


Course of Social Participation in the First 2 Years After Stroke and Its Associations With Demographic and Stroke-Related Factors

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Daan P. J. Verberne, MSc^{1,2} , Marcel W. M. Post, PhD^{3,4},
Sebastian Köhler, PhD¹, Leanne M. Carey, PhD^{5,6},
Johanna M. A. Visser-Meily, PhD, MD^{3,7},
and Caroline M. van Heugten, PhD^{1,2,8}

Abstract

Background. Many persons with stroke experience physical, cognitive, and emotional problems that contribute to restrictions in social participation. There is, however, a lack of knowledge on the long-term course of participation over time post-stroke. **Objective.** To describe the time course of participation up to 2 years post-stroke and to identify which demographic and stroke-related factors are associated with this time course. **Methods.** This was a multicenter, prospective cohort study following 390 persons with stroke from hospital admission up to 2 years (at 2, 6, 12, and 24 months). Multilevel modeling with linear and quadratic time effects was used to examine the course of the frequency of vocational and social/leisure activities, experienced restrictions, and satisfaction with participation. **Results.** The frequency of vocational activities increased up to 1 year post-stroke and leveled off thereafter. Older and lower-educated persons showed less favorable courses of participation than younger and higher-educated persons, respectively. The frequency of social/leisure activities decreased post-stroke. Participation restrictions declined up to 1 year post-stroke and leveled off thereafter. Persons dependent in activities of daily living (ADL) kept experiencing more restrictions throughout time than independent persons. Satisfaction with participation increased slightly over time. **Conclusions.** Changes in participation occurred mostly in the first year post-stroke. Particularly older and lower-educated persons, and those dependent in ADL showed less favorable courses of participation up to 2 years post-stroke. Clinicians can apply these findings in identifying persons most at risk of long-term unfavorable participation outcome and, thus, target rehabilitation programs accordingly.

Keywords

social participation, prognosis, stroke, demography

Introduction

Stroke can lead to long-lasting physical problems such as mobility limitations,¹ cognitive problems such as attention or memory deficits,² and emotional problems such as anxiety,^{3,4} depressive symptoms,³⁻⁵ and fatigue.^{4,6} The population of persons surviving a stroke^{7,8} increases, consistent with major improvements in acute stroke care (eg, stroke units, thrombolysis, and thrombectomy^{9,10}), but this also means that more people have to deal with the long-lasting consequences of stroke.^{11,12} These consequences contribute to the deterioration of social participation post-stroke.¹³⁻¹⁷ Importantly, persons with stroke view social participation (*participation* hereafter) as a central aspect of their recovery.^{18,19}

¹Maastricht University Medical Center, Netherlands

²Limburg Brain Injury Center, Maastricht, Netherlands

³Utrecht University and De Hoogstraat Rehabilitation, Utrecht, Netherlands

⁴University of Groningen, Netherlands

⁵La Trobe University, Melbourne, Australia

⁶Florey Institute of Neuroscience and Mental Health, Melbourne, Australia

⁷University Utrecht, Netherlands

⁸Maastricht University, Netherlands

Corresponding Author:

Caroline M. van Heugten, PhD, School for Mental Health and Neuroscience (MHeNs), Maastricht University, PO 616 UNS 40, Maastricht, 6200 MD, Netherlands.

Email: c.vanheugten@maastrichtuniversity.nl

Participation can be defined as involvement in a life situation such as paid work, family, or community life,¹⁷ which consists of actual performed activities,²⁰ such as the frequency of observable actions and behaviors,²¹⁻²³ and the subjective experience of persons,²⁰ such as experienced restrictions and satisfaction.²¹⁻²³

In previous studies, it was observed that the frequency of activities decreases in persons with stroke, relative to their premorbid levels.^{16,24-28} This particularly applies to vocational activities (work, unpaid work, and household activities), but social activities decrease after stroke, too.²⁸ Four months after discharge from outpatient rehabilitation, 50% of persons with stroke still experienced participation problems.²⁹ Social activity levels have been reported to be lower in persons with stroke at 1 year post-stroke than in healthy controls,³⁰ a level that remained stable up to 3 years.³¹ Past studies showed that only 39% of persons with stroke were satisfied with their lives as a whole after 1 year,¹⁶ which might be even lower up to 3 years post-stroke,³² especially in socially inactive persons.³³

Although studies have shed some light on the course of participation over time post-stroke, it is difficult to get a good understanding of how levels of participation develop and change over time. This is a result of the use of cross-sectional designs,^{16,24,26,27,33} longitudinal designs limited to either only the first 6 months^{13,25,28,29} or only the long-term levels of participation after stroke,^{31,32,34} studies only incorporating 2 time points,³⁵ and many different participation measures, some measuring the frequency of activities and others the subjective experience of participation.³⁶

Research into factors associated with participation post-stroke could lead to identifying possible risk factors of an unfavorable outcome. Earlier studies showed that demographic factors such as older age at stroke onset,^{14,37} lower levels of education,^{29,38} and female sex³⁷ were related to a less favorable outcome in terms of participation, along with stroke-related factors such as dependence in activities of daily living (ADL),^{39,40} more severe stroke,³⁷ and lower levels of cognitive functioning.^{26,29} However, these factors are yet to be examined in relation to the course of participation over time and as such to be identified as possible risk factors.

To get a more detailed and comprehensive understanding of participation over time, it is necessary to include repeated measurements of objective (ie, frequency of activities) as well as subjective (ie, experienced restrictions and satisfaction) aspects of participation. Furthermore, it is important to identify persons in the early stage after stroke, who are at risk of an unfavorable outcome in the long term. At this point in time, potential risk factors can be easily determined through available information, including demographics and stroke-related information, and rehabilitation care can be provided. Consequently, we studied participation over a 2-year follow-up in a clinical cohort of persons with stroke

in order to answer the following research questions: how does participation develop over the first 2 years after stroke in terms of frequency, restrictions, and satisfaction? Moreover, which demographic and stroke-related factors are associated with this time course?

Methods

Design and Procedure

The current study is part of the Restore4stroke Cohort, a multicenter, prospective cohort study of persons with stroke described in detail elsewhere.⁴¹ Persons with ischemic or intracerebral hemorrhagic stroke (first ever and recurrent) were recruited from 6 general hospitals in the Netherlands and followed for up to 2 years. The Restore4stroke study was approved by the Committee on Research involving Human Subjects of the St Antonius Hospital in Nieuwegein (the Netherlands) and by the medical ethics committees of all participating hospitals. Written informed consent was obtained from all persons.

The Restore4stroke cohort study consists of 5 assessments: at stroke onset (ie, within first week of admission; T1) and at 2 (T2), 6 (T3), 12 (T4), and 24 (T5) months post-stroke. Nurses extracted information from medical charts on stroke-related factors and ADL dependence at 4 days post-stroke (assessed by the neurologist). At first assessment (T1), information on demographic factors was gathered as well as retrospective data on premorbid levels of vocational and social/leisure activities by consulting the patient or a family member. Premorbid level of functioning was considered T0. In the subsequent assessments, persons with stroke completed the questionnaires themselves. In addition, a trained research assistant conducted a cognitive screening at T2 and T3.

Participants

Persons with stroke were included if they had a clinically confirmed diagnosis of stroke (ischemic or intracerebral hemorrhagic lesion) as assessed by the neurologist in the hospital using standard procedures (eg, computed tomography scans) and suffered this stroke within the past 7 days. Persons were excluded if they (1) had a comorbid condition that was anticipated to interfere with study outcomes (eg, neuromuscular disease); (2) had a premorbid Barthel Index (BI)⁴² score of 17 or lower, indicative of premorbid ADL dependence; (3) had insufficient command of the Dutch language to understand and complete questionnaires (as judged by the clinician); and (4) were already suffering from cognitive decline premorbidly, as indicated by a score ≥ 1 on the hetero-anamnesis list cognition.⁴³ The current study only included those persons living at home (ie, community dwelling) because participation levels of persons

living at home cannot be compared with those living in a nursing home. As the institutionalized group was very small, which therefore did not permit separate analyses, persons with stroke who lived in a nursing home at T5 were excluded.

Measures

Outcome Measure. The Utrecht Scale for Evaluation of Rehabilitation–Participation (USER-P) was used, which is a valid, reliable, and responsive self-report questionnaire on participation.^{22,23,44} The USER-P was used for its strong psychometric foundations, its unique perspective in combining the objective as well as the subjective aspects of participation, and prior use in studies involving persons with stroke.^{28,29,37,39,40} It consists of 3 scales: Frequency of participation, experienced participation Restrictions, and Satisfaction with participation.

The Frequency scale, Part A, measures self-perceived vocational activities per week across 4 items: the number of hours spent on paid work, unpaid work, education, and housekeeping. Each item is scored on a scale from 0 (*none at all*) to 5 (≥ 36 hours). The Frequency scale Part B measures self-perceived frequency of social/leisure activities during the past 4 weeks across 7 items: physical exercise, going out, day trips, leisure activities at home, visiting family or friends, visit of family at your home, contact with others. Each item is scored on a scale from 0 (*not at all*) to 5 (≥ 19 times).

The Restrictions scale consists of 11 items that measure self-perceived restrictions experienced with vocational, leisure, and social activities (eg, from paid work to visiting family and friends). The extent of experienced restrictions for each activity is scored on a scale from 0 (*not possible to perform*) to 3 (*performed without difficulty*). If the patient does not perform the activity for reasons other than stroke, a “not applicable” score can be recorded.

The Satisfaction scale consists of 10 items relating to self-perceived satisfaction with vocational, leisure, and social activities (ie, generally comparable with the restrictions items). Satisfaction is rated on a scale from 0 (*very dissatisfied*) to 4 (*very satisfied*). “Not applicable” can be recorded on 2 items in this scale if one does not perform vocational activities or does not have a partner.

All scale sum scores are converted to range from 0 to 100, with higher scores indicative of higher levels of participation (ie, more participation, less restrictions, and higher satisfaction). The Frequency scale (Parts A and B) was also administered in the first week post-stroke to collect information on premorbid level of participation (ie, 4 weeks before stroke, T0). In subsequent assessments, all USER-P scales were administered.

Independent Variables. Information on age, sex, level of education, stroke characteristics (type, hemisphere, severity), destination after discharge and independence in ADL were

collected at T1. Education was measured according to the Dutch classification method of Verhage,⁴⁵ with scores ranging from 1 to 7, and higher scores indicative of higher completed education. Stroke severity was assessed by the National Institutes of Health Stroke Scale (NIHSS),⁴⁶ with higher scores indicative of more severe stroke symptoms (range 0-30). The BI was used to assess independence in ADL,⁴² wherein higher scores indicate more independence in ADL (range 0-20). Cognitive functioning was assessed at T2 using the Montreal Cognitive Assessment (MoCA),⁴⁷ which is a brief cognitive screening method, with scores ranging from 0 to 30. Higher scores indicate better cognitive functioning.

Analyses

Characteristics of the included population, and subsequently the frequencies of activities of the USER-P, were described using median scores with ranges. For the frequencies of the Restrictions and Satisfaction scales, the items were dichotomized as follows: responses on the Restrictions Scale were coded into “0 = *restrictions*” (“activity not possible” to “activity possible with difficulties”) and “1 = *no restrictions*” (“activity possible without difficulties”). Satisfaction items were dichotomized into “0 = *not satisfied*” (“very dissatisfied” to “neutral”) and “1 = *satisfied*” (“satisfied” to “very satisfied”). “Not applicable” answers were recoded as missing.

The trajectories of post-stroke participation were modeled by multilevel (growth curve) modeling with the total scores of Frequency Part A (vocational activities) and Part B (social/leisure activities), Restrictions, and Satisfaction as the dependent variables in separate models. With this statistical technique, all available data could be used. As a first step, an unconditional means model (without any predictors) was fitted, with random intercepts across persons to account for the fact that repeated measures are correlated within individuals. The linear and quadratic functions of time were added in sequence, with time entered as a continuous variable (2, 6, 12, and 24 months). Likelihood ratio tests were used to assess model fit. Random slopes were allowed if the model was significantly better compared with a model with only random intercepts based on likelihood ratio testing. Likewise, covariance structures were specified according to best fit. Herewith, it was examined whether the addition of a quadratic time function added on the linear model. The best-fitting model was then used for testing main effects as well as main and interaction effects between the dichotomous predictors and time (linear as well as quadratic).

In total, 6 predictors were of interest: age as dichotomized with a median split into young (≤ 67) and old (≥ 68), sex, education into low (≤ 5) or high (≥ 6 ; completed higher professional education or have a university degree), NIHSS dichotomized into no/mild symptoms (≤ 4) and moderate/

Table 1. Characteristics of All Persons With Stroke (n = 390).^a

Characteristics	Restore4stroke	
	n Total	n (%) or Median (Range)
Male sex	390	254 (65.1)
Age in years at stroke	390	67.4 (24.5-93.5)
High education level ^b	379	101 (25.9)
Ischemic stroke	390	363 (93.1)
Stroke hemisphere	384	
Left		156 (40.6)
Right		165 (43.0)
Cerebellum or brainstem		63 (16.4)
NIHSS total score at 4 days post-stroke	390	2.0 (0-22.0)
No stroke symptoms (NIHSS = 0)		94 (24.1)
Mild stroke symptoms (NIHSS = 1-4)		220 (56.4)
Moderate stroke symptoms (NIHSS = 5-12)		69 (17.7)
Moderate-severe stroke symptoms (NIHSS ≥ 13)		7 (1.8)
Destination after discharge from hospital	390	
Home		277 (71.0)
Rehabilitation center		59 (15.1)
Nursing home		54 (13.8)
ADL assessed with the BI		
4 Days post-stroke (T1)	390	19.5 (0-20.0)
2 Months post-stroke (T2)	350	20.0 (2.0-20.0)
6 Months post-stroke (T3)	351	20.0 (4.0-20.0)
Cognitive functioning assessed with MoCA		
2 Months post-stroke (T2)	344	24.0 (5.0-30.0)
6 Months post-stroke (T3)	345	25.0 (9.0-30.0)

Abbreviations: ADL, activities of daily living; BI, Barthel Index; MoCA, Montreal Cognitive Assessment; NIHSS, National Institutes of Health Stroke Scale.

^aMedians are displayed because continuous variables are not normally distributed.

^bPersons with stroke who completed higher professional education or have a university degree.

severe symptoms (>4), the MoCA total scores for cognitive functioning at T2 into low (≤25) and high (>25), and the BI at T1 into ADL dependent (≤17) and ADL independent (>17). If a predictor showed a significant association with the averaged participation over time (main effects analyses), interaction terms between the predictor and time (linear and quadratic terms) were added to the model to assess whether groups differed in trajectories in participation over time (ie, forward selection). Subsequently, the premorbid means (T0) of the Frequency scale Part A and B were described for those groups showing significant interactions with time. An α of 5% (2-sided) was set for significance testing. All statistical analyses were performed with IBM SPSS Statistics for Macintosh, Version 24.0 (New York).

Results

Characteristics

Of the 395 participants in the Restore4stroke cohort, 390 met the inclusion criteria (5 persons with stroke lived at a

nursing home at T5 and were, therefore, excluded from analyses). Table 1 provides demographic and stroke-related information of the included participants. Median age at stroke onset was 67 years, and 65% were men. The great majority suffered an ischemic stroke (93%). More than half of the participants experienced mild stroke symptoms (56%) and were independent in ADL at T1. Most participants (71%) were directly discharged to their homes.

Course of Participation Over Time

Table 2 shows raw median scores (with range) of the 4 outcome scales of the USER-P over time. The appendix shows the frequencies, experienced restrictions, and satisfaction with participation scores per activity (on item level).

Part A: Vocational Activities. The best-fitting model of frequency of participation in vocational activities (Part A) over time included a significant positive linear effect of time as well as a significant negative quadratic effect of time (Table 3). The positive linear effect is indicative of an increase in vocational

Table 2. Medians and Ranges for USER-P Participation Domains for All Included Participants at Each Time Point.

	T0, Premorbid		T2, 2 Months Post-stroke		T3, 6 Months Post-stroke		T4, 12 Months Post-stroke		T5, 24 Months Post-stroke	
	n	Median (Range)	n	Median (Range)	n	Median (Range)	n	Median (Range)	n	Median (Range)
Total score frequency	378	33.6 (0-67.1)	342	27.9 (0-56.4)	340	28.4 (0-58.2)	324	28.8 (0-72.9)	317	28.9 (0-82.9)
Part A: vocational activities	377	20.0 (0-66.7)	341	10.0 (0-50.0)	340	10.0 (0-55.0)	308	10.0 (0-100)	307	15.0 (0-50.0)
Part B: social and leisure activities	376	45.7 (0-91.4)	342	42.9 (0-82.9)	340	45.7 (0-91.4)	322	42.9 (0-82.9)	314	40.0 (0-82.9)
Restrictions Scale	—	—	340	75.8 (12.1-100)	339	81.8 (3.0-100)	322	83.3 (14.3-100)	314	88.9 (16.7-100)
Satisfaction Scale	—	—	337	65.6 (18.8-100)	336	67.5 (9.4-100)	311	69.4 (2.8-100)	300	70.8 (0-100)

Abbreviation: USER-P, Utrecht Scale for Evaluation of Rehabilitation–Participation.

Table 3. Rate of Change in Frequency of Participation in Vocational Activities and Social/Leisure Activities Over Time Post-stroke.

	Part A: Vocational Activities				Part B: Social and Leisure Activities			
	Unconditional Means Model	Growth Model ^a	Main Effects ^b	Interaction Models	Unconditional Means Model	Growth Model ^a	Main Effects ^b	Interaction Models
Intercept	14.49**	11.70**			42.50**	43.50**		
Time factors								
Time		0.42**				-0.10*		
Time ²		-0.01*				NA		
Demographic factors								
Age (1 = old)			-7.80**	-4.35**			-2.25	—
× Time				-0.60*				—
× Time ²				0.01				—
Sex (1 = woman)			-0.67	—			2.16	—
× Time				—				—
× Time ²				—				—
Education (1 = high)			2.44*	0.12			6.54**	5.54**
× Time				0.56*				0.11
× Time ²				-0.02*				NA
Stroke-related factors								
Stroke severity (1 = severe)			-3.79*	-3.38*			-3.21	—
× Time				-0.08				—
× Time ²				0.00				—
ADL (1 = independent)			5.38**	4.70**			2.76	—
× Time				0.16				—
× Time ²				-0.01				—
Cognitive functioning (1 = high)			4.40**	2.74			6.88**	6.27**
× Time				0.32				0.07
× Time ²				-0.01				NA
Log-likelihood	9930.18	9426.87**			11 200.68	10 720.55**		
df	2	6			2	5		

Abbreviations: ADL, activities of daily living; NA, not applicable; interaction effect is not applicable.

Note: For the log-likelihood, a significance refers to the log-likelihood ratio testing that compares the unconditional means model to the growth model.

^aGrowth model includes random intercept and random slope.

^bForward selection of predictors for introduction in interaction model ($P < .05$).

* $p < .05$

** $p \leq .001$

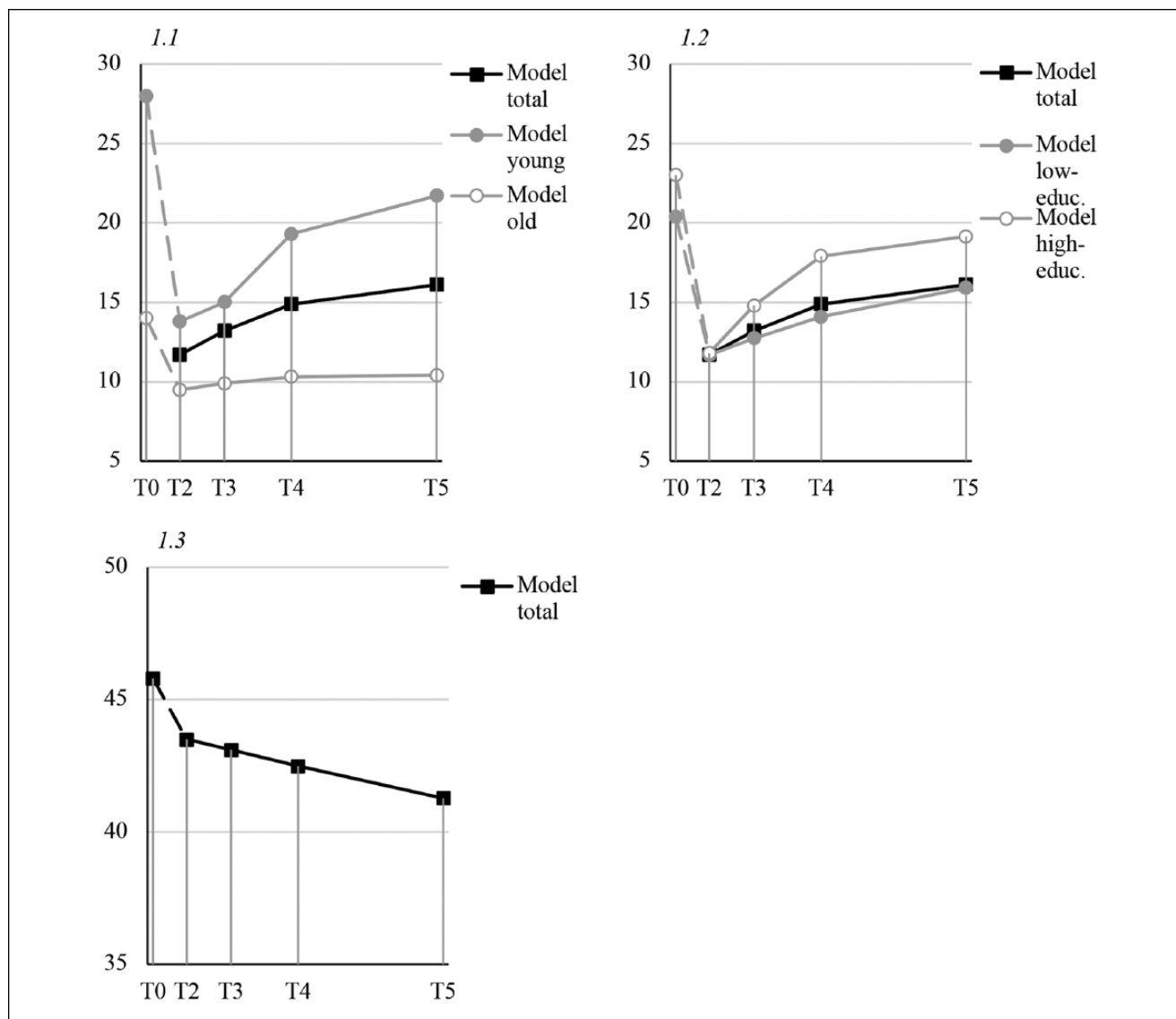


Figure 1. Section 1.1: vocational activities over time in interaction with age. Section 1.2: vocational activities over time in interaction with educational level. Section 1.3: Leisure activities over time. All scales originally range from 0 to 100; pre-morbid levels (T0) are not incorporated in the models and, therefore, followed by dashed lines.

activities up to T4 and the negative quadratic effect of the smaller increase in vocational activities from T4 to T5 (Figure 1, section 1.1).

Main effects analyses (ie, associations averaged over all time points) showed that young age and high educational level were significantly associated with more hours spent on vocational activities averaged over time. This association with more hours spent on vocational activities averaged over time was also observed for mild stroke severity, high ADL independence, and higher levels of cognitive functioning. Therefore, these variables were separately entered in the best fitting model (Table 3).

A significant time by age interaction effect was observed (Table 3), which showed that hours spent on vocational

activities over time increased more for younger persons than for their older peers (Figure 1, section 1.1). Young persons showed a pre-morbid mean of 28.0 (SD = 12.2) and older persons a mean of 13.9 (SD = 9.1) in vocational activities. With regard to educational level, both a linear and quadratic time by educational level interaction effect were observed (Table 3). Higher-educated persons increased significantly more in vocational activities than lower-educated persons, but this increase also significantly leveled off over time (Figure 1, section 1.2). Low-educated participants showed a pre-morbid mean of 20.5 (SD = 12.5) and high-educated persons a mean of 23.1 (SD = 13.8). No other significant interaction effects of the predictors with the linear or quadratic effect of time were found (Table 3).

Table 4. Rate of Change in Experienced Restrictions and Satisfaction With Participation Over Time Post-stroke.

	Restrictions				Satisfaction			
	Unconditional Means Model	Growth Model ^a	Main Effects ^b	Interaction Models	Unconditional Means Model	Growth Model ^a	Main Effects ^b	Interaction Models
Intercept	77.56**	70.67**			66.38**	62.67**		
Time factors								
Time		1.24**				0.63**		
Time ²		-0.04**				-0.02*		
Demographic factors								
Age (1 = old)			-6.63**	-2.83			-2.27	—
× Time				-0.64				—
× Time ²				0.01				—
Sex (1 = woman)			-6.96**	-7.07*			-3.24*	-2.15
× Time				0.05				-0.28
× Time ²				-0.00				0.01
Education (1 = high)			6.20*	8.41*			1.55	—
× Time				-0.59				—
× Time ²				0.02				—
Stroke-related factors								
Stroke severity (1 = severe)			-12.50**	-17.02**			-6.61**	-8.45*
× Time				0.91				0.14
× Time ²				-0.02				0.01
ADL (1 = independent)			14.24**	17.63**			9.34**	7.24**
× Time				-0.78*				0.56
× Time ²				0.03				-0.02
Cognitive functioning (1 = high)			7.22**	6.26*			3.87*	2.97
× Time				0.16				0.13
× Time ²				-0.00				-0.00
Log-likelihood	11 827.41	11 137.41**			11 027.93	10 495.75**		
df	2	6			2	6		

Abbreviation: ADL, activities of daily living.

Note: For the log-likelihood, a significance refers to the log-likelihood ratio testing that compares the unconditional means model to the growth model.

^aGrowth model includes random intercept and random slope.

^bForward selection of predictors for introduction in interaction model ($P < .05$).

* $p < .05$

** $p \leq .001$

Part B: Social/Leisure Activities. The best-fitting model of the course of participation in social/leisure activities (Part B) included a significant negative linear effect of time (Table 3), indicative of a decrease in social/leisure activities after T3 (Figure 1, section 1.3).

High educational level and high cognitive functioning were significantly associated with a higher frequency of social/leisure activities averaged over time, but no significant interaction effects with the linear effect of time were found (Table 3).

Restrictions. The best-fitting model of the course of experienced restrictions in participation included a linear and quadratic time effect (Table 4). The positive linear effect is indicative of the increase in restrictions score (indicating less restrictions) up to T4 and the negative quadratic effect of the smaller increase from T4 to T5 (Figure 2, section 2.1).

Young age, male sex, and high level of education as well as lower stroke severity, ADL independence, and high cognitive functioning were significantly associated with less experienced restrictions with participation averaged over time (Table 4). A significant time by ADL independence interaction effect was found (Table 4). Persons with ADL dependence showed a significantly stronger decrease in experienced restrictions the first year post-stroke than those independent in ADL (Figure 2, section 2.1). No other significant interaction effects with time were found (Table 4).

Satisfaction. The best fitting model for the course of satisfaction with participation included a linear and quadratic time effect (Table 4). Again, the positive linear effect is indicative of the increase in satisfaction up to T4 and the negative quadratic effect of the smaller increase from T4 to T5 (Figure 2, section 2.2).

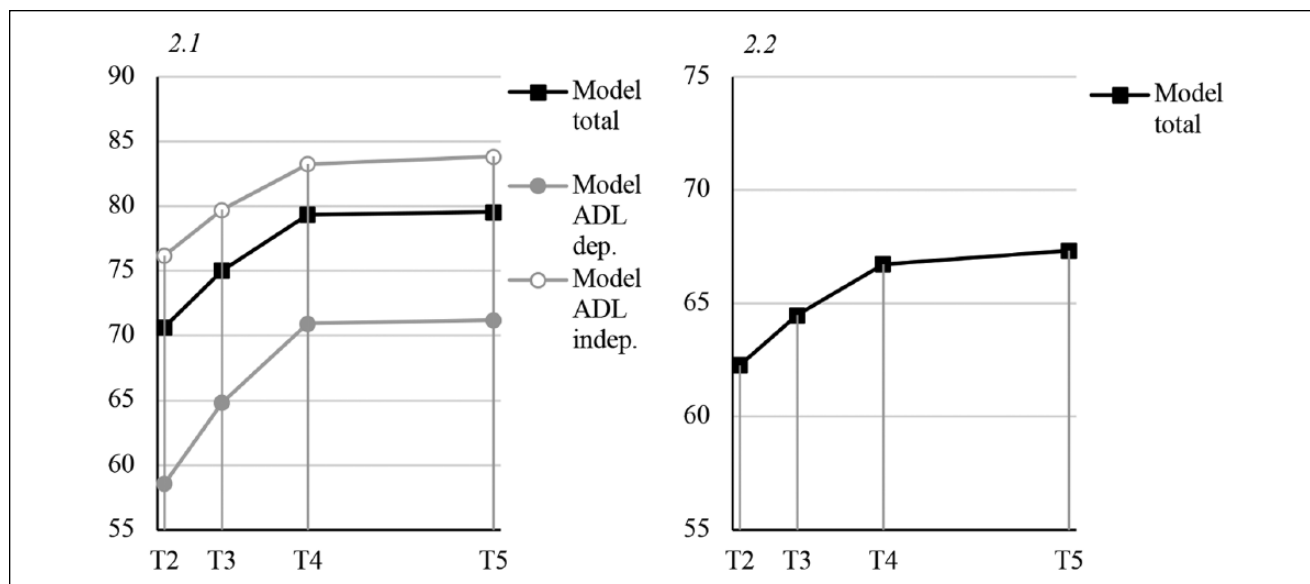


Figure 2. Section 2.1: experienced restrictions with participation over time in interaction, with independence in activities of daily life (ADL). Section 2.2: Satisfaction with participation over time. All scales originally range from 0 to 100. Higher scores on the restrictions scale are indicative of less-experienced restrictions.

On average, male participants had significantly higher levels of satisfaction. In addition, lower stroke severity, high ADL independence, and high cognitive functioning were associated with higher levels of satisfaction. However, no significant interaction effects with the linear or quadratic effects of time were found (Table 4).

Discussion

In this prospective cohort study, the course of participation post-stroke and its associated factors were examined from stroke onset up to 2 years post-stroke. Results showed that total frequency of participation generally increased during the first year and then remained relatively stable for up to 2 years. Interestingly, hours spent on vocational activities increased, whereas the frequency of social and leisure activities decreased from stroke onset to 2 years post-stroke. The extent of experienced restrictions (or difficulties) with participation decreased especially during the first year and remained stable thereafter. Satisfaction with participation showed a small but significant increase throughout the 2-year time span.

Earlier studies found that participation post-stroke was decreased in comparison with pre-morbid levels^{16,24-26} and increased during the first 6 months.⁴⁸ A similar trend, an increase in the first 6 months followed by stability, has been observed for measures of health-related quality of life.^{39,49} Our study adds to this literature by showing an increase particularly in vocational activities and a decrease in experienced restrictions with participation during the entire first

year post-stroke. Participation levels and experienced restrictions seemed to stabilize thereafter, as earlier observed for level of social activity.³⁰ In contrast, the frequency of leisure activities seemed to decrease, which might be a result of a trade-off with vocational activities. This might suggest that persons invest more time in vocational activities post-stroke because these might be considered activities that “need” to be done, possibly at the expense of the time available for social/leisure activities. It could also be a result of individuals not succeeding in maintaining high-demanding (physical) activities.²⁴ However, the frequencies per activity reported here suggest that the persons with stroke in this study succeeded relatively well in maintaining the more demanding physical activities (when looking at sports, going out, and day trips). Intriguingly, less-demanding activities such as receiving visitors and having contact via telephone or computer seem to decrease in frequency over time. The apparent decrease in leisure activities post-stroke should be examined more in depth in future research.

The demographic and stroke-related predictors were all, in a certain way, related to the outcome measures of participation. These results, therefore, confirm and extend the findings of previous cross-sectional studies on the influence of demographic^{14,29,31,37,38} and stroke-related^{16,26,29,37,50} factors on level of participation post-stroke. Particularly, older and lower-educated persons were at risk of less favorable outcomes in terms of participation over time, whereas women were less satisfied with participation. Furthermore, moderate/severe stroke, ADL dependence, and low

cognitive functioning were predictive of a less favorable outcome in both objective and subjective levels of participation. In addition, individuals with low cognitive functioning also showed lower levels of leisure/social activities.

More important, we showed that persons who are older, lower educated, or dependent in ADL follow distinct courses and are particularly at risk of poor participation outcome. Those aged 68 years and older showed a relatively small decrease in vocational activities from prestroke to post-stroke, which could also be because they had already retired from work at this age. They additionally experienced significantly more restrictions with participation in contrast to their younger peers, which might be related to experiencing more anxiety symptoms because earlier studies have shown anxiety to be predictive of poor participation outcome in older individuals.³⁷ Advancing age in general, as an explanation for unfavorable participation outcome is less likely to play a role here, because the USER-P was modified in this study to ask specifically for restrictions caused by stroke. Despite similar premorbid levels, lower-educated persons showed a significantly smaller increase in time spent on vocational activities post-stroke than their higher-educated peers. Additionally, lower-educated persons stayed on lower levels of performing social/leisure activities. These insights into different trajectories across education levels specify the earlier observed association of educational level with frequency of participation.^{29,38} Furthermore, although ADL-dependent persons showed a stronger decrease in experienced restrictions with participation, they still experienced more restrictions at 2 years post-stroke than their ADL-independent peers. This might be a result of the relationship with stroke severity.⁵¹ Moreover, it is likely that ADL-dependent persons show a steeper recovery curve because they have to recover more functions.

This study has a number of strengths and limitations. First of all, it provides a comprehensive insight into the course of participation by serial assessments over 2 years post-stroke in a large stroke sample. This allowed for well-powered longitudinal analyses. Importantly, it included the objective as well as the subjective aspects of participation. Specifically, we report not only on the activities that people with stroke participate in, but also on self-perceived restrictions and satisfaction in the engagement in those activities. Multilevel analyses were performed, and supplemental data on item level responses of the USER-P were presented in an attempt to provide the most comprehensive view of this time course. The generalizability to institutionalized patients, however, is expected to be limited because of the focus on community-dwelling patients. Furthermore, 93.1% of the cohort suffered from an ischemic stroke, which could limit the

generalizability to patients with other types of stroke (eg, hemorrhages) and to the wider stroke population in which ischemic stroke represents 87%.⁵² Nevertheless, the cohort is comparable on baseline characteristics with international—for example, Australian—cohorts of community-dwelling people with stroke.³⁵ Next, the USER-P has some limitations: frequency of activities can be difficult to estimate by patients; premorbid levels of participation are likely to be overestimated by patients; and finally, work-related factors and household activities are valued equally in Part A (as they add up), whereas they might be valued differently by the patients. Because this study had an exploratory character, we did not control for multiple testing, nor did we study in depth how the factors might interact. Although we identified several potential determinants of the course of participations, future research should be more hypothesis driven and include examinations of (shared) potential pathways and should focus on other related factors as well.

Implications

In this study, several factors were found that might help in identifying persons with stroke at early stages who are at risk of poor outcome in participation up to 2 years. This information (ie, demographics, NIHSS and BI score, cognitive functioning) is readily available from standard clinical assessments and could thus be used by clinicians without additional assessments. It might be of clinical interest that a relatively large proportion (17-46%) of individuals with stroke remain dissatisfied with participation in certain activities in the chronic phase. This suggests that they might not have adapted optimally to their experienced restrictions post-stroke. Emotional factors and personal factors should be taken into account in future research because earlier research showed that anxiety, depression, and fatigue are related to participation as well as life satisfaction.^{31,37,40} Additionally, from earlier studies, we know that a passive coping style is related to lower health-related quality of life.⁵³

Conclusion

In conclusion, our findings suggest that the course of participation is particularly defined by the first year post-stroke because most changes occur during this period. Furthermore, older, lower-educated, and ADL-dependent persons with stroke are particularly at risk of an unfavorable course of participation over time. Clinicians should take these findings into account during regular follow-up consults. Future research could focus on the role of emotional factors or the adaptation process in the identification of these at-risk persons with stroke.

Appendix

	T0		T2		T3		T4		T5	
	n	Frequency (%)	n	Frequency (%)	n	Frequency (%)	n	Frequency (%)	n	Frequency (%)
Part A: Vocational activities										
Paid work	376		341		340		312		308	
None at all		62.0		80.6		75.9		69.6		71.8
1-24 Hours		10.6		10.0		14.7		14.4		9.4
≥25 Hours		27.4		9.4		9.4		16.0		18.8
Unpaid work	378		340		340		309		310	
None at all		68.8		81.2		77.9		75.7		71.6
1-24 Hours		29.4		17.9		21.5		23.3		28.1
≥25 Hours		1.9		.9		.6		1.0		.3
Education	373		341		339		306		306	
None at all		93.6		99.1		97.1		95.8		94.8
1-24 Hours		5.6		.9		2.7		3.6		5.2
≥25 Hours		.8		.0		.3		.7		.0
Household activities	374		341		340		323		314	
None at all		4.5		12.3		9.7		11.1		8.9
1-24 Hours		79.1		79.5		83.5		81.4		80.9
≥25 Hours		16.4		8.2		6.8		7.4		10.2
Part B: Leisure and social activities										
Sports/physical exercise	374		342		340		324		314	
Not at all		22.5		25.1		17.1		19.4		21.0
1-10 Times		46.3		44.2		47.4		53.7		51.0
≥11 Times		31.3		30.7		35.6		26.9		28.0
Going out	375		342		339		321		314	
Not at all		34.1		48.2		39.5		37.7		35.7
1-10 Times		64.3		50.6		59.3		60.4		62.7
≥11 Times		1.6		1.2		1.2		1.9		1.6
Day trips	375		342		338		323		313	
Not at all		21.9		37.7		26.0		25.1		26.8
1-10 Times		70.9		56.7		67.2		69.3		66.8
≥11 Times		7.2		5.6		6.8		5.6		6.4
Leisure activities	375		342		340		323		311	
Not at all		12.0		16.4		12.4		10.2		12.2
1-10 Times		40.0		42.1		45.3		48.6		44.1
≥11 Times		48.0		41.5		42.4		41.2		43.7
Visiting family or friends	374		342		335		321		310	
Not at all		7.0		18.1		10.4		10.0		9.4
1-10 Times		79.9		76.0		80.0		81.0		82.9
≥11 Times		13.1		5.8		9.6		9.0		7.7
Receiving visitors	375		341		340		322		312	
Not at all		4.0		4.7		6.2		5.9		9.3
1-10 Times		77.6		68.9		78.8		81.1		77.2
≥11 Times		18.4		26.4		15.0		13.0		13.5
Contact via PC/telephone	375		342		340		324		315	
Not at all		5.3		7.6		8.5		6.2		13.3
1-10 Times		44.0		43.6		52.4		54.9		52.7
≥11 Times		50.7		48.8		39.1		38.9		34.0

(continued)

Appendix (continued)

Restrictions scale^b

	T0		T2		T3		T4		T5	
	n	Restrictions (%)	n	Restrictions (%)	n	Restrictions (%)	n	Restrictions (%)	n	Restrictions (%)
(Un)paid work/education	—	—	127	80.3	126	65.9	121	55.4	120	47.5
Household activities	—	—	306	63.7	323	55.4	297	53.2	291	49.5
Outside activities	—	—	313	58.8	321	47.7	303	40.6	296	39.2
Sports/physical exercise	—	—	283	62.2	296	57.1	276	55.8	274	48.5
Going out	—	—	221	57.5	254	52.0	239	44.8	247	43.7
Day trips	—	—	256	59.8	285	51.9	270	51.1	266	48.5
Leisure activities	—	—	303	36.0	302	33.4	295	29.5	284	25.0
Relationship with partner	—	—	224	23.2	237	31.2	221	35.3	206	32.5
Visiting friends	—	—	314	52.9	319	45.5	298	39.3	301	36.5
Receiving visitors	—	—	329	24.0	327	27.2	300	22.0	295	21.0
Contact via PC/telephone	—	—	319	16.9	320	19.4	298	19.8	283	19.1

Satisfaction scale

	T0		T2		T3		T4		T5	
	n	Not satisfied (%)	n	Not satisfied (%)	n	Not satisfied (%)	n	Not satisfied (%)	n	Not satisfied (%)
(Un)paid work/education ^b	—	—	126	53.2	124	37.1	126	31.0	129	30.2
Household activities	—	—	334	46.7	334	40.1	310	38.1	297	34.3
Outside activities	—	—	336	52.1	337	41.8	313	36.1	399	34.0
Sports/physical exercise	—	—	335	58.5	335	50.4	307	46.9	291	48.1
Going out	—	—	333	57.4	332	50.9	304	46.4	290	46.2
Day trips	—	—	337	58.2	335	51.9	307	45.9	298	44.0
Leisure activities	—	—	340	33.5	335	29.0	313	30.4	301	24.3
Relationship partner ^b	—	—	237	13.9	238	13.0	226	16.4	222	17.6
Relationship with family	—	—	338	13.6	335	15.2	314	14.0	304	17.8
Contact with friends	—	—	341	15.8	336	18.5	317	20.2	305	21.3

Abbreviations: PC, personal computer; USER-P, Utrecht Scale for Evaluation of Rehabilitation-Participation.

^aFrequencies displayed are valid percentages. Restrictions items are dichotomized as follows: 0 (not possible to perform) to 2 (able to perform but with difficulty) = restrictions experienced; 3 (performed without difficulty) = no restrictions experienced. Satisfaction items are dichotomized as follows: 0 (very dissatisfied) to 2 (neutral) = not satisfied; 3 (satisfied) and 4 (very satisfied) = satisfied.

^bThe sample (n) for which the activity is applicable is displayed (persons for whom the activity is not applicable are not displayed).


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ORCID iD

Daan P. J. Verberne  <https://orcid.org/0000-0002-1005-0664>.

References

- van de Port IG, Kwakkel G, van Wijk I, Lindeman E. Susceptibility to deterioration of mobility long-term after stroke: a prospective cohort study. *Stroke*. 2006;37:167-171.
- Lesniak M, Bak T, Czepiel W, Seniow J, Czlonkowska A. Frequency and prognostic value of cognitive disorders in stroke patients. *Dement Geriatr Cogn Disord*. 2008;26:356-363.
- Bergersen H, Frosli KF, Sunnerhagen SK, Schanke AK. Anxiety, depression, and psychological well-being 2 to 5 years post-stroke. *J Stroke Cerebrovasc Dis*. 2010;19:364-369.

4. Hackett ML, Kohler S, O'Brien JT, Mead GE. Neuropsychiatric outcomes of stroke. *Lancet Neurol*. 2014;13:525-534.
5. Schepers V, Post M, Visser-Meily A, van de Port I, Akhmouch M, Lindeman E. Prediction of depressive symptoms up to three years post-stroke. *J Rehabil Med*. 2009;41:930-935.
6. Snaphaan L, van der Werf S, de Leeuw FE. Time course and risk factors of post-stroke fatigue: a prospective cohort study. *Eur J Neurol*. 2011;18:611-617.
7. Hallstrom B, Jonsson AC, Nerbrand C, Norrving B, Lindgren A. Stroke incidence and survival in the beginning of the 21st century in southern Sweden: comparisons with the late 20th century and projections into the future. *Stroke*. 2008;39:10-15.
8. Benatru I, Rouaud O, Durier J, et al. Stable stroke incidence rates but improved case-fatality in Dijon, France, from 1985 to 2004. *Stroke*. 2006;37:1674-1679.
9. Mokin M, Rojas H, Levy EI. Randomized trials of endovascular therapy for stroke—impact on stroke care. *Nat Rev Neurol*. 2016;12:86-94.
10. Addo J, Crichton S, Bhalla A, Rudd AG, Wolfe CD, McKeivitt C. Impact of implementing evidence-based acute stroke interventions on survival: the South London Stroke Register. *PLoS One*. 2013;8:e61581.
11. Donnellan C, Hevey D, Hickey A, O'Neill D. Defining and quantifying coping strategies after stroke: a review. *J Neurol Neurosurg Psychiatry*. 2006;77:1208-1218.
12. Hommel M, Trabucco-Miguel S, Joray S, Naegele B, Gonnet N, Jaillard A. Social dysfunctioning after mild to moderate first-ever stroke at vocational age. *J Neurol Neurosurg Psychiatry*. 2009;80:371-375.
13. Rochette A, Bravo G, Desrosiers J, St-Cyr Tribble D, Bourget A. Adaptation process, participation and depression over six months in first-stroke individuals and spouses. *Clin Rehabil*. 2007;21:554-562.
14. Singam A, Ytterberg C, Tham K, von Koch L. Participation in complex and social everyday activities six years after stroke: predictors for return to pre-stroke level. *PLoS One*. 2015;10:e0144344.
15. Desrosiers J, Rochette A, Noreau L, Bourbonnais D, Bravo G, Bourget A. Long-term changes in participation after stroke. *Top Stroke Rehabil*. 2006;13:86-96.
16. Hartman-Maeir A, Soroker N, Ring H, Avni N, Katz N. Activities, participation and satisfaction one-year post stroke. *Disabil Rehabil*. 2007;29:559-566.
17. World Health Organization. *Towards a Common Language for Functioning, Disability and Health: ICF*. Geneva, Switzerland: World Health Organization; 2002.
18. Woodman P, Riazi A, Pereira C, Jones F. Social participation post stroke: a meta-ethnographic review of the experiences and views of community-dwelling stroke survivors. *Disabil Rehabil*. 2014;36:2031-2043.
19. Burton CR. Living with stroke: a phenomenological study. *J Adv Nurs*. 2000;32:301-309.
20. Dijkers MP. Issues in the conceptualization and measurement of participation: an overview. *Arch Phys Med Rehabil*. 2010;91(9, suppl):S5-S16.
21. 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;19:459-481.
22. 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;34:478-485.
23. 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;43:1003-1009.
24. Hildebrand M, Brewer M, Wolf T. The impact of mild stroke on participation in physical fitness activities. *Stroke Res Treat*. 2012;2012:548682.
25. Edwards DF, Hahn M, Baum C, Dromerick AW. The impact of mild stroke on meaningful activity and life satisfaction. *J Stroke Cerebrovasc Dis*. 2006;15:151-157.
26. Appelros P. Characteristics of the Frenchay Activities Index one year after a stroke: a population-based study. *Disabil Rehabil*. 2007;29:785-790.
27. Drummond A. Leisure activity after stroke. *Int Disabil Stud*. 1990;12:157-160.
28. Blömer AM, van Mierlo ML, Visser-Meily JM, van Heugten CM, Post MW. Does the frequency of participation change after stroke and is this change associated with the subjective experience of participation? *Arch Phys Med Rehabil*. 2015;96:456-463.
29. van der Zee CH, Visser-Meily JM, Lindeman E, Kappelle JL, Post MW. Participation in the chronic phase of stroke. *Top Stroke Rehabil*. 2013;20:52-61.
30. Schepers VP, Visser-Meily AM, Ketelaar M, Lindeman E. Prediction of social activity 1 year post-stroke. *Arch Phys Med Rehabil*. 2005;86:1472-1476.
31. Jansen HE, Schepers VP, Visser-Meily JM, Post MW. Social activity one and three years post-stroke. *J Rehabil Med*. 2012;44:47-50.
32. Ostwald SK, Godwin KM, Cron SG. Predictors of life satisfaction in stroke survivors and spousal caregivers after inpatient rehabilitation. *Rehabil Nurs*. 2009;34:160-167, 174.
33. Boosman H, Schepers VP, Post MW, Visser-Meily JM. Social activity contributes independently to life satisfaction three years post stroke. *Clin Rehabil*. 2011;25:460-467.
34. Egan M, Davis CG, Dubouloz CJ, Kessler D, Kubina LA. Participation and well-being post-stroke: evidence of reciprocal effects. *Arch Phys Med Rehabil*. 2014;95:262-268.
35. Tse T, Yusoff BSZ, Churilov L, et al; START Research Team. Increased work and social engagement is associated with increased stroke specific quality of life in stroke survivors at 3 months and 12 months post-stroke: a longitudinal study of an Australian stroke cohort. *Top Stroke Rehabil*. 2017;24:405-414.
36. Tse T, Douglas J, Lentin P, Carey L. Measuring participation after stroke: a review of frequently used tools. *Arch Phys Med Rehabil*. 2013;94:177-192.
37. de Graaf JA, van Mierlo ML, Post MWM, Achterberg WP, Kappelle LJ, Visser-Meily JMA. Long-term restrictions in participation in stroke survivors under and over 70 years of age. *Disabil Rehabil*. 2018;40:637-645.
38. Nichols-Larsen DS, Clark PC, Zeringue A, Greenspan A, Blanton S. Factors influencing stroke survivors' quality of life during subacute recovery. *Stroke*. 2005;36:1480-1484.

39. van Mierlo ML, van Heugten CM, Post MW, Hajos TR, Kappelle LJ, Visser-Meily JM. Quality of life during the first two years post stroke: the Restore4Stroke Cohort study. *Cerebrovasc Dis*. 2016;41:19-26.
40. Kruisheer EM, Wajer HIMC, Visser-Meily JMA, Post MWM. Course of participation after subarachnoid hemorrhage. *J Stroke Cerebrovasc Dis*. 2017;26:1000-1006.
41. 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;9:148-154.
42. Collin C, Wade DT, Davies S, Horne V. The Barthel ADL Index: a reliability study. *Int Disabil Stud*. 1988;10:61-63.
43. 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.
44. 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;42:752-757.
45. Verhage F. *Intelligence and Age: Study With Dutch People Aged 12-77*. Assen, Netherlands: Van Gorcum; 1964.
46. Brott T, Adams HP Jr, Olinger CP, et al. Measurements of acute cerebral infarction: a clinical examination scale. *Stroke*. 1989;20:864-870.
47. 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;53:695-699.
48. Desrosiers J, Demers L, Robichaud L, et al. Short-term changes in and predictors of participation of older adults after stroke following acute care or rehabilitation. *Neurorehabil Neural Repair*. 2008;22:288-297.
49. Ronning OM, Stavem K. Determinants of change in quality of life from 1 to 6 months following acute stroke. *Cerebrovasc Dis*. 2008;25:67-73.
50. Cockburn J, Smith PT, Wade DT. Influence of cognitive function on social, domestic, and leisure activities of community-dwelling older people. *Int Disabil Stud*. 1990;12:169-172.
51. Akbari S, Ashayeri H, Fahimi MA, Kamali M, Lyden PD. The correlation of independency in activities of daily living performance with cognitive status and the intensity of neurological impairment in right-handed stroke patients. *NeuroRehabilitation*. 2011;29:311-316.
52. Benjamin EJ, Blaha MJ, Chiuve SE, et al; American Heart Association Statistics Committee and Stroke Statistics Subcommittee. Heart Disease and Stroke Statistics-2017 update: a report from the American Heart Association. *Circulation*. 2017;135:e146-e603.
53. van Mierlo M, van Heugten C, Post MWM, Hoekstra T, Visser-Meily A. Trajectories of health-related quality of life after stroke: results from a one-year prospective cohort study. *Disabil Rehabil*. 2018;40:997-1006.



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Author/s:

Verberne, DPJ; Post, MWM; Kohler, S; Carey, LM; Visser-Meily, JMA; van Heugten, CM

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