Illness perceptions of stroke survivors: Predictors and changes over time – A 1 year follow-up study

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ABSTRACT

Objective: To describe the illness perceptions (IP) of stroke patients in the first year post stroke; to identify patient clusters with comparable IP trajectories and determine their associations with health.

Methods: This prospective study included consecutive stroke patients after medical rehabilitation. Three and 12 months post stroke they completed the Brief Illness Perception Questionnaire (B-IPQ) and questionnaires on physical and mental health. All eight IP and their changes over time were described. Clusters of patients with comparable IP trajectories were constructed by k-means clustering, with subsequent comparison of patient characteristics. Multivariable logistic regression analyses were conducted to determine the association between IP clusters and 12-month mental health.

Results: Hundred-and-eighty-four patients were included (men n = 107 [58.2%]; mean age 61.1 [SD 12.7] years). At 3 months, the scores of the IP *coherence* (mean 3.0, SD 2.3) and *treatment control* (mean 3.2, SD 2.5) were lowest (best), and *consequences* (mean 6.1, SD 2.8) and anticipated *timeline* (mean 6.0, SD 2.7) were highest (worst). At 12 months, the *timeline* and *treatment control* scores had significantly worsened. Three clusters of the trajectories of IP were identified, and designated as 'favourable', 'average', and 'unfavourable'. The unfavourable cluster was significantly associated with worse physical and mental health at 3 months (unadjusted) and depressive symptoms at 12 months.

Conclusion: Stroke patients' IP partly changed between 3 and 12 months post stroke. Patients with an unfavourable IP trajectory had a higher chance of depressive symptoms at 12 months. Illness perceptions could be considered as an additional target of treatment.

1. Introduction

Worldwide, stroke is one of the leading causes of disability and mortality [1]. Stroke may lead to impairments in functioning, limitations in activities, and restrictions in participation, and may affect health-related quality of life (HRQOL) [2]. Within the first years post stroke, a third (pooled prevalence 31%) [3] of stroke patients develops depressive symptoms and a quarter (pooled prevalence 23%) reports to suffer from anxiety [4]. Health outcomes after stroke are influenced by sociodemographic, clinical, treatment-related, and psychological factors [5,6].

As to the psychological factors, post stroke outcomes can be influenced by one's *perceptions* of the illness [7–10]. Stroke patients with negative ('maladaptive') illness perceptions (IP) had more distress [7], lower medication adherence [8,9], and more difficulties returning to work [10]. The concept of illness perceptions (IP) is a major component of the Common Sense Model (CSM), stating that a patient forms mental representations of symptoms and disease, in order to make sense of and manage the illness [11,12]. Illness perceptions comprise the patients' beliefs about the symptoms, duration, cause, and consequences of the disease; the perceived emotional impact; his/her concern and understanding, and his/her beliefs about the controllability of the disease

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[12,13]. Patients do not hold IP in isolation, they are part of a schema [14]. Patients change and update this schema based on incoming information and subconscious hypothesis testing [11]. Illness perceptions appear a modifiable target of treatment; personalised counselling interventions were shown to be effective for patients with myocardial infarct and diabetes [15,16]. In order to measure IP in the CSM context, the Illness Perception Questionnaire (IPQ; 1996) was developed [17]. In 2002 a revised version (IPQ-R) was published, containing additional scales 13. As there was a (clinical) need for more rapid assessment of IP, a brief version of the IPQ-R was developed. The Brief IPQ (B-IPQ) contains eight items, all having 0–10 scales [18], concerning perceived consequences, timeline (acute-chronic), personal control, treatment control, identity (symptoms), concern about the illness, coherence of the illness, and emotional response. The ninth item asks the patient to list the three most likely causes for his/her illness.

In patients with stroke, research on IP is scarce. In a descriptive study one year after stroke (*n* = 15, mean age 73.3, 73% female) on average the participants believed they understood their disease relatively well (*coherence*), experienced relatively low *emotional impact*, but experienced moderate *personal control* and believed that treatment was only moderately helpful (*treatment control*) [19]. In a longitudinal study on stroke patients' and caregivers' distress, patients (*n* = 42, mean age 65.1, 43% female) experienced relatively few *consequences* but reported little *coherence* and low *personal control*. Also, they foresaw only moderate effects of treatment, this IP becoming more negative between 10 days and 3 months post stroke [7]. No studies have yet described the patients' perceptions of the *causes* of stroke. The course of IP over time as well as the associations with patient characteristics and health outcomes have not been explored either.

In other patient groups the concept of IP has been more extensively investigated, both descriptive and in relation to patient characteristics and health outcomes. Predictors of maladaptive IP included female sex [20], disability, multi-morbidity [21], fatigue [22], depressive symptoms [20], and anxiety [23]. Changes in IP over time were demonstrated in patients with obesity, chronic obstructive pulmonary disease, heart disease, and osteoarthritis [24–26], and appeared unfavourably related to disease progression. In the cluster of oesophageal cancer patients in which IP became more negative over time, levels of anxiety increased [26]. Illness perceptions have been object of intervention, aimed at adjusting unhelpful IP into more adaptive ones. In patients with cardiovascular disease, in-hospital counselling beneficially influenced coherence, concern, and beliefs about the causes of disease [15], and resulted in fewer symptoms and a higher rate of work resumption [27]. Patients with type 2 diabetes reported better personal control, a better understanding, an increased belief in treatment effectiveness, and experienced fewer symptoms, lower levels of concern and distress, and better medication adherence [28]. The mediating effect of IP in the relation between intervention and depression was shown by Jonsbu et al. (2013) in a 3-session CBT programme for patients with non-cardiac chest pain and benign palpitations: A change in illness *concern* mediated about 40% and a change in *personal control* mediated about 50% of the change in depression [29].

In summary, IP are related to a range of health outcomes and have been influenced by personalised interventions in other disease categories. Exploring the course of IP and the relation with physical and mental health in stroke patients will provide insight into the opportunity and necessity of targeting IP as part of rehabilitation treatment, additional to medication and cognitive behavioural therapy [30]. We conducted a prospective study in a large sample of stroke patients who underwent inpatient specialised medical rehabilitation, and aimed to: 1) describe the IP of stroke patients and their course between 3 and 12 months after the start of rehabilitation; 2) identify clusters of patients with comparable IP trajectories and determine their characteristics; 3) identify the associations between IP clusters and mental health 12 months after the start of rehabilitation.

2. Method

2.1. Design and setting

This study is part of the Stroke Cohort Outcome REhabilitation (SCORE-) project; a multicentre prospective observational cohort study (Dutch trial register no. 4293) currently ongoing in two Dutch rehabilitation facilities [31]. These rehabilitation facilities offer multidisciplinary rehabilitation treatment including physical, occupational, and speech-language therapy, social work, and consultations with a clinical psychologist [32]. In patients with cognitive, psychological, or behavioural impairments, the rehabilitation team discusses a patients' awareness and emotional impact of the illness, but not his/her perceptions thereof. Follow-up data were used from patients who were included in the SCORE-study by March 2016. The study protocol was approved by the Medical Ethics Board of the Leiden University Medical Center (LUMC). All study procedures were executed in accordance with the Helsinki Declaration [33]. All participants signed informed consent. The study was reported according to the STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) guidelines.

2.2. Study sample

The study sample consisted of consecutive stroke patients who were admitted for inpatient multidisciplinary specialised rehabilitation. As compared to the total stroke population, these are relatively young patients, with multiple and complex impairments, and able to return home after rehabilitation. Their average length of stay in the rehabilitation clinic is 1.5 months. For the SCORE-study, patients were invited who were ≥ 18 years old and had an ischemic or haemorrhagic stroke < 6 months ago. Patients with pre-existent psychiatric disorder or dementia, or unable to complete questionnaires in Dutch due to severe aphasia or non-Dutch ethnicity, were excluded. Within the first week after admission, patients received an information letter from the treating rehabilitation specialist. Subsequently, a research assistant visited the patient for further explanation. All patients who provided informed consent and completed the questionnaire at baseline were included.

2.3. Data collection

At the start of rehabilitation (baseline), sociodemographic and clinical characteristics were collected using the patients' medical files and a baseline questionnaire. Three and 12 months after the start of rehabilitation, IP and health outcomes were assessed by means of a questionnaire. Based on the participants' preference, the questionnaires were sent by post or by email.

2.4. Outcome measures

Illness perceptions were measured using the B-IPQ [18] For the items on the perceived symptoms (*identity*), anticipated duration (*timeline)*, and perceived *consequences*, *concern*, and *emotional impact* regarding the disease, a higher score (range 0–10) implies more negative, or maladaptive, IP. For the items on perceived *personal control, treatment control*, and *coherence*, a higher score implies more positive, or adaptive, IP. Before data analyses, the scoring of the latter 3 items was reversed in order to facilitate interpretation. The *cause* item is an open question in which the respondent can indicate the 3 most important perceived causes of stroke, in order of importance. The B-IPQ showed good test-retest reliability, and concurrent, predictive, and discriminant validity in various populations [34]. It was cross-culturally adapted into Dutch [35,36]. It should be noted that for stroke survivors, higher scores on *identity*, *timeline*, and *consequences* cannot be considered maladaptive per se, but higher scores indicate a more negative view of the disease.

Disease-specific quality of life was assessed using the 39-item Stroke and Aphasia Quality of Life Scale (SAQOL-39NLg), that was validated for use in people with and without aphasia. The SAQOL-39NLg contains the domains physical (16 items), communicative (7 items), and psychosocial (16 items) functioning [37]. Questions are phrased as *'In the last week, how difficult was it for you to…'* Each item can be answered on a 1 ('could not do it at all') to 5 ('no difficulties') scale. The total score of each scale equals the mean of the item scores. The cross-culturally adapted Dutch version showed good internal consistency and test-retest reliability, and moderate convergent validity [38]. For this study, only the physical and communication scales were used, as psychosocial functioning was measured with the more comprehensive Hospital Anxiety and Depression Scale (HADS). Considering the phrasing of the items, the SAQOL-39NLg was used as a proxy for physical and communicative functioning.

Anxiety and depression were determined by means of the Hospital Anxiety and Depression Scale (HADS) comprising two subscales: Anxiety and Depression. Each subscale consists of 7 items that can be scored on a 4-point scale, adding up to a maximum sum score of 21. Scores were dichotomised using the recommended cut-off score of ≥ 8 to indicate symptoms of depression or anxiety [39]. The HADS scales have good internal consistency, good to excellent sensitivity and specificity, and good to very good concurrent validity [40].

2.5. Sociodemographic characteristics

Sex and date of birth were derived from the patients' medical files. Level of education and living situation were assessed by means of a questionnaire. The patients' level of education was measured using a 6-point scale and split into 3 categories: Low, intermediate, and high education. Living situation was defined as 'with others' versus alone.

2.6. Clinical characteristics

Stroke type (ischaemic, haemorrhagic) and localisation (right, left, posterior, stem, both sites) were derived from the patients' medical files. Comorbidities were measured using the 'Dutch Life Situation Cohort Questionnaire', a 16-item questionnaire on the most common chronic diseases in the Dutch population, including e.g. diabetes mellitus, heart disease, rheumatic disorders [41]. The respondent can indicate the presence (yes/no) of each disease. The level of independence in activities of daily living upon admission was assessed using the Barthel Index (BI) [42], which comprises 10 items on e.g. bathing, feeding, and mobility; its total score ranges between 0 (worst) to 20 (best). It has an excellent internal consistency (Cronbach's α 0.84 to 0.96) and good inter-observer reliability (Spearman's r 0.77) in patients with stroke. Whether patients still had treatment in the rehabilitation facility upon completion of the 3-months questionnaire was derived from self-report.

2.7. Data analyses

First, baseline characteristics (means [SD], medians [inter quartile range, IQR], numbers [percentages]) were described for all patients who completed the B-IPQ at 3 and 12 months. The differences between responders and non-responders to the 12-months questionnaire were assessed with unpaired *t*-tests, Mann-Whitney *U* tests and χ^2 tests, depending on the distribution of the data. Data analyses were conducted in IBM SPSS v. 24.0 (objectives 1 and 2) and in R v. 3.3.3 (objective 3).

For the first objective (description of the IP and their course between 3 and 12 months after the start of rehabilitation) items 1–8 of the B- IPQ at 3 and 12 months after stroke were presented. The means (SD) or medians (interquartile range; IQR) were described, depending on the distribution of the data. Higher values imply more negative IP. To examine the changes of items 1–8 between 3 and 12 months, paired samples *t*-tests were conducted for each IP. To assess the effect sizes of

the comparisons, Cohen's d values were calculated. Cohen's d values of 0.2, 0.5 and 0.8 were considered small, medium and large respectively [43].

In addition, the numbers (%) of patients whose scores had decreased with one or more points were computed, as well as the numbers (%) of patients whose scores had increased or remained equal (≥ 0). Additionally, the perceived *cause* (item 9) that was indicated by the patients as the most important, at 3 months, were coded and categorized by two authors (IG and WP) independently. Inconsistencies between the authors were discussed and solved.

For the second objective (identification of clusters of patients with comparable IP trajectories and determine their characteristics), k-means clustering was applied as recommended by Clatworthy et al. [44] In case a patient had a missing IP value, the items was imputed by applying a single imputation with random forests. After that, k-means clustering with a predefined number of 4 clusters was performed using the IP scores at 3 and 12 months. Then, the characteristics of the patients in each cluster were identified and compared using analysis of variance (ANOVA) for normally distributed continuous variables, Kruskal-Wallis test for non-normally distributed continuous variables, and χ^2 tests for dichotomous variables. Age, sex, stroke hemisphere, HRQOL physical domain, HRQOL communication domain, depressive symptoms (yes/no), anxiety (yes/no), comorbidities (< 2 vs ≥ 2) and treatment at 3 months (yes/no) were included in these analyses. In case of significant ($p < .05$) differences across groups, post hoc analyses were conducted (Games-Howell for normally distributed and Kruskal-Wallis pairwise comparisons for non-normally distributed variables), to which a Bonferroni-corrected significance level of $0.05/3 = 0.017$ was applied.

For the third objective (identification of the associations between IP clusters and 12-month mental health), a multivariable logistic regression analysis was conducted with the HADS depressive symptoms (yes/no) at 12 months as the dependent variable and variables that are likely of influence on depressive symptoms, i.e. IP cluster, age, sex, social support (living with others vs alone) [45], HADS depressive symptoms (yes/no), and HADS anxiety (yes/no) at 3 months as the independent variables. A comparable analysis was conducted for HADS anxiety at 12 months as the dependent variable. 'Cluster' was incorporated in the model as two dummy variables, with the largest cluster being the reference category.

3. Results

3.1. Study sample and baseline characteristics

Until March 2016 368 patients were invited to the SCORE study of whom 244 (63.2%) signed informed consent. The main reasons not to participate included 'problems with language', 'impaired vision', or 'high burden'. One-hundred-and-eighty-four participants (75.4%) provided data on one or more IP 3 months after the start of rehabilitation, and were included in the current study (Fig. 1).

Their mean age was 61.1 (SD 12.7), 107 (58.2%) were male, 144 (78.3%) had an ischaemic stroke, and the average Barthel Index upon admission was 14.2 (SD 5.4). The median number of days between stroke and inclusion into the study was 24.0 (IQR 17.3; 36.0). At 3 months, depressive symptoms were reported by 49 (28.0%) patients and 35 (19.9%) reported symptoms of anxiety (Table 1) Ten patients (5.5%) still stayed at the rehabilitation facility as an inpatient and 92 participants (50%) had treatment as an outpatient. Twelve months after stroke, 151 patients provided data on IP. Among the patients who did not ($n = 33$), the proportion of higher educated patients and of patients who had finished rehabilitation treatment was significantly higher.

3.2. Description of illness perceptions and the course over time

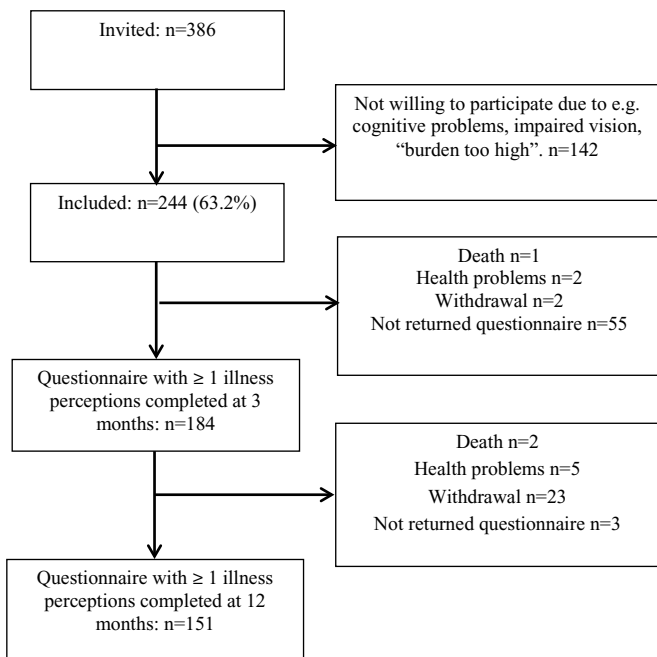The IP are presented in Table 2. At 3 months, *coherence* (mean 3.0,

Fig. 1. Flow diagram of stroke patients recruited for the SCORE-study until March 15, 2016.

12 months they perceived the treatment was less effective than they perceived at 3 months. On average, the other IP remained comparable over time, with approximately 33% of patients having a higher and 67% having an equal of lower score at 12 as compared to 3 months. All Cohen's d values were below 0.2, except for timeline (0.28), and treatment control (0.43), which approached a medium effect.

The question on the most important perceived cause of stroke (Table 3) was answered by 110 patients. The causes that were mentioned most frequently were 'stress/ worries/ fatigue' ($n = 26$, 23.6%), 'cholesterol, blood pressure, overweight, diabetes' ($n = 25$, 22.7%), and 'lifestyle' ($n = 19$, 17.3%).

3.3. Clusters of patients with comparable IP trajectories and their characteristics

Three clusters were discerned of patients with comparable IP trajectories, based on their IP scores at 3 and 12 months (Fig. 2a-c → below main text). In cluster 1 (n = 28; 18.8%), the smallest group, the scores at 3 and 12 months were relatively low (positive). In cluster 2 (n = 57; 38.8%) the scores were close to the average of the whole sample. In cluster 3 ($n = 64$; 43.0%), the scores were relatively high (negative). In all clusters, patients developed a less favourable view on the treatment effect *(treatment control)* over time. In clusters 2 and 3, patients developed a less favourable view of the duration of the disease but experienced more *personal control* over time. In Table 4, the differences in patient characteristics across clusters can be found. Significant differences across clusters were found, with the participants in cluster 3 having the most unfavourable scores, for physical functioning ($p < .001$), communication ($p = .003$), depressive symptoms ($p < .001$) and anxiety ($p < .001$).

3.4. Associations between IP clusters and mental health at 12 months

The multivariable logistic regression models revealed that depressive symptoms (Exp(B) 6.68, 95%CI 2.13; 20.91) at 3 months was the

SD 2.3) and *treatment control* (mean 3.2, SD 2.5) had the lowest scores (positive) and *consequences* (mean 6.1, SD 2.8) and *timeline* (mean 6.0, SD 2.7) had the highest scores (negative). Nine months later, 81 patients had a higher (more negative) score on *timeline*, meaning that at 12 months patients thought that their disease had a longer duration than they initially thought at 3 months (mean change 0.84, 95%CI 0.36; 1.32). Seventy-nine (56.4%) patients had a higher score on *treatment control* (mean change 1.42, 95%CI 0.87; 1.97), meaning that at

Table 1
Baseline characteristics of stroke patients included in the analysis of illness perceptions as part of the SCORE-study.

	Patients in analyses at 3 months. n = 184	Patients in analyses at 12 months. n = 151	Patients not in analyses at 12 months. n = 33	p
Sociodemographic characteristics				
Age (mean; SD)	61.09 (12.69)	60.58 (12.58)	63.45 (13.09)	0.24
Sex (male; n, %)	107 (58.2)	91 (60.3)	16 (48.5)	0.25
Education (n, %)				
Low	79 (45.4)	58 (40.8)	21 (65.5)	0.01
Middle	43 (24.7)	36 (25.4)	7 (21.9)	Low vs other: 0.01
High	52 (29.9)	48 (33.8)	4 (12.5)	
Living situation (together; n, %)	126 (68.5)	103 (71.5)	23 (74.2)	0.83
Clinical characteristics				
Stroke type (ischemic; n, %)	144 (78.3)	119 (78.8)	25 (75.8)	0.82
Stroke localisation (n, %)				
Left	84 (45.9)	71 (47.3)	13 (39.4)	0.63
Right	48 (42.6)	64 (42.7)	14 (42.4)	Left vs other: 0.45
Other	21 (11.5)	15 (10.0)	6 (18.2)	
Barthel Index (mean, SD) n = 139	14.2 (5.4)	14.2 (5.3)	14.1 (5.6)	0.97
Comorbidities (median, IQR)	1.0 (1.0; 2.0)	1.0 (1.0; 2.0)	1.5 (0.0; 2.8)	0.80
Days between stroke and inclusion, median (IQR)	24.0 (17.3; 36.0)	24.0 (17.0; 36.0)	24.0 (20.0; 35.5)	0.54
Health status and treatment 3 months post stroke				
SAQOL-39NLg physical scale (median, IQR)	4.31 (3.63; 4.81)	4.31 (3.63; 4.79)	4.34 (3.59; 4.81)	0.74
SAQOL-39NLg communication scale (median, IQR)	4.80 (4.14; 5.00)	4.71 (4.14; 5.00)	4.84 (4.36; 5.00)	0.23
HADS Depressive symptoms (yes; n, %)	49 (28.0)	39 (26.7)	10 (34.5)	0.50
HADS Anxiety (yes; n, %)	35 (19.9)	29 (19.9)	6 (20.0)	> 0.99
Treatment at 3 months (in- or outpatient; n, %)	102 (56.0)	91 (61.1)	11 (33.3)	0.01

SD: standard deviation. IQR: inter quartile range. SAQOL-39NLg: Stroke and Aphasia Quality Of Life Scale, HADS: Hospital Anxiety and Depression Scale. NA: not applicable. *Higher = better.

Table 2

Illness perceptions and health outcomes of stroke patients included in the analysis of illness perceptions as part of the SCORE-study, changes between 3 and 12 months after the start of rehabilitation, and the number (%) of patients with equal or improving versus worsening scores.

Illness perceptions	3 months. n = 184. Mean (SD)	12 months. n = 151. Mean (SD)	Change 12–3 months. Mean (95%CI)	Cohen's d	p	Increase (worse), n (%)	Equal or decrease (better), n (%)
Consequences	6.1 (2.8)	6.0 (2.7)	−0.26 (−0.63; 0.11)	−0.11	0.17	50 (33.3)	100 (66.7)
Timeline	6.0 (2.7)	7.8 (2.9)	0.84 (0.36; 1.32)	0.28	0.001	81 (55.1)	66 (44.9)
Personal control	4.6 (2.7)	4.2 (2.7)	−0.46 (−0.97; 0.05)	−0.15	0.08	44 (29.7)	104 (70.3)
Treatment control	3.2 (2.5)	4.5 (3.2)	1.42 (0.87; 1.97)	0.43	< 0.001	79 (56.4)	61 (43.6)
Identity	5.6 (2.6)	5.5 (2.5)	−0.11 (−0.47; 0.26)	−0.05	0.56	49 (32.5)	102 (67.5)
Concern	5.2 (2.9)	5.1 (2.8)	−0.29 (−0.79; 0.14)	−0.11	0.18	50 (33.3)	100 (66.7)
Coherence	3.0 (2.3)	3.0 (2.6)	0.09 (−0.36; 0.54)	0.03	0.71	53 (35.1)	98 (64.9)
Emotional response	4.8 (2.9)	4.6 (2.8)	−0.18 (−0.60; 0.30)	−0.06	0.47	47 (31.8)	101 (68.2)
Physical functioning and communication	3 months. n = 184. Mean (SD)	12 months. n = 151. Mean (SD)	Change 12–3 months. Mean (95%CI)		p	Decrease (worse), n (%)	Equal or increase (better), n (%)
SAQOL-39NLg Physical, mean (SD)	4.09 (0.84)	4.14 (0.79)	0.08 (−0.01; 0.16)	0.08	0.09	63 (43.4)	82 (56.6)
SAQOL-39NLg Communication, mean (SD)	4.45 (0.76)	4.41 (0.73)	−0.005 (−0.09; 0.08)	−0.01	0.91	51 (35.2)	94 (64.8)
Depressive symptoms and anxiety	3 months. n = 184. Mean (SD)	12 months. n = 151. Mean (SD)	Change 12–3 months. Mean (95%CI)		p	Equal or increase (worse), n (%)	Decrease (better), n (%)
HADS Depressive symptoms, mean (SD)	5.42 (4.10)	5.00 (4.20)	−0.30 (−0.84; 0.27)	−0.30	0.26	79 (56.4)	61 (43.6)
HADS Anxiety, mean (SD)	5.30 (4.14)	5.01 (3.82)	−0.23 (−0.66; 0.19)	−0.23	0.28	89 (63.1)	25 (36.9)

SD: standard deviation. SAQOL-39NLg: Stroke and Aphasia Quality Of Life Scale. HADS: Hospital Anxiety and Depression Scale.

Table 3

Most important cause of stroke as perceived by stroke patients included in the analysis of illness perceptions as part of the SCORE-study, 3 months after the start of rehabilitation.

Most important perceived cause of stroke	N	%
Stress, worries, or fatigue	26	23.6
Cholesterol, blood pressure, diabetes mellitus type 2, or overweight	25	22.7
Lifestyle	19	17.3
Underlying somatic disorder or blood vessel malformation	13	11.8
Healthcare use (malpractice) or medication (side effects)	9	8.2
Genetics	8	7.3
Coincidence or bad luck	8	7.3
Age	2	1.8
Total	110	100

strongest predictor for depressive symptoms at 12 months, whereas age, sex, and living situation were not associated with the outcome (Table 5). Moreover, patients in clusters 1 and 2 had a lower risk of depressive symptoms than patients in cluster 3 (Exp(B) = 0.26, 95%CI 0.05; 1.46 and Exp(B) = 0.25, 95%CI 0.07; 0.98, respectively), with the variable 'cluster 2 vs cluster 3' being statistically significant. Anxiety at

12 months was significantly associated with depressive symptoms (Exp (B) 4.61, 95%CI 1.33; 15.94) and anxiety (Exp(B) 7.79, 95%CI 2.27; 27.98) at 3 months, but not with any of the other variables. The Nagelkerke R^2 of the models were 0.45 and 0.43 respectively.

4. Discussion

We investigated the IP of stroke patients after rehabilitation and its relation to mental health. Three months after the start of inpatient rehabilitation, on average patients believed that the rehabilitation treatment would contribute to a large extent to their recovery (*treatment control*) and that they understood their disease relatively well (*coherence*). However they believed the disease would have a long duration (*timeline*) and that the disease had a large influence (*consequences)* on their lives. Nine months thereafter, their perception of disease duration had slightly but significantly deteriorated, and the IP on treatment control had worsened as well. Three clusters were discerned of patients with comparable IP trajectories between 3 and 12 months: Clusters of relatively favourable (1), average (2) and unfavourable IP (3). As expected, the unfavourable cluster was associated with worse physical and mental health at 3 months. Last, a relation between IP and 12-

Table 4

The associations between sociodemographic, clinical, 3-month health-related, and treatment-related factors, and clusters of patients with comparable illness perceptions trajectories after stroke.

	Cluster 1 (favourable) n = 28	Cluster 2 (average) n = 57	Cluster 3 (unfavourable) n = 64	p omnibus	p posthoc
Age, mean (SD)	62.1 (15.0)	61.9 (11.5)	58.8 (12.4)	0.33	
Male sex, n (%)	18 (64.3)	37 (64.9)	35 (54.7)	0.46	
Living alone, n (%)	7 (25.0)	10 (18.5)	23 (37.7)	0.10	
Right hemisphere stroke, n (%)	12 (44.4)	24 (42.1)	28 (43.8)	0.97	
≥2 Comorbidities, n (%)	12 (50.0)	16 (38.1)	29 (56.9)	0.36	
SAQOL-39NLg Physical scale, median (IQR)*	4.85 (4.44; 5.00)	4.38 (3.94; 4.75)	3.78 (3.02; 4.44)	< 0.001	Cluster 1 vs 2: 0.03 Cluster 1 vs 3: < 0.001 Cluster 2 vs 3: 0.004
SAQOL-39NLg Communication scale, median (IQR)*	4.86 (4.71; 5.00)	4.86 (4.14; 5.00)	4.43 (3.86; 5.00)	0.003	Cluster 1 vs 2: 0.59 Cluster 1 vs 3: 0.005 Cluster 2 vs 3: 0.07
HADS Depressive symptoms (yes = 1)	2 (7.4)	4 (7.4)	32 (50.8)	< 0.001	Post hoc tests NA, unbalanced groups
HADS Anxiety (yes = 1)	0 (0.0)	4 (7.4)	24 (38.1)	< 0.001	Post hoc tests NA, unbalanced groups
Treatment (yes = 1)	8 (28.6)	37 (66.1)	46 (73.0)	< 0.001	Cluster 1 vs 2: 0.003 Cluster 1 vs 3: < 0.001 Cluster 2 vs 3: > 0.99

SD: standard deviation. IQR: inter quartile range. SAQOL-39NLg: Stroke and Aphasia Quality Of Life Scale. HADS: Hospital Anxiety and Depression Scale. NA: not applicable. *Higher = better.

Table 5
Results of the logistic regression analyses with depressive symptoms and anxiety at 12 months as dependent variables and patient characteristics, IP cluster, and 3-month depressive symptoms and anxiety as independent variables, in stroke patients participating in the SCORE-study.

Independent variable	HADS depressive symptoms, 12 months			HADS anxiety, 12 months		
	Exp(B)	95%CI	p	Exp(B)	95%CI	p
Constant	0.05		0.07	0.08		0.13
Cluster 1 vs 3	0.26	0.05; 1.46	0.13	0.34	0.03; 3.28	0.32
Cluster 2 vs 3	0.25	0.07; 0.98	0.046	1.05	0.27; 4.11	0.35
Age, years	1.02	0.97; 1.06	0.48	1.00	0.96; 1.04	0.95
Sex (1 = male)	1.82	0.62; 5.34	0.28	1.33	0.44; 4.04	0.62
Living situation (1 = together)	1.27	0.41; 3.91	0.68	1.13	0.34; 3.82	0.84
Depression at 3 months (HADS)	6.68	2.13; 20.91	0.001	4.61	1.33; 15.94	0.02
Anxiety at 3 months (HADS)	2.48	0.74; 8.39	0.14	7.97	2.27; 27.98	0.001
Nagelkerke R^2	0.45			0.43		

HADS: Hospital Anxiety and Depression Scale.

month depressive symptoms was demonstrated. In fact, except for depressive symptoms and anxiety at 3 months, IP cluster (2 vs 3) was the only variable significantly associated with depressive symptoms at 12 months.

The results of our study underscored the findings of Grünich et al. on *coherence* being among the most favourable IP after stroke [19], indicating that patients understood their illness relatively well. Our finding of a declining belief in the effectiveness of treatment (*treatment control*) in the first year post stroke was also in line with a previous study in stroke [7], as well as in an observational study among dialysis and predialysis patients with chronic kidney failure [46]. Stroke patients may insufficiently realize the persistence of impairments after treatment until their return to normal life, as described in qualitative research [47]. This may also explain their perception of disease duration becoming more unfavourable over time.

As anticipated, patients with more impairments and limitations in physical functioning and communication at 3 months were more likely to be in the unfavourable IP cluster, as they experienced more symptoms and consequences. Our finding of a relation between IP cluster and depressive symptoms at 12 months was in line with the study of Twiddy et al., who used the General Health Questionnaire to measure distress [7]. Likewise, in breast cancer patients a more negative IP cluster led to more distress after 6 months. [48] Additionally, longitudinal observational studies in patients with various illnesses, such as oesophageal cancer and osteoarthritis, revealed that patients of whom IP *worsened* over time had higher likelihood of becoming more anxious and depressed [25,26].'

As to the perception of the cause of their stroke, a quarter of all patients primarily attributed their disease to stress, worries, or fatigue. The attribution of the disease to chronic stress was previously described in various studies among patients with cardiovascular disease [49]. In a qualitative study among nine transient ischemic attack (TIA) and stroke survivors, 6 patients acknowledged at least one 'external' factor such as stress or fate as the cause of their disease, and all 3 patients who mentioned stress considered this as uncontrollable [50]. As described in the literature, the perceived locus of causality (internal or external) and controllability of the disease can influence the patients' coping strategy [51] and may guide future behaviours, including lifestyle and adherence to rehabilitation. Informing patients on the controllability of the risk and consequences of stroke may contribute to the prevention of recurrence and adherence to rehabilitation.

From the analyses on the course of IP, both of individual items and within the clusters, it appeared that the items on *treatment control* and *personal control* acted different than the other items. This phenomenon was described previously in research among patients with heart disease [52], cancer [53] and multi-morbidity [54]. The study of Timmermans et al. among heart patients, factor analyses on the B-IPQ revealed two factors, i.e. 'consequences' (identity, concern, consequences, emotional response; α = 0.80) and 'control' (treatment control, personal control,

coherence; α = 0.52), with item 2 (timeline) belonging to none of the factors. They found that the total and 'consequences' scale on the B-IPQ correlated with medical and psychological factors and sex, whereas the 'control' scale did not [52]. Therefore they recommend to calculate a total score only for the consequences scale, or analyse all eight items in their own right, which we did in our study.

This is the first comprehensive longitudinal study which describes IP, the changes therein, and the relation with mental health in a sample of stroke patients that is much larger than in previous studies. In contrast to most other studies using the B-IPQ, the 'cause' item was analysed as well. The cluster analyses had several advantages: By making clusters, patients with comparable IP can more easily be characterised in terms of sociodemographic characteristics and health. Moreover, when entering clusters instead of individual items as covariates in a regression model, the risk of type 1 error is reduced as multiple testing is avoided. Several limitations can be mentioned. The first limitation concerns selection bias, which may have distorted the results. Of the stroke patients starting with inpatient rehabilitation, only half participated in the study ánd completed the 3 month questionnaire. Patients with the 'worst' health condition, in terms of cognitive functioning, language, and vision, did not participate. Moreover, the higher educated and those who had finished treatment were more likely to not complete the follow-up questionnaire. Second, the timing of the first assessment was suboptimal; IP were only assessed after the rehabilitation trajectory. Thus, we did not provide insight into the 'added value' of rehabilitation for influencing IP. Third, a potential limitation of our study is the use of the B-IPQ. Although the concurrent, predictive and discriminative validity were shown to be good, the content validity has been questioned. In each subscale of the B-IPQ only one item was used instead of 4 to 6 as in the original IPQ-R, making it difficult to capture the entire construct. Moreover, a 'think aloud study' among 11 patients with various health problems revealed repeated misinterpretations in some of the items of the B-IPQ [55]. However, in that study an adapted version was used in which the instructions to the respondent were unclear, in contrast to our study. In fact, we believe that for stroke patients, the B-IPQ is more feasible and acceptable than the more extensive IPQ-R. As several patients stated in a pilot phase of the SCORE study: extensive questionnaires would be too difficult or tiring to complete.

This study reveals valuable information for health professionals. It became clear that IP of stroke patients are variable over time and that they are related with depressive symptoms. Considering this, IP may be susceptible to CBT and/or self-management interventions. In a systematic review on studies using the B-IPQ, Broadbent et al. described that well designed interventions often succeeded in changing or more IP [34]. For example, in a sample of patients with irritable bowel syndrome, Chilcot and Moss Morris showed that a CBT self-management program enhanced personal control, facilitated more coherent understanding of the illness, and reduced perceptions of severe and

distressing consequences of the illness. Moreover they concluded that changes in IP predicted and partially mediated a reduction of symptom severity and an improvement in social adjustment over time [56]. For the rehabilitation setting specifically, these findings are relevant as well. Janssen et al. showed that changes in IP during cardiac rehabilitation were associated with enhanced quality of life [57]. French et al. demonstrated that more favourable IP predicted attendance at cardiac rehabilitation among acute myocardial infarction patients [58]. The effects of CBT and/or self-management interventions in this specific patient group, and the mediating effects of IP on depressive symptoms and other outcomes, should be unravelled in future research. Ultimately, adequately addressing IP in patients with stroke may enrich rehabilitation and prevent the occurrence of depressive symptoms.

5. Conclusion

Illness perceptions partly change over time in the first year after stroke. Patients with worse physical and mental health 3 months after stroke have a less favourable IP trajectory over time. Patients with an overall favourable IP trajectory have a lower risk of depressive symptoms at 12 months. Health professionals in rehabilitation have a role in the assessment of IP after stroke as it may be an additional target of treatment, most importantly in patients with worse physical and mental health.

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Conflict of interest

The authors have no competing interests to report.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.jpsychores.2018.10.019.

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