Trajectories of health-related quality of life after stroke

Citation for published version (APA):

van Mierlo, M. L., van Heugten, C., Post, M. W. M., Hoekstra, T., & Visser-Meily, A. (2018). Trajectories of health-related quality of life after stroke: results from a one-year prospective cohort study. *Disability and Rehabilitation*, 40(9), 997-1006. <https://doi.org/10.1080/09638288.2017.1292320>

Document status and date:

Published: 01/05/2018

DOI:

[10.1080/09638288.2017.1292320](https://doi.org/10.1080/09638288.2017.1292320)

Document Version:

Publisher's PDF, also known as Version of record

Document license:

Taverne

Please check the document version of this publication:

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
- The final author version and the galley proof are versions of the publication after peer review.
- The final published version features the final layout of the paper including the volume, issue and page numbers.

[Link to publication](#)

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal.

If the publication is distributed under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license above, please follow below link for the End User Agreement:

www.umlib.nl/taverne-license

Take down policy

If you believe that this document breaches copyright please contact us at:

repository@maastrichtuniversity.nl

providing details and we will investigate your claim.

ORIGINAL ARTICLE

Trajectories of health-related quality of life after stroke: results from a one-year prospective cohort study

Maria van Mierlo^a, Caroline van Heugten^{b,c}, Marcel W. M. Post^{a,d} , Trynke Hoekstra^{e,f} and Anne Visser-Meily^a

^aBrain Center Rudolf Magnus and Center of Excellence for Rehabilitation Medicine, University Medical Center Utrecht and De Hoogstraat Rehabilitation, Utrecht, The Netherlands; ^bDepartment of Psychiatry and Neuropsychology, School for Mental Health and Neuroscience, Maastricht University, Maastricht, The Netherlands; ^cDepartment of Neuropsychology and Psychopharmacology, Maastricht University, Maastricht, The Netherlands; ^dCenter for Rehabilitation and Department of Rehabilitation Medicine, University of Groningen, and University Medical Center Groningen, Groningen, The Netherlands; ^eFaculty of Earth and Life Sciences, Department of Health Sciences, and the EMGO Institute for Health and Care Research, VU University, Amsterdam, The Netherlands; ^fDepartment of Epidemiology and Biostatistics, VU University Medical Center, Amsterdam, The Netherlands

ABSTRACT

Purpose: To identify trajectories of physical and psychosocial health-related quality of life (HRQoL) from two months to one-year post stroke and to determine the factors that are associated with trajectory membership.

Method: Multicenter prospective cohort study in which 351 stroke patients were followed up at 2, 6, and 12 months post stroke. Latent class growth mixture modeling was used to determine trajectories of physical and psychosocial HRQoL. Multinomial regression analyses were performed to predict trajectory membership. Potential predictors were demographic, stroke-related, and psychological factors.

Results: Four trajectories were identified for both physical and psychosocial HRQoL: high, low, recovery, and decline. Comparing the low and recovery trajectories, the groups with low HRQoL were more likely to have higher scores for neuroticism. Comparison of the decline and high trajectories yielded the following predictors of physical HRQoL: discharged to a rehabilitation setting, less acceptance and more neuroticism, pessimism, helplessness, and passive coping. Predictors of psychosocial HRQoL were: discharged to a rehabilitation setting, less self-efficacy, and proactive coping, and more helplessness and passive coping.

Conclusions: The present study identified four distinct trajectories of physical and psychosocial HRQoL. The findings indicate that psychological factors are the most important factors in identifying stroke patients at risk of unfavorable HRQoL trajectories. Using these factors will help to identify vulnerable patients and guide rehabilitation in the early stages post stroke.

ARTICLE HISTORY

Received 24 February 2016
Revised 22 November 2016
Accepted 16 December 2016

KEYWORDS

Health-related quality of life; longitudinal studies; rehabilitation; stroke

► IMPLICATIONS FOR REHABILITATION

- Clinicians should be aware that health-related quality of life follows distinct trajectories stable high, stable low, recovery, or decline, after onset of stroke.
- Determining relevant psychological factors, in particular helplessness and passive coping, in stroke patients early after stroke is important because these are predictors of unfavorable health-related quality of life trajectories.

Introduction

Stroke is a leading cause of death and disability in the Western world. Major improvements in acute stroke care have resulted in more people surviving a stroke, but many of them experience long-term difficulties in their physical [1], cognitive [2], and emotional functioning [3].

This has led to growing interest in health-related quality of life (HRQoL) issues [4,5]. HRQoL refers to “how health impacts on an individual’s ability to function and his or her perceived well-being in physical, mental, and social domains of life” [6], and can be seen as an overarching multidimensional construct, comprising different domains of one’s life, such as physical, functional, psychological, and social health [7].

Research has shown that stroke patients perceive lower HRQoL than the general population [8,9], which is still the case five years post stroke [10]. Research into the course of HRQoL over time has generally focused on the first 6 months post stroke and has revealed diverging results. Some studies found improvement of HRQoL from one to six months post stroke [11,12], whereas another study found that HRQoL increased during inpatient rehabilitation, but decreased in the six months thereafter [13]. Only a few studies have investigated a longer follow-up period, up to 12 months and 16 months post stroke [14–16]. Two of these studies also made a distinction between physical and psychosocial HRQoL, but their results were inconclusive and contradictory [14,15]. The reasons for this divergence are unclear.

Currently, most longitudinal studies use averaged group data to examine changes over time. However, recovery after stroke is a dynamic process in which patients' outcome after stroke is heterogeneous and characterized by individual recovery patterns [17]. Investigating averaged group data can therefore obscure distinctive subgroups of patients with specific trajectories of HRQoL [18]. According to Bonanno [19], there are four characteristic trajectories in response to trauma: resilience, with no or little dysfunction; recovery, with relatively mild and short-lived dysfunction after onset of the trauma but return to pre-trauma levels of HRQoL in due course; delayed dysfunction, in which decrease of HRQoL occurs at a later stage after the event; and chronic dysfunction, HRQoL is decreased after the onset of trauma and remains low over time. Investigating the existence of different trajectories of HRQoL post stroke can help to identify those patients who adapt well after stroke and those who are at risk of unfavorable HRQoL trajectories early after stroke.

Research into the predictors of HRQoL has identified demographic and stroke-related factors, such as age, physical impairment, and functional independence, to be independent predictors of HRQoL [20,21]. However, these factors together explain only a small part of the variance of HRQoL. Psychological factors reflect the way people approach situations and adjust to chronic illness and therefore influence HRQoL [22,23]. A recent review identified factors such as coping, optimism, and neuroticism as determinants of stroke patients' HRQoL [24]. However, the reviewed studies were mostly small and had a cross-sectional design, so that evidence for the importance of psychological factors for HRQoL post stroke is still limited [24].

Hence, the first aim of the present study was to identify trajectories of physical and psychosocial HRQoL from two months to one-year post stroke. The second aim was to determine factors associated with physical and psychosocial HRQoL trajectory membership. It was hypothesized that the physical and psychosocial trajectories proposed by Bonanno would be present and that physical HRQoL trajectories would show stronger associations with stroke-related factors, and psychosocial HRQoL trajectories more psychological factors.

Methods

Design and procedure

The current study is part of the multicenter prospective longitudinal Restore4Stroke Cohort study, in which new stroke survivors were followed for two years [25]. Patients were included in the study between March 2011 and March 2013. Six general hospitals in the Netherlands participated and the medical ethics committees of all participating hospitals approved the study protocol. Written informed consent was obtained from all included patients. The present study reports data collected at stroke onset and two, six, and twelve months post stroke.

The first assessment concerned demographic and stroke-related factors. After informed consent had been given, information on stroke-related factors, as assessed by the neurologist on day four, was extracted from the medical charts. Information on demographic factors was obtained from the patient or family members. The second assessment took place two months post stroke. During this assessment, patients were asked to complete self-report scales on HRQoL and all psychological factors. In addition, trained research assistants assessed independence in activities of daily living (ADL), comorbidity, and cognition. The third and fourth assessments took place at six and twelve months post

stroke, respectively, and involved administering the self-report scale on HRQoL.

Subjects

Stroke patients were eligible for this study if they had a clinically confirmed diagnosis of stroke (ischaemic or intracerebral hemorrhagic lesion) and had suffered their stroke within the last seven days. All patients had to be at least 18 years old.

Patients were excluded if they: (a) had a serious other condition which could be expected to interfere with the study outcomes; (b) had already been dependent regarding ADL before their stroke as defined by a Barthel Index (BI) score of 17 or lower [26]; (c) had insufficient command of Dutch to complete the questionnaires (based on clinical judgment); or (d) had already been suffering from cognitive decline before their stroke, as defined by a score of 1 or higher on the Heteroanamnesis List Cognition [27].

It was aimed to include 500 patients in the study and have 300 participate in the one-year follow-up. Drop-out rates however turned out to be less than anticipated so that inclusion was terminated early.

Measures

HRQoL was assessed with the Short Stroke Specific Quality of Life Scale (SS-QoL-12) [28]. The SS-QoL-12 consists of 12 items, each scored on a 5-point scale. A physical (e.g., "Did you have to stop and rest more than you would like when walking or using a wheelchair?") and a psychosocial (e.g., "I felt I was a burden to my family") subscore can be computed, measured with six items each. Subscale scores are the average of the item scores and a higher score indicates higher levels of physical or psychosocial HRQoL. This scale has been especially developed for stroke patients. Internal consistency figures of the physical functioning (Cronbach's alpha 0.78–0.83) and the psychosocial functioning (Cronbach's alpha 0.77–0.89) scales were good and these scores explained 91–94% and 88–95% of the variance of the respective subtotal scores of the original SS-QoL [28].

Independent variables: demographic and stroke-related factors

Information about gender, age, and level of education was collected. For level of education we used the Dutch classification system of Verhage (range 1–7) [29]. The severity of the stroke was assessed with the National Institutes of Health Stroke Scale (NIHSS) (range 0–42) [30]. ADL was assessed two months post stroke, using the BI (range 0–20) [23]. Comorbidity was assessed with the Cumulative Illness Rating scale (CIRS) [31]. This scale consists of 13 items (range 0–48). Item 11 on neurological impairments was excluded in the analyses, because this item asks for neurological impairment including the stroke itself. Cognitive functioning was assessed with the Montreal Cognitive Assessment (MoCA) (range 0–30) [32].

Independent variables: psychological factors

Extraversion and neuroticism were assessed with the Neuroticism and Extraversion scales of the Eysenck Personality Questionnaire Revised Short Scale (EPQ-RSS-N and E) [33]. The extraversion (e.g., "Are you a talkative person?") and neuroticism (e.g., "Does your mood often go up and down?") scales both consist of 12 items with dichotomous (yes/no) response options.

Optimism and pessimism were assessed with the Life Orientation Test-Revised (LOT-R) [34]. Optimism (e.g., "In uncertain

times, I usually expect the best") and pessimism (e.g., "If something can go wrong for me, it will") are assessed with three items each.

Self-efficacy was assessed with the General Self-Efficacy Scale (GSES) [35]. The GSES consists of 10 items, an example question being "I am confident that I could deal efficiently with unexpected events".

Illness cognitions were assessed with the Illness Cognition Questionnaire (ICQ) [36]. The ICQ consists of three subscales: helplessness (e.g., "My illness frequently makes me feel helpless"), acceptance (e.g., "I can accept my illness well"), and perceived benefits (e.g., "My illness has made life more precious to me"), and each subscale consists of six items.

Proactive coping competencies were assessed with the Utrecht Proactive Coping Competence List (UPCC) [37]. The UPCC consists of 21 items, an example question being "To what extent do you have the capacity to recognize signals that something might go wrong".

Passive coping was assessed with the passive reaction pattern subscale of the Utrecht Coping List (UCL-P) (e.g., "take refuge in fantasies") [38]. This subscale consists of seven items.

Statistical analyses

Patients who completed one or more measurements were included in the analysis. Descriptive statistics were computed using SPSS (version 22.0) (SPSS Inc., Chicago, IL). Different trajectories of psychosocial and physical HRQoL were identified by fitting a latent class growth mixture model to the data, [39,40] using the Mplus software program 7.11 (Muthén & Muthén, Los Angeles, CA). Latent class growth mixture models are based on regression and structural equation modeling techniques. This technique assumes that there are subgroups in the sample that each have a unique trajectory with unique growth parameters. The optimal model is one in which the individuals within a subgroup are most similar to each other and most different from the individuals in other subgroups. The optimal number of trajectories was determined using the Bayesian information criterion (BIC) and the bootstrap likelihood ratio test (BLRT). A difference in the BIC value of at least 10 points between two models indicates that the model with the lower BIC value has a better model fit [41]. A significant BLRT suggests that the model with k number of classes is significantly better than the previous model with $k - 1$ number of classes [42]. Furthermore, patients were assigned to the trajectory to which they had the highest probability of belonging to, using posterior probabilities. An average posterior probability that approaches 1.0 suggests a good model fit, and a probability of 0.8 or higher is preferred [40]. The optimal model is chosen according to statistical fit and clinical interpretation.

Multinomial bivariate regression analyses were performed to predict trajectory membership taking into account the uncertainty in posterior class membership probabilities [43,44]. Demographic factors, stroke-related factors, and psychological factors were entered as independent variables. Level of education was dichotomized into low (up to completed secondary education) and high (completed University of Professional Education or higher). Dependency in ADL was dichotomized into "dependent" (BI <18) and "independent" (BI ≥18) and cognitive functioning was dichotomized into "impaired cognitive functioning" (MoCA <26) and "normal cognitive functioning" (MoCA ≥26), because of skewed distributions. Assumptions of linearity were met. Multivariate analysis to control for confounders was not possible because of small numbers of patients in several trajectories. The critical value of p was set at 0.05 for all analyses and was corrected for multiple testing ($0.005/6 = 0.0083$).

Table 1. Stroke patients' characteristics ($N = 351$).

Demographic factors	
Male gender, %	64.4
Age in years; mean (SD)	66.8 (12.5)
Marital status, living together, %	69.5
High education level ^a , %	27.4
Stroke-related factors	
Ischaemic stroke, % ($n = 350$)	93.1
Left hemisphere, % ($n = 347$)	39.5
Severity of stroke four days post stroke, mean (SD)	2.6 (3.1)
No stroke symptoms (NIHSS 0), %	24.8
Minor stroke symptoms (NIHSS 1–4), %	57.0
Moderate stroke symptoms (NIHSS 5–12), %	16.5
Moderate to severe stroke symptoms (NIHSS ≥13), %	1.7
ADL four days post stroke, mean (SD) ($n = 344$)	17.0 (4.7)
ADL-dependent (BI ≤17), %	32.5
ADL two months post stroke, mean (SD) ($n = 338$)	19.3 (2.0)
ADL-dependent (BI ≤17), %	9.5
Cognitive functioning two months post stroke, mean (SD) ($n = 333$)	23.6 (3.9)
Cognitively impaired (MoCA ≤25), %	67.0
Comorbidity, mean (SD) ($n = 338$)	6.0 (2.8)
Destination after discharge from hospital, %	
Home	71.8
Rehabilitation center	14.0
Nursing home	14.2

^aCompleted University of Professional Education or higher.

NIHSS: National Institute of Health Stroke Scale; ADL: Activities of daily living; BI: Barthel Index; MoCA: Montreal Cognitive Assessment.

Results

A total of 395 stroke patients were included in the Restore4Stroke Cohort study, of whom 343 (86.8%) participated at two months, 344 (87.1%) at six months, and 328 (83.0%) at one year post stroke. Main reasons for drop-out were patients who had died and patients who refused further participation. A total of 351 patients completed at least one measurement with HRQoL data and were included in the analyses (88.9%). Patient characteristics are displayed in Table 1. Table 2 presents descriptive statistics of HRQoL and the psychological measures two months post stroke.

Identifying HRQoL trajectories

A linear model was specified that takes the unequally spaced time points into account. Non-linear models were considered, but showed worse statistical fit compared to the linear model. Table 3 presents the results of the fit indices for models with 1–5 trajectories of physical and psychosocial HRQoL. According to the BIC, BLRT, and average posterior probabilities, the 5-trajectory model for physical HRQoL was superior. The 5-trajectory model consisted of a stable high and a stable low physical HRQoL trajectory, while the other three trajectories were intermediate trajectories which were intertwined with each other. One of the trajectories concerned only a very small group of patients ($n = 3$), making a meaningful interpretation difficult. Therefore, the 4-trajectory model was selected for physical HRQoL, consisting of a stable high, a stable low and two intermediate trajectories, with one of the latter increasing between two months and six months (i.e., recovery) and one slightly decreasing in the same period (i.e., decline) (Figure 1 and Table 4).

According to the BIC, BLRT and average posterior probabilities, the 4-trajectory model for psychosocial HRQoL was superior, and this was therefore selected. It consisted of a stable high and a stable low psychosocial HRQoL trajectory and two intermediate trajectories, with one of the latter increasing between two months

Table 2. Descriptive statistics of the health-related quality of life and psychological measures at two months post stroke.

Factor	Measure	Range	Actual range	N	Cronbach's alpha	Mean (SD)
HRQoL – Physical	SS-QoL-12	1–5	1.2–5	332	0.77	4.1 (0.8)
HRQoL – Psychosocial	SS-QoL-12	1–5	1–5	332	0.86	3.7 (1.1)
Extraversion	EPQ-RSS-E	0–12	0–12	335	0.83	7.1 (3.2)
Neuroticism	EPQ-RSS-N	0–12	0–12	335	0.83	3.6 (3.1)
Optimism	LOT-R	0–12	2–12	335	0.61	8.2 (2.1)
Pessimism	LOT-R	0–12	0–12	334	0.72	4.4 (2.8)
Self-efficacy	GSES	10–40	10–40	334	0.92	31.6 (6.3)
Helplessness	ICQ	6–24	6–24	335	0.88	11.9 (4.9)
Acceptance	ICQ	6–24	6–24	335	0.88	16.4 (4.8)
Perceived benefits	ICQ	6–24	6–24	335	0.83	15.1 (4.8)
Proactive coping	UPCC	1–4	1.5–4	334	0.93	3.1 (0.6)
Passive coping	UCL-P	7–28	7–23	335	0.72	10.5 (2.8)

HRQoL: Health-Related quality of life; SS-QoL-12: Stroke Specific Quality of Life Scale; EPQ-RSS-E: Eysenck Personality Questionnaire Revised Short Scale Extraversion; EPQ-RSS-N: Eysenck Personality Questionnaire Revised Short Scale Neuroticism; LOT-R: Life Orientation Test-Revised; GSES: General Self-Efficacy Scale; ICQ: Illness Cognition Questionnaire; UPCC: Utrecht Proactive Coping Competence List; UCL-P: Utrecht Coping List passive reaction pattern subscale.

Table 3. Fit indices for models with 1–5 trajectories of physical and psychosocial HRQoL.

Physical HRQoL									
Number of trajectories	BIC	BLRT	Average posterior probability	Entropy	Number of patients in each trajectory class				
					1	2	3	4	5
Physical HRQoL									
1	1731.967	NA	1.0	NA	351				
2	1707.318	$p < 0.001$	0.895	0.731	273	78			
3	1689.257	$p < 0.001$	0.874	0.787	254	74	23		
4	1667.653	$p < 0.001$	0.868	0.808	227	46	20	58	
5	1652.770	$p < 0.001$	0.906	0.846	3	59	54	218	17
Psychosocial HRQoL									
1	2573.452	NA	1.0	NA	351				
2	2546.187	$p < 0.001$	0.907	0.706	244	107			
3	2522.731	$p < 0.001$	0.851	0.741	211	96	44		
4	2512.672	$p < 0.001$	0.835	0.731	158	54	64	75	
5	2506.350	$p < 0.001$	0.809	0.762	157	72	8	59	55

BIC: Bayesian Information Criterion; BLRT: Bootstrap Likelihood Ratio Tests; NA: Not applicable.

Figure 1. Four-trajectory model of physical HRQoL.

and six months (i.e., recovery) and one slightly decreasing in the same period (i.e., decline) (Figure 2 and Table 4).

Predictors of physical and psychosocial HRQoL

Possible determinants of each physical and psychosocial HRQoL trajectory are displayed in Table 5. Multinomial bivariate regression analyses were performed to determine the predictors which could discriminate between the physical and psychosocial HRQoL trajectories (Table 6). Comparisons between the low and high trajectories are presented because we expected that the largest

differences would be found between these trajectories. In addition, comparison is presented for the low vs. recovery trajectory and the decline vs. high trajectory, as these comparisons are clinically most relevant. The other three comparisons (recovery vs. high, decline vs. recovery, and low vs. decline) are presented in Appendix 1.

Compared with the patients in the high physical HRQoL trajectory ($N = 227$), patients in the low trajectory ($N = 46$) were more likely to have a more severe stroke, to be discharged to a rehabilitation setting, dependent in ADL two months post stroke, to have higher scores for neuroticism, pessimism, feelings of helplessness

Table 4. Physical and psychosocial HRQoL values and confidence intervals for the four different trajectories.

	2m post stroke	6m post stroke	12m post stroke
Physical HRQoL			
High (<i>n</i> = 227)	4.48 SD 0.03 (4.42–4.54) <i>n</i> = 217	4.62 SD 0.02 (4.57–4.67) <i>n</i> = 222	4.52 SD 0.03 (4.46–4.59) <i>n</i> = 214
Low (<i>n</i> = 46)	2.88 SD 0.08 (2.71–3.05) <i>n</i> = 41	3.18 SD 0.08 (3.01–3.34) <i>n</i> = 45	3.16 SD 0.10 (2.95–3.36) <i>n</i> = 43
Recovery (<i>n</i> = 20)	2.91 SD 0.10 (2.70–3.11) <i>n</i> = 20	4.31 SD 0.09 (4.12–4.50) <i>n</i> = 20	4.05 SD 0.18 (3.68–4.43) <i>n</i> = 20
Decline (<i>n</i> = 58)	4.14 SD 0.06 (4.01–4.27) <i>n</i> = 54	3.48 SD 0.06 (3.36–3.59) <i>n</i> = 55	3.78 SD 0.10 (3.58–3.97) <i>n</i> = 48
Psychosocial HRQoL			
High (<i>n</i> = 158)	4.53 SD 0.03 (4.46–4.60) <i>n</i> = 153	4.57 SD 0.04 (4.50–4.65) <i>n</i> = 152	4.56 SD 0.05 (4.46–4.65) <i>n</i> = 146
Low (<i>n</i> = 54)	2.16 SD 0.07 (2.02–2.31) <i>n</i> = 50	2.28 SD 0.07 (2.14–2.42) <i>n</i> = 53	2.48 SD 0.10 (2.27–2.68) <i>n</i> = 53
Recovery (<i>n</i> = 64)	2.63 SD 0.07 (2.50–2.77) <i>n</i> = 63	3.97 SD 0.09 (3.79–4.14) <i>n</i> = 63	4.02 SD 0.09 (3.83–4.20) <i>n</i> = 59
Decline (<i>n</i> = 75)	3.78 SD 0.07 (3.64–3.91) <i>n</i> = 66	3.23 SD 0.07 (3.09–3.37) <i>n</i> = 74	3.16 SD 0.08 (3.03–3.32) <i>n</i> = 67

Note: values are Mean SD (CI). Values are calculated with SPSS.

m: months.

Figure 2. Four-trajectory model of psychosocial HRQoL.

and passive coping, and to have lower scores for acceptance and proactive coping. Comparing the low (*N* = 46) and recovery (*N* = 20) trajectories shows that the patient group with low physical HRQoL was more likely to have higher scores for neuroticism. Compared with patients in the high physical HRQoL trajectory (*N* = 227), patients in the decline trajectory (*N* = 58) were more likely to be discharged to a rehabilitation setting, to have higher scores for neuroticism, pessimism, feelings of helplessness and passive coping, and to have lower scores for acceptance.

Compared with the patients in the high psychosocial HRQoL trajectory (*N* = 158), patients in the low trajectory were more likely to be dependent in ADL two months post stroke, to have higher scores for comorbidity, neuroticism, pessimism, helplessness and passive coping, and to have lower scores for optimism, self-efficacy, acceptance, perceived benefits, and proactive coping. Comparing the low (*N* = 54) with the recovery (*N* = 64) trajectory showed that the patient group with low psychosocial HRQoL was more likely to have higher scores for neuroticism. Compared with the patients in the high physical HRQoL trajectory (*N* = 158), patients in the decline trajectory (*N* = 75) were more likely to be discharged to a rehabilitation setting, to have higher scores for helplessness and passive coping, and to have lower scores for self-efficacy and proactive coping.

Discussion

The present study identified four distinct trajectories for both physical and psychosocial HRQoL in stroke patients during the first-year post stroke. Trajectories identified for both physical and psychosocial HRQoL were: high, low, recovery and decline. Psychological factors proved to be the strongest associated with trajectory membership.

To our knowledge, this is the first study to identify different trajectories in the course of physical and psychosocial HRQoL post stroke and to determine predictors of these different trajectories. In the present study, many patients showed a high stable physical (65%) and high stable psychosocial (45%) HRQoL trajectory. Resilience with little or no dysfunction is the most common outcome in response to potential trauma [19], which is in agreement with what we found in the present study. The other three trajectories suggested in the literature, were partially found in the present study. The low HRQoL trajectory corresponds to the chronic dysfunction trajectory, while the recovery and decline HRQoL trajectories correspond to the recovery and delayed dysfunction trajectories proposed by Bonanno, respectively. However, HRQoL scores in the recovery trajectory did not reach the level of HRQoL found in the high trajectory one year post stroke. Further, in the decline trajectory, the decrease in HRQoL was minor and ended up at a moderate level.

It is difficult to compare our findings with those of earlier studies, because earlier findings were inconclusive: one study found a decline in psychosocial HRQoL between 6 and 12 months [14], while in another study psychosocial HRQoL increased and physical HRQoL decreased between 4 and 16 months post stroke [15]. The findings of the present study indicate that where there is recovery of HRQoL, most of it takes place in the first months post stroke. This is in agreement with the assumed time-frame for functional recovery after stroke, which involves most of the functional recovery taking place in the first six months post stroke [17], and recovery reaching a plateau at an average of three to six months after stroke onset [45]. It is surprising that we found the same time-frame for the recovery of HRQoL post-stroke, as we assume that adaption post stroke, especially psychosocial adaptation, is a continuous process which stretches over a long period that begins when the patient starts to realize that there will be no full

Table 5. Demographic, stroke-related, and psychological factors for different trajectories of physical and psychosocial HRQoL.

	Physical HRQoL				Psychosocial HRQoL			
	Class 1, high (n = 227)	Class 2, low (n = 46)	Class 3, recovery (n = 20)	Class 4, decline (n = 58)	Class 1, high (n = 158)	Class 2, low (n = 54)	Class 3, recovery (n = 64)	Class 4, decline (n = 75)
Demographic factors								
Gender, male %	66.5	65.2	65.0	55.2	67.1	64.8	60.9	61.3
Age in years; mean (SD)	64.7 (11.6)	72.3 (12.0)	67.2 (13.9)	70.2 (13.8)	66.2 (12.0)	65.3 (13.1)	68.1 (14.4)	67.9 (11.3)
Marital status, living together, %	71.4	69.6	60	65.5	69.0	74.1	68.8	68
High education level ^a , %	30.8	19.6	10.0	25.9	29.1	22.2	20.3	33.3
Stroke-related factors								
Severity of stroke four days post stroke, mean (SD)	2.2 (2.5)	3.9 (4.4)	3.8 (4.8)	3.0 (2.8)	2.2 (2.7)	2.9 (3.8)	2.9 (3.7)	2.9 (2.7)
Discharge home from hospital, %	81.1	52.2	55.0	56.9	81	63.0	70.3	60.0
ADL-dependent (BI ≤ 17), %	2.3	38.6	20.0	11.1	3.2	17.0	15.9	11.9
Cognitively impaired (MoCA ≤ 25), %	61.6	82.5	65.0	77.8	58.1	72.5	73.8	77.3
Comorbidity, mean (SD)	3.7 (2.5)	4.8 (2.6)	3.8 (2.7)	4.8 (3.2)	3.6 (2.5)	4.6 (2.3)	3.6 (2.7)	4.8 (3.2)
Psychological factors								
Extraversion	7.3 (3.1)	6.4 (3.3)	6.5 (4.0)	7.0 (3.3)	7.7 (3.1)	6.5 (3.4)	6.5 (3.3)	6.8 (3.1)
Neuroticism	3.2 (3.0)	5.1 (3.3)	3.1 (2.4)	4.5 (3.1)	2.5 (2.6)	6.1 (3.7)	4.1 (2.5)	3.8 (3.0)
Optimism	8.4 (2.1)	7.4 (2.2)	8.3 (2.0)	7.8 (2.3)	8.7 (2.0)	6.8 (2.0)	7.8 (2.2)	8.3 (2.0)
Pessimism	4.0 (2.8)	5.3 (2.5)	3.7 (2.3)	5.3 (2.7)	3.7 (2.9)	5.2 (2.7)	5.0 (2.4)	4.6 (2.5)
Self-efficacy	32.2 (6.2)	29.3 (7.8)	30.1 (4.4)	31.3 (5.8)	33.7 (5.7)	28.6 (7.4)	30.2 (5.5)	30.2 (6.0)
Helplessness	10.3 (4.1)	16.6 (4.7)	15.0 (4.1)	13.3 (5.0)	9.4 (3.9)	15.9 (4.5)	14.2 (4.8)	12.4 (4.1)
Acceptance	17.6 (4.6)	13.5 (4.8)	14.0 (3.8)	14.9 (4.6)	18.4 (4.5)	12.9 (4.0)	14.5 (4.3)	16.3 (4.4)
Perceived benefits	15.3 (4.7)	13.9 (5.5)	15.2 (4.2)	14.8 (5.1)	15.9 (4.9)	12.9 (4.3)	15.0 (4.4)	14.9 (4.8)
Proactive coping	3.2 (0.5)	2.8 (0.7)	2.9 (0.4)	3.0 (0.6)	3.3 (0.5)	2.7 (0.7)	2.9 (0.5)	3.0 (0.5)
Passive coping	9.9 (2.4)	12.4 (3.7)	11.2 (2.7)	11.4 (3.0)	9.4 (2.2)	12.7 (3.7)	11.1 (2.4)	11.0 (2.5)

Note: There were some missing values on cognition, comorbidity and all psychological variables. The number of patients on these measures varied for physical HRQoL: high: 218–220; low: 40–44; decline: 53–54. The number of patients on these measures varied for psychosocial HRQoL: high: 154–155; low: 51–53; recovery: 61–63; decline: 65–67. These values are calculated with SPSS.

^aCompleted University of Professional Education or higher (see also Table 1).

Table 6. Multinomial bivariate regression analyses to distinguish between the physical and psychosocial HRQoL trajectories ($n = 351$).

	Physical HRQoL			Psychosocial HRQoL			Decline (reference) vs. high		
	Low (reference) vs. high		Low (reference) vs. recovery	Decline (reference) vs. high		Low (reference) vs. recovery	Decline (reference) vs. high		Decline (reference) vs. high
	Odds ratio	95%CI		Odds ratio	95%CI		Odds ratio	95%CI	
Demographic factors									
Gender (female)	0.98	0.41–2.36							
Age	0.93	0.88–0.98							
Relationship (yes)	1.07	0.43–2.65							
Education (high)	2.10	0.72–6.13							
Stroke-related factors									
Severity of stroke	0.81	0.70–0.94							
Discharge (home)	5.17	2.16–12.39							
ADL (independent)	109.40	5.60–2135.29							
Cognition (normal)	1.92	0.76–4.86							
Comorbidity	0.84	0.73–0.96							
Psychological factors									
Extraversion	1.11	0.97–1.27							
Neuroticism	0.79	0.69–0.89							
Optimism	1.32	1.05–1.64							
Pessimism	0.82	0.72–0.93							
Self-efficacy	1.09	1.02–1.17							
Helplessness	0.69	0.62–0.78							
Acceptance	1.30	1.12–1.52							
Perceiving benefits	1.10	0.96–1.25							
Proactive coping	5.65	1.95–16.42							
Passive coping	0.70	0.60–0.82							

Note: values in bold are significant.

recovery of functioning, despite rehabilitation efforts in the first 3–6 months [46]. In any case, the present results indicate that it is important to be aware of this comparable time-frame for the recovery of HRQoL post stroke, and to identify and start caring for patients at risk of unfavorable HRQoL trajectories as early as two months post stroke, and preferable already in the acute phase.

The second aim of this study was to determine factors that are associated with physical and psychosocial trajectory membership, in order to identify those patients at risk of poor adaptation post stroke. These are the patients in the low and decline HRQoL trajectories, and they made up about 30–37% of our total patient group, which is somewhat higher than Bonanno proposed for the chronic dysfunction and delayed dysfunction trajectories (10–20%) [19]. Two months post stroke, the low and recovery trajectories both had a relatively low physical and psychosocial HRQoL score, while the decline and high trajectories both had a relatively high physical and psychosocial HRQoL score (Figures 1 and 2). Thus, it is possible and relevant to discriminate the low from the recovery trajectory and the decline from the high trajectory as early as two months post stroke.

Compared with the recovery HRQoL patient groups, the groups with low physical and psychosocial HRQoL were only more likely to have higher scores for neuroticism. Fortunately, more factors were found to distinguish between the decline and high trajectories. For the decline versus high trajectory, the following predictors were found for physical HRQoL: being discharged to a rehabilitation setting, less acceptance, and more neuroticism, pessimism, helplessness, and passive coping. Predictors for psychosocial HRQoL were largely the same: being discharged to a rehabilitation setting, less self-efficacy and proactive coping, and more helplessness and passive coping. We had hypothesized that physical trajectories would be predicted more by stroke-related factors and psychosocial trajectories more by psychological factors. Our results show that psychosocial trajectory membership is indeed predicted more by psychological factors, but these psychological factors are also more important than stroke-related factors in predicting physical trajectory membership. This means that psychological factors are more important in determining HRQoL trajectory membership than demographic and stroke-related factors. This is promising, because stroke-related factors are difficult to modify after the acute phase, while some of the psychological factors may be amendable to treatment.

The psychological predictors that we found may be used to modify the vulnerable trajectories into more favorable trajectories. Neuroticism and pessimism are personality traits which are assumed to remain relatively stable throughout life [47]. Fortunately, however, it has been shown that coping styles are modifiable; traumatic brain injury patients can be taught to make use of more adaptive coping styles, such as active problem-focused styles [48]. A study assessing an individualized stroke self-management intervention found positive results in terms of changing self-efficacy after stroke [49]. Furthermore, studies of patients with other chronic diseases, such as rheumatic diseases, have reported promising results concerning the possibility of modifying illness cognitions by means of multidisciplinary rehabilitation treatment and cognitive behavioral therapy [36]. More research is necessary to find out if there are more factors which determine favorable or unfavorable HRQoL trajectories post stroke and how these factors can be changed.

Strengths and limitations

The study had several strengths and limitations. One of the strengths is that it included a large group of stroke patients

($N=351$) examined in a longitudinal design, with several follow-up assessments up to one year post stroke. Another is that this is the first study to investigate the course of psychosocial and physical HRQoL on the basis of several trajectories. Finally, we investigated predictors that can discriminate between these trajectories, taking into account a broad range of potential predictors.

However, interpretation of our results must take account of the following limitations. First, most patients included in the present study seemed to have suffered a minor stroke, and experienced minor physical problems. A possible explanation for this is that patients who had suffered a severe stroke may have had difficulty understanding the instructions for the study and may not have been able to provide informed consent within one week after the event. As we included a relatively “mildly” affected patient sample based on NIHSS and BI scores, our results may not hold for more severely disabled stroke patients typically admitted to rehabilitation centers or nursing homes.

Furthermore, in this study we investigated the association between a broad spectrum of demographic, stroke-related and psychological factors and trajectory membership of physical and psychosocial HRQoL, however, more variables could be important in these association, such as social support.

Finally, the number of trajectories we choose is, in part, determined by the size of the sample. The significant BLRT results (Table 3) suggest that more trajectories may exist in the population, and the limited number of patients in several trajectories made multivariate analysis with correction for confounders impossible.

Conclusion

Stroke patients who suffer a stroke can show psychosocial and physical HRQoL trajectories that can be characterized as stable high or low, recovery, or decline. The findings indicate that psychological factors are the most important factors associated with trajectory membership. Determining these predictors as early as two months post stroke will help to identify those patients at risk of unfavorable physical and psychosocial HRQoL trajectories, and to guide rehabilitation in the early stages post stroke.

Acknowledgements

We would like to thank all patients for their contribution to this study. Furthermore, we want to thank the staff of the participating Dutch hospitals, as well as all research assistants who collected the data at St. Antonius Hospital (Nieuwegein), Diaconessenhuis (Utrecht), Canisius Wilhelmina Hospital (Nijmegen), TweeSteden Hospital (Tilburg), St. Elisabeth Hospital (Tilburg), and Catharina Hospital (Eindhoven).

Disclosure statement

This research project is funded by the VSB Fonds [grant number 89000004], and co-ordinated by ZonMw (Dutch Organization for Health Research and Development).

Funding

This research project is funded by the VSB Fonds [grant number 89000004], and co-ordinated by ZonMw (Dutch Organization for Health Research and Development).

ORCID

Marcel W. M. Post <http://orcid.org/0000-0002-2205-9404>

References

- [1] Van de Port IGL, Kwakkel G, van Wijk I, et al. Susceptibility to deterioration of mobility long-term after stroke: a prospective cohort study. *Stroke*. 2006;37:167–171.
- [2] Leśniak M, Bak T, Czepiel W, et al. Frequency and prognostic value of cognitive disorders in stroke patients. *Dement Geriatr Cogn Disord*. 2008;26:356–363.
- [3] Schepers V, Post M, Visser-Meily A, et al. Prediction of depressive symptoms up to three years post-stroke. *J Rehabil Med*. 2009;41:930–935.
- [4] Carod-Artal FJ, Egido JA. Quality of life after stroke: the importance of a good recovery. *Cerebrovasc Dis*. 2009;27(Suppl. 1):204–214.
- [5] Carod-Artal J, Egido JA, González JL, et al. Quality of life among stroke survivors evaluated 1 year after stroke: experience of a stroke unit. *Stroke*. 2000;31:2995–3000.
- [6] Coons SJ, Rao S, Keininger DL, et al. A comparative review of generic quality-of-life instruments. *Pharmacoeconomics*. 2000;17:13–35.
- [7] Post MW. Definitions of quality of life: what has happened and how to move on. *Top Spinal Cord Inj Rehabil*. 2014;20:167–180.
- [8] Kauhanen ML, Korpelainen JT, Hiltunen P, et al. Domains and determinants of quality of life after stroke caused by brain infarction. *Arch Phys Med Rehabil*. 2000;81:1541–1546.
- [9] Haley WE, Roth DL, Kissela B, et al. Quality of life after stroke: a prospective longitudinal study. *Qual Life Res*. 2011;20:799–806.
- [10] De Wit L, Theuns P, Dejaeger E, et al. Long-term impact of stroke on patients' health-related quality of life. *Disabil Rehabil*. 2016. [Epub ahead of print]. doi: 10.1080/09638288.2016.1200676
- [11] Rønning OM, Stavem K. Determinants of change in quality of life from 1 to 6 months following acute stroke. *Cerebrovasc Dis*. 2008;25:67–73.
- [12] Robinson-Smith G, Johnston MV, Allen J. Self-care self-efficacy, quality of life, and depression after stroke. *Arch Phys Med Rehabil*. 2000;81:460–464.
- [13] Hopman WM, Verner J. Quality of life during and after inpatient stroke rehabilitation. *Stroke*. 2003;34:801–805.
- [14] Suenkel IH, Nowak M, Misselwitz B, et al. Timecourse of health-related quality of life as determined 3, 6 and 12 months after stroke. Relationship to neurological deficit, disability and depression. *J Neurol*. 2002;249:1160–1167.
- [15] Jönsson A, Lindgren I, Hallström B, et al. Determinants of quality of life in stroke survivors and their informal caregivers. *Stroke*. 2005;36:803–808.
- [16] Algrén B, Fridlund B, Cieza A, et al. Factors associated with health-related quality of life after stroke: a 1-year prospective cohort study. *Neurorehabil Neural Repair*. 2012;26:266–274.
- [17] Langhorne P, Bernhardt J, Kwakkel G. Stroke rehabilitation. *Lancet*. 2011;377:1693–1702.
- [18] Yu HW, Chen DR, Chiang TL, et al. Disability trajectories and associated disablement process factors among older adults in Taiwan. *Arch Gerontol Geriatr*. 2015;60:272–280.
- [19] Bonnano GA, Mancini AD. The human capacity to thrive in the face of potential trauma. *Pediatrics*. 2008;121:369–375.
- [20] Sturm JW, Donnan GA, Dewey HM, et al. Quality of life after stroke: the North East Melbourne Stroke Incidence Study (NEMESIS). *Stroke*. 2004;35:2340–2345.
- [21] Haacke C, Althaus A, Spottke A, et al. Long-term outcome after stroke: evaluating health-related quality of life using utility measurements. *Stroke*. 2006;37:193–198.
- [22] Taylor GH, Todman J, Broomfield NM. Post-stroke emotional adjustment: a modified social cognitive transition model. *Neuropsych Rehab*. 2011;21:808–824.
- [23] Visser-Meily JMA, Rhebergen ML, Rinkel GJE, et al. Long-term health-related quality of life after aneurismal subarachnoid hemorrhage: relationship with psychological symptoms and personality characteristics. *Stroke*. 2009;40:1526–1529.
- [24] Van Mierlo ML, Schröder C, Van Heugten CM, et al. The influence of psychological factors on Health-Related Quality of Life after stroke: a systematic review. *Int J Stroke*. 2014;9:341–348.
- [25] Van Mierlo ML, Van Heugten CM, Post MWM, et al. A longitudinal cohort study on quality of life in stroke patients and their partners: restore4stroke cohort. *Int J Stroke*. 2014;9:148–154.
- [26] Collin C, Wade DT, Davies S, et al. The Barthel ADL index: a reliability study. *Int Disabil Stud*. 1988;10:61–63.
- [27] Meijer R, van Limbeek J, de Haan R. Development of the stroke-unit discharge guideline. Choice of assessment instruments for prediction in the subacute phase post-stroke. *Int J Rehabil Res*. 2006;29:1–8.
- [28] Post MWM, Boosman H, Van Zandvoort MM, et al. Development and validation of a short version of the Stroke-Specific Quality of Life Scale. *J Neurol Neurosurg Psychiatry*. 2011;82:283–286.
- [29] Verhage F. Intelligentie en leeftijd: Onderzoek bij Nederlanders van twaalf tot zevenenzeventig jaar [Intelligence and age: study among Dutch people from age 12 to 77]. Van Gorcum, Assen 1964.
- [30] Brott T, Adams HP, Olinger CP, et al. Measurements of acute cerebral infarction: a clinical examination scale. *Stroke*. 1989;20:864–870.
- [31] Linn BS, Linn MW, Gurel L. Cumulative illness rating scale. *J Am Geriatr Soc*. 1968;16:622–626.
- [32] Nasreddine ZS, Phillips NA, Bédirian V, et al. The Montreal cognitive assessment, MoCA: a brief screening tool for mild cognitive impairment. *J Am Geriatr Soc*. 2005;53:695–699.
- [33] Sanderman R, Arrindell WA, Ranchor AV, et al. Het meten van persoonlijkheidskenmerken met de Eysenck personality questionnaire (EPQ): Een handleiding. [Measuring personality traits with the Eysenck Personality Questionnaire (EPQ): an instruction manual]. Noordelijk Centrum voor Gezondheidsvraagstukken, Groningen; 1995.
- [34] Scheier MF, Carver CS, Bridges MW. Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self-esteem): a reevaluation of the life orientation test. *J Pers Soc Psychol*. 1994;67:1063–1078.
- [35] Scholz U, Doña BG, Sud S, et al. Is general self-efficacy a universal construct? Psychometric findings from 25 countries. *Eur J Psychol Assess*. 2002;18:242–251.
- [36] Evers AWM, Kraaimaat FW, van Lankveld W, et al. Beyond unfavorable thinking: the illness cognition questionnaire for chronic diseases. *J Consult Clin Psychol*. 2001;69:1026–1036.
- [37] Bode C, Thoolen B, de Ridder D. Het meten van proactieve coping vaardigheden: psychometrische eigenschappen van de Utrechtse Proactieve Coping Competentie lijst (UPCC)

- [Dutch]. [Measuring proactive coping competences: psychometric properties of the Utrecht Proactive Coping Competence List (UPCC)]. PSEG. 2008;36:81–91.
- [38] Eriksen HR, Olff M, Ursin H. The CODE: a revised battery for coping and defense and its relations to subjective health. *Scand J Psychol.* 1997;38:175–182.
- [39] Muthén B, Muthén L. Integrating person-centered and variable centered analyses: growth mixture modeling with latent trajectory classes. *Alcoholism Clin Exp Res.* 2000;24:882–891.
- [40] Jung T, Wickrama KAS. An introduction to latent class growth analysis and growth mixture modeling. *Social Pers Psych Compass.* 2008;2:302–317.
- [41] Raftery A. Bayesian model selection in social research. *Sociol Methodol.* 1995;25:111–163.
- [42] Nylund K, Asparouhov T, Muthén B. Deciding on the number of classes in latent class analysis and growth mixture modelling: a Monte Carlo simulation study. *Struct Equ Model.* 2007;14:535–569.
- [43] Vermunt JK. Latent class modeling with covariates: two improved three-step approaches. *Polit Anal.* 2010; 18:450–469.
- [44] Asparouhov T, Muthén B. Auxiliary variables in mixture modeling: a 3-step approach using Mplus. *Mplus Web Notes.* 2014;1–51; [cited 2016 Apr 02]. Available from: <http://www.statmodel.com/examples/webnotes/webnote15.pdf>.
- [45] Kwakkel G, Kollen BJ. Predicting activities after stroke: what is clinically relevant?. *Int J Stroke.* 2013;8:25–32.
- [46] Brands IMH, Wade DT, Stapert SZ, et al. The adaptation process following acute onset disability: an interactive two-dimensional approach applied to acquired brain injury. *Clin Rehabil.* 2012;26:840–852.
- [47] Larsen RJ, Buss DM. Personality dispositions over time: stability, change, and coherence. In: *Personality psychology: domains of knowledge about human nature.* 2nd ed. New York: McGraw-Hill; 2005. p. 138–140.
- [48] Anson K, Ponsford J. Who benefits? Outcome following a coping skills group intervention for traumatically brain injured individuals. *Brain Inj.* 2006;20:1–13.
- [49] Jones F, Mandy A, Partridge C. Changing self-efficacy in individuals following a first time stroke: preliminary study of a novel self-management intervention. *Clin Rehabil.* 2009;23:522–533.

Appendix 1

Intercepts and slopes for models with 1–5 trajectories, for both physical and psychosocial HRQoL.

Model solution	Trajectories				
	1	2	3	4	5
Physical HRQoL					
1	4.122/0.104				
2	4.366/0.146	3.316/–0.039			
3	4.479/0.051	3.356/–0.118	2.996/1.195		
4	4.477/0.132	2.989/0.248	3.005/1.315	4.414/–0.631	
5	1.181/–0.128	4.121/–0.627	3.171/0.307	4.523/0.134	2.993/1.375
Psychosocial HRQoL					
Trajectories					
1	3.645/0.176				
2	4.056/0.255	2.759/0.011			
3	4.362/–0.076	2.625/0.090	2.532/1.453		
4	4.503/0.040	2.248/0.186	2.649/1.254	3.799/–0.499	
5	4.526/0.006	2.873/0.931	1.685/2.709	3.913/–0.671	2.234/0.199

Note: values are intercept/slope.