

Does the frequency of participation change after stroke and is this change associated with the subjective experience of participation?

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ORIGINAL ARTICLE

Does the Frequency of Participation Change After Stroke and Is This Change Associated With the Subjective Experience of Participation?



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Abstract

Objective: To investigate changes in the frequency of participation 6 months poststroke compared with prestroke; and to establish whether the change is associated with participation restrictions and satisfaction with participation 6 months poststroke.

Design: Inception cohort study. Prestroke frequency of participation was measured retrospectively in the first week poststroke. Frequency, participation restrictions, and satisfaction with participation were assessed 6 months poststroke.

Setting: General hospitals and home residences.

Participants: Patients with stroke (N = 325; 65.5% men; mean age, 66.9 ± 12.2y) admitted to 1 of 6 participating general hospitals.

Interventions: Not applicable.

Main Outcome Measure: Utrecht Scale for Evaluation of Rehabilitation-Participation (0–100), which consists of 3 scales: frequency, restrictions, and satisfaction. The frequency scale consists of 2 parts: vocational activities (work, volunteer work, education, household activities) and leisure and social activities.

Results: Vocational activities showed a large decrease (effect size: 0.6) poststroke; leisure and social activities showed a small decrease (effect size: 0.13) poststroke. In multiple regression analyses, both the frequency of participation in vocational activities 6 months poststroke and the decrease in vocational activities compared with before the stroke were significantly associated with the participation restrictions experienced and satisfaction with participation after controlling for age, sex, level of education, dependency in activities of daily living, cognitive functioning, and presence of depressive symptoms. The presence of depressive symptoms showed the strongest association with the subjective experience of participation.

Conclusions: The frequency of participation decreased after a stroke, and this decrease was associated with participation restrictions experienced and satisfaction with participation. Resuming vocational activities and screening and, if applicable, treatment of depressive symptoms should be priorities in stroke rehabilitation.

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Stroke is a major health problem worldwide.¹ The various physical, cognitive, behavioral, and emotional problems associated with stroke can negatively affect participation in daily life.²⁻⁷ Because participation is one of the main priorities in rehabilitation care, it is

important to measure rehabilitation outcomes in terms of participation.

In the *International Classification of Functioning, Disability and Health* (ICF), participation in daily life is defined as involvement in a life situation.⁸ Participation is a broad concept with both an objective and a subjective dimension.⁹⁻¹² The objective dimension concerns observable actions and behaviors

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(eg, amount or frequency of participation), whereas the subjective dimension reflects someone's experiences and feelings about participation (eg, restrictions, satisfaction).^{9,12} The objective and subjective dimensions are only weakly related; therefore, it is important to measure both.¹¹⁻¹³

Several studies have investigated poststroke participation by assessing only the objective dimension or both the objective and subjective dimension, using various measures.^{5,7,13-18} Because one of the main goals of rehabilitation care is to minimize participation restrictions caused by stroke and to help patients return to their preinjury level of participation, it is important to assess a person's prestroke functioning.¹⁷ Of the studies that investigated participation, only a few focused on both pre- and poststroke participation. These studies found a decrease in the frequency of participation poststroke compared with before the stroke.^{5,7,14,15,19}

It is likely that such a decrease is associated with participation restrictions that patients experienced and less satisfaction with participation poststroke. To our knowledge, however, this association has not been investigated previously. It is unknown whether subjective experiences of poststroke participation are more strongly associated with the frequency of participation poststroke or with the difference between the prestroke and poststroke frequency of participation.

The overall aims of this study were therefore to investigate whether a stroke contributes to changes in the frequency of participation and whether a change in the frequency of participation after stroke is associated with the restrictions experienced and satisfaction with participation. This association was corrected for age, sex, level of education, dependency in activities of daily living (ADL), cognitive functioning, presence of depressive symptoms, and poststroke frequency of participation because previous studies found associations between these variables and participation.^{5-7,13,14,16} We hypothesized that patients would participate less after a stroke and that both restrictions experienced and satisfaction with participation would be associated with the decrease in the frequency of participation.

Methods

Design and procedure

The present study is part of the longitudinal cohort study called Restore4Stroke.²⁰ The present study used data collected at stroke onset and 6 months poststroke. Patients at the stroke units of 6 general hospitals in The Netherlands were invited to participate.²⁰ The first assessment was conducted during the first week poststroke. Information on stroke-related factors was collected from medical files by the nurse practitioner of the hospital. Information on demographic factors and prestroke frequency of participation were obtained from the patient or family members.

At 6 months poststroke, a follow-up assessment was conducted by a trained research assistant at the patient's place of residence.

List of abbreviations:

| | |
|--------------------|--|
| ADL | activities of daily living |
| BI | Barthel Index |
| ICF | International Classification of Functioning, Disability and Health |
| USER-Participation | Utrecht Scale for Evaluation of Rehabilitation-Participation |

The study was approved by the medical ethics committee of the St Antonius Hospital in Nieuwegein (The Netherlands) and by the medical ethics committees of the other participating hospitals. All patients gave informed consent.²⁰

Participants

Patients were enrolled in the Restore4Stroke Cohort study within the first 7 days after stroke. Patients were included if they had suffered a stroke (ischemic or intracerebral hemorrhagic lesion) and were at least 18 years of age. Patients were excluded if they had another serious condition that could interfere with the study outcome; had been dependent in basic ADL before the stroke occurred, defined as a Barthel Index (BI)²¹ score of ≤ 17 ; had insufficient command of the Dutch language, based on clinical judgment; or had suffered cognitive decline prior to the stroke, defined by a score of ≥ 1 on the Heteroanamnesis List Cognition.²² Our analyses also excluded patients with incomplete participation data.

Measures

Dependent variable: participation

Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) is a self-report questionnaire consisting of 3 scales: frequency of participation, participation restrictions experienced, and satisfaction with participation. The frequency scale measures the objective level of participation, whereas the restrictions and satisfaction scales provide information about the subjective rating of participation. It is a valid and reliable generic instrument to measure participation and has been used in patients with stroke in previous studies.^{11,13,23}

The frequency scale consists of 11 items. Part A (vocational activities) measures the number of hours in a regular week spent on paid work, unpaid work, education, and housekeeping, on a scale from 0 (none at all) to 5 (≥ 36 h). The 7 items in part B (leisure and social activities) measure the frequency of sports and physical exercise, going out, making day trips, leisure activities at home, visiting family or friends, receiving visits from family or friends, and contact by computer or telephone during the last 4 weeks. The item scores range from 0 (not at all) to 5 (≥ 19 times).

The restrictions scale consists of 11 items on difficulties experienced with vocational, leisure, and social activities. This scale asks patients to rate the severity of the restrictions of participation caused by the stroke. Scores range from 0 (not possible to perform) to 3 (performed without difficulty). A score of not applicable is recorded if the patient does not perform the activity for reasons other than stroke.

The satisfaction scale consists of 10 items about satisfaction with vocational, leisure, and social activities. Scores range from 0 (very dissatisfied) to 4 (very satisfied). Not applicable can be chosen in 2 items: if patients do not perform any vocational activities or if they do not have a partner.

All scales yield a sum score ranging from 0 to 100, with a higher score indicating a higher level of participation, meaning a higher frequency, less restrictions experienced, and more satisfaction.^{11,20} The frequency scale of the USER-Participation was used within the first week after stroke onset to collect information about the patients' frequency of participation in the 4 weeks before the stroke. After 6 months, all 3 scales were administered.

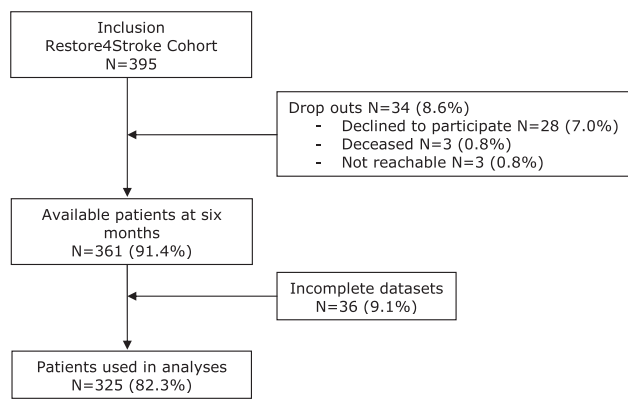


Fig 1 Flowchart of participating patients.

Independent variables: demographics and stroke-related factors

Information about sex, age, and level of education were collected. Level of education was classified according to criteria developed by Verhage²⁴ and dichotomized into low (up to completed secondary education) or high (completed university of professional education or higher).²⁵ Information on the type of stroke and the hemisphere involved were obtained from medical charts. The severity of the stroke was assessed with the National Institute of Health Stroke Scale,²⁶ administered 4 days poststroke.

ADL dependency was measured with the BI, which includes items such as personal care, dressing and undressing, and climbing stairs. This measure is valid and reliable for patients with stroke.^{21,27} Scores range from 0 to 20, and patients with a score ≤ 17 were considered dependent. The BI was administered at 4 days and 6 months poststroke. The analyses used the BI score at 6 months.

Cognitive functioning was assessed with the Montreal Cognitive Assessment,²⁸ a brief cognitive screening tool suitable for use in patients with stroke. The measure is valid and reliable. Scores range from 0 to 30, and patients with a score ≥ 26 are considered to have no cognitive problems.^{28,29}

The depression subscale of the Hospital Anxiety and Depression Scale was used to assess the presence of depressive symptoms.³⁰ Scores range from 0 to 21, and patients with a score ≥ 8 are considered to experience depressive symptoms.^{30,31}

Statistical analyses

All analyses of data were conducted with IBM SPSS Statistics 20.^a A significance level of .05 was established. Descriptive statistics were used to provide information about the study population and outcome variables. Variables were checked for the assumption of normality, using scatterplots and quantile-quantile plots. One-way analyses of variance and chi-square tests were performed to evaluate differences in baseline characteristics between patients and dropouts and patients with incomplete datasets. Paired *t* tests were used to determine significant differences in the frequency of participation before and after stroke. Effect sizes were calculated to examine which part of the frequency scale (ie, vocational or leisure and social) contributed most to a

Table 1 Patient characteristics (n = 395)

| Characteristic | Patients (N = 325) | Dropouts and Patients With Incomplete Datasets (n = 70) |
|---|--------------------|---|
| Female sex | 112 (34.5) | 27 (38.6) |
| Age (y) | 66.9 \pm 12.2 | 65.4 \pm 14.7 |
| High education level* | 90 (27.7) | 12 (20.3) [†] |
| Ischemic stroke | 302 (92.9) | 66 (94.3) |
| Stroke hemisphere (n = 321) | | |
| Left | 124 (38.6) | 34 (50.0) [‡] |
| Right | 143 (44.6) | 24 (35.3) |
| Cerebellum or brainstem | 54 (16.8) | 10 (14.7) |
| Severity of stroke (NIHSS) [§] | 2.5 \pm 2.8 | 4.1 \pm 4.5 |
| No stroke symptoms (NIHSS score 0) | 81 (24.9) | 13 (18.6) |
| Minor stroke symptoms (NIHSS scores 1–4) | 188 (57.9) | 33 (47.1) |
| Moderate stroke symptoms (NIHSS scores 5–12) | 52 (16.0) | 19 (27.2) |
| Moderate to severe stroke symptoms (NIHSS score ≥ 13) | 4 (1.2) | 5 (7.1) |
| Destination after discharge from hospital | | |
| Home | 236 (72.6) | 42 (60.0) |
| Rehabilitation center | 43 (13.2) | 16 (22.9) |
| Nursing home | 46 (14.2) | 12 (17.1) |
| Living situation 6mo poststroke | | |
| Home | (309) 95.1 | NA |
| Rehabilitation center | (1) 0.3 | NA |
| Nursing home | (15) 4.6 | NA |
| ADL (BI) | | |
| 4d poststroke [§] | 17.1 \pm 4.5 | 15.5 \pm 6.0 |
| 6mo poststroke | 19.4 \pm 1.5 | NA |
| Cognitive functioning 6mo poststroke (MoCA) | 24.6 \pm 3.5 | NA |
| Depression 6mo poststroke (HADS-D) | 4.7 \pm 4.0 | NA |

NOTE. Values are n (%) or mean \pm SD.

Abbreviations: HADS-D, Hospital Anxiety and Depression Scale depression subscale; MoCA, Montreal Cognitive Assessment; NA, not applicable; NIHSS, National Institutes of Health Stroke Scale.

* Completed university of professional education or higher.

[†] n = 59.

[‡] n = 68.

[§] *P* < .05.

change in the frequency of participation.³² Wilcoxon signed-rank tests were used to analyze differences for each item on the frequency scale between the prestroke situation and 6 months poststroke.

Two backward multiple linear regression analyses were performed to investigate the relation between the poststroke frequency of participation and the change in this frequency after stroke on the one hand, and restrictions experienced and satisfaction about participation on the other hand, controlling for various covariates (ie, age, sex, level of education, ADL dependency, cognitive

Table 2 Mean scores on the 3 scales of USER-Participation (N=325) and calculated effect sizes

| Scale | Before the Stroke | 6mo Poststroke | Difference | Effect Size |
|---------------------------------------|-------------------|----------------|------------|-------------|
| Total score on the frequency scale | 33.4±10.7 | 28.6±10.8 | -4.8±10.8* | .45 |
| Part A: work and household activities | 21.0±12.6 | 13.4±9.9 | -7.6±11.4* | .60 |
| Part B: leisure and social activities | 45.9±16.2 | 43.8±16.7 | -2.1±17.5† | .13 |
| Restrictions scale | NA | 78.0±21.0 | NA | NA |
| Satisfaction scale | NA | 66.7±17.2 | NA | NA |

NOTE. The scores on the frequency scale are shown both for the total score and for individual parts A and B. Values are mean ± SD or as otherwise indicated.

Abbreviation: NA, not applicable.

* $P < .001$

† $P < .05$.

functioning, presence of depressive symptoms). The significance level to remove variables from the model was set at $P > .10$.

Results

A total of 395 patients were enrolled in the Restore4Stroke study. As shown in figure 1, datasets of 325 patients were complete and were used in the analyses. Of the 36 incomplete datasets, 3 were incomplete because of aphasia. Patient characteristics are displayed in table 1. There were no significant differences in terms of baseline characteristics between patients and dropouts and patients with incomplete datasets. However, dropouts and patients with incomplete datasets were significantly more likely to have a higher score on the National Institutes of Health Stroke Scale and BI 4 days poststroke (see table 1).

Mean scores of the USER-Participation are displayed in table 2. In general, the frequency score for vocational and leisure and social activities on the USER-Participation scale had decreased significantly 6 months after the stroke compared with before the stroke (-4.8 ± 10.8 , $P < .001$). However, the change score ranged from -36.1 to 21.8 , indicating that some patients scored higher on the frequency scale after their stroke than before it (32.9%). Furthermore, 0.9% of the patients showed no change, and 66.2% of the patients showed a decrease in their frequency of participation. The frequency of vocational activities (part A) decreased more than the frequency of leisure and social activities (part B) (see table 2). The frequency of vocational activities decreased in 59.4% of the patients, remained unchanged in 27.4%, and increased in 13.2%. The frequency of leisure and social activities decreased in 49.5% of the patients, remained unchanged in 8%, and increased in 42.5%.

Scores on the 4 individual items in part A of the frequency scale showed a significant reduction 6 months poststroke compared with the prestroke situation; the largest changes were found for performing paid work and household activities. The individual items on leisure activities (part B) did not show significant changes poststroke. Two of the social activity items (ie, visiting family or friends, contact by telephone or computer) showed significant decreases poststroke (table 3).

Experienced restrictions and satisfaction

The mean scores for experienced restrictions and satisfaction at 6 months poststroke were 78.0 ± 21.0 and 66.7 ± 17.2 , respectively. More than 50% of the patients mentioned restrictions regarding paid work (67.2%), sports and physical exercise (56.5%),

household tasks (54.9%), daytrips (51.8%), and going out (51.4%). More than 40% of the patients were not satisfied with their frequency of daytrips (50.8%), sports and physical exercise (49.8%), going out (49.8%), outdoor mobility (41.2%), and household tasks (40.1%).

Relation between objective and subjective participation

The changes in frequency for the individual parts of the frequency scale (see table 2) indicate that the decrease was greater and the effect size was larger for part A (vocational activities). Therefore, the linear regression analyses were performed with the 2 parts of the frequency scale as separate independent variables.

Experienced restrictions were associated with the frequency of poststroke vocational activities but also with the change in this frequency (table 4). Being a woman, ADL dependency, presence of depressive symptoms, poststroke vocational activities, and change in vocational activities together explained 44% of the variance of participation restrictions experienced 6 months poststroke.

Satisfaction with participation was also associated with the poststroke frequency of vocational activities and with the change in the frequency of vocational activities (table 5). Being a woman, presence of depressive symptoms, poststroke vocational activities, and change in vocational activities together explained 38.8% of the variance of satisfaction with participation 6 months poststroke.

An analysis of the total score on the frequency scale, rather than of parts A and B separately, yielded somewhat different results. The frequency of poststroke participation, but not the change in this frequency, was significantly associated with participation restrictions and satisfaction with participation (both $P < .001$).

Discussion

We hypothesized that patients would participate less after a stroke and that a decrease in the frequency of participation would be associated with experiencing more restrictions and less satisfaction. The first hypothesis was confirmed: on average, patients participated substantially less in vocational activities and slightly less in leisure and social activities 6 months poststroke. The second hypothesis was partially confirmed. Both the change in frequency of vocational activities and the poststroke frequency of

Table 3 Frequency scale of USER-Participation: hours and number of times for each item before stroke and 6 months poststroke (N=325)

| Part A: Work and Household Activities | | | |
|---|----------------------------|-------------------------|-------|
| Hours Spent Per Week, Per Item | Patients Before Stroke (%) | Patients Poststroke (%) | P* |
| Paid work | | | |
| None at all | 61.7 [†] | 76.0 | <.001 |
| 1–24h | 10.5 [†] | 15.1 | |
| ≥25h | 27.8 [†] | 8.9 | |
| Unpaid work | | | |
| None at all | 67.1 | 77.8 | <.001 |
| 1–24h | 31.1 | 21.6 | |
| ≥25h | 1.8 | 0.6 | |
| Education | | | |
| None at all | 94.1 [‡] | 97.5 [‡] | .011 |
| 1–24h | 5.3 [‡] | 2.5 [‡] | |
| ≥25h | 0.6 [‡] | 0 [†] | |
| Household activities | | | |
| None at all | 4.9 | 10.8 | <.001 |
| 1–24h | 79.4 | 82.4 | |
| ≥25h | 15.7 | 6.8 | |
| Part B: Leisure and Social Activities | | | |
| No. of Times Engaged in Each Item in the Last 4wk | Patients Before Stroke (%) | Patients Poststroke (%) | P* |
| Sports and physical exercise | | | |
| Not at all | 21.4 [§] | 16.6 | .047 |
| 1–10 times | 48.2 [§] | 48.3 | |
| ≥11 times | 30.4 [§] | 35.1 | |
| Going out | | | |
| Not at all | 34.0 [†] | 38 [†] | .612 |
| 1–10 times | 64.5 [†] | 60.8 [†] | |
| ≥11 times | 1.5 [†] | 1.2 [†] | |
| Daytrips | | | |
| Not at all | 21.6 [†] | 25.4 [§] | .231 |
| 1–10 times | 71.6 [†] | 67.8 [§] | |
| ≥11 times | 6.8 [†] | 6.8 [§] | |
| Leisure activities at home | | | |
| Not at all | 11.1 [†] | 12.0 | .353 |
| 1–10 times | 41 [†] | 44.6 | |
| ≥11 times | 47.9 [†] | 43.4 | |
| Visiting family or friends | | | |
| Not at all | 5.9 [§] | 10.3 | .027 |
| 1–10 times | 81.1 [§] | 79.7 | |
| ≥11 times | 13 [§] | 10.0 | |
| Receiving visitors | | | |
| Not at all | 3.1 [§] | 5.8 | .197 |
| 1–10 times | 78.7 [§] | 79.1 | |
| ≥11 times | 18.2 [§] | 15.1 | |
| Contact by computer or telephone | | | |
| Not at all | 4.6 [§] | 8.6 | <.001 |
| 1–10 times | 44.3 [§] | 52.3 | |
| ≥11 times | 51.1 [§] | 39.1 | |

NOTE. The answer categories of the USER-Participation frequency scale are combined into 3 categories in this table.

* P values based on Wilcoxon signed-rank test; all categories per item combined.

[†] n=324.

[‡] n=322.

[§] n=323.

^{||} n=321.

Table 4 Linear regression analysis: variables explaining restrictions of participation experienced 6 months poststroke

| Variable | β | Std β | P |
|--|---------|-------------|-------|
| Constant | 55.14 | | <.001 |
| Demographic factors | | | |
| Age | | | — |
| High education level | | | — |
| Female sex | −4.27 | −.10 | .022 |
| Stroke-related factors* | | | |
| Cognitive functioning (MoCA) | | | — |
| ADL dependency (BI) | −19.55 | .27 | <.001 |
| Presence of depressive symptoms (HADS-D) | −15.68 | −.32 | <.001 |
| Participation (USER-Participation) | | | |
| Change in vocational frequency | .23 | .13 | .005 |
| Change in leisure and social frequency | | | — |
| Vocational frequency poststroke* | .57 | .27 | <.001 |
| Leisure and social frequency poststroke* | .10 | .08 | NS |

Abbreviations: β , unstandardized regression coefficient; HADS-D, Hospital Anxiety and Depression Scale depression subscale; MoCA, Montreal Cognitive Assessment; NS, not significant; Std β , standardized regression coefficient; —, variables removed from the analysis using a backward procedure.

* Six months poststroke.

vocational activities were significantly associated with subjective experiences. However, change in frequency and the poststroke frequency of leisure and social activities were not significantly associated with subjective experiences. This is one of the first

Table 5 Linear regression analysis: variables explaining satisfaction about participation 6 months poststroke

| Variable | β | Std β | P |
|--|---------|-------------|-------|
| Constant | 64.27 | | <.001 |
| Demographic factors | | | |
| Age | | | — |
| High education level | | | — |
| Female sex | −3.35 | −.09 | .035 |
| Stroke-related factors* | | | |
| Cognitive functioning (MoCA) | | | — |
| ADL dependency (BI) | | | — |
| Presence of depressive symptoms (HADS-D) | −18.62 | −.46 | <.001 |
| Participation (USER-Participation) | | | |
| Change in vocational frequency | .16 | .11 | .019 |
| Change in leisure and social frequency | | | — |
| Vocational frequency poststroke* | .38 | .22 | <.001 |
| Leisure and social frequency poststroke* | .09 | .09 | NS |

Abbreviations: β , unstandardized regression coefficient; HADS-D, Hospital Anxiety and Depression Scale depression subscale; MoCA, Montreal Cognitive Assessment; NS, not significant; Std β , standardized regression coefficient; —, variables removed from the analysis using a backward procedure.

* Six months poststroke.

studies to show not only that patients with stroke experience a decrease in participation after stroke, but also that this decrease is independently related to the subjective experience of participation.

Leisure and social activities contributed less to the decrease on the frequency scale than vocational activities. The former types of activity are probably easier to adjust to. For example, sports can be performed with the same frequency but with less intensity. Such adjustments are more difficult to make in paid or unpaid work because of social and other pressures.

Approximately one third of our study population showed a stable or even increased total frequency of participation poststroke. If a decrease regarding one part of the scale (eg, working fewer hours) is compensated by an increase regarding other items (eg, increasing social activities), this change leads to a stable or even increased total frequency of participation poststroke compared with the prestroke situation. Besides, for some patients, experiencing a mild stroke might be a wake-up call to change their lifestyle and become more active. Stimulating patients to be active is also a common goal of stroke rehabilitation. A study by Edwards et al¹⁴ found that 26% of the patients with mild stroke did not show a lower activity level after a stroke compared with before stroke, which is only slightly below the percentage found in our study.

We found that 67.2% of our study population experienced restrictions in performing paid work, whereas other studies reported fewer restrictions regarding this item, ranging from 12% to 45.2%.^{13,16,33} This discrepancy might be explained by the timing of our follow-up measurement, (ie, 6mo poststroke) versus 12 months poststroke in the study by Eriksson et al¹⁶ or by different cutoff points used to dichotomize this variable in these studies.^{13,16} The finding that more restrictions were reported for vocational activities than for social activities is also in agreement with a previous study.³³

In regard to satisfaction, not only was the total score on this scale similar to the findings of previous studies, but the items about which patients were dissatisfied were also the same.¹³ Patients were the least dissatisfied about their social contacts, whereas more than one third of the patients were dissatisfied with vocational activities.^{5,13,16}

The presence of depressive symptoms showed the strongest association with the experienced restrictions and degree of satisfaction in our study, based on a comparison of the standardized β weights in tables 4 and 5. Other studies also reported the importance of the presence of depressive symptoms in explaining experienced restrictions or satisfaction.^{5,13,14,16} It remains unclear, however, whether it is the depressive symptoms that cause a more unfavorable subjective experience of participation or the other way around.

Study strengths

One of the strengths of this study was the large study population, which was recruited at 6 different hospitals. The prestroke frequency of participation was assessed 1 week poststroke. Although this is a retrospective assessment, the short time after the stroke may make this assessment more reliable than the retrospective assessments of prestroke participation 6 to 12 months poststroke used in other studies.^{5,7,14,15,19} Furthermore, the USER-Participation is a measure assessing multiple dimensions of participation with similar items. Previous studies that assessed both objective and subjective participation used different measures with partly diverging items, hampering the comparison between objective and subjective participation.

Study limitations

A possible limitation of this study is the use of a self-report measure to assess objective participation. Results could have been different if actual participation had been measured in other ways (eg, by observation or a Global Positioning System).³⁴ However, observation is not a feasible method, and leisure or social activities performed at home (eg, receiving visitors) cannot be measured by a Global Positioning System. A second limitation is that the patient's family was allowed to fill out the frequency scale at the first assessment if necessary, which could have led to bias. However, given that this questionnaire measures the objective dimension of participation, this was not expected to produce different answers.

Finally, the proportion of patients in our study who suffered an ischemic stroke (92.9%) was higher than we expected based on population figures (85%).^{35,36} One possible explanation for this is that hemorrhagic lesions are generally more severe,³⁷ which may result in greater difficulty understanding the instructions for participating in the study and not being able to provide informed consent within 1 week after the event. Another possible explanation is that patients with hemorrhagic stroke are more often treated in university hospitals, whereas our study included patients from general hospitals.

Future research

Our findings indicate a moderate association between the objective and subjective experience of participation poststroke. The next step would be to study the course of this association over time because a change in the association between objective and subjective participation might occur over time as patients with stroke adapt to their situation in the long term.

Conclusions

The findings of the present study imply that even in a hospital-based sample in which most patients had no or minor stroke symptoms and function independently in ADL, having a stroke is associated with decreased participation and participation problems. These findings underline the relevance of rehabilitation for this group. Participation is a complex topic comprising different elements regarding various activities. Administration of the USER-Participation instrument can be useful to identify participation problems and establish rehabilitation treatment goals regarding participation.

Depressive symptoms were associated with participation problems, pointing to the value of assessing depressive symptoms in rehabilitation. Poststroke rehabilitation care should focus on a combination of participation resumption poststroke, especially in regard to work and household activities and treatment of depressive symptoms, if applicable.

Supplier

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Keywords

Rehabilitation; Social participation; Stroke

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References

1. World Health Organization. The world health report 2003: shaping the future. Geneva: World Health Organization; 2003.
2. Hendricks HT, van Limbeek J, Geurts AC, Zwarts MJ. Motor recovery after stroke: a systematic review. *Arch Phys Med Rehabil* 2002;83:1629-37.
3. Lai SM, Studenski S, Duncan PW, Perera S. Persisting consequences of stroke measured by the Stroke Impact Scale. *Stroke* 2002;33:1840-4.
4. Leśniak M, Bak T, Czepiel W, Seniów J, Członkowska A. Frequency and prognostic value of cognitive disorders in stroke patients. *Dement Geriatr Cogn Disord* 2008;26:356-63.
5. Hartman-Maeir A, Soroker N, Ring H, Avni N, Katz N. Activities, participation and satisfaction one-year post-stroke. *Disabil Rehabil* 2007;29:559-66.
6. Desrosiers J, Demers L, Robichaud L, Vincent C, Belleville S, Ska B. Short-term changes in and predictors of participation of older adults after stroke following acute care or rehabilitation. *Neurorehabil Neural Repair* 2008;22:288-97.
7. Hildebrand M, Brewer M, Wolf T. The impact of mild stroke on participation in physical fitness activities. *Stroke Res Treat* 2012;2012:548682.
8. World Health Organization. Towards a common language for functioning, disability and health ICF. Geneva: World Health Organization; 2002.
9. Dijkers MP. Issues in the conceptualization and measurement of participation: an overview. *Arch Phys Med Rehabil* 2010;91(9 Suppl):S5-16.
10. Van der Zee CH, Kap A, Mishre RR, Schouten EJ, Post MW. Responsiveness of four participation measures to changes during and after outpatient rehabilitation. *J Rehabil Med* 2011;43:1003-9.
11. Post MW, Van der Zee CH, Hennink J, Schafrat CG, Visser-Meily JM, Van Berlekom SB. Validity of the Utrecht Scale for Evaluation of Rehabilitation-Participation. *Disabil Rehabil* 2012;34:478-85.
12. Brown M, Dijkers MP, Gordon WA, Ashman T, Charatz H, Cheng Z. Participation objective, participation subjective a measure of participation combining outsider and insider perspectives. *J Head Trauma Rehabil* 2004;19:459-81.
13. Van der Zee CH, Visser-Meily JM, Lindeman E, Kapelle LJ, Post MW. Participation in the chronic phase of stroke. *Top Stroke Rehabil* 2013;20:52-61.
14. Edwards DF, Hahn M, Baum C, Dromerick AW. The impact of mild stroke on meaningful activity and life satisfaction. *J Stroke Cerebrovasc Dis* 2006;15:151-7.
15. Appelros P. Characteristics of the Frenchay Activities Index one year after a stroke: a population-based study. *Disabil Rehabil* 2007;29:785-90.
16. Eriksson G, Aasnes A, Tistad M, Guidetti S, Von Koch L. Occupational gaps in everyday life one year after stroke and the association with life satisfaction and impact of stroke. *Top Stroke Rehabil* 2012;19:244-55.
17. Holbrook M, Skilbeck CE. An activities index for use with stroke patients. *Age Ageing* 1983;12:166-70.
18. Gadidi V, Katz-Leurer M, Carmeli E, Bornstein NM. Long-term outcome poststroke: predictors of activity limitation and participation restriction. *Arch Phys Med Rehabil* 2011;92:1802-8.
19. Drummond A. Leisure activity after stroke. *Int Disabil Studies* 1990;12:157-60.

20. Van Mierlo ML, Van Heugten CM, Post MW, Lindeman E, De Kort PL, Visser-Meily JM. A longitudinal cohort study on quality of life in stroke patients and their partners: Restore4Stroke Cohort. *Int J Stroke* 2014;9:148-54.
21. Collin C, Wade DT, Davies S, Horne V. The Barthel ADL Index: a reliability study. *Int Disabil Stud* 1988;10:61-3.
22. Meijer R, van Limbeek J, de Haan R. Development of the stroke-unit discharge guideline. Choice of assessment instruments for prediction in the subacute phase post-stroke. *Int J Rehabil Res* 2006;29:1-8.
23. Van der Zee CH, Priesterbach AR, Van der Dussen L, et al. Reproducibility of three self-report participation measures: the ICF Measure of Participation and Activities Screener, the Participation Scale, and the Utrecht Scale for Evaluation of Rehabilitation-Participation. *J Rehabil Med* 2010;42:752-7.
24. Verhage F. [Intelligence and age: study with Dutch people from age 12 to 77] [Dutch]. Assen: Van Gorcum; 1964.
25. Passier PE, Visser-Meily JM, Van Zandvoort MJ, Post MW, Rinkel GJ, Van Heugten C. Prevalence and determinants of cognitive complaints after aneurysmal subarachnoid hemorrhage. *Cerebrovasc Dis* 2010;29:557-63.
26. Brott T, Adams HP, Olinger CP, et al. Measurements of acute cerebral infarction: a clinical examination scale. *Stroke* 1989;20:864-70.
27. Hsueh IP, Lin JH, Jeng JS, Hsieh CL. Comparison of the psychometric properties of the functional independence measure, 5 item Barthel Index, and 10 item Barthel Index in patients with stroke. *J Neurol Neurosurg Psychiatry* 2002;73:188-90.
28. Nasreddine ZS, Phillips NA, Bedirian V, et al. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *J Am Geriatr Soc* 2005;53:695-9.
29. Pendlebury ST, Cuthbertson FC, Welch SJ, Mehta Z, Rothwell PM. Underestimation of cognitive impairment by Mini-Mental State Examination versus the Montreal Cognitive Assessment in patients with transient ischemic attack and stroke: a population-based study. *Stroke* 2010;41:1290-3.
30. Zigmond AS, Snaith RP. The Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand* 1983;67:361-70.
31. Bjelland I, Dahl AA, Haug TT, Neckelmann D. The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *J Psychosom Res* 2002;52:69-77.
32. Cohen J. A power primer. *Psychol Bull* 1992;112:155-9.
33. D'Alisa S, Baudo S, Mauro A, Miscio G. How does stroke restrict participation in long-term post-stroke survivors? *Acta Neurol Scand* 2005;112:157-62.
34. McCluskey A, Ada L, Dean CM, Vargas J. Feasibility and validity of a wearable GPS device for measuring outings after stroke. *ISRN Rehabilitation* 2012;2012:823180.
35. Roger VL, Go AS, Lloyd-Jones DM, et al. Heart disease and stroke statistics—2012 update: a report from the American Heart Association. *Circulation* 2012;125:e2-220.
36. Intercollegiate Stroke Working Party. National clinical guideline for stroke. 4th ed. London: Royal College of Physicians; 2012.
37. Andersen KK, Olsen TS, Dehlendorff C, Kammersgaard LP. Hemorrhagic and ischemic strokes compared: stroke severity, mortality, and risk factors. *Stroke* 2009;40:2068-72.