Perceived Participation After Stroke: The Influence of Activity Retention, Reintegration, and Perceived Recovery

Gunilla Eriksson, M. Carolyn Baum, Timothy J. Wolf, Lisa Tabor Connor

OBJECTIVE. We sought to determine the extent to which perceptions of participation in everyday occupations were affected in a sample of people with predominantly mild stroke. Demographic variables, stroke severity, community integration, participation in everyday occupations, and perceptions of recovery were examined as potential contributors to their perceptions of participation.

METHOD. We conducted a cross-sectional study with 116 people with mild to moderate first stroke assessed approximately 6 mo after stroke.

RESULTS. Perceptions of participation assessed using the Stroke Impact Scale varied (range = 519–100), with a mean score of 82. Regression analyses revealed three factors that contributed to perceptions of participation: retention of previous activities, reintegration in home and community, and perception of stroke recovery.

CONCLUSION. Although the majority of participants reported a high level of perceived participation, more than a third failed to report successful participation.


Everyday life becomes more challenging after having a stroke. The consensus in the literature is that regardless of severity, stroke restricts participation in everyday occupations (Daniel, Wolfe, Busch, & McKevitt, 2009; Duncan et al., 1997, 1999; Edwards, Hahn, Baum, & Dromerick, 2006; Hartman-Maeir, Soroker, Ring, Avni, & Katz, 2007; Rochette, Desrosiers, Bravo, St-Cyr-Tribble, & Bourget, 2007). The World Health Organization (2001), in the International Classification of Functioning, Disability and Health (ICF), has defined participation as “involvement in a life situation” (p. 10).

Although participation is beginning to be considered in outcome studies after stroke, Salter et al. (2005) reported in their review that no clinical or scientific consensus exists regarding important indicators of successful participation. Participation as it is described in the ICF is complex to measure because it is related to quality of life, autonomy, and doing with others and depends on environmental influences (Salter et al., 2005). Participation is also subjectively determined because it is a person’s report of his or her own perceptions of fulfillment of personal and societal goals (Perenboom & Chorus, 2003).

The ICF definitions of participation and participation restrictions are not very useful, however, because everything we do from birth to death is being involved in life situations (Dijkers, 2010). For the purposes of this article, we adopted the perspective of Mallinson and Hammel (2010) that participation...
necessarily occurs at the intersection of what a person can do, has the affordances to do, and is not prevented from doing by the world in which he or she lives and seeks to participate. Their perspective encompasses social participation (Rochette, Korner-Bitensky, & Levasseur, 2006), community integration (Resnik & Allen, 2007), and participation in everyday occupations (Law, 2002).

Experiences of participation in everyday life have been explored in qualitative studies in older adults (Haak, Dahlin Ivanoff, Fänge, Sixsmith, & Iwarsson, 2007), people with brain injuries (Häggström & Lund, 2008), and people with chronic pain (Borell, Asaba, Rosenberg, Schultz, & Townsend, 2006). According to the findings in these studies, participation is experienced as multidimensional and incorporates agency, active engagement in doing for self and for others, togetherness, and belonging. Hammel et al. (2008) highlighted issues such as opportunities for choice and control, personal and societal responsibilities, social connection and inclusion, and societal access as prerequisites for participation.

The Stroke Impact Scale (SIS; Duncan et al., 1999) was developed with input from people with stroke and their significant others to measure the perceived impact of stroke in everyday life as identified by people with stroke and their proxies. One of the domains assesses perceived participation in everyday life; the respondent answers questions such as, “How has stroke affected your ability to participate in the activities that you usually do, things that are meaningful to you and help you to find purpose in life?” Hence, one might argue that the SIS Participation domain captures several areas that were identified in the qualitative studies (Borell et al., 2006; Haak et al., 2007; Häggström & Lund, 2008; Hammel et al., 2008) concerning how participation was experienced and also covers the more overarching view of participation (Mallinson & Hammel, 2010). Therefore, we consider the SIS Participation domain to be a broad-based indicator of perceived successful participation after stroke.

The objective of the current study was to determine the extent to which perceptions of participation in the broadest sense were affected in people who had had a mild to moderate stroke. We then explored how community integration and reported participation in everyday occupations contributed to their perceptions of participation. An understanding of the impact of stroke and influences on perceived participation may guide occupational therapy practitioners in better helping clients return to community life by focusing their efforts on the most important factors affecting participation.

**Method**

**Research Design**

The study had a prospective cross-sectional research design. All data were obtained with approval from the Washington University Human Research Protection Office. Participants gave informed consent during their acute hospital stay to contribute their medical record to the stroke registry and to be contacted for future studies. At the time of follow-up assessment, participants gave informed consent for the collection of outcome data.

**Participants**

Study participants were recruited through the Cognitive Rehabilitation Research Group (CRRG) of the Program of Occupational Therapy, Washington University School of Medicine in St. Louis, MO. The CRRG registers patients from the stroke service at Barnes–Jewish Hospital. A nurse coordinator evaluated and recorded stroke severity with the National Institutes of Health Stroke Scale (NIHSS; Brott et al., 1989), premorbid activity of daily living (ADL) ability with the Barthel Index (Mahoney & Barthel, 1965), orientation with the Short Blessed Test (Katzman et al., 1983), and demographic information for all patients. Participants were admitted to the acute stroke service from October 2002 to November 2006. We included patients who had an acute NIHSS score $>15$ or a diagnosis of dementia, schizophrenia, or sickle-cell anemia. Four to 9 mo after stroke onset, participants were contacted and asked to enroll in a follow-up study focused on outcomes after mild to moderate stroke that included these measures as part of a larger battery of tests. Participants received usual and customary rehabilitative care, but for many people, this amounted to no services. We did not track the amount of rehabilitation received by participants enrolled in this study.

**Instruments**

The NIHSS assesses cognitive, sensory, and motor impairments as indicators of neurological severity. This 13-item test produces scores ranging from $0 = \text{no deficit}$ to $46 = \text{severe deficit}$. Scores $\leq 5$ indicate mild impairment; $6–15$, moderate impairment; and $\geq 16$, severe impairment. The original NIHSS study evaluated scale reliability and found that most items had good to excellent test–retest reliability; average $k$ ranged from $.49$ to $.95$ and a mean $\kappa = .69$. Interrater reliability was good to excellent as well, with average $k$ ranging from $.66$ to $.77$ for two test administrations with four examiners (Brott et al., 1989). Comparison of the 90-day NIHSS score
with 3-mo clinical outcomes showed high validity. Correlation coefficients between NIHSS and the Barthel Index ($r = -0.81$), the Rankin Scale ($r = 0.86$), and the Glasgow Outcome Scale ($r = 0.84$) were significant (Lyden et al., 1999). NIHSS total score obtained from the acute hospital stay was used as an independent variable in the regression analysis.

The SIS is a self-report questionnaire of 59 items in eight domains including perceived strength, memory and thinking, emotions, communication, ADLs and instrumental activities of daily living, mobility, hand function, and participation. The questions in each domain are scored from 1 to 5, and scores ranging from 0 to 100 are generated for each domain. The instrument also includes one item that assesses the person’s overall perception of recovery. This item is presented in the form of a vertical visual analog scale ranging from 0 = no recovery to 100 = full recovery. The SIS Participation domain (Domain 8) has nine questions that ask the participant to rate his or her limitations in the past 4 wk in (1) work, volunteer, or other activities; (2) social activities; (3) quiet recreation; (4) active recreation; (5) role as a family member or friend; (6) participation in spiritual or religious activities; (7) ability to feel emotionally connected to others; (8) ability to control life as he or she wishes; and (9) ability to help others.

The eight scales of the SIS have high reliability, with Cronbach’s alphas ranging from .83 to .90 and intraclass correlation coefficients (ICCs) ranging from .70 to .92, except for the Emotion domain (ICC = .57; Duncan et al., 1999). Validity of the eight scales has been established through Rasch analysis (Duncan, Bode, Min Lai, & Perera, 2003). Concurrent validity (Duncan et al., 1999) and construct validity (Edwards & O’Connell, 2003) have also been established. In the data analyses reported in this article, the score on the Participation domain was used as the dependent variable in a multiple regression analysis, and the recovery score was used as an independent variable.

The Reintegration to Normal Living Index (RNL; Wood-Dauphinee, Opzoomer, Williams, Marchand, & Spitzer, 1988) is a global assessment of the perceived quality of life of people with a disability. The RNL is used to document how well the person perceives having resumed normal life activities after an incapacitating injury or illness. The RNL assesses the person’s satisfaction with self-care, daily activities, mobility, leisure activities, and family roles. People respond to 11 statements to rate their reintegration into their premorbid pattern of living. Items are scored from 1 to 5, with a maximum score of 55; higher scores indicate higher levels of satisfaction and reintegration. The RNL has been found to have high test–retest reliability ($r = 0.80$; Korner-Bitensky, Wood-Dauphinee, Siemiatycki, Shapiro, & Becker, 1994) and high internal consistency with patients, significant others, and health professionals ($\alpha = 0.90, 0.92, \text{ and } 0.95$, respectively; Wood-Dauphinee et al., 1988). The RNL has high construct validity, demonstrated by high correlations with the Quality of Life Index, the Herth Hope Index, and the Life Scale Satisfaction Scale ($r_s = 0.59–0.71$; Bluvol & Ford-Gilboe, 2004; McColl, Paterson, Davies, Doubt, & Law, 2000; Wood-Dauphinee et al., 1988). The total RNL score was used as an independent variable in this analysis.

The Activity Card Sort (ACS; Baum & Edwards, 2001) assesses reported participation in 80 instrumental, social, and high- and low-demand physical leisure activities. A sorting methodology is used; participants sort photographs of people performing various activities into categories. For this study, participants sorted the cards using the descriptors not done before stroke, continued after stroke, doing less after stroke, and given up after stroke. The current activity level score is the number of activities being performed now, scored by degree of involvement. The retained score is the percentage of prestroke activities being done. ACS has high internal consistency. Everard, Lach, Fisher, and Baum (2000) reported alpha coefficients of ≥.71 or greater for the four domains measured; Carpenter et al. (2007) reported alphas of ≥.83. Test–retest reliability has been reported as high, with ICCs ranging from .71 (Carpenter et al., 2007) to .98 (Chan, Chung, & Packer, 2006). Evidence is available for construct (Sachs & Josman, 2003), concurrent (Carpenter et al., 2007; Everard et al., 2000), and discriminant validity (Edwards et al., 2006; Katz, Karpin, Lak, Furman, & Hartman-Maeir, 2003). The percentage retained activity score was used as an independent variable in the analysis.

**Data Collection**

At 4 to 9 mo (mean = 6.4 mo) posthospitalization, participants who had a first-time stroke, a premorbid Barthel Index score >90, and no significant memory problems as operationalized by a Short Blessed Test score <9 were contacted by trained interviewers from the CRRG staff who were unaware of the study goals to complete a 90-min telephone or in-person interview using a standardized script. Interviews required no interpretation by the interviewer; thus, no interrater reliability estimates were necessary for this study. All of these patients lived independently in the community at the time of the interview. To be included in the analysis, participants needed to have an NIHSS score obtained at the
time of hospitalization and to have completed the SIS, ACS, and RNL.

Data Analysis

All statistical analyses were conducted using SPSS for Windows (Version 18; SPSS Inc., Chicago). Descriptive statistics were computed for all variables. Correlation coefficients (Pearson product–moment correlations or Spearman rank order correlations, as appropriate) were calculated to examine the relationships among demographic variables, activities retained poststroke, community reintegration, and the SIS Participation domain score. We calculated correlation coefficients to determine which variables to include in the multiple regression analysis exploring their influence on perceived participation (SIS Domain 8). The demographic variables that significantly \(^{<} .05\) correlated with the SIS Participation domain were selected as independent variables, together with stroke severity. We also plotted distributions to check for normality. Although several of the variables of interest to the analysis were skewed, Pearson and Spearman correlations were computed for all variables. Correlation coefficients to determine which variables to include in the multiple regression analysis exploring their influence on perceived participation (SIS Domain 8).

Results

One hundred sixty-one participants completed the follow-up assessment battery. Of those, 45 were missing at least one of the required measures. Thus, our final sample size for analysis was 116. All participants had an NIHSS score \(<15\) (per inclusion criteria of the larger study), and of those, only 17 participants had had a moderate stroke. The mean age in the sample was 62.4 yr; 54% were at or younger than age 65 yr, and 29% were younger than age 55. The characteristics of the study participants are presented in Table 1.

Scores on the Participation domain of the SIS were distributed widely in the sample, with a range of 19–100; 12.5% scored 19–50, and 23.2% scored 51–79. Further, 64.3% scored \(\geq80\), and of those, 32.2% scored 100. The median score was 90.6.

Significant but modest correlations were obtained between the SIS Participation domain score and stroke severity (NIHSS; \(r = –.25, p < .01\) and marital status \(r^{2} = .25, p < .01\)). The correlations between SIS participation and RNL \((r = .71, p < .0001)\), the ACS percentage retained scores \((r = .67, p \leq .0001)\), and SIS perceived recovery after stroke \((r = .53, p \leq .001)\) were more robust. Correlations between SIS Participation and age at stroke onset \((r = –.045)\) and gender of participant \((r = –.13)\) were not statistically significant and were not included in the regression model (Table 2).

The model that included the variables with significant zero-order correlations with SIS Participation explained 61% of the variance (adjusted \(R^{2}\)). Significant predictors of perceived participation revealed by the regression model are presented in Table 2.

Table 1. Participant Characteristics (\(N = 116\)) and Assessment Scores

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Mean (SD) or n (%)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>56 (48.3)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>60 (51.7)</td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married or cohabiting</td>
<td>66 (56.9)</td>
<td></td>
</tr>
<tr>
<td>Divorced, never married, or widowed</td>
<td>49 (42.2)</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>1 (0.9)</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>71 (61.2)</td>
<td></td>
</tr>
<tr>
<td>African-American</td>
<td>45 (38.8)</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>62.4 (12.7)</td>
<td>31–90</td>
</tr>
<tr>
<td>Education, yr</td>
<td>12.9 (2.9)</td>
<td>6–22</td>
</tr>
<tr>
<td>NIHSS total score</td>
<td>3.26 (2.8)</td>
<td>0–14</td>
</tr>
<tr>
<td>Retained instrumental ADL activities (ACS)</td>
<td>83.9 (19.3)</td>
<td>31–100</td>
</tr>
<tr>
<td>SIS Domain 8: Participation</td>
<td>82.0 (20.7)</td>
<td>19–100</td>
</tr>
<tr>
<td>SIS Recovery</td>
<td>79.9 (18.6)</td>
<td>0–100</td>
</tr>
<tr>
<td>RNL total</td>
<td>46.2 (6.9)</td>
<td>30–55</td>
</tr>
</tbody>
</table>

Note. — = not applicable; ACS = Activity Card Sort; ADL = activity of daily living; NIHSS = National Institute of Stroke Scale; RNL = Reintegration to Normal Living Index; SD = standard deviation; SIS = Stroke Impact Scale.

Table 2. Results of a Regression Analysis Performed With SIS Participation Domain Score as the Dependent Variable

<table>
<thead>
<tr>
<th>Variable</th>
<th>(p)</th>
<th>(b)</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital status</td>
<td>NS</td>
<td>–0.339</td>
<td>–1.90–1.22</td>
</tr>
<tr>
<td>NIHSS</td>
<td>NS</td>
<td>–0.204</td>
<td>–1.11–0.71</td>
</tr>
<tr>
<td>Perceived recovery (SIS)</td>
<td>&lt;.05</td>
<td>0.197</td>
<td>0.047–0.347</td>
</tr>
<tr>
<td>Retained activities (ACS)</td>
<td>&lt;.0001</td>
<td>0.451</td>
<td>0.261–0.641</td>
</tr>
<tr>
<td>Community reintegration (RNL)</td>
<td>&lt;.0001</td>
<td>1.21</td>
<td>0.75–1.67</td>
</tr>
</tbody>
</table>

Note. ACS = Activity Card Sort; CI = confidence interval; NIHSS = National Institutes of Health Stroke Scale; NS = not significant; RNL = Reintegration to Normal Living Index; SIS = Stroke Impact Scale. \(b\) = unstandardized regression coefficient.
were perceived recovery on the SIS, percentage of activities retained on the ACS, and RNL total score. Multicollinearity tests indicated that these variables were not collinear and thus contributed uniquely to SIS participation (all variance inflation factors were less than 2.5). NIHSS score and marital status were not significant predictors of SIS Participation in this model.

Discussion

One of the most striking findings of this study is that perceptions of participation in everyday life varied widely in this sample (range 19–100). A third of participants perceived that they were fully participating in their pre-stroke activities (participation score of 80 or better), whereas 12% perceived their participation to be limited (<50 on the Participation domain score). The mean domain score of 82, however, indicates that this sample perceived their participation as high compared with other samples with mild and moderate stroke (Carod-Artal, Coral, Trizotto, & Moreira, 2008; Duncan et al., 1999, 2002; Edwards & O’Connell, 2003; Nichols-Larsen, Clark, Zeringue, Greenspan, & Blanton, 2005), in which all mean scores were between 50.6 and 67.6. One difference with this study sample versus others in the literature was that only 14.7% of the sample (n = 17) scored in the moderate range of impairment. Although this characteristic of our sample limits the ability to generalize our findings to all people with stroke, it emphasizes that the range of SIS Participation scores in this sample was wide despite that the majority had a mild stroke, indicating the importance of exploring factors contributing to perceived participation.

In our study, three factors significantly influenced the level of perceived participation on the SIS: (1) retention of pre-stroke activities, (2) reintegration into the community, and (3) perception of recovery 6 mo after the stroke. Factors that did not significantly influence perceived participation were age, gender, and marital status. Severity of the stroke at the acute stage decidedly did not influence perceived participation 6 mo later.

Several studies of people with stroke have used life satisfaction as a long-term outcome measure as it relates to participation. One might argue that these studies also shed light on factors contributing to perceived successful participation. Hartman-Maeir et al. (2007) found that retained activities significantly influenced the level of life satisfaction, and Mayo, Wood-Dauphinée, Côté, Duncan, and Carlton (2002) found perceived community integration to be the most influential factor. Vestling, Tufvesson, and Iwarsson (2003) found that return to work and satisfaction with financial situation, leisure, and contacts with friends had an impact on overall life satisfaction. This finding was contradicted by Johansson and Bernspång (2003), who did not find any correlation between work status and level of life satisfaction. In a Norwegian sample, Sveen, Thommessen, Bautz-Holter, Wylle, and Laake (2004) showed that retaining leisure activities predicted subjective well-being 6 mo after stroke. These studies support our findings that retaining previous activities and being reintegrated in the community are essential factors for perceived successful participation. Our finding that perceived recovery after stroke also contributed to the perception of successful participation might be self-evident, but to the best of our knowledge the previous literature has not explicitly reported this finding.

The retention of activities in daily life and the perception of being reintegrated into the community after having a stroke were two of the contributing factors to perceived successful participation in this study, a finding very much in line with the theoretical foundations of occupational therapy. The third contributing factor, perceived degree of recovery, might be seen in two ways: either one perceives recovery as required before resuming activities at home or in the community, or one experiences a higher extent of recovery as one perceives that everyday life has regained a rhythm recognized from prestroke life. However, our findings support the latter assertion as more consistent with occupational science—that participation in everyday occupations improves people’s health and well-being (Law, 2002; Yerxa, 1998).

In this study, we were unable to detect a significant relationship between acute stroke severity as evaluated by the NIHSS and level of perceived participation at 6 mo. This lack of relationship between stroke severity and perceived participation is consistent with results from a study restricted to people with mild stroke conducted by Edwards et al. (2006). The sample in the current study included 17 (14.7%) participants with moderate stroke, and because of the broader range of stroke severity, one might have predicted a stronger association between perceived participation and NIHSS scores than that found in previous studies. However, this was not the case. It remains for future work to uncover the relative role of stroke severity in explaining perceived participation. Perceived recovery had a strong relationship to perceived participation, however, indicating that the subjective perspective on the impact of stroke seems to be a better indicator of perceived successful participation than the objective assessment on severity of stroke, but this conclusion warrants further exploration.
Limitations

Several issues limit the generalizability of these findings to the broader population of people with stroke. First, as emphasized earlier, the sample consisted primarily of people with mild stroke, although it included some with moderate stroke. The perceived participation restrictions of this sample as a whole were modest, but the range of restrictions was striking. These results warrant further investigation by both researchers and clinicians.

Second, the average age at stroke in our sample was quite young: 62 yr. However, age at first stroke is decreasing, and our sample may represent the new reality of poststroke life in the United States (Wolf, Baum, & Connor, 2009). Because our sample was younger than other samples reported in the literature (e.g., Duncan et al., 1999), direct comparisons of our findings to others is more difficult. Further, it may be that younger adults give up fewer activities than their older counterparts and thus experience less perceived restriction in participation. A recent study in our laboratory, however, indicates that younger adults give up the same percentage of activities after a mild stroke than older adults do, but the nature of the activities that are limited or given up differs with age (Wolf, Brey, Baum, & Connor, 2012).

Finally, we did not measure in this study other aspects of perceived participation that are clearly important for a fuller understanding of the broader concept. For instance, we did not include a measure of social support or of the meaningfulness of relationships to perception of participation. These aspects remain to be explored in future work.

Implications for Occupational Therapy Practice

The results of this study have the following implications for occupational therapy practice:

- Nearly two-thirds of the participants in this sample reported a high level of perceived participation. However, more than a third of participants with predominantly mild strokes failed to report perceived successful participation, indicating that rehabilitation intervention is crucial to support reintegration into community and everyday occupations.
- Clinicians should not assume that people with mild to moderate stroke will not experience restrictions in participation. Assessment of perceived participation is necessary as a follow-up when people return to the community. This assessment should also include potential contributing factors to perceived participation, such as reported retention of prestroke activities and community reintegration.
- Actual doing of wanted and needed activities and a sense of being integrated into the community are essential elements of perceived participation 6 mo after stroke. These components can be targets for clinical intervention to improve participation.
- This study points to the need for occupational therapy practitioners to measure and design interventions focused on participation even in people who are able to perform self-care and do not appear to need traditional, medical model–defined rehabilitation services. ▲

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