

Participation in daily life activities at two months after stroke predicts long-term health-related quality of life

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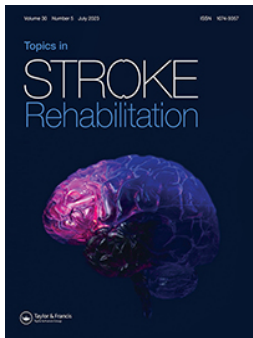
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Participation in daily life activities at two months after stroke predicts long-term health-related quality of life

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ABSTRACT

Background: After stroke, many patients experience problems with participation in daily activities. Improving participation is the main goal in stroke rehabilitation. However, the longitudinal relationship between participation and health-related quality of life (HRQoL) remains unclear.

Objectives: This study aimed to examine (1) the predictive value of participation at two months on long-term HRQoL and (2) the longitudinal relationship between participation and HRQoL.

Methods: In this multicenter, prospective cohort study, patients were assessed at two and 12 months after stroke. Participation was measured with the Restriction subscale of the Utrecht Scale for Evaluation of Rehabilitation – Participation. HRQoL was assessed with the three-level version of the EuroQoL five dimensions questionnaire index score.

Results: This study included 291 patients. Mean age was 66.6 ± 12.4 years, 64.3% were male and mean National Institutes of Health Stroke Scale (NIHSS) was 2.5 ± 2.9 . Multivariable linear regression, adjusted for demographic characteristics, stroke characteristics, physical and cognitive impairment, showed that a higher level of participation at two months correlated with a higher HRQoL at one year ($B = .004$; 95% CI $-.002-.005$). Patients whose participation improved had a greater increase in HRQoL, compared to patients without improvement ($0.080 \pm .21$ versus $-.054 \pm .21$; $p < .001$).

Conclusions: The level of participation at two months post-stroke predicts HRQoL at one year. Improvement in participation during the first year after stroke is associated with improvement in HRQoL. We recommend including the assessment of participation in daily activities at follow-up visits.

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Introduction

The global burden of stroke is high: studies have estimated a prevalence of more than 80 million stroke survivors worldwide in 2016.¹ A substantial proportion of patients with stroke suffer from impairments, such as physical disability, cognitive problems and emotional complaints.^{1–4}

Participation is defined as a person's "involvement in a life situation," including daily activities and social roles.⁵ After stroke, large numbers of patients experience restrictions of participation, for example in household activities, social activities and return to work.⁶ While the level of participation tends to improve over time, restrictions might

persist in the long term: many patients report participation restrictions at five years after stroke.^{7–9}

Participation restrictions are associated with symptoms of depression, cognitive problems, immobility and activity limitations.^{10–12} In addition, a lower level of participation restrictions is associated with environmental factors such as the amount of social support, being in a relationship or not, and access to appropriate health and social services.^{13,14}

In clinical practice, participation restrictions after stroke are illustrative of the consequences of stroke on a patient's daily functioning. Improving a patient's level of participation is the main goal of

stroke rehabilitation.¹⁵ Therefore, the assessment of participation restrictions facilitates referral for rehabilitation treatment based on patient-centered needs.^{15–17} The relevance of assessing participation in stroke care could be even greater if participation early after stroke predicts long-term health-related quality of life (HRQoL), and if an improvement in participation correlates with an improvement in HRQoL. The last is of great clinical importance, since the primary goal of rehabilitation therapy is to improve the level of participation over time, aiming to improve patients' long-term quality of life. If quality of life would be better in patients with an improvement in participation, this would underline the importance of rehabilitation therapy that could achieve this improvement. While this relationship might be expected, it has not been demonstrated as such in previous studies.

Multiple studies have examined the cross-sectional association between participation and HRQoL at various time points.^{18,19} Most of these studies demonstrated that participation and HRQoL are related, but not all findings were consistent, as the magnitude of the correlations ranged from “no association” to a “strong association.”^{18,20} While most studies examined the association in a cross-sectional manner, fewer reported on the longitudinal relationship between participation and HRQoL and even less on the predictive value of early participation on long-term HRQoL. One study demonstrated that the level of participation on 3 months and 12 months post-stroke predicts the level of HRQoL on the same time points.²¹ Only one previous study showed that early participation is independently associated with long-term HRQoL and concluded that participation is a modifiable predictor of HRQoL.²² To the best of our knowledge, there have been no studies to examine if an improvement in the level of participation leads to an improvement in HRQoL.

The aims of this study were to examine (1) the predictive value of participation restrictions two months after stroke for HRQoL one year after stroke and (2) the longitudinal relationship between participation and HRQoL after stroke. Our hypotheses were that (1) early participation restrictions were predictive of long-term HRQoL and (2) that participants who showed improvement

in participation in the first year after stroke would show greater improvements in HRQoL compared to those who did not show improvement in participation.

Methods

Design and procedure

The current study is part of a multicenter, prospective, longitudinal cohort study called the Restore4stroke Cohort. This cohort study has been conducted in six general hospitals in the Netherlands and included 395 patients between March 2011 and March 2013.²³ The study complies with the guidelines on ethical principles for medical research involving human subjects from the Declaration of Helsinki and was approved by the Committee on Research involving Human Subjects of the St. Antonius Hospital in Nieuwegein in the Netherlands (R10.41A, February 2011) and by the medical ethics committees of all participating hospitals. Written informed consent was obtained from all participating patients.

In the Restore4stroke Cohort, patients were assessed from stroke onset up to 24 months after stroke. Data obtained within the first week after stroke (T1), two months after stroke (T2) and one year after stroke (T3) were used for the current paper. If patients met the eligibility criteria and provided written informed consent, research nurses extracted demographic and medical information from the medical charts at T1. Data at T2 were obtained by a trained research assistant. The data at T3 were collected by means of questionnaires that were completed by the patients on paper or online. The protocol of the Restore4stroke Cohort has been described in more detail elsewhere.²³ The data that support the findings of this study are available from the corresponding author upon reasonable request. This manuscript conforms to the STROBE guideline for cohort studies.

Participants

Patients were considered eligible when a clinical diagnosis of stroke (either ischemic or hemorrhagic) had been established in the past seven days, as confirmed by a neurologist. The following exclusion criteria were applied: (1) comorbidity

interfering with the study outcomes (e.g. progressive neuromuscular diseases, neurodegenerative diseases or severe psychiatric diseases that substantially influenced the study outcomes), (2) dependence in activities of daily living before the stroke, as defined by a Barthel Index (BI) score of 17 or lower, (3) insufficient command of the Dutch language, based on clinical judgment, and (4) cognitive decline before stroke as defined by a score of one or higher on the Heteroanamnesis List Cognition.²⁴

Patients from the Restore4stroke Cohort were included in the current paper if the following measurements had been completed at T2 and T3: the Restriction subscale of the Utrecht Scale for Evaluation of Rehabilitation – Participation (USER-P Restriction) and the three-level version of the EuroQoL five dimensions questionnaire (EQ-5D-3 L). As the current study is a secondary analysis of the Restore4stroke Cohort, a sample size calculation was not performed for the current paper; details about the sample size calculation of the Restore4stroke Cohort have been published in detail previously.²³

Measures

Demographics and stroke characteristics

At T1, the following demographic characteristics were recorded: sex, age, marital status and level of education. Recorded stroke characteristics included type of stroke and stroke severity. Stroke severity was measured with the National Institutes of Health Stroke Scale (NIHSS). The NIHSS ranges from zero to 42 and a higher score indicates greater severity.²⁵ The Collin and Wade version of the BI was used to measure functional independence in activities of daily living. This version of the BI ranges from zero to 20; a higher score reflects greater independence in activities of daily living.²⁶

At T2, cognitive functioning after stroke was assessed with the Montreal Cognitive Assessment (MoCA). The MoCA includes ten items with a total score ranging from zero to 30, and a higher score indicates better cognitive functioning.²⁷

Participation

At T2 and T3, participation was measured with the USER-P Restriction instrument. The USER-P Restriction instrument was chosen because it is validated to measure the concept of participation in patients rehabilitating after stroke and demonstrated to have a good responsiveness compared to other instruments.^{28–30} The USER-P Restriction examines if a total of 11 subdomains of participation can be performed “independently without difficulty,” “with difficulty,” “with assistance” or “cannot be performed.” The 11 subdomains measured by the USER-P Restriction are the following daily activities: (un)paid work or education, household duties, outdoor mobility, sports or other physical exercise, going out, day trips and other outdoor activities, leisure activities at home, relationship with partner, visits to family or friends, family or friends coming to visit at home and contacting others by phone or computer. The USER-P Restriction compares the current situation with the situation before the stroke for each subdomain. The sum of the items is converted to a 0–100 scale, with a higher score being indicative of fewer restrictions, so a higher level of participation.^{28,29,31}

Health-related quality of life (HRQoL)

At T2 and T3, HRQoL was measured with the EQ-5D-3 L. The EQ-5D-3 L consists of five items, viz. “mobility,” “self-care,” “usual activities,” “pain or discomfort” and “anxiety or depression.” Each item has three levels: “no problems,” “some problems” and “extreme problems.” An index score of the EQ-5D-3 L was obtained using the index score calculator. The index score ranges from –0.329 to 1.000 in Dutch normative populations.³² A lower index score reflects more problems, so a lower HRQoL.^{32,33}

Statistical analysis

All patients from the Restore4stroke Cohort who were excluded from the analyses of this paper were compared with the included patients with regard to demographics, stroke characteristics and data on the MoCA, USER-P Restriction and EQ-5D-3 L index score at T2.

Demographic and stroke characteristics were analyzed using descriptive statistics. Marital status was recorded as being married or not being married. Educational level was dichotomized into “low” (≤ 5) versus “high” (≥ 6 ; i.e. having completed higher professional education or university), based on the Dutch classification system developed by Verhage.³⁴ Stroke type was divided into ischemic and hemorrhagic stroke. Length of hospital admission due to stroke was recorded in days. USER-P Restriction sum scores at T2 and T3, and EQ-5D-3 L index scores at T2 and T3 were analyzed using descriptive statistics.

The association between the predictor of interest, i.e. the USER-P Restriction at T2, and the dependent variable, the EQ-5D-3 L index score at T3, was examined using bivariate linear regression. Bivariate linear regression was also performed for the following covariates: sex, age at stroke, marital status, educational level, type of stroke, NIHSS, BI, length of hospital stay and MoCA score. If the predictor of interest was significantly associated with the dependent variable, a multivariable model was constructed, which was adjusted for the aforementioned covariates. The assumptions of linearity, homoscedasticity, multicollinearity, and normally distributed errors were checked.

Next, the change in the EQ-5D-3 L index scores at T2 and T3 was computed by subtracting scores at T2 from the scores at T3, resulting in a delta (Δ) EQ-5D-3 L index score. A Δ USER-P Restriction score was computed accordingly. A Pearson correlation coefficient was calculated to explore the relationship between Δ EQ-5D-3 L index scores and Δ USER-P Restriction scores. Furthermore, the cohort was divided into two groups: patients with an improvement in USER-P Restriction scores, i.e. an improvement in participation, and patients without improvement in USER-P Restriction scores, i.e. a decline or no change in participation between T2 and T3. Patients with a maximum USER-P Restriction score (100) at T2 were excluded from this analysis, because their score could not improve any further. Since the Δ EQ-5D-3 L index scores were not normally distributed, the differences between

patients with improvement in participation versus no improvement in participation were analyzed for statistical significance using a Mann-Whitney U test.

A p-value of .05 was used to determine statistical significance. IBM SPSS version 25.0 was used for analyses.

Results

A total of 395 patients were included in the original Restore4stroke Cohort study. Of these, 104 patients (26.3%) were excluded from the current study based on missing data at T2 or T3. Patients dropped out because of the following reasons: 11 patients (10.6%) had died, 28 patients (26.9%) refused further participation, 7 patients (6.7%) were lost to follow-up, 5 patients (4.8%) were not able to complete the questionnaires at T2 because of aphasia, 14 patients (13.4%) did not return any of the questionnaires at T2 and/or T3 and 39 patients (37.5%) did return questionnaires at T2 and T3, but did not return a (completed) USER-P Restriction and/or EQ-5D-3 L questionnaire at T2 and/or T3. This resulted in 291 patients (73.7%) being included in the current analyses. Baseline data for included and excluded patients are presented in Table 1. The mean age of the included patients was 66.6 ± 12.4 years, and 64.3% were male.

Table 2 shows the results of the bivariate and multivariable linear regression. Bivariate linear regression demonstrated that a higher USER-P Restriction score at T2 was associated with a significantly higher EQ-5D-3 L index score at T3 (unstandardized beta (B) = .004; 95% confidence interval (95% CI) = .003–.005). With regard to the covariates, lower age, lower NIHSS, higher BI and higher MoCA were associated with significantly higher EQ-5D-3 L index scores in the bivariate linear regression. Multivariable linear regression demonstrated that a higher USER-P Restriction score at T2 remained significantly associated with a higher EQ-5D-3 L index score at T3 (B = .004; 95% CI = .002–.005), after adjustment for sex, age, marital status, educational level, type of stroke, NIHSS, BI, length of hospital stay and MoCA score. With regard to the covariates, marital status and the BI remained associated with a better

Table 1. Baseline characteristics.

	Total group of included patients (<i>n</i> = 291)	Excluded patients (<i>n</i> = 104)	p-value
sex (% male)	64.3	66.3	.722
age in years (mean \pm SD)	66.6 \pm 12.4	70.0 \pm 13.2	.766
marital status (% married)	69.8	65.4	.460
high education level (%)	27.1	24.7	.688
ischemic stroke (%)	92.4	95.2	.578
first stroke (%)	86.3	93.3	.251
Stroke location			
Left hemisphere (%)	112 (38.5)	46 (44.2)	0.420
Right hemisphere (%)	126 (43.3)	41 (39.4)	
Vertebrobasilar (%)	50 (17.2)	14 (13.5)	
Unknown (%)	3 (1.0)	3 (2.9)	
NIHSS (mean \pm SD)	2.5 \pm 2.9	3.6 \pm 3.7	.005
BI (mean \pm SD)	17.2 \pm 4.4	15.8 \pm 5.6	.047
length of hospital stay in days (mean \pm SD)	8.1 \pm 5.4	10.4 \pm 13.2	.002
Discharge destination after hospital admission			
Home (%)	215 (73.9)	63 (60.6)	0.016
Inpatient rehabilitation (%)	76 (26.1)	41 (39.4)	
MoCA at 2 months (mean \pm SD)	23.7 \pm 3.7	22.6 \pm 5.1 ^a	.213
USER-P Restriction at 2 months (mean \pm SD)	72.2 \pm 22.6	77.7 \pm 20.3 ^b	.125
EQ-5D-3 L index score at 2 months (mean \pm SD)	.74 \pm .22	.72 \pm .25 ^c	.810

BI indicates Barthel Index; EQ-5D-3 L, three-level version of the EuroQoL Five Dimensions; MoCA, Montreal Cognitive Assessment; NIHSS, National Institutes of Health Stroke Scale; SD, standard deviation; USER-P Restriction, the Restriction subscale of the Utrecht Scale for Evaluation of Rehabilitation – Participation. Bold values illustrate statistical significance defined as a p-value <.05.

^a*n* = 58.

^b*n* = 52.

^c*n* = 52.

Table 2. Linear regression: effects of participation at two months on HRQoL at one year after stroke.

		HRQoL measured by EQ-5D-3 L at one year post-stroke							
		Bivariate analyses				Multivariable analysis ^a			
	Reference	B (95% CI)	SE	Standardized Beta	p-value	B (95% CI)	SE	Standardized Beta	p-value
sex	male	-.049 (-.101–.004)	.027	-.107	.068	-.031 (-.082–.019)	.025	-.069	.218
age in years		.003 (-.005–.000)	.001	-.143	.015	-.001 (-.003–.001)	.001	-.077	.188
marital status	not married	.016 (-.039–.071)	.028	.033	.576	-.065 (-.119 – -.011)	.027	-.137	.018
education level	low education level	.028 (-.029–.085)	.029	.057	.330	-.007 (-.058–.045)	.026	-.013	.8015
type of stroke	ischemic	.049 (-.040–.139)	.045	.064	.278	.064 (-.014–.142)	.040	.082	.109
NIHSS		-.016 (-.024 – -.008)	.004	-.222	<.001	.001 (-.008–.010)	.005	.016	.799
BI		.019 (.014–.024)	.0003	.386	<.001	.012 (.005–.019)	.003	.246	.001
length of hospital stay in days		-.007 (-.012 – -.003)	.002	-.182	.002	.000 (-.004–.005)	.002	.005	.936
MoCA		.009 (.002–.016)	.003	.152	.010	.002 (-.005–.009)	.003	.032	.580
USER-P Restriction		.004 (.003–.005)	.001	.462	<.001	.004 (.002–.005)	.001	.373	<.001

B indicates unstandardized beta; BI, Barthel Index; CI, Confidence Interval; EQ-5D-3 L, three-level version of the EuroQoL Five Dimensions; MoCA, Montreal Cognitive Assessment; NA, not applicable; NIHSS, National Institutes of Health Stroke Scale; SE, standard error; USER-P Restriction, Restriction subscale of the Utrecht Scale for Evaluation of Rehabilitation – Participation. Bold values illustrate statistical significance defined as a p-value <.05.

a. Adjusted for sex, age at stroke, marital status, educational level, type of stroke, National Institutes of Health Stroke Scale (NIHSS), Barthel Index (BI), length of hospital stay in days and Montreal Cognitive Assessment (MoCA).

EQ-5D-3 L index score at T3 in the multivariable linear regression analysis. Other covariates were not associated with EQ-5D-3 L at T3 in the multivariable model.

Next, the study sample was divided into patients showing improvement in participation between T2 and T3 (*n* = 174; 59.8%) and those not showing improvement in participation (*n* = 63; 21.6%). This resulted in a total of 237 patients to be analyzed,

because patients with a maximum USER-P Restriction score at T2 were excluded from the subsequent analysis (*n* = 54; 18.6%). **Table 3** displays the mean and delta scores of the USER-P Restriction and EQ-5D-3 L index scores for the two groups. At T2, the EQ-5D-3 L index scores were comparable for both groups. Patients showing improvement in participation between T2 and T3 had a significantly higher EQ-5D-3 L index score at T3 (.77 \pm .20 versus

Table 3. Changes over time in USER-P restriction and EQ-5D-3 L index scores .

	No improvement in USER-P Restriction (<i>n</i> = 63) ^a	Improvement in USER-P Restriction (<i>n</i> = 174) ^a	p-value
USER-P Restriction at 2 months	74.6 ± 16.1	62.7 ± 20.7	<.001
USER-P Restriction at 12 months	63.1 ± 18.3	82.3 ± 17.6	<.001
Δ USER-P Restriction ‡	−11.5 ± 9.6	19.5 ± 14.1	<.001
EQ-5D-3 L index score at 2 months	.71 ± .22	.69 ± .21	.559
EQ-5D-3 L index score at 12 months	.66 ± .25	.77 ± .20	.001
Δ EQ-5D-3 L index score ^b	−.054 ± .16	.080 ± .21	<.001

EQ-5D-3 L indicates three-level version of the EuroQoL Five Dimensions; USER-P Restriction, the Restriction subscale of the Utrecht Scale for Evaluation of Rehabilitation – Participation. Bold values illustrate statistical significance defined as a p-value <.05.

^aPatients with a maximum score (100) on the USER-P Restriction at two months were excluded (*n* = 54).

^bDifference in USER-P Restriction or EQ-5D-3 L scores between two months and 12 months.

.66 ± .25; *p* = .001) and a significantly higher Δ EQ-5D-3 L index score (.080 ± .21 versus −.054 ± .16; *p* < .001) compared to patients without improvement in participation. The Δ EQ-5D-3 L index score was significantly correlated with the Δ USER-P Restriction score (*r* = .379; *p* < .001).

Discussion

This study demonstrated that a higher level of participation at two months after stroke predicted a higher HRQoL at one year. Besides, we showed that if participation improved during the first year after stroke, HRQoL increased as well.

Our findings are in line with previous studies that have shown that a higher level of participation after stroke is associated with a higher HRQoL.^{18,20,22} While the vast majority of previous studies examined this relationship in a cross-sectional manner, two longitudinal cohort studies (*n* = 134 and *n* = 500) found that a higher level of participation was associated with a higher HRQoL after stroke.^{21,22} Our study reaffirms this longitudinal relationship in a large cohort, and adds to this knowledge that an increase in participation is associated with an increase in HRQoL and that no (further) improvement in HRQoL occurred without such an improvement of participation.

While participation and HRQoL are closely related, these concepts have key differences and both are uniquely important in patients' lives after stroke. Knowledge of the applicability of measurements of participation and HRQoL and insight in the relationship between those, is of great value for health care professionals working at stroke services. Participation can be defined as a person's "involvement in a life situation;" participation is what

a person does in real life, with or without a health condition, and is influenced by personal and environmental factors.⁵ HRQoL can be defined as "those aspects of self-perceived well-being that are related to or affected by the presence of disease or treatment".³⁵ Logically speaking, both characteristics are likely to be negatively impacted by stroke and its possible physical, cognitive, emotional, and social consequences. Therefore, it is not surprising to find a relationship between participation and long-term HRQoL. However, as little research has been conducted examining participation as a determinant of long-term HRQoL after stroke, our study provides additional insights into this relationship.

Currently, HRQoL assessment is widely used and has grown to be an important patient-reported outcome measure in medical research.³⁶ While the assessment of participation is used to evaluate outcomes as well, it also plays a pivotal role in clinical decision-making in stroke care. The assessment of participation, as a diagnostic instrument, facilitates the assessment of a patient's needs in terms of rehabilitation treatment. Besides, the goal of rehabilitation after stroke is not only to stimulate functional recovery but also, or even more so, to improve the level of participation.^{15,37} Since the assessment of participation has an essential role in clinical stroke rehabilitation, it is important to know that participation, and its improvement, predicts a widely accepted outcome parameter such as HRQoL. Besides, a low level of participation with a high HRQoL might be acceptable to some patients, whereas a high level of participation with a low HRQoL might be not. Therefore, it is relevant to determine the relationship between improvement of participation and higher HRQoL.

This study demonstrated a relationship between participation and long-term HRQoL, independent of physical impairments. According to the International Classification of Functioning, Disability and Health model, a health condition (e.g. stroke) can lead to disability at the following three levels: (1) impairments (e.g. paralysis or cognitive impairment), (2) activity limitations (e.g. having trouble walking) and (3) participation restrictions (e.g. not being able to return to work).⁵ Our study showed that activity limitations (measured with the BI) and patient-reported participation restrictions (measured with the USER-P Restriction) are significantly associated with a lower HRQoL in multivariable analysis. Remarkably, measurements of impairment (with the NIHSS and MoCA) were related to HRQoL in bivariate analysis, but not in multivariable analysis. Previous systematic reviews, in other fields of neurology, showed comparable results among patients with spinal cord injury and Parkinson's disease.^{38,39} This suggests that it is not the severity of the disease nor the physical or cognitive impairment itself, but the impact of impairment on a person's daily functioning, that determines HRQoL.

Our findings underline guideline recommendations to screen all patients with stroke not only for possible impairments, but also for the broader effects of stroke at the level of participation.^{40,41} This recommendation is even more relevant as aggregated evidence shows that approximately half of all patients with stroke report unmet needs with regard to activities and participation.⁴² Since rehabilitation interventions seem to improve participation in patients with stroke, the options for rehabilitation services can be discussed if a restriction of participation is found.^{8,16,43} Moreover, specifying the participation restrictions experienced by a patient in terms of concrete subdomains, such as sports or return to work, helps with patient-centered goal-setting and supports shared decision making for a follow-up plan.¹⁷ Therefore, when patients with stroke are assessed after the acute phase, for example at outpatient clinics after discharge, we recommend evaluating participation comprehensively with validated instruments, such as the USER-P Restriction. If

participation restrictions are found, rehabilitation interventions should be considered and discussed.

The following strengths of our study can be mentioned. First, this was a multicenter, longitudinal, prospective cohort study. Second, a large number of patients completed the long-term follow-up measurements, which made it possible to adjust for multiple variables in a linear regression analysis. Third, as patients were included in hospitals within seven days after stroke, the current cohort describes a general stroke population with varying discharge destinations.

A limitation of the study is that patients with comorbidities interfering with the study outcomes were excluded. This led to a selection bias of previously healthy patients with presumably higher levels of participation and HRQoL. Furthermore, a substantial number of patients were excluded from the current analysis based on missing data. Lastly, a previous review showed that the minimal clinically important difference (MCID) for the EQ-5D-3 L index score ranged widely, from .03 to .52, and also showed that the MCID had not been examined in a stroke population. The five-level variant of the EQ-5D index score has been examined in one study among 65 stroke patients, in which the MCID was .10.⁴⁴ However, whether or not the statistically significant improvement in HRQoL in the current paper is clinically relevant for stroke patients cannot be determined with certainty.⁴⁵

Conclusions

This multicenter, prospective, cohort study showed that a higher level of participation at two months after stroke independently predicts a higher long-term HRQoL at one year after stroke. In addition, an improvement in participation in the first year after stroke is associated with an improvement in HRQoL. Therefore, we recommend incorporating the assessment and treatment of a patient's restrictions of participation in daily activities at follow-up visits.

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Disclosure statement

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Availability of data and material

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Authors' contributions

- Conception and design of the study: JdG, JS, JV, MP
- Data acquisition and analysis: CH, JdG, JS, JV, MP
- Interpretation of data: CH, JdG, JS, JV, MP, RvdB, VK
- Drafting the article: JdG, JS, JV, MP
- Revising the article for valuable intellectual content: CH, JdG, JS, JV, MP, RvdB, VK
- Approval of final version: CH, JdG, JS, JV, MP, RvdB, VK

Consent to participate

All participants provided informed consent.

Consent for publication: all authors have read and approved the submitted manuscript, the manuscript has not been submitted elsewhere nor published elsewhere in whole or in part.

Ethical approval

The study complies with the Declaration of Helsinki and was approved by the Committee on Research involving Human Subjects of the St. Antonius Hospital in Nieuwegein in the Netherlands (R10.41A, February 2011) and by the medical ethics committees of all participating hospitals.

Non-standard abbreviations and acronyms

BI Barthel Index
EQ-5D-3 L EuroQoL five dimensions questionnaire
HRQoL health-related quality of life
MoCA Montreal Cognitive Assessment
NIHSS National Institutes of Health Stroke Scale
USER-P Restriction Restriction subscale of the Utrecht Scale for Evaluation of Rehabilitation – Participation

References

1. GBD. Stroke collaborators. global, regional, and national burden of stroke, 1990-2016: a systematic analysis for the global burden of disease study 2016. *Lancet Neurol.* 2015;18(5): 439–458. 2019.
2. Katzan IL, Thompson NR, Uchino K, Lapin B. The most affected health domains after ischemic stroke. *Neurology.* 2018;90(16):e1364–71. doi:10.1212/WNL.0000000000005327.
3. Slenders JPL, Verberne DPJ, Visser-Meily JMA, Van den Berg-Vos RM, Kwa VIH, van Heugten CM. Early cognitive and emotional outcome after stroke is independent of discharge destination. *J Neurol.* 2020;267(11):3354–3361. doi:10.1007/s00415-020-09999-7.
4. Sexton E, McLoughlin A, Williams DJ, et al. Systematic review and meta-analysis of the prevalence of cognitive impairment no dementia in the first year post-stroke. *Eur Stroke J.* 2019;4(2):160–171. doi:10.1177/2396987318825484.
5. World Health Organization. Towards a common language for functioning, disability, and health: ICF. *Int Classification Functioning Disabil Health.* 2002;10. <https://cdn.who.int/media/docs/default-source/classification/icf/icfbeginnersguide.pdf>
6. Schnitzler A, Jourdan C, Josseran L, Azouvi P, Jacob L, Genet F. Participation in work and leisure activities after stroke: a national study. *Ann Phys Rehabil Med.* 2019;62(5):351–355. doi:10.1016/j.rehab.2019.04.005.
7. Palstam A, Sjodin A, Sunnerhagen KS, Katsanos AH. Participation and autonomy five years after stroke: a longitudinal observational study. *PLoS One.* 2019;14(7):e0219513. doi:10.1371/journal.pone.0219513.
8. Engel-Yeger B, Tse T, Josman N, Baum C, Carey LM. Scoping review: the trajectory of recovery of participation outcomes following stroke. *Behav Neurol.* 2018;2018:5472018. doi:10.1155/2018/5472018.
9. Verberne DPJ, Post MWM, Kohler S, Carey LM, Visser-Meily JMA, van Heugten CM. Course of social participation in the first 2 years after stroke and its associations with demographic and stroke-related factors. *Neurorehabil Neural Repair.* 2018;32(9):821–833. doi:10.1177/1545968318796341.
10. Lee Y, Nicholas ML, Connor LT. Identifying emotional contributors to participation post-stroke. *Top Stroke Rehabil.* 2021;30(2):1–13. doi:10.1080/10749357.2021.2008597.
11. de Graaf JA, Schepers VPM, Nijse B, et al. The influence of psychological factors and mood on the course of participation up to four years after stroke. *Disabil Rehabil.* 2022;44(10):1855–1862. doi:10.1080/09638288.2020.1808089.
12. Ezekiel L, Collett J, Mayo NE, Pang L, Field L, Dawes H. Factors associated with participation in life situations for adults with stroke: a systematic review. *Arch Phys Med Rehabil.* 2019;100(5):945–955. doi:10.1016/j.apmr.2018.06.017.

13. Della Vecchia C, Viprey M, Haesebaert J, et al. Contextual determinants of participation after stroke: a systematic review of quantitative and qualitative studies. *Disabil Rehabil.* 2019;43(13):1–13. doi:10.1080/09638288.2019.1679897.
14. Ianni C, Magee L, Dagli C, Nicholas ML, Connor LT. Self-reported emotional health and social support but not executive function are associated with participation after stroke. *Top Stroke Rehabil.* 2022;1–10. doi:10.1080/10749357.2022.2110192.
15. Winstein CJ, Stein J, Arena R, et al. Guidelines for adult stroke rehabilitation and recovery: a guideline for health-care professionals from the American heart association/ American stroke association. *Stroke.* 2016;47(6):e98–169. doi:10.1161/STR.0000000000000098.
16. Obembe AO, Eng JJ. Rehabilitation interventions for improving social participation after stroke: a systematic review and meta-analysis. *Neurorehabil Neural Repair.* 2016;30(4):384–392. doi:10.1177/1545968315597072.
17. Miller KK, Lin SH, Neville M. From hospital to home to participation: a position paper on transition planning poststroke. *Arch Phys Med Rehabil.* 2019;100(6):1162–1175. doi:10.1016/j.apmr.2018.10.017.
18. Wang R, Langhammer B. Predictors of quality of life for chronic stroke survivors in relation to cultural differences: a literature review. *Scand J Caring Sci.* 2018;32(2):502–514. doi:10.1111/scs.12533.
19. Ekstrand E, Brogårdh C. Life satisfaction after stroke and the association with upper extremity disability, sociodemographics, and participation. *PM&R.* 2022;14(8):922–930. doi:10.1002/pmrj.12712.
20. Vincent-Onabajo GO, Hamzat TK, Owolabi MO. Consistent determinants of health-related quality of life in the first 12 months after stroke: a prospective study in Nigeria. *Top Stroke Rehabil.* 2015;22(2):127–133. doi:10.1179/1074935714Z.00000000033.
21. Kwok T, Pan JH, Lo R, Song X. The influence of participation on health-related quality of life in stroke patients. *Disab and Rehabil.* 2011;33(21–22):1990–1996. doi:10.3109/09638288.2011.553709.
22. White J, Magin P, Attia J, Sturm J, McElduff P, Carter G. Predictors of health-related quality of life in community-dwelling stroke survivors: a cohort study. *Fam Pract.* 2016;33(4):382–387. doi:10.1093/fampra/cmww011.
23. van Mierlo ML, van Heugten CM, Post MWM, et al. A longitudinal cohort study on quality of life in stroke patients and their partners: restore4Stroke Cohort. *Int J Stroke.* 2014;9(1):148–154. doi:10.1111/j.1747-4949.2012.00882.x.
24. 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):1–8. doi:10.1097/01.mrr.0000175269.59788.41.
25. Brott T, Adams HP, Olinger CP, et al. Measurements of acute cerebral infarction: a clinical examination scale. *Stroke.* 1989;20(7):864–870. doi:https://doi.org/10.1161/01.STR.20.7.864.
26. Collin C, Wade DT, Davies S, Horne V. The Barthel ADL Index: a reliability study. *Int Disabil Stud.* 1988;10(2):61–63. doi:10.3109/09638288809164103.
27. Nasreddine ZS, Phillips NA, BÃ© Dirian V, et al. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *J Am Geriatr Soc.* 2005;53(4):695–699. doi:10.1111/j.1532-5415.2005.53221.x.
28. Post MW, van der Zee CH, Hennink J, et al. Validity of the Utrecht scale for evaluation of rehabilitation-participation. *Disabil Rehabil.* 2012;34(6):478–485. doi:10.3109/09638288.2011.608148.
29. Post, van der Zee CH, Kap A, Rambaran Mishre R, Schouten EJ, Post M. Responsiveness of four participation measures to changes during and after outpatient rehabilitation. *J Rehabil Med.* 2011;43(11):1003–1009. doi:10.2340/16501977-0879.
30. de Graaf JA, Volkers EJ, Schepers VPM, Visser-Meily VPM, Post JMA, de Graaf MWM. Validity of the Utrecht scale for evaluation of rehabilitation-participation restrictions scale in a hospital-based stroke population 3 months after stroke. *Top Stroke Rehabil.* 2022;29(7):516–525. doi:10.1080/10749357.2021.1956047.
31. van der Zee CH, Baars-Elsinga A, Visser-Meily JMA, Post JM, van der Zee MW. Responsiveness of two participation measures in an outpatient rehabilitation setting. *Scand J Occup Ther.* 2013;20(3):201–208. doi:10.3109/11038128.2012.754491.
32. Versteegh M, Vermeulen M, Evers MAA, GAd W, Prenger R, Stolk A. Dutch tariff for the five-level version of EQ-5D. *Value Health.* 2016;19(4):343–352. doi:10.1016/j.jval.2016.01.003.
33. Hunger M, Sabariego C, Stollenwerk B, Cieza A, Leidl R. Validity, reliability and responsiveness of the EQ-5D in German stroke patients undergoing rehabilitation. *Qual Life Res.* 2012;21(7):1205–1216. doi:10.1007/s11136-011-0024-3.
34. Verhage F. *Intelligence and Age: Study with Dutch People Aged.* Assen: Van Gorcum; 1964.
35. Ebrahim S. Clinical and public health perspectives and applications of health-related quality of life measurement. *Social Sci Med.* 1995;41(10):1383–1394. doi:10.1016/0277-9536(95)00116-o.
36. Haraldstad K, Wahl A, Andenæs R, et al. A systematic review of quality of life research in medicine and health sciences. *Qual Life Res.* 2019;28(10):2641–2650. doi:10.1007/s11136-019-02214-9.
37. Zhang Q, Schwade M, Smith Y, Wood R, Young L. Exercise-based interventions for post-stroke social participation: a systematic review and network meta-analysis. *Int J Nurs Stud.* 2020;111:103738. doi:10.1016/j.ijnurstu.2020.103738.
38. van Uem JM, van Uem JMT, Marinus J, et al. Health-related quality of life in patients with Parkinson's disease—A systematic review based on the ICF model.

- Neurosci Biobehav Rev.* 2016;61:26–34. doi:[10.1016/j.neubiorev.2015.11.014](https://doi.org/10.1016/j.neubiorev.2015.11.014).
39. Dijkers M. Quality of life after spinal cord injury: a meta analysis of the effects of disablement components. *Spinal Cord.* 1997;35(12):829–840. doi:[10.1038/sj.sc.3100571](https://doi.org/10.1038/sj.sc.3100571).
 40. Gittler M, Davis AM. Guidelines for adult stroke rehabilitation and recovery. *JAMA.* 2018;319(8):820–821. doi:[10.1001/jama.2017.22036](https://doi.org/10.1001/jama.2017.22036).
 41. Teasell R, Salbach NM, Foley N, et al. Canadian stroke best practice recommendations: rehabilitation, recovery, and community participation following stroke. part one: rehabilitation and recovery following stroke; 6th edition update 2019. *Int J Stroke.* 2020;15(7):763–788. doi:[10.1177/1747493019897847](https://doi.org/10.1177/1747493019897847).
 42. Chen T, Zhang B, Deng Y, Fan JC, Zhang L, Song F. Long-term unmet needs after stroke: systematic review of evidence from survey studies. *BMJ Open.* 2019;9(5):e028137. doi:[10.1136/bmjopen-2018-028137](https://doi.org/10.1136/bmjopen-2018-028137).
 43. Lee D, Heffron JL, Mirza M. Content and effectiveness of interventions focusing on community participation post-stroke: a systematic review. *Arch Phys Med Rehabil.* 2019;100(11):2179–92.e1. doi:[10.1016/j.apmr.2019.06.008](https://doi.org/10.1016/j.apmr.2019.06.008).
 44. Chen P, Lin KC, Liing RJ, Wu CY, Chen CL, Chang KC. Validity, responsiveness, and minimal clinically important difference of EQ-5D-5L in stroke patients undergoing rehabilitation. *Qual Life Res.* 2016;25(6):1585–1596. doi:[10.1007/s11136-015-1196-z](https://doi.org/10.1007/s11136-015-1196-z).
 45. Coretti S, Ruggeri M, McNamee P. The minimum clinically important difference for EQ-5D index: a critical review. *Expert Rev Pharmacoecon Outcomes Res.* 2014;14(2):221–233. doi:[10.1586/14737167.2014.894462](https://doi.org/10.1586/14737167.2014.894462).