Comprehensive measurement of long-term outcomes and costs of rehabilitation in patients with stroke

Meijeren-Pont, W. van

Chapter 5

Patient activation during the first 6 months after the start of stroke rehabilitation

van Meijeren-Pont W | Tamminga SJ | Fiocco M | Gonzalez Avila A | Volker G | Janssen SMJ | Vliet Vlieland TPM | Oosterveer DM | on behalf of the SCORE study group

Archives of Physical Medicine and Rehabilitation. 2022;103(7):1360-1367.

Abstract

Objective

To examine patient activation from the start of stroke rehabilitation and its course up until the 6-month follow-up.

Design

Inception cohort study with a follow-up of 6 months.

Setting

Multidisciplinary rehabilitation facility.

Participants

A total of 478 stroke patients (n=478) who received inpatient or outpatient rehabilitation, with a median age of 63.0 years (interquartile range, 56.0-70.0 years) with 308 (64.2%) being men. The study was completed by 439 (91.8%) patients.

Interventions

Not applicable.

Main Outcome Measures

Patient activation was measured with the Patient Activation Measure (PAM) (score 0-100, 4 levels, where a higher score and level denotes more patient activation). The PAM was measured at the start of the rehabilitation (baseline) and 3 and 6 months thereafter and was analyzed using the multivariate mixed model analysis.

Results

At baseline, the mean PAM score was 60.2±14.3, with the number of patients in PAM levels 1, 2, 3, and 4 being 76 (17.8%), 85 (19.9%), 177 (41.4%), and 90 (21.0%), respectively. The multivariate mixed-model analysis demonstrated that the PAM score increased over time (baseline 60.2±14.3) vs 3 months 60.7±14.8 vs 6 months 61.9±18.0; *P* .007). Between baseline and 6 months, 122 patients (41.4%) remained at the same PAM level, 105 patients (35.6%) increased, and 68 patients (23.1%) decreased. At all time points, >35% of patients were in level 1 or 2.

Conclusions

PAM scores increased slightly over time from the start of rehabilitation up to the 6 month follow-up. However, more than one-third of patients remained at low levels (ie, level 1 and 2) of patient activation, which indicates that specific interventions during rehabilitation to increase patient activation might be of value.

Introduction

Stroke is a common health problem worldwide, leading 50% of patients to develop a chronic condition with a combination of motor, communication, cognitive, or emotional limitations[1-5].

In patients with chronic conditions, such as stroke, self-management is of great importance[6]. Self-management refers to the strategies, decisions, and activities individuals take to manage a long-term health condition[7]. Specifically in patients with stroke, 3 subdomains of self-management strategies can be distinguished: focusing on prevention of a secondary stroke, adherence to exercises, and enhancement of participation and activities of daily living[6]. A review has shown that adding training for these self-management strategies during stroke rehabilitation can improve activities of daily living and independence[8].

To use self-management strategies, patient activation is a prerequisite[9]. Patient activation is defined as one's role in the care process and having the knowledge, skills, and confidence to manage one's health and health care. A review demonstrated that patients with chronic conditions who are more activated have better health outcomes and better care experiences than those who are less activated. However, patients with stroke were not included[10].

Until now, there was only 1 questionnaire that measures patient activation: the Patient Activation Measure (PAM)[11]. The PAM distinguishes passive patients who experience no influence on their health from active patients who do experience this influence.

Although having a sufficient level of activation is important for patients with stroke, research on this topic in patients with stroke is scarce. To our knowledge, there are only a few studies done in community-based[12-15] or hospital-based[16] patients with stroke. These studies show different levels of patient activation, varying between a level where patients are disengaged and overwhelmed[16] to a level where patients are maintaining behaviours and pushing further[12].

Increasing patient activation during stroke rehabilitation is not explicitly included in stroke rehabilitation guidelines as a treatment goal[17,18]. Consequently, stroke rehabilitation is mainly aimed at improving limitations after stroke and is not specifically aimed at increasing patient activation[19]. We therefore hypothesized that patient activation does not improve or only slightly improves during and after stroke rehabilitation. Therefore, the aim of this prospective observational study is to examine patient activation at the start of the rehabilitation, and the course of patient activation up until the 6 month follow-up.

Methods

Study design

This study was part of the Stroke Cohort Outcomes of REhabilitation (SCORE) study, a cohort study in a rehabilitation facility, which started in March 2014 and ended in December 2019. This study has been described extensively elsewhere[20]. The protocol of the study is registered in the Netherlands Trial Register. This study is reported according to the STrengthening the Reporting of OBservational studies in Epidemiology guidelines[21].

Study population

Consecutive patients with stroke who received inpatient or outpatient multidisciplinary rehabilitation were invited by the rehabilitation physician to participate in the SCORE study when they (1) were 18 years or older; (2) had a first or recurrent stroke less than 6 months prior; (3) had no psychiatric disorder or dementia; and (4) were able to complete questionnaires in Dutch. After patients were checked for their eligibility, were willing to participate, and provided written informed consent, they were included in the study.

Procedure

The protocol of the study was approved by the Medical Ethics Board of the Leiden University Medical Center (NL465321.058.13).

Patients filled in questionnaires on paper or online, depending on their preference. When there was no response within 10 days, patients were contacted by telephone or e-mail, with a maximum of 2 reminders.

The PAM was added to the set of questionnaires in March 2016. Therefore, the current study comprises patients between March 2016 and December 2019 who completed the PAM at least at 1 time point. When patients had extreme changes on the PAM at different time points (ie, a maximum score of 100 at one time point and a minimum score of 0 at another time point), they were considered as outliers and excluded.

Assessments

At the start of the rehabilitation (ie, baseline) baseline characteristics and patient reported-outcome measures were collected.

Baseline characteristics

Age, sex, and type of stroke (ischemic/haemorrhagic) were extracted from the patients' medical file. A questionnaire was used to assess the level of education (6-point scale split into 3 categories according to the Dutch system, ie, low, medium, high), living situation (married or living with a partner), paid work before stroke, and the number of comorbidities (by the Dutch study on Life Situation Questionnaire[22]). Questions about lifestyle prior to stroke included smoking (≥ 1 cigarette per day), alcohol (≥2 glasses per day), and physical activity (30 minutes of moderate to intensive daily physical activity.

A nurse assessed the Barthel Index at baseline only in patients receiving inpatient rehabilitation. This is a measure of functional independence with a score ranging from 0-20, where higher scores indicate more functional independence[23].

Patient-reported outcome measures

Health-related quality of life (HRQoL) was assessed with the EuroQol 5-Dimension 3-Level (EQ-5D-3L)[24]. The EQ-5D-3L, which consists of 5 questions concerning 5 domains (ie, mobility, self-care, usual activities, pain/discomfort, anxiety/depression), leads to an index ranging from -0.33 (worst imaginable health state) to 1 (best imaginable health state). In addition, the EQ-5D-3L comprises a visual analogue scale, ranging from 0-100.

The Stroke Impact Scale (SIS)[25] was used to measure self-reported effect of stroke on the domains mobility, communication, memory and thinking, and mood and emotions. Summative scores for each domain range from 0-100, where higher scores indicate better functionality.

Patient activation

Patient activation was assessed at baseline, at 3 months and at 6-month follow-up by means of the PAM[11]. This generic measure consists of 13 items, with ratings on a 5-point Likert-type scale (disagree strongly, disagree, agree, agree strongly, and not applicable). Total scores range from 0-100, where higher scores denote higher patient activation[9].

The PAM score can be divided in 4 progressively higher activation levels. Patients at level 1 (score 0.0-47.0) may not yet understand that their role is important. Patients at level 2 (score 47.1-55.1) lack confidence and knowledge to take action. Patients at level 3 (55.2-72.4) are beginning to take action, whereas patients at level 4 (72.5-100) are proactive about health and take action to perform many recommended health behaviours[26].

The Dutch version of the PAM has shown adequate psychometric properties in people with a chronic illness[27]. In persons with neurological conditions (patients without stroke) the PAM was found to have good internal reliability and to be valid for research purposes[28].

Statistical analyses

Data were analysed with SPSS Statistics for Windows Version 22.0. Data were presented descriptively. A *p* value of .05 was considered statistically significant.

To analyze whether there were differences in baseline characteristics between patients with paired measurements on the PAM at baseline and at 6 months and patients without paired measurements, Mann–Whitney U tests, Fisher exact tests, and chi-square tests were used, where appropriate. The same tests were used to compare all patients included in the current analyses and patients who were excluded in the current analyses (because they did not complete the PAM or were outliers).

Baseline characteristics of patients at the 4 PAM levels were compared using chi-square tests and Kruskal-Wallis tests. Post hoc tests with Bonferroni correction to correct for multiple testing were performed in case of significant differences.

To evaluate the course of the PAM scores, univariate and multivariate linear mixed-model analyses were used. A random slope and intercept model with unstructured covariance structure was fitted with measurements at baseline, 3 months, and 6-month follow-up. Possible confounders, that is, age, SIS communication, SIS memory and thinking, and SIS mood and emotions, were selected based on clinical experience. When significant in the univariate analysis, the covariable was incorporated in the multivariate model. The normality assumption of the model was checked by visual inspection of the residuals.

To evaluate the course of PAM levels for individual patients, descriptive statistics were used. For patients who filled in the PAM at baseline and at 6 months, PAM levels at these time points were graphically shown in a Sankey diagram.

Results

Between March 2016 and December 2019, a total of 506 patients with stroke were included in the SCORE study (Figure 1). Of them, 28 (5.5%) were excluded from the current analyses because 26 did not complete a PAM at any time point, and 2 had a maximal PAM score of 100 at one time point and a minimal PAM score of 0 at another time point. The frequency of an ischemic stroke was lower in these excluded patients than in the included 478 patients (64.3% versus 82.1%, $p < .001$). Other characteristics were not significantly different between these groups (results not shown).

Figure 1. Flowchart of patients with stroke included in the study between March 2016 and December 2019.

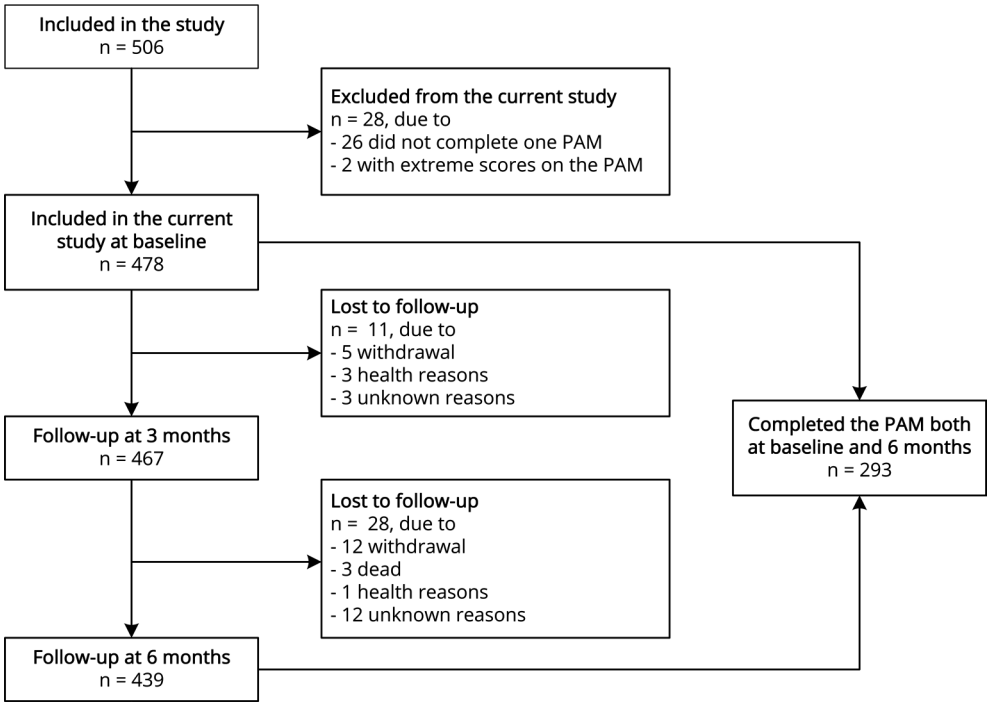


Table 1. Baseline and clinical characteristics and patient-reported outcome measure scores of patients with stroke included in the statistical analyses.

Characteristic	**Total Group Included in Analyses** (n = 478)		**Paired Measurements on the PAM at Baseline and 6 months** (n = 293)		**No Paired Measurements on the PAM** (n = 185)		***p* value***
	n		n		n		
Age (y), median (IQR)	477	63.0 (56.0-70.0)	293	64.0 (57.0-70.0)	184	62.0 (53.0-69.0)	**.041**
Men, n (%)	478	306 (64.0)	293	186 (63.5)	185	120 (64.9)	.770
Education, n (%)	469		292		177		.340
Low		197 (42.0)		128 (43.8)		69 (39.0)	
Medium		134 (28.6)		85 (29.1)		49 (27.7)	
High		138 (29.4)		79 (27.1)		59 (33.3)	
Married or living with a partner, n (%)	466	285 (61.2)	290	188 (64.8)	176	97 (55.1)	**.040**
Paid work before stroke, n (%)[†]	258	193 (74.8)	155	115 (74.2)	113	85 (75.2)	.888
No. of comorbidities, median (IQR)	392	2.0 (1.0-3.0)	249	2.0 (1.0-3.0)	143	2.0 (1.0-3.0)	.638
Smoking ≥1cigarettes/d prestroke, n (%)	465	155 (33.3)	287	80 (27.9)	178	75 (42.1)	**.002**
Alcohol ≥2 glasses/d prestroke, n (%)	458	48 (10.5)	283	28 (9.9)	175	20 (11.4)	.639
Physically active, n (%)	457	151 (33.0)	286	89 (31.1)	171	62 (36.3)	.261
Ischemic stroke, n (%)	475	390 (82.1)	293	241 (82.3)	182	149 (81.9)	.903
Inpatient rehabilitation, n (%)	478	379 (79.3)	293	226 (77.1)	185	153 (82.7)	.165
Barthel Index, median (IQR)[‡]	309	17.0 (12.0-19.0)	191	17.0 (12.0-19.0)	118	16.5 (10.0-18.0)	.115
HRQoL EQ-5D-3L index, median (IQR)	434	0.78 (0.56-0.86)	282	0.78 (0.57-0.89)	152	0.76 (0.52-0.86)	.112
HRQoL EQ-5D-3L VAS, median (IQR)	442	66.0 (50.0-80.0)	287	66.0 (50.0-80.0)	155	65.0 (50.0-80.0)	.405
SIS mobility, median (IQR)	445	83.3 (53.9-97.2)	289	83.3 (60.9-97.2)	156	77.8 (38.9-94.4)	**.013**
SIS communication, median (IQR)	450	92.9 (75.0-100.0)	290	92.9 (78.6-100.0)	160	92.9 (75.0-100.0)	.902
SIS memory and thinking, median (IQR)	450	85.7 (67.9-96.4)	289	85.7 (71.4-96.4)	161	85.7 (67.9-96.4)	.579
SIS mood and emotions, median (IQR)	449	77.8 (66.7-88.9)	290	77.8 (66.7-88.9)	159	77.8 (66.7-88.9)	.775

Abbreviations: HRQoL, health-related quality of life; SIS, stroke impact scale; VAS, visual analogue scale.
**P* values of comparison between patients who completed the PAM at baseline and 6 mo and patients without paired measurement on the PAM. Mann–Whitney *U* tests for continuous variables, Fisher Exact tests for ordinal variables and χ^2 tests for dichotomous variables, where appropriate.
[†] Only for patients aged <66 y.
[‡] Only for inpatients.

Table 1 shows the characteristics and patient-reported outcome measure scores of all included patients. Median age of all 478 patients was 63.0 years (interquartile range [IQR], 56.0-70.0 years) and 306 of them (64.0%) were men. The 293 patients with paired measurements on the PAM at baseline and at 6 months were significantly older (median, 64.0 years [IQR, 57.0-70.0 years] vs median, 62.0 years [IQR, 53.0-69.0 years], $p = .041$), were more often married or living with a partner (188 [64.8%] vs 97 [55.1%], $p = .040$), were smoking less often (80 [27.9%] vs 75 [42.1%], $p = .002$) and had a higher score for mobility (median, 83.3 [IQR 60.9-97.2] vs median, 77.8 [IQR 38.9-94.4], $p = .013$) than the 185 patients who did not have paired measurements on the PAM at baseline and at 6 months.

PAM scores and levels at baseline

At baseline 426 patients completed the PAM with a mean score of 60.2±14.3. In the 4 levels, 75 patients (17.6%) were in level 1, 85 (20.0%) in level 2, 177 (41.5%) in level 3 and 89 (20.9%) in level 4 (Table 2). Between the patients at the different levels, there were significant differences at baseline in age ($p = .040$), number of comorbidities ($p = .016$), HRQoL (EQ-5D-3L index $p < .001$ and visual analog scale $p = .001$), communication ($p = .007$), memory and thinking ($p < .001$), and mood and emotions ($p < .001$). The results of the post hoc analyses indicate more comorbidities, lower HRQoL, lower SIS communication, lower SIS memory and thinking, and lower SIS mood and emotions in patients in level 1 than patients in level 4 (all $p < .05$) (Table 2).

Table 2. Baseline characteristics of patients of each PAM level.

Characteristic	Level 1 n = 75 PAM 43.4 (3.9)		Level 2 n = 85 PAM 51.2 (1.7)		Level 3 n = 177 PAM 60.3 (4.7)		Level 4 n = 89 PAM 82.9 (9.4)		*p* value*
	n		n		n		n		
Age (y), median (IQR)	75	61.0 (53.0-66.0)	85	64.0 (55.0-69.5)	177	64.0 (57.0-70.0)	88	64.5 (56.0-70.8)	**.040**[†]
Men, n (%)	75	40 (53.3)	85	56 (65.9)	177	119 (67.2)	89	58 (65.2)	.196
Education, n (%)	74		84		176		88		.356
Low		36 (48.6)		40 (47.6)		72 (40.9)		32 (36.4)	
Medium		19 (25.7)		26 (31.0)		45 (25.6)		26 (29.5)	
High		19 (25.7)		18 (21.4)		59 (33.5)		30 (34.1)	
Married or living with a partner, n (%)	73	38 (52.1)	84	45 (53.6)	173	114 (65.9)	88	58 (65.9)	.071
Paid work before stroke, n (%)[‡]	53	36 (67.9)	43	33 (76.7)	93	66 (71.0)	46	39 (84.8)	.220
No. of comorbidities, median (IQR)	58	2.0 (2.0-4.0)	68	2.0 (1.0-3.0)	144	2.0 (1.0-3.0)	82	2.0 (1.0-3.0)	**.016**[§]
Smoking ≥1cigarettes/d prestroke, n (%)	74	25 (33.8)	82	34 (41.5)	172	56 (32.6)	88	29 (33.0)	.542
Alcohol ≥2 glasses/d prestroke, n (%)	74	8 (10.8)	81	10 (12.3)	170	21 (12.4)	86	7 (8.1)	.764
Physically active, n (%)	73	26 (35.6)	81	25 (30.9)	169	56 (33.1)	85	26 (30.6)	.898
Ischemic stroke, n (%)	75	61 (81.3)	83	64 (77.1)	176	153 (86.9)	89	72 (80.9)	.229
Inpatient rehabilitation, n (%)	75	56 (74.7)	85	67 (78.8)	177	144 (81.4)	89	67 (75.3)	.562
Barthel Index, median (IQR)[‖]	48	15.0 (10.0-18.0)	53	16.0 (11.0-18.0)	118	18.0 (12.0-20.0)	56	17.0 (11.3-19.0)	.139
HRQoL EQ-5D-3L index, median (IQR)	70	0.59 (0.39-0.78)	80	0.73 (0.52-0.86)	173	0.78 (0.64-0.90)	85	0.81 (0.66-0.90)	**<.001**[¶]
HRQoL EQ-5D-3L VAS, median (IQR)	73	0.77 (0.59-0.86)	84	0.77 (0.62-0.89)	170	0.86 (0.72-0.93)	86	0.86 (0.74-0.93)	**.001**[#]
SIS mobility, median (IQR)	74	77.8 (51.4-94.4)	83	80.6 (58.3-93.8)	172	86.8 (61.1-97.2)	89	83.3 (54.2-100.0)	.257
SIS communication, median (IQR)	73	85.7 (71.4-96.4)	85	91.7 (71.4-100.0)	175	92.9 (78.6-100.0)	87	96.4 (82.1-100.0)	**.007**[**]
SIS memory and thinking, median (IQR)	74	78.6 (60.7-92.9)	85	82.1 (67.9-92.9)	175	85.7 (67.9-96.4)	87	92.9 (78.6-100.0)	**<.001**[††]
SIS mood and emotions, median (IQR)	75	72.2 (58.3-81.3)	85	75.0 (63.9-82.7)	176	80.6 (66.7-88.9)	87	83.3 (72.2-88.9)	**<.001**[‡‡]

Abbreviations: HRQoL, health-related quality of life; SIS, stroke impact scale; VAS, visual analogue scale.

**P* values are given of Kruskall-Wallis and Chi² tests, where appropriate.
[†] Only for patients aged <66 y.
[‖] Only administered for inpatients.

Post-hoc comparison: significant difference between [†]PAM levels 1 and 3 ($p = .036$)
[§] PAM levels 1 and 4 ($p = .013$)
[¶] PAM levels 1 and 2 ($p = 0.038$), 1 and 3 ($p < .001$), and 1 and 4 ($p < .001$)
[#] PAM levels 1 and 3 ($p = .020$), 1 and 4 ($p = .010$), 2 and 3 ($p = .049$), and 2 and 4 ($p = .025$)
[**] PAM levels 1 and 4 ($p = .004$)
[††] PAM levels 1 and 3 ($p = .026$), 1 and 4 ($p < .001$), and 2 and 4 ($p = .011$)
[‡‡] PAM levels 1 and 3 ($p < .001$), 1 and 4 ($p < .001$), 2 and 3 ($p = .018$), and 2 and 4 ($p = .001$).

Table 3. PAM for patients with stroke who received rehabilitation at baseline and 3- and 6-month follow-up.

PAM		n	Baseline	n	3 Months	n	6 Months
PAM score, mean ± SD		426	60.2±14.3	367	60.7±14.8	335	61.9±18.0
PAM levels, n (%)		426		367		335	
	1		75 (17.6)		57 (15.5)		52 (15.5)
	2		85 (20.0)		77 (21.0)		68 (20.3)
	3		177 (41.5)		157 (42.8)		128 (38.2)
	4		89 (20.9)		76 (20.7)		87 (26.0)

PAM scores over time

At 3 month follow-up, 367 patients completed the PAM with a mean score of 60.7±14.8 and at 6 months 335 patients had a mean score of 61.9±18.0 (Table 3). In the univariate analysis, the PAM score did not significantly improve over time (β=0.80; 95% Confidence Interval (CI), -0.14 to 1.73; p = .094) (Table 4). Further analysis of the significantly related covariates showed that old age and worse communication, memory and thinking and mood and emotions had a negative effect on the PAM score as a function of time. In the multivariate analysis, including the significant related covariates, the PAM score did improve over time (β=7.85; CI, 2.17 to 13.52; p = .007) (see Table 4). Only higher mood and emotions remained significantly related with higher PAM scores (β=0.19; CI, 0.10 to 0.27; p < .001). Old age had a negative effect on improvement over time (β =-0.11; CI, -0.20 to -0.02; p = .016).

Table 4. PAM comparison for patients with stroke who received rehabilitation between baseline and 3- and 6-month follow-up.

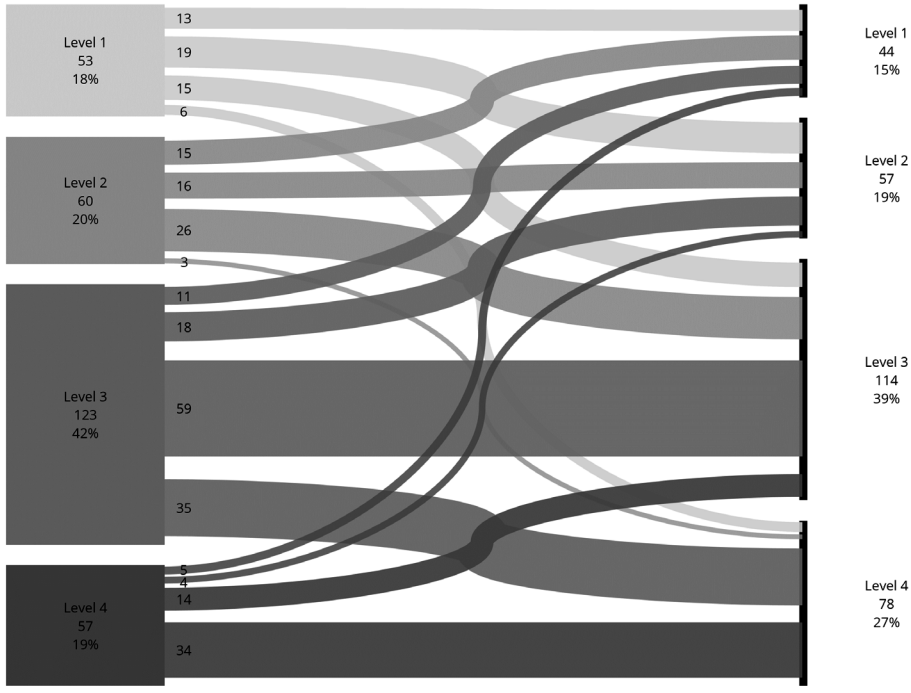
Variable	β (CI)	*p* value*
Univariate mixed-model analyses		
Time	0.80 (-0.14 to 1.73)	.094
Multivariate mixed-model analyses		
Time	7.85 (2.17 to 13.52)	**.007**
SIS communication	0.02 (-0.08 to 0.12)	.703
SIS memory and thinking	0.07 (-0.01 to 0.15)	.079
SIS mood and emotions	0.19 (0.10 to 0.27)	**<.001**
Age	0.04 (-0.07 to 0.15)	.504
Age x time	-0.11 (-0.20 to -0.02)	**.016**

* *P* value of linear mixed model.

Course of PAM levels

The course of PAM levels is visualized in Figure 2. From baseline up until 6 months, 122 patients (41.6%) remained at the same level. Of these patients, 13 (10.7%) remained in level 1 and 16 (13.1%) remained in level 2. There were 104 patients (35.5%) who improved in PAM level: 80 improved 1 level and 24 improved 2 levels or more. On the other hand, 67 patients (23.1%) decreased in PAM level: 47 decreased 1 level and 20 decreased 2 levels or more.

Figure 2. Sankey diagram of PAM levels of patients with stroke who received rehabilitation with paired measurements at baseline and 6 mo (n=293).



Discussion

This study showed that on a group level PAM scores in patients with stroke increased from the start of the rehabilitation up until the 6-month follow-up in multivariate analysis. At the individual level, 104 patients (35.5%) improved 1 or 2 PAM levels. However, the overall mean change in PAM scores was small and no significant increase in PAM score was found in the univariate analysis. At the individual level, one-third of patients were in level 1 or 2 of patient activation at all time points, and 23.1% of patients decreased in PAM level. These results are in line with our hypothesis that patient activation would not or only slightly improve during and after stroke rehabilitation.

The mean PAM score at baseline of the patients with stroke in the present study is in the same range as PAM scores in three other studies with community-based patients with stroke (60.2 versus 56.4-65.7)[13-15]. Moreover, the mean PAM score in the present study was much lower than the mean score (75.3) of stroke patients in the study of Kidd et al.[12]. The authors stated that patient activation was probably lower based on interviews with these patients[12]. In contrast, the mean PAM score in the present study was higher than in a cross-sectional study with patients with stroke from a tertiary hospital (60.2 versus 51.56)[16]. The authors hypothesized that this low patient activation might be because of underdeveloped health literacy and health care awareness[16].

A strength of this study is that it gives insight in the course of patient activation in patients with stroke during the first 3 months after stroke when most recovery takes place[29] and also up until 6 months when it is thought that a plateau effect is reached[29]. Another strength of our study is that PAM levels are described. This information at the individual patient level of knowledge and skill to self-manage allows physicians and therapists to target self-care education and provide support for each patient's needs while presumably being more effective in supporting patient's self-management[9].

Previous studies found that a low level of patient activation was associated with low income, using less preventive screening measures (eg, health screening), unhealthy behaviours (eg, smoking), worse clinical indicators (eg, systolic blood pressure), more visits to the emergency department, more admissions to the hospital[30], and more unmet medical needs and inappropriate use of the health care system[31]. In contrast to these previous studies, patients in PAM level 1 did not report significantly more unhealthy behaviours prestroke. However, they did have more comorbidities than patients in PAM level 4. Moreover, patients in level 1 had lower HRQoL, lower self-rated communication, memory and thinking, and mood and emotions compared than patients in level 4. In other words, patients who are more severely affected by their stroke, have a lower level of patient activation.

Furthermore, the number of patients with a low level of activation (level 1 and 2) was >35% at all time points. In addition, the PAM score decreased markedly in a number of patients over time. This subgroup of patients may specifically need attention and support. For patients with a low level of activation, it could be of value to introduce a tailored intervention on those aspects of patient activation that they have difficulty with. In case the level of activation of patients in level 1 does not improve, the care they receive might be more directed to compensation strategies. Patients in level 2 and 3 might benefit from interventions targeted at patient activation as a part of rehabilitation. Interventions were proven to be effective in increasing patient activation in patients with diabetes and other chronic conditions, and the highest increase was seen in patients with the lowest activation levels[10,32]. In patients with stroke, 3 different interventions were studied, which aimed at improving patient activation[13-15]. Of the 3 only 1 was significantly effective[15]. This intervention was a home-based social worker–led case management program

combined with a website providing stroke-related information. However, the exact mechanisms remain uncertain[15]. These interventions have not yet been tested in more affected patients with stroke who receive rehabilitation. This should be addressed in future research.

Study limitations

Because the PAM has not yet been validated specifically in patients with stroke, this can be considered a limitation of this study. Based on our data and 2 previous studies[12,28], there is some doubt regarding the content validity of the PAM, that is, the degree to which the content of an instrument is an adequate reflection of the construct to be measured, looking at relevance of the items, as well as comprehensiveness and comprehensibility[33]. In our study, 2 patients (0.4%) had a maximum score of 100 and a minimum score of 0 at another time point, and 11 patients (3.8%) increased or decreased 3 levels between baseline and after 6 months. It is unclear whether these patients were truly differently activated or whether there was a problem with comprehensibility because of cognitive or communicative limitations. These doubts are further substantiated by the study of Kidd et al.[12], where there seemed differences in patient activation described by PAM scores and interviews, and a study done in a population with neurologic conditions which showed that individual activation levels were underestimated due to differences in item difficulties[28]. This advocates for validation of the PAM in a population of patients with stroke who receive rehabilitation. Because the minimal important change of the PAM in patients with stroke is unknown, it was not possible to interpret whether the slight improvement observed in the present study is perceived as an important change by stroke patients. This advocates for determining the minimal important change of the PAM in patients with stroke.

A larger percentage of patients with haemorrhagic stroke were excluded from our analysis. Although the percentage of excluded patients was low (5.5%), we cannot preclude that this could have influenced the generalisability of our results. Furthermore, the 293 patients with paired measurements on the PAM at baseline and at 6 months differed significantly from the 185 who did not have paired measurements on age, living situation, smoking and mobility. Therefore, the course of PAM levels might not be generalizable to the whole population.

Conclusions

The mean PAM score in patients with stroke increased over time but only slightly. Moreover, about one-third of patients remained at low levels of patient activation, and patients decreased in their level of patient activation. This indicates that there is room for improvement because no specific interventions for increasing patient activation are part of current rehabilitation treatment. Further research is needed to determine the effectiveness of interventions to improve patient activation for this specific population.

References

1. Langhorne P, Bernhardt J, Kwakkel G. Stroke rehabilitation. Lancet. 2011;377(9778):1693-1702.
2. Langhorne P, Coupar F, Pollock A. Motor recovery after stroke: a systematic review. Lancet Neurol. 2009;8(8):741-54.
3. Lazar RM, Boehme AK. Aphasia As a Predictor of Stroke Outcome. Curr Neurol Neurosci Rep. 2017;17(11):83.
4. van Rijsbergen MW, Mark RE, de Kort PL, Sitskoorn MM. Subjective cognitive complaints after stroke: a systematic review. J Stroke Cerebrovasc Dis. 2014;23(3):408-20.
5. Carod-Artal FJ, Egido JA. Quality of life after stroke: the importance of a good recovery. Cerebrovasc Dis. 2009;27 Suppl 1:204-14.
6. Fletcher S, Kulnik ST, Demain S, Jones F. The problem with self-management: Problematising self-management and power using a Foucauldian lens in the context of stroke care and rehabilitation. PLoS One. 2019;14(6):e0218517.
7. Boger EJ, Demain SH, Latter SM. Stroke self-management: a focus group study to identify the factors influencing self-management following stroke. Int J Nurs Stud. 2015;52(1):175-87.
8. Parke HL, Epiphaniou E, Pearce G, Taylor SJ, Sheikh A, Griffiths CJ, et al. Self-Management Support Interventions for Stroke Survivors: A Systematic Meta-Review. PLoS One. 2015;10(7):e0131448.
9. Hibbard JH, Mahoney ER, Stockard J, Tusler M. Development and testing of a short form of the patient activation measure. Health Serv Res. 2005;40(6 Pt 1):1918-30.
10. Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. Health Aff (Millwood). 2013;32(2):207-14.
11. Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. Health Serv Res. 2004;39(4 Pt 1):1005-26.
12. Kidd L, Lawrence M, Booth J, Rowat A, Russell S. Development and evaluation of a nurse-led, tailored stroke self-management intervention. BMC Health Serv Res. 2015;15:359.
13. McNaughton H, Weatherall M, McPherson K, Fu V, Taylor WJ, McRae A, et al. The effect of the Take Charge intervention on mood, motivation, activation and risk factor management: Analysis of secondary data from the Taking Charge after Stroke (TaCAS) trial. Clin Rehabil. 2021;35(7):1021-31.
14. Kersten P, McPherson KM, Kayes NM, Theadom A, McCambridge A. Bridging the goal intention-action gap in rehabilitation: a study of if-then implementation intentions in neurorehabilitation. Disabil Rehabil. 2015;37(12):1073-81.
15. Reeves MJ, Fritz MC, Woodward AT, Hughes AK, Coursaris CK, Swierenga SJ, et al. Michigan Stroke Transitions Trial. Circ Cardiovasc Qual Outcomes. 2019;12(7):e005493.
16. Sui W, Wan LH. Association between patient activation and medication adherence in patients with stroke: A cross-sectional study. Front Neurol. 2021;12:722711.
17. De Jong AWL, Passier PECA. Behandelkader CVA. Treatment framework stroke; 2016.
18. Dippel DWJ, van der Worp HB, Hofmeijer J, et al. Guideline cerebral infarction and stroke. Utrecht: Nederlandse Vereniging voor Neurologie 2019.

19. Dobkin BH. Behavioral self-management strategies for practice and exercise should be included in neurologic rehabilitation trials and care. Curr Opin Neurol. 2016;29(6):693-9.

20. Groeneveld IF, Meesters JJL, Arwert HJ, Rambaran Mishre AD, Vliet Vlieland TPM, Goossens PH. Research design of an analysis of structure, process and outcomes. Practice variation in stroke rehabilitation. Nederlands Tijdschrift voor Revalidatiegeneeskunde 2015;37(3):134-7.

21. von Elm E, Altman DG, Egger M, Pocock SJ, Gotzsche PC, Vandenbroucke JP, et al. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: guidelines for reporting observational studies. Int J Surg. 2014;12(12):1495-9.

22. Permanent research into the living situation. [Internet]. Available from: http://www.scp.nl/Onderzoek/Bronnen/Beknopte_onderzoeksbeschrijvingen/Permanent_onderzoek_naar_-de_leefsituatie_POLS. [Accessed 2nd April 2020].

23. Quinn TJ, Langhorne P, Stott DJ. Barthel index for stroke trials: development, properties, and application. Stroke. 2011;42(4):1146-51.

24. EQ-5D-3L About EQ-5D. [Internet]. Available from: https://euroqol.org/eq-5d-instruments/eq-5d-3l-about/. [Accessed 26th June 2020].

25. Duncan PW, Wallace D, Lai SM, Johnson D, Embretson S, Laster LJ. The Stroke Impact Scale version 2.0. Evaluation of reliability, validity, and sensitivity to change. Stroke. 1999;30(10):2131-40.

26. Greene J, Hibbard JH, Sacks R, Overton V, Parrotta CD. When patient activation levels change, health outcomes and costs change, too. Health Aff (Millwood). 2015;34(3):431-7.

27. Rademakers J, Nijman J, van der Hoek L, Heijmans M, Rijken M. Measuring patient activation in the Netherlands: translation and validation of the American short form Patient Activation Measure (PAM13). BMC Public Health. 2012;12:577.

28. Packer TL, Kephart G, Ghahari S, Audulv A, Versnel J, Warner G. The Patient Activation Measure: a validation study in a neurological population. Qual Life Res. 2015;24(7):1587-96.

29. Zeiler SR, Krakauer JW. The interaction between training and plasticity in the poststroke brain. Curr Opin Neurol. 2013;26(6):609-16.

30. Hibbard JH, Cunningham PJ. How engaged are consumers in their health and health care, and why does it matter? Res Brief. 2008(8):1-9.

31. Greene J, Hibbard JH. Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. J Gen Intern Med. 2012;27(5):520-6.

32. Almutairi N, Hosseinzadeh H, Gopaldasani V. The effectiveness of patient activation intervention on type 2 diabetes mellitus glycemic control and self-management behaviors: a systematic review of RCTs. Prim Care Diabetes. 2020;14(1):12-20.

33. Terwee CB, Prinsen CAC, Chiarotto A, Westerman MJ, Patrick DL, Alonso J, et al. COSMIN methodology for evaluating the content validity of patient-reported outcome measures: a Delphi study. Qual Life Res. 2018;27(5):1159-70.