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The influence of psychological factors and mood on the course of participation up to four years after stroke

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ABSTRACT

Purpose: (1) To explore the course of participation from two months up to four years after stroke, and (2) to examine if adaptive and maladaptive psychological factors and mood measured at two months after stroke are determinants of the course of participation during this period.

Materials and methods: Prospective cohort study in which 369 individuals with stroke were assessed at stroke onset, two months, six months, one year, two years and three to four years after stroke. The Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) restrictions subscale was used to measure participation. Psychological factors were clustered into adaptive (proactive coping, self-efficacy, extraversion and optimism) and maladaptive (passive coping, neuroticism and pessimism) psychological factors. The Hospital Anxiety and Depression Scale was used to assess mood.

Results: Although improvements in participation were observed up to one year after stroke, considerable long-term restrictions in social and physical domains persisted. More mood problems and less adaptive psychological factors were independent determinants of worse participation up to four years after stroke.

Conclusions: Participation improves in the first 12 months after stroke and stabilizes afterwards. Mood problems and less adaptive psychological factors negatively influence the course of participation over time up to four years after stroke.

➤ IMPLICATIONS FOR REHABILITATION

- Follow-up assessments after stroke should not only focus on cognitive and motor impairment, but also encompass screening on mood problems and adaptive psychological factors.
- Implementation of a routine follow-up assessment one year after stroke can be beneficial as restrictions in participation are unlikely to diminish spontaneously from then onwards.

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Stroke; social participation; community participation; psychological factors; mood; long-term effects

Introduction

Stroke is the third most common cause of disability in the world [1], causing considerable long-term restrictions in social and community participation [2]. Participation, defined as "the person's involvement in a life situation" [3], is considered an important outcome of stroke rehabilitation as it provides clinicians valuable person-centered information on the impact of stroke on daily life [4]. Mirroring recovery of physical and cognitive functioning in the first months post-stroke, improvements in participation after stroke are observed in the first six months up to one year after stroke [5–9]. The course of participation beyond the first year after stroke remains largely unclear, as long-term prospective cohort studies regarding this subject are scarce and follow-up duration of these studies rarely exceeded one year. Nevertheless, many persons with stroke still experience restrictions in participation one year after stroke, including the domains outdoor mobility, work, housekeeping and partner relationships [10–12]. One study found participation in social activities to remain stable between one and three years after stroke [13], but another study reported a decline in participation in

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daily activities between six months and two to four years after stroke [14].

Mood problems and psychological factors are prominent among the many factors associated with participation levels in the long term after stroke [14–16]. Mood problems, including symptoms of anxiety and depression, are common in both the subacute and chronic phase after stroke [17]. Psychological factors, including coping styles and personality traits, are notable determinants of mood problems [18] and are suggested to have even more impact on participation after stroke than physical disabilities [2,19]. Surprisingly, psychological factors are often overlooked in current stroke literature; they are, for example, not included in a recent systematic review studying biopsychosocial determinants of long-term participation after stroke [20]. Also, longitudinal studies exploring the influence of psychological factors on participation are needed to reveal causal relationships and effects of time [21]. By identifying determinants influencing the course of participation, stroke survivors at risk for restrictions in participation in the chronic phase can be selected timely and potentially modifiable determinants can be managed.

Therefore, the first aim of this study was to explore the course of participation from two months up to four years after stroke. The second aim was to test whether adaptive and maladaptive psychological factors and mood problems measured at two months after stroke are determinants of the course of participation up to four years after stroke.

Methods

Design

The current study is an extension of the multicenter prospective longitudinal Restore4Stroke Cohort study and used data collected at stroke onset, two months, six months, one year, two years and four years after stroke [22]. Participants were recruited from six general hospitals in the Netherlands between March 2011 and March 2013. The Medical Ethics committees of all participating hospital approved this study. Written informed consent was obtained from all participants.

Participants

Patients were eligible if they had a clinically confirmed diagnosis of ischemic or hemorrhagic stroke, gave informed consent within seven days after symptom onset and were at least 18 years old. Patients were excluded from the study if they (1) had a serious other condition that could interfere with study outcomes; (2) had been dependent in basic activities of daily living before the stroke occurred (defined by a Barthel Index score of $\leq$17 [23]); (3) had insufficient command of Dutch language, based on clinical judgment; or (4) had suffered cognitive decline prior to the stroke (defined by a score of $\geq$1 on the Heteroanamnesis List Cognition [24]). Participants who completed the participation measure at least once after stroke were included in the analysis.

Procedure

After informed consent was obtained, stroke-related factors (type of stroke, hemisphere and stroke severity) assessed by the neurologist on day four after stroke were retrieved from the medical files. Demographic factors were obtained from the participant or from family members. At two months after stroke, screening on cognitive functioning, psychological factors and mood was conducted by a trained research assistant. Also, participants were asked to complete a self-report participation questionnaire at two and six months, and one, two and three to four years after stroke.

Dependent variables

The Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) restrictions subscale was used to measure participation at two and six months, and one, two and three to four years after stroke [11]. The restrictions subscale consists of 11 items, concerning difficulties experienced with vocational, leisure and social activities caused by the stroke (e.g., housekeeping, outdoor activities and partner relationship). Response categories are: "not possible," "with assistance," "with difficulty," and "without difficulty". A "not applicable" option is available for all items in case an activity is not performed for other reasons or a restriction is not attributed to the stroke. The total score of the restrictions subscale ranges from 0–100 and is based on items that are applicable. A higher score indicates a more favorable level of participation (fewer experienced restrictions). The USER-Participation has previously shown satisfactory validity and reliability [25] and excellent responsiveness in stroke patients [26,27].

Independent variables

Demographic factors

Information about gender, age, marital status and level of education was collected. Level of education was dichotomized into low (up to completed secondary education) and high (completed higher secondary professional education or university).

Stroke-related factors

Information about severity of stroke, history of stroke, hemisphere, stroke type, ADL dependency, cognitive functioning, length of stay in the hospital and discharge destination was collected. Stroke severity was assessed with the National Institutes of Health Stroke Scale (NIHSS) four days after stroke [28]. Scores range from 0–42 and higher scores indicate more severe stroke. ADL dependency was assessed using the BI four days after stroke. Scores range from 0–20 and higher scores indicate fewer ADL dependencies [23]. Cognitive functioning two months after stroke was assessed using the Montreal Cognitive Assessment (MoCA) [29]. Scores range from 0–30 and higher scores indicate better cognitive functioning. Discharge destination after hospitalization was categorized into home or inpatient rehabilitation.

Mood

The severity of mood problems two months after stroke was assessed by the Hospital Anxiety and Depression Scale (HADS), which has good psychometric properties and is commonly used for stroke population [30]. Scores range from 0 to 42, a higher score indicating more mood problems.

Psychological factors

All psychological factors were measured with valid and reliable scales at two months after stroke [22,31–35].

Optimism and pessimism were assessed with the Life Orientation Test-Revised [31]. This questionnaire consists of six items, three items each measuring optimism and pessimism and are scored on a five-point scale.

Neuroticism and extraversion were assessed with the Neuroticism and Extraversion scales of the Eysenck Personality Questionnaire Revised Short Scale [32]. Both scales consist of 12 items with dichotomous (yes/no) response option.

Passive coping was assessed with the passive reaction pattern subscale of the Utrecht Coping List [33]. This subscale consists of seven items scored on a 4-point scale and is found to be reliable and valid to assess passive coping [33]. Proactive coping competencies were assessed with the Utrecht Proactive Coping Competence List [34]. This list consists of 21 items scored on a 4-point scale.

Self-efficacy was assessed with the General Self-Efficacy Scale [35]. This scale consists of 10 items scored on a 4-point scale.

Statistical analysis

All analyses were conducted with IBM SPSS statistics version 24 (IBM, Armonk, NY). Descriptive statistics were used to describe participant characteristics and dependent variables.

Psychological scales

We clustered adaptive and maladaptive psychological factors, based on theoretical arguments and findings of exploratory factor analyses as described in an earlier study [36]. Passive coping, neuroticism and pessimism are maladaptive psychological factors associated with decreased quality of life after stroke, whereas proactive coping, self-efficacy, extraversion and optimism are adaptive psychological factors associated with increased quality of life after stroke [21,37–40].

First, scores on all measures were standardized to obtain a common metric (mean = 0 and SD = 1). After that, the adaptive psychological factor score (A-PF) was computed as the average of the standardized scores on extraversion, optimism, proactive coping and self-efficacy. Similarly, the maladaptive psychological factor score (M-PF) was computed as the average of the standardized scores on neuroticism, pessimism and passive coping.

Item scores USER-Participation. The USER-Participation restrictions items were dichotomized to quantify the presence of persisting restrictions. "With difficulty," "with assistance," and "not possible" were defined as "restrictions" and "without difficulty" was defined as "no restrictions". The differences in participation scores between different timepoints were analyzed in participants who completed the follow up till three to four years after stroke. To ascertain overall differences over time across all test occasions in total participation scores and in participation item scores, the Friedman's test and Cochrane's Q test were calculated respectively. To ascertain differences between two consecutive test occasions in total participation scores and participation item scores, the Wilcoxon signed-rank test and McNemar's test were calculated, respectively.

Mixed model

The course of participation over time after stroke was analyzed using a linear mixed model. All available data could be used as participants who completed the follow-up assessment at least once were available for the mixed model analysis. This statistical method contains fixed effects (differences from the overall mean) and random effects (variance component, allowing the average response to vary between clusters) and can be used to explore the course of participation using repeated measurements over time. In this way, we were able to explore the influence of the maladaptive and adaptive psychological scales and mood problems on the course of participation over time, taking into account the effects of known predictors such as demographic and stroke-related factors.

First, the course of participation over time was modelled with time as continuous variable, using the exact dates of measurements for every single participant. Since this course over time is non-linear, both linear and quadratic functions of time were added in sequence [41]. Time was entered as random factor, with random intercepts across persons. The USER-Participation restrictions subscale was entered as continuous variable. Secondly, potential predictors were added as fixed factors to the linear mixed model, using a hierarchical approach: known predictors were entered into the model first. The predictors were divided into "demographic" (age, gender, education), "stroke-related" (NIHSS, MoCA, discharge destination), "psychological factors" (A-PF, M-PF) and "mood" (HADS). Age, NIHSS, MoCA, HADS, A-PF and M-PF were entered as continuous variables. Gender, education and discharge destination (inpatient rehabilitation vs. home) were entered as dichotomous variables. Maximum-likelihood estimation was used to assess model fit (-2loglikelihood). Bivariate associations between mood, M-PF and A-PF were tested using Spearman correlations.

In the first model (model 1), stroke-related and demographic variables were fitted. In the second model, the stroke-related factors and demographic factors combined with either mood (model 2a), M-PF (model 2 b) or A-PF (model 2c) were fitted. Lastly, a model was fitted with all variables together (model 3). Predictors were separately tested for possible interactions with time (linear and quadratic terms). A $p < 0.05$ was considered as statistically significant.

Results

A total of 395 participants were included in the Restore4Stroke study. The number of participants who completed the participation measure differed at each time point: 343 participants at two months, 344 participants at six months, 326 participants at one year, 319 participants at two years and 136 participants at three to four years after stroke. A total of 369 participants completed the participation measure at least once and were available for the mixed model analysis. Twenty-six participants (6.6%) had missing participation data at all time points as they had dropped out during the first two months of this study: two participants had died, 16 refused further participation, one was lost to follow-up and seven participants dropped out because of an insufficient general physical condition.

Participant characteristics are presented in Table 1. Except for age and at stroke onset and ADL dependency at two months after stroke, there were no significant differences in baseline characteristics between participants and dropouts at three to four years after stroke.

Course of participation

The course of participation (total and item scores) over time of participants who completed the follow up till three to four years after stroke ($n = 136$) are presented in Table 2 and Figure 1. A total of 233 participants (59%) had dropped out of the study population ($n = 395$) during follow-up: 33 participants had died, 120 refused further participation, 71 were lost to follow-up and

Table 1. Participant characteristics.

Study participants:		Total ($n = 369$)	At 4 years ($n = 136$)	Dropouts ($n = 233$)	p Values[b]
Demographic factors					
Sex (% male)		64.5	68.4	62.2	0.415
Age in years		66.7 ± 12.4	64.0 ± 10.9	68.3 ± 12.9	0.020*
Marital status (% living together)		69.4	74.3	66.5	0.284
High education level (%)[a]		27.0	27.2	26.8	0.959
Stroke-related factors					
Ischemic stroke (%)		93.0	91.9	93.6	0.690
Left hemisphere (%)		40.2	34.8	43.3	0.257
First stroke (%)		87.5	85.3	88.8	0.168
Severity of stroke four days after stroke (NIHSS)		2.7 ± 3.2	2.7 ± 3.0	2.7 ± 3.3	0.738
No stroke symptoms (% NIHSS 0)		24.4	23.5	24.9	
Minor stroke symptoms (% NIHSS 1-4)		56.1	56.6	55.8	
Moderate stroke symptoms (% NIHSS 5-12)		17.3	18.4	16.7	
Severe stroke symptoms (% NIHSS $\geq$ 13)		2.2	1.5	2.6	
ADL 2 months after stroke (BI)		20 ± 2.1	20 ± 1.3	20 ± 2.4	0.022*
% ADL-dependent (BI $\leq$17)		9.4	4.6	12.2	0.019*
Cognitive functioning 2 months after stroke (MoCA)		23.6 ± 4.0	24.3 ± 3.6	23.1 ± 4.2	0.119
% cognitively impaired (MoCA $\leq$ 25)		67.6	60.0	72.2	0.076
Length of stay in hospital (in days)		8.5 ± 6.2	8.0 ± 5.5	8.8 ± 6.6	0.289
Discharge home after hospital stay (%)		71.0	75.0	68.7	0.374
Mood					
Mood 2 months after stroke (HADS)		9.4 ± 7.3	9.7 ± 6.5	9.2 ± 7.7	0.366
% impaired (HADS $\geq$11)		37.4	44.3	33.2	0.170
Psychological functioning					
Extraversion (EPQ-RSS-E)	$n = 345$	7.1 ± 3.2	7.1 ± 3.4	7.1 ± 3.1	0.989
Neuroticism (EPQ-RSS-N)	$n = 345$	3.6 ± 3.1	3.6 ± 3.3	3.7 ± 3.0	0.679
Optimism (LOT-R)	$n = 346$	8.2 ± 2.1	8.1 ± 2.0	8.2 ± 2.2	0.788
Pessimism (LOT-R)	$n = 345$	4.4 ± 2.8	4.2 ± 2.6	4.5 ± 2.9	0.521
Self-efficacy (GSES)	$n = 345$	31.6 ± 6.4	32.0 ± 5.6	31.3 ± 6.8	0.782
Proactive coping (UPCC)	$n = 345$	64.8 ± 11.9	66.1 ± 10.7	64.0 ± 12.5	0.385
Passive coping (UCL-P)	$n = 346$	10.5 ± 2.8	10.7 ± 2.6	10.4 ± 3.0	0.266

Values are percentages or mean ± SD. ADL: activities of daily living; BI: Barthel Index; EPQ-RSS-N and EPQ-RSS-E: Eysenck Personality Questionnaire Revised Short Scale Neuroticism and Extraversion; GSES: General Self-Efficacy Scale; LOT-R: Life Orientation Test-Revised; UCL-P: Utrecht Coping List; UPCC: Utrecht Proactive Coping Competence List.
[a]Completed University of Professional Education and higher.
[b]Comparison between population 'at four years' and 'dropouts'.
*p values are significant ($p < 0.05$).

Table 2. Course of participation after stroke of participants who completed the follow up till four years after stroke ($n = 136$).

USER-P restriction scale[a]	2 months[c]	6 months[c]	1 year[c]	2 years[c]	4 years[c]	p Value[c]
Mean (SD)	74.1 (±21.3)	80.9 (±18.3)#	82.9 (±19.0)#	82.1 (±21.2)	83.0 (±20.1)	<0.001*
Median	75.8	85.7	87.5	91.3	91.8	
IQR	57.6–93.9	69.7–96.7	70.8–100	66.8–100	70.9–100	
Restriction scale items:			Persisting restrictions in items USER-P (%)[b]			
Work/education	78.3	66.7	47.3#	46.6	35.7	<0.001*
Housekeeping	60.8	52.0	48.4	44.8	42.5	0.002*
Mobility	59.5	44.9#	34.4#	34.1	30.0	<0.001*
Physical exercise	62.2	54.2	53.2	46.7	51.6	0.020*
Going out	59.6	47.1#	36.0	41.8	38.3	<0.001*
Outdoor activities	60.2	48.6#	46.0	48.3	44.6	0.002*
Leisure indoors	39.0	27.5#	24.8	20.8	20.5	<0.001*
Partner relationship	22.6	31.3	33.3	31.5	32.2	0.397
Visits to family/friends	49.6	40.3	29.5	33.3	30.5	<0.001*
Visits from family/friends	24.4	27.3	18.9	21.1	17.8	0.118
Telephone/PC contact	16.7	19.4	21.5	16.9	20.3	0.723

IQR: interquartile range.
[a]USER-P restriction scale: higher score indicates good level of participation (less restrictions).
[b]USER-P restriction items values are percentages of participants who are restricted.
[c]Different p values were calculated to ascertain significant differences between all time points (cited with *) and between two consecutive time points (cited with#).
#p values are significant ($p < 0.05$), comparing the cited time point with the previous time point.
*p values are significant ($p < 0.05$), comparing all time points.

35 participants dropped out because of an insufficient general physical condition.

Overall participation improved over time up to four years after stroke ($p < 0.001$). Improvements took place between two and six months ($p < 0.001$) and six months and a year ($p = 0.012$) after stroke. Almost all item scores improved between two months and four years after stroke, except for partner relationship, visits from family/friends and telephone/pc contact. Restrictions in going out ($p = 0.029$), outdoor activities ($p = 0.024$) and leisure indoors ($p = 0.015$) improved between two and six months after stroke.

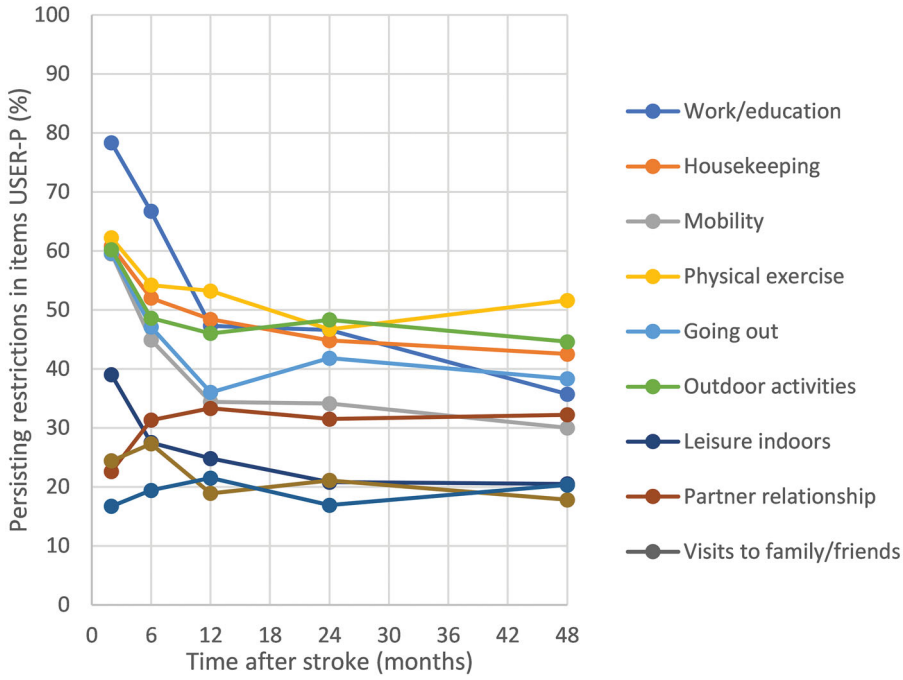

Figure 1. The course of the proportion of participants (who completed the follow up till four years after stroke, $n = 136$) experiencing restrictions in participation items over time.

Table 3. Linear mixed model analyses showing the predictions of participation restrictions (USER-P restrictions subscale) over time.

	Model 1: basic model		Model 2a: HADS		Model 2b: M-PF		Model 2c: A-PF		Model 3: final model	
	Coef. β	95% CI	Coef. β	95% CI	Coef. β	95% CI	Coef. β	95% CI	Coef. β	95% CI
Intercept	63.03**	45.56–80.50	84.60**	68.09–101.11	100.51**	80.50–120.53	35.79**	17.96–53.61	66.44**	43.67–89.21
Time	0.44**	0.28–0.60	0.45**	0.29–0.61	0.43**	0.27–0.59	0.44**	0.28–0.60	0.44**	0.28–0.61
Time*Time	−0.01**	−.01–0	−0.01**	−0.01–0	−0.01**	−0.01–0	−0.01**	−0.01–0	−0.01**	−0.01–0
Age	−0.13	−0.28–0.02	−0.21*	−0.34–−0.07	−0.16*	−0.30–−0.02	−0.12	−0.26–0.02	−0.18*	−0.32–−0.05
Gender	6.80**	3.23–10.37	5.25**	2.08–8.43	5.15*	1.73–8.57	6.00**	2.63–9.36	5.08*	1.94–8.22
Education	0.40	−3.21–4.02	−0.13	−3.31–3.05	1.04	−2.38- 4.47	1.49	−1.91-4.88	0.53	−2.62–3.69
Stroke severity (NIHSS)	−1.12**	−1.77–−0.47	−1.34**	−1.91–−0.77	−0.99*	−1.61–−0.38	−0.96*	−1.57–−0.34	−1.18**	−1.75–−0.61
Cognitive functioning (MoCA)	0.89**	0.41–1.36	0.67*	0.24–1.09	0.58*	0.12–1.03	0.77**	0.32–1.21	0.68*	0.26–1.11
Discharge destination	−9.58**	−13.97–−5.20	−8.05**	−11.93–−4.17	−10.27**	−14.42–−6.12	−10.32**	−14.46–−6.17	−9.15**	−13.02–−5.29
Emotional functioning (HADS)			−1.08**	−1.29–−0.86					−0.95**	−1.24–−0.66
Maladaptive psychological scale					−0.56**	−0.72–−0.39			0.02	−0.19-0.24
Adaptive psychological scale							0.58**	0.42-0.75	0.27*	0.09-0.44
−2 Restricted Log Likelihood Ratio	11720.76		11513.00		11575.97		11567.72		11380.49	

β: standardized regression coefficient; CI: confidence interval.
*$p < 0.05$.
**$p < 0.001$.

Restrictions in work/education improved between six months and one year ($p = 0.039$) and restrictions in mobility improved between two months and one year ($p = 0.004$). At three to four years after stroke, a considerable percentage of participants experienced restrictions in participation, such as physical exercise (51.6%), outdoor activities (44.6%) and housekeeping (42.5%).

Mixed model analyses

No significant interaction effects between time and other variables were found. The results of the linear mixed model analyses are presented in Table 3.

Model 1

Model 1 (including stroke-related and demographic variables) showed that female gender, a more severe stroke, impaired cognitive functioning and discharge to inpatient rehabilitation were associated with worse participation.

Model 2

Model 2 showed that, adjusted for demographic and stroke related factors, more mood problems (model 2a), more M-PF (model 2 b) and less A-PF (model 2c) were all associated with worse participation.

Model 3

Model 3 (including stroke related factors, demographic factors, mood, A-PF and M-PF) showed that more mood problems and less A-PF were associated with worse participation. In contrast to model 2 b, M-PF was not significantly associated with participation when taking emotional functioning and A-PF into account. Based on the comparison of the -2Restricted Log Likelihood Ratios, model 3 showed the best fit of all models. Spearman

correlations between mood and M-PF ($r = 0.66$, 95% CI = 0.59–0.72, $p < 0.001$), mood and A-PF ($r = 0.48$, 95% CI = 0.39–0.56, $p < 0.001$) and M-PF and A-PF ($r = 0.51$, 95% CI = 0.42–0.59, $p < 0.001$) were strong.

Discussion

This study shows that the course of participation improves up to one year after stroke and stabilizes afterwards. Considerable restrictions in participation were observed after one year, predominantly in dynamic activities such as physical exercise, outdoor activities and housekeeping. Furthermore, less adaptive psychological factors and mood problems assessed at two months after stroke were associated with worse participation up to four years after stroke. Early detection of mood problems after stroke can be achieved using the HADS. The development of a brief screening tool is needed to enable early detection of adaptive psychological factors after stroke. Timely treatment of mood problems and the development of interventions promoting adaptive psychological factors during rehabilitation could potentially prevent restrictions in long-term participation after stroke.

In alignment with other studies, the improvements in participation over time largely took place in the first six months and stabilized after twelve months [13,14,42]. Possibly, persons with stroke are able to adjust their lives according to their new situation as soon as their functional recovery is stabilizing, explaining the similarity in course of functional recovery and participation [43]. Although no improvements in participation have been observed in persons with stroke after one to four years in this study, qualitative research shows the course of participation in chronic stroke is a dynamic and individual process influenced by several interacting personal and contextual factors [44,45]. As improvements in participation cease after one year, nearly half of persons with stroke face restrictions in social and physical domains four years after stroke, predominantly in dynamic activities requiring both mobility and cognitive skills. This has also been observed in previous studies, including a rehabilitation population and a cross-sectional study at four years after stroke [11,46].

Previous literature also described associations between various adaptive psychological factors and participation, even in multivariate analyses when taking into account the presence of depressive symptoms [47–49]. In a cross-sectional study, hopeful thinking, self-esteem and the absence of depressive symptoms were identified as most important predictors of participation 12 months after stroke [47]. In a prospective cohort study, acceptance of stroke and the presence of depressive symptoms were among the main contributors of participation in social roles up to six months after stroke [48]. In another prospective cohort study, positive affect was identified as independent predictor of social participation three months after discharge from the rehabilitation center [49]. As these studies lacked a long-term follow-up, this is the first study proving adaptive psychological factors being notable determinants of the course of participation up to four years after stroke.

The importance of adaptive psychological factors is also shown in recent qualitative research, as stroke survivors state that the ability to accept stroke-related problems and adapt accordingly are key to successful participation after stroke [50–52]. Interestingly, adaptive psychological factors are not fixed over time, as they seem to deteriorate during the first two years after stroke [36]. This emphasizes the importance of the development of interventions to enhance adaptive psychological factors during early stages of rehabilitation, for example interventions promoting self-efficacy, proactive coping and being optimistic [53,54].

The association between maladaptive psychological factors and participation vanished in the final model. The strong correlation between maladaptive factors and mood problems could be a possible explanation. Maladaptive psychological factors such as passive coping have been determined as independent predictors of the presence of mood problems in earlier studies [18,55–57]. Therefore, it seems plausible that mood problems mediated the effect of maladaptive factors on the course of participation in the final model of this study.

The relation between psychological factors and participation has also been studied in other neurological diseases, although most studies mainly focused on maladaptive psychological factors [58–60]. Cross-sectional studies identified helplessness in persons with amyotrophic lateral sclerosis and lower self-efficacy scores in persons with spinal cord injury as psychological factors related to restrictions in participation [58,59]. A longitudinal study of persons with traumatic brain injury identified passive coping, neuroticism and mood problems as determinants of restrictions in participation [60].

Study strengths

This is the first study using adaptive and maladaptive psychological clusters to study determinants of participation after stroke. The use of mixed model analyses, which allowed us to include all available data, the large sample size and long-term follow-up increased the power of the study. The study population represents the stroke population well, as inclusion took place in hospitals within seven days of stroke onset. This study builds on previous publications using the Restore4Stroke cohort to study demographic and stroke-related factors as determinants of participation [12,41,42]. The current study adds a prolonged follow-up duration up to four years after stroke and insight into the relation between participation and psychological factors.

Study limitations

Firstly, the study population largely consisted of relatively mild stroke patients with mostly ischemic strokes. Although this is in line with the epidemiology of stroke, it could negatively affect the generalizability of the results to more severely affected stroke patients and those with other types of strokes. Secondly, more than half of the study population dropped out during follow-up. However, apart from age and ADL dependency, no significant differences at baseline were found between the participants still in the study at four years and the dropouts. Thirdly, despite the USER-P restriction subscale specifically asks for restrictions caused by the stroke, it could have been challenging for participants to distinguish restrictions in participation caused by the stroke and those due to, for example, normal aging or comorbidities. This may have caused an overestimation of restrictions in participation over time caused by the stroke [61].

Conclusions

Among persons with stroke participation restrictions are considerable up to four years after stroke, especially in dynamic activities requiring both mobility and cognitive skills. Improvements in participation are only observed up to one year after stroke. Hence, the addition of a follow-up assessment one year after stroke can be beneficial as restrictions in participation are likely to be

permanent from then onwards. Both mood problems and less adaptive psychological factors are independently associated with worse participation up to four years after stroke. Therefore, follow-up assessments after stroke should not only focus on cognitive and motor impairment, but also encompass screening on mood problems and adaptive psychological factors.

Disclosure statement

The authors declare no conflict of interest.

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Data availability statement

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

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