH Stroke Scale Total	−0.286**	−0.283**	−0.326**
SIS Emotion	0.354**	0.498**	0.533**
MOS Social Support Total	0.275**	0.537**	0.431**
DKEFS Trail Making	0.299**	0.268**	0.240**
ACS	–	0.487**	0.517**
RNL	–	–	0.621**

*$p < .05$, **$p < .01$; DKEFS = Delis-Kaplan Executive Functioning System; SIS-PR = Stroke Impact Scale – Participation/Role Function domain; MOS = Medical Outcome Survey

For SIS Participation/Role Function, a moderate level of variance (39%) was accounted for by the predictors, $F(5,110) = 14.093$, $p = .0001$. As was found for the ACS, the same variables were significant independent predictors: residual neurological impairment and SIS Emotion. Contrary to the ACS, education failed to reach significance. Social support and executive function were not significant predictors of SIS Participation/Role Function.

Table 3. Multiple regression results for % Retained on Activity Card Sort, Reintegration to Normal Living Index, and SIS Participation and Role Function participation measures.

Predictor Variables	% Retained ACS		RNL		SIS-PR Domain	
	β-weight	p-value	β-weight	p-value	β-weight	p-value
Education in years	0.211	.015*	0.186	.019*	0.135	.083
NIH Stroke Scale Total	−0.195	.027*	−0.199	.014*	−0.230	.004*
SIS Emotion	0.239	.027*	0.226	.018*	0.394	.000*
MOS Social Support Total	0.049	.636	0.337	.001*	0.150	.115
DKEFS Trails Condition 4	0.124	.180	−0.002	.979	0.002	.977
R^2	0.264		0.402		0.390	

*p < .05, **p < .01; NIH = National Institute of Health; SIS = Stroke Impact Scale; MOS = Medical Outcome Survey; DKEFS = Delis-Kaplan Executive Function System

In sum, the predictors accounted for a moderate amount of variance for all participation outcome measures, with emotional health and residual neurological impairment being significant independent predictors across all outcome measures. Social support was a significant predictor only for the RNL. Education was a significant independent predictor for both the ACS and the SIS. Notably, executive functioning, as measured by trail making performance on the D-KEFS, was not a significant independent predictor for any of the three participation measures. Additionally, no significant collinearity (all Variance Inflation Factor statistics < 2) was found among independent variables in any of the regression analyses.

Discussion

This study sought to determine the extent to which executive function, perceived emotional health, and perceived availability of social support contributed to participation in community-dwelling stroke survivors including people with aphasia using three measures of participation. A secondary aim of this study was to determine if the participation outcome measures represented a similar participation construct based on evidence that similar independent variables would serve as predictors across measures.

Similar findings were seen across participation outcome measures. Although the study population had, on average, a stroke over 3 years ago and had mild residual neurological impairment, results indicated a moderate level of participation restriction demonstrated across measures. Participation restrictions from the Activity Card Sort and the Stroke Impact Scale-Participation/Role Function domain were similar, both measures indicating that stroke survivors rated their participation at 70% of pre-stroke levels.

Zero-order correlations of the predictor variables (Education, NIH Stroke Scale Total, SIS Emotion, MOS Social Support Total, and DKEFS Trail Making) revealed moderate associations with all three participation measures indicating that lower levels of education, more residual neurological impairment, poorer emotional health, social support and cognitive function were associated with poorer participation outcomes.

In the subsequent regression analyses, predictor variables accounted for moderate amounts of total variance in each outcome: 26.4%, 40.2%, and 39%, for the ACS, RNL, and SIS-PR respectively. In the regression analyses, overall emotional health status (SIS Emotion scores) and residual neurological impairment, largely reflecting greater motor limitations, were found to be significant independent predictors consistently across all three participation measures. These findings are consistent with reports in the literature of greater participation restrictions in those with poorer mental health-[5,11,12,50,51] and with greater stroke severity [e.g.,[1]].

For both the ACS and RNL analyses, educational attainment was found to be an additional significant independent predictor, consistent with results of Van der Zee et al. (2013),[10] but failed to reach significance as an independent predictor for the SIS-PR. The study sample had an average of approximately 15 years of education, indicating a range skewed toward the higher end. Perhaps a more representative group in terms of education level may have yielded different results, and perhaps an even stronger relationship between education and participation outcomes.

The association between self-perceived social support with the retention of pre-stroke activities on the ACS was somewhat smaller in magnitude than its association with the other two participation

outcomes. This may reflect the fact that the ACS contains many items in the instrumental activities and leisure domains that do not generally require social support to do them, whereas the SIS-PR and RNL questions are generally more reflective of social aspects of participation.

Interestingly, the RNL was the only participation measure for which the MOS-Social Support was a significant independent predictor. Other studies have reported social support to be related to a variety of participation outcomes,[21] and perceived levels of social support to be the strongest predictor of participation frequency using the Par-Pro Measure of Home and Community Participation.[52] For more insight into why the RNL may be more sensitive to social support, we further inspected the RNL items and compared them to items on the ACS and SIS-PR. Because the RNL scores include measures of self-efficacy and satisfaction (e.g. "I am able to participate in social activities with my family, friends, and business acquaintances as necessary or desirable") and self-acceptance (e.g. "In general, I am comfortable with myself when I am in the company of others"), the RNL outcomes may refer to the perceived *quality* of participation after stroke, as opposed to the more quantitative-focused measures, such as percent of activities retained on the ACS or perceived return to prior roles and activity levels on the SIS-PR. This difference may underlie why the MOS Social Support predictor was related to the RNL scores. Further research is necessary to determine if *quality* of participation is related to the level of social support.

Of note, executive functioning was not an independent predictor of participation for any of our three outcome measures. The mean scaled score on the DKEFS Trail Making assessment in our sample was 6 with a standard deviation of 4.2, indicating that the lack of relationship between executive function and participation was not likely due to ceiling effects, nor a lack of variability in individual scores. Prior work has demonstrated that executive abilities support participation and are associated with restrictions in participation of complex IADLs, social roles, and leisure activities.[5,53,54] Similar to our findings, Bertolin et al. (2018),[1] obtained no significant relationship between executive functioning and participation, included only persons at least 6 months post stroke, and used the same Trail Making task to measure executive functioning.

Study limitations and recommendations

This study had several limitations that may have influenced the results. For one, the study used a cross-sectional design and relied upon convenience sampling. Further, our sample was limited purposefully to persons living in the community. Participants had higher educational attainment than the general population, thereby limiting the generalizability of our findings.

By only using one paper-pencil measure of executive function in a standardized environment, this study may have neglected other key aspects of executive functioning that may better predict participation outcomes.[1,55] Additionally, impaired self-awareness, a form of executive dysfunction, has also been observed in the literature to produce more positive self-reports of performance and participation than people demonstrate in real life[56–58] and we had no measure of self-awareness in this investigation. Future studies may benefit from the incorporation of performance-based measures of executive dysfunction (e.g. Fride et. al., 2016) as these have been shown to predict activity participation more accurately in unstructured and natural environments[59,60] and an assessment of self-awareness to enable a more comprehensive understanding of barriers and facilitators to post-stroke participation.

Clinical implications and conclusions

The findings of this study identify both emotional health and social support as modifiable factors that may be addressed via stroke rehabilitation. Further, our results identified lower education levels and higher stroke severity as risk factors to less optimal participation outcomes. There is a recognized need to address lasting participation restrictions in community-dwelling chronic stroke survivors. In those with mild stroke, successful community reintegration goes beyond simply addressing basic activities of daily living. Clinicians can better support stroke survivors, their families, and their caregivers by educating them on the importance of emotional health recovery and helping them to identify social supports to facilitate and improve meaningful participation.

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ORCID

Lisa Tabor Connor http://orcid.org/0000-0002-9776-8328

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