Quality of Life during the First Two Years Post Stroke

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Quality of Life during the First Two Years Post Stroke: The Restore4Stroke Cohort Study

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Key Words

Activities of daily living · Stroke care · Stroke outcome · Quality of life

Abstract

Background: Little information is available about the course of quality of life (QoL) post stroke and how dependency on activities of daily living (ADL) influences this course. The aim of this study was therefore to describe the course of QoL from 2 months up to 2 years post stroke and to study the influence of ADL dependency in the first week post stroke. **Methods:** This is a multicenter prospective longitudinal cohort study in which 368 stroke patients were included and data were collected at 1 week, 2 months, 6 months, 12 months and 24 months post stroke. QoL assessment included measures of health-related quality of life (HRQoL) (short stroke-specific Quality of Life Scale), emotional functioning (Hospital Anxiety and Depression Scale), participation (Utrecht Scale for Evaluation of Rehabilitation-Participation), and life satisfaction (2LS). Dependency on ADL was defined as having a Barthel Index score ≤ 17 four days post stroke.

Generalized Estimating Equations analyses were performed to examine the course of the 4 domains of QoL. Furthermore, the possible confounding effect of age, gender, marital status, level of education and discharge destination was examined. **Results:** Results showed that HRQoL, participation and life satisfaction improved during the first year post stroke, with most changes occurring in the first 6 months. Furthermore, patients dependent in ADL scored consistently lower on all 4 QoL domains and test occasions compared to ADL-independent patients. In both patient groups separately, no changes over time were found in emotional functioning. ADL-independent patients improved in HRQoL ($p = 0.002$), participation ($p < 0.001$) and life satisfaction ($p = 0.020$) between 2 and 6 months and in life satisfaction ($p = 0.003$) between 6 and 12 months also. ADL-dependent patients improved in HRQoL ($p = 0.009$) between 2 and 6 months and in participation between 2 and 6 months ($p = 0.001$) and between 6 and 12 months ($p = 0.031$). Furthermore, they experienced no changes in life satisfaction. No confounding effect was found after adding age, gender, marital status, level of education and discharge destination. **Conclusions:** Most improvement in QoL occurred up to 6 months post stroke

and showed different patterns for specific domains of QoL and for patients with and without dependency in ADL in the first week post stroke. It is therefore important to differentiate between these different domains of QoL when the long-term perspective is considered. Furthermore, patients dependent in ADL consistently scored lower on all QoL domains and did not reach the level of QoL of patients independent of QoL.

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Stroke is a chronic condition that can lead to serious consequences in terms of physical [1], cognitive [2] and emotional problems [3], but may also affect social reintegration [4] and life satisfaction [5]. Assessment of impairment and disability alone provides insufficient information about the entire impact of stroke [6–8]. This has led to growing interest in psychosocial concepts such as quality of life (QoL) [6, 7].

Changes in QoL post stroke have been investigated using health-related quality of life (HRQoL) measures or by assessing specific domains of QoL, such as emotional functioning, participation and life satisfaction. Most studies investigated the course of HRQoL only up to the first 6 months post stroke [9–11]. The few studies that used a longer follow-up period showed inconclusive and contradictory results [8, 12, 13]. The long-term course of HRQoL post stroke is therefore still unclear. Moreover, taking a closer look at specific QoL domains, the course of emotional functioning, participation and life satisfaction post stroke is not clear [14–23].

Investigating the long-term course of QoL after stroke will provide insight into the enduring consequences caused by stroke and will contribute to our knowledge about the expected outcome for patients. In addition, in the first week after stroke, decisions about discharge destination and rehabilitation treatment are made on the basis of the expected outcome, of which activities of daily living (ADL) is an important determinant [12]. Hence, the aim of this study was to describe the course of QoL from 2 months up to 2 years post stroke and to study the influence of ADL dependency in the first week post stroke.

Methods

Design and Procedure

This study is part of the multicenter prospective longitudinal Restore4Stroke Cohort study [24]. In this study, newly referred stroke patients were recruited in 6 general hospitals in the

Netherlands between March 2011 and March 2013 and followed for 2 years. The medical ethics committees of all participating hospitals gave their approval, and informed consent was obtained from all included patients. This study reports data at stroke onset and at 2, 6, 12 and 24 months post stroke.

After informed consent had been given, the first assessment concerned demographic and stroke-related factors. Information on stroke-related factors (e.g. type of stroke, hemisphere, stroke severity) and ADL dependency, as assessed by the neurologist on day 4, was extracted from the medical charts. Information on demographic factors was obtained from the patient or from family members. The second, third, fourth and fifth assessments took place 2, 6, 12 and 24 months post stroke. During these assessments, patients were asked to complete self-report scales on HRQoL, emotional functioning, participation restrictions and life satisfaction. Furthermore, during the second assessment, 2 months post stroke, a cognitive screening was conducted by a trained research assistant.

Subjects

Stroke patients were eligible for this study if they had a clinically confirmed diagnosis of stroke (ischemic or intracerebral hemorrhagic lesion), irrespective of severity, and had suffered their stroke within the last 7 days. All patients had to be at least 18 years old.

Patients were excluded from the study if they (1) had a serious other condition that was anticipated to interfere with the study outcomes; (2) were already dependent regarding ADL before their stroke as defined by a Barthel Index (BI) score of 17 or lower [25]; (3) had insufficient command of the Dutch language to understand and complete the questionnaires (based on clinical judgment); or (4) were already suffering from cognitive decline before their stroke as defined by a score of 1 or higher on the Heteroamnesia List Cognition [26].

Measures

Dependent Variables

QoL was assessed with 4 measures: the short stroke-specific Quality of Life Scale (SS-QoL-12) [27], the Hospital Anxiety and Depression Scale (HADS) [28, 29], the participation restrictions subscale of the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation-R) [4, 30] and the 2 Life Satisfaction questions (2LS) [31].

The SS-QoL-12 [27] is a disease-specific HRQoL measure. The SS-QoL-12 consists of 12 items each scored on a 5 point scale. Items are averaged to obtain a mean score, and a higher score indicates a higher level of HRQoL. The SS-QoL-12 is a valid measure to assess HRQoL after stroke [27].

The HADS was used to assess emotional functioning in terms of depressive and anxiety symptoms. This measure consists of 14 items, and the score ranges from 0 to 42. A higher score indicates more emotional problems [28]. The HADS has shown good psychometric properties and is commonly used for stroke patients [28, 29].

The USER-Participation-R was used to assess experienced participation restrictions [4, 30]. This scale consists of 11 items addressing difficulties experienced with vocational, leisure, and social activities caused by the stroke. Scores range from 0 to 100 and a higher score reflects better participation (fewer experienced restrictions). The USER-Participation has shown satisfactory reli-

ability and validity and has been used for stroke patients previously [4].

The 2LS was used to assess life satisfaction [31]. This measure consists of 2 items. The first item assesses current life satisfaction on a 6-point scale. The second item assesses current life satisfaction in comparison to life satisfaction before the stroke on a 7-point scale. The sum of these 2 questions ranges from 2 to 13, where a higher score indicates a higher level of life satisfaction. The 2LS has shown satisfactory validity and has been used in earlier publications [31, 32].

Independent Variables

Information about gender, age, marital status, level of education, discharge destination, stroke severity, and ADL dependency was collected. For level of education, we used the Dutch classification system of Verhage (range 1–7) [33]. Scores were dichotomized into low (up to completed secondary education) and high levels of education (completed university of professional education or higher). Discharge destination after hospitalization was categorized into home or inpatient rehabilitation. Stroke severity was assessed with the National Institutes of Health Stroke Scale [34]. Cognitive functioning was assessed using the Montreal Cognitive Assessment (range 0–30) 2 months post stroke [35]. The Montreal Cognitive Assessment is a brief cognitive screening tool suitable for use in stroke patients [35]. ADL dependency was assessed using the BI, which is a validated measure often used in stroke [25]. The BI score was dichotomized into dependent (BI <18) and independent (BI ≥18) scores.

Statistical Analyses

Patients who completed one or more measurements were included in the analysis. Descriptive statistics were used to describe patients' characteristics and dependent variables using SPSS (version 22.0; IBM Corp., Armonk, N.Y., USA). To study the course of QoL, Generalized Estimating Equation (GEE) analyses with an exchangeable correlation structure was performed on the 4 dependent variables [36]. For each outcome measure, a GEE model was created with the measurement point as the main determinant, entered in the models as a set of 3 dummy variables. To examine the course of the dependent variables in each time period, different dummy variables were used as a reference, meaning that the course was examined in 3 different time periods; from 2 to 6 months post stroke, from 6 to 12 months post stroke, and from 12 to 24 months post stroke. A major advantage of GEE is that patients with partly missing measurements do not have to be excluded from the analyses. To study whether there was a difference in course over time on the 4 dependent variables between patients who were independent in ADL and those who were dependent, first a model was analyzed that included the time dummies, the dichotomized BI score and interaction terms between the time dummies and the dichotomized BI score. If an interaction term was not significant, the analysis was repeated using a model including only the time dummies and the dichotomous BI score.

The possible confounding effect of age, gender, marital status, level of education and discharge destination on the course of QoL was examined by adding these variables to the model. These characteristics were considered to be confounders if the coefficient of the time dummies or the dichotomous ADL score respectively changed more than 10% after adding the characteristics to the

model. If not, they were left out of the analyses. p values of <0.05 were considered to be statistically significant. GEE analyses were carried out using STATA, version 12.0.

Results

A total of 395 stroke patients were included in the Restore4Stroke Cohort study. Three hundred and forty three patients participated in the assessments 2 months post stroke (86.8%), 344 at 6 months post stroke (87.1%), 326 at 1 year post stroke (82.5%), and 310 at 2 years post stroke (78.5%). A total of 368 patients completed at least one measurement with QoL data and were included in the analyses (93.2%).

Table 1 presents patients' characteristics for the total patient group and for patients who were dependent and independent in ADL 4 days post stroke, separately. The mean age at stroke onset was 66.8 (SD 12.3) years, and 64.4% of the patients were male. Four days post stroke, the mean BI score was 16.9 (SD 4.8) and 32.6% of the patients were dependent on ADL. Furthermore, 70.9% of the patients had been discharged directly home from the hospital. A comparison between patients who were dependent and independent of ADL showed that the patients dependent on ADL were older, had a partner less often, suffered a more severe stroke, and were more often discharged to inpatient rehabilitation.

Course of HRQoL

GEE analyses showed no statistically significant interaction effects between time and ADL dependency for all 4 QoL measures. In the subsequent analyses without the interaction terms, significant differences between the 2 ADL groups were found ($p \leq 0.001$). Thus, it was decided to analyze the 2 ADL groups independently in addition to analyses performed on the total population. The possible confounders were therefore analyzed separately in the patient groups dependent and independent in ADL.

Table 2 presents descriptive statistics of QoL at each measurement and table 3 presents the course of QoL for the total patient group separately for patients who were independent in ADL and patients who were dependent in ADL. No confounding effect was found after adding age, gender, marital status, level of education and discharge destination to the 2 separate models.

The score on the SS-QoL-12 increased between 2 and 6 months post stroke for both the total group ($p < 0.001$) and for both groups separately (dependent $p = 0.009$; independent $p = 0.002$; fig. 1). The score on the HADS did

Table 1. Patients characteristics (n = 368)

	Total group (n = 368)	BI ≤17 (n = 120)	BI >17 (n = 248)
Demographic factors			
Sex, male	64.4	60.8	66.1
Age in years	66.8±12.3	70.3±12.6	65.1±11.9*
Marital status, living together	69.3	60.8	73.4*
High education level ^a	27.2	23.3	29.0
Stroke-related factors			
Ischemic stroke	92.9	91.7	93.5
Left hemisphere	40.8 ^b	30.8	45.7
Severity of stroke 4 days post stroke	2.7±3.2	4.7±4.3	1.8±1.9*
No stroke symptoms (NIHSS 0)	24.5	10.8	31.0
Minor stroke symptoms (NIHSS 1–4)	56.2	47.5	60.5
Moderate stroke symptoms (NIHSS 5–12)	17.1	35.0	8.5
Moderate to severe stroke symptoms (NIHSS ≥13)	2.2	6.7	0.0
ADL 4 days post stroke	16.9±4.8	11.2±4.6	19.6±0.7*
Cognitive functioning 2 months post stroke	23.6±4.0 ^c	23.0±4.1 ^d	23.8±3.9 ^e
Cognitively impaired (MoCA ≤25)	67.5	72.4	65.4
Destination after discharge from hospital			
Home	70.9	32.5	89.5*
Rehabilitation	29.1	67.5	10.5

NIHSS = National Institutes of Health Stroke Scale; MoCA = Montreal Cognitive Assessment. Values are percentages or mean ± SD.

^a Completed University of Professional Education and higher; ^b n = 363; ^c n = 345; ^d n = 105; ^e n = 240.

* Significant difference between the patients dependent and independent in ADL 4 days post stroke.

Table 2. Descriptive statistics of quality life at each measurement separately for patients dependent (n = 120) and independent (n = 248) in ADL 4 days post stroke (mean ± SD)

	2 months post stroke	6 months post stroke	1 year post stroke	2 years post stroke
ADL dependent (n = 120)	n = 105–106	n = 112	n = 109–111	n = 98–101
SS-QoL-12	3.6±0.9	3.7±0.8	3.7±0.8	3.7±0.9
HADS	10.4±7.1	11.3±7.1	11.3±6.7	12.0±7.8
USER-Participation-R	62.2±23.1	68.1±23.0	70.6±21.3	70.0±24.0
2LS	6.9±2.2	6.8±2.1	6.7±2.1	6.9±2.4
ADL independent (n = 248)	n = 234–238	n = 232–233	n = 216–220	n = 219–221
SS-QoL-12	4.1±0.8	4.2±0.7	4.2±0.8	4.1±0.8
HADS	8.9±7.2	8.8±7.0	8.6±6.7	9.3±7.3
USER-Participation-R	78.0±20.1	82.0±18.7	83.5±19.0	83.7±21.2
2LS	7.6±2.0	7.8±2.0	8.2±1.9	7.9±2.2

Higher scores on the SS-QoL-12, USER-Participation-R, and 2LS means better outcome. Higher scores on the HADS means worse outcome.

not change between 2 months and 2 years post stroke for both the total group and for both groups separately (fig. 2). The total patient group and the patient group independent in ADL showed an increase on the USER-Participation restrictions, meaning that they experienced fewer restrictions, between 2 and 6 months post stroke

($p < 0.001$; fig. 3). Furthermore, patients who were dependent in ADL 4 days post stroke showed an increase on the USER-Participation restrictions between 2 months and 1 year post stroke (2–6 months post stroke, $p = 0.001$, and 6–12 months post stroke, $p = 0.031$). The score on the 2LS showed an increase for the total patient group between 6

Table 3. GEE analyses for the course of quality of life from 2 months up to 2 years post stroke for the total group (n = 368) and separately for patients dependent (n = 120) and independent (n = 248) in ADL 4 days post stroke

Variables	Model for SS-QoL-12			Model for HADS			Model for USER-Participation-R			Model for 2LS		
	B	SE	p value	B	SE	p value	B	SE	p value	B	SE	p value
Total group (n = 368)												
Constant	3.56	0.07		10.95	0.58		62.4	1.88		6.6	0.18	
Time (T3–T2)	0.14	0.03	<0.001	0.14	0.29	0.622	5.04	0.99	<0.001	0.17	0.11	0.113
Time (T4–T3)	–0.01	0.03	0.751	–0.06	0.26	0.826	2.29	0.86	0.008	0.23	0.10	0.018
Time (T5–T4)	–0.03	0.03	0.402	0.49	0.29	0.089	–0.84	0.90	0.352	–0.11	0.10	0.274
BI (dependent)	0.47	0.08	<0.001	–2.18	0.68	0.001	14.6	2.06	<0.001	1.05	0.20	<0.001
ADL dependent (n = 120)												
Constant	3.53	0.08		10.36	0.66		60.80	2.23		6.85	0.21	
Time (T3–T2)	0.19	0.07	0.009	0.97	0.55	0.077	6.52	2.02	0.001	–0.11	0.20	0.569
Time (T4–T3)	–0.04	0.06	0.508	–0.09	0.46	0.839	3.86	1.79	0.031	–0.01	0.17	0.953
Time (T5–T4)	0.01	0.07	0.855	0.46	0.60	0.445	–2.04	1.95	0.295	0.14	0.19	0.459
ADL independent (n = 248)												
Constant	4.05	0.05		9.03	0.46		77.64	1.308		7.51	0.13	
Time (T3–T2)	0.11	0.04	0.002	–0.23	0.34	0.505	4.40	1.10	<0.001	0.30	0.13	0.020
Time (T4–T3)	<0.01	0.04	0.936	–0.05	0.32	0.885	1.46	0.92	0.113	0.35	0.12	0.003
Time (T5–T4)	–0.05	0.04	0.230	0.51	0.31	0.105	–0.19	0.96	0.840	–0.24	0.13	0.055

B = Unstandardized coefficient; SE = standard error. T2 = 2 months post stroke; T3 = 6 months post stroke; T4 = 1 year post stroke; T5 = 2 years post stroke. Bold = Statistically significant.

Fig. 1. The course of HRQoL.

Fig. 2. The course of emotional functioning.

and 12 months post stroke ($p = 0.018$; fig. 4). The patient group independent in ADL showed an increase from 2 months up to 12 months post stroke (2–6 months post stroke, $p = 0.020$, and 6–12 months post stroke, $p = 0.003$). On the other hand, no increase on the 2LS was found for the patient group dependent in ADL.

Discussion

This study showed a general improvement of QoL from 2 months up to 2 years post stroke and patients independent in ADL consistently scored higher on all 4 QoL domains. Changes occurred only during the first

Fig. 3. The course of participation restrictions.

year and mostly during the first 6 months post stroke. This is largely in agreement with the assumed time frame for functional recovery after stroke, which involves most of the functional recovery taking place in the first 6 months post stroke [37, 38].

It is, however, remarkable that we found this same time frame for recovery in QoL. We assume that adaptation post stroke is a continuous process that stretches over a longer period that begins when the patient starts to realize that there will be no full recovery of functioning, despite rehabilitation efforts in the first 3–6 months [39]. A possible explanation is that in this study, even the ADL-dependent patients were on average only moderately dependent in ADL 4 days post stroke and had already regained functioning in terms of ADL in the first few weeks post stroke. Additional analysis (not presented in the results) showed that 2 months post stroke, only 10% of the patients were dependent in ADL in comparison to 33% of the patients 4 days post stroke. Furthermore, even though on average these patient groups showed no further signs of recovery 1 year after stroke, it is plausible that on an individual level, patients still show signs of recovery or decline. For example, a study on mobility found that between 1 and 3 years post stroke, a decline in mobility occurred in 21% of the patients, and approximately 7% of the patients had improved mobility [40]. Furthermore, another study found individual variation in the experience of depressive symptoms in the first years post stroke while the percentage of patients experiencing depressive symptoms during these years stayed relatively the same [41].

Fig. 4. The course of life satisfaction.

Looking at the different domains, we do see differences in the course of QoL. HRQoL, participation restrictions and life satisfaction showed improvement over time, whereas emotional functioning did not. The stable levels of emotional functioning found in this study, were in accordance with a recent study in which stability of depression was found during the first 18 months post stroke [16]. Emotional functioning is strongly related with psychological factors, such as neuroticism and passive coping [42, 43], and personality factors such as neuroticism are assumed to remain relatively stable throughout life.

In the patient group independent in ADL, life satisfaction increased up to 1 year post stroke and remained stable after that. In another research, it was also found that life satisfaction improved up to 1 year post stroke. Furthermore, this study found that once life satisfaction was restored, it remained stable, and poor life satisfaction at 1 year post stroke remained poor for the subsequent years [23]. Most studies investigating general HRQoL with a follow-up period up to 6 months post stroke found an improvement in HRQoL [9–11]. The results from these studies are largely in accordance with results from this study. Improvement in participation, however, was seen for a longer period, especially in the group of ADL-dependent patients. This may reflect the adaptation process, which needs more time from those patients who spend the most time and energy in improving daily activities in the first months post stroke; increasing levels of participation will follow later in those patients.

Strengths and Limitations

This has several strengths. First, a large group of patients ($n = 368$) was examined in a longitudinal design with repeated assessments up to 2 years post stroke. Second, results were analyzed with an advanced statistical technique; this allowed patients with at least one completed assessment to be included in the analyses, meaning that more patients were included in the analyses. Third, we investigated QoL from a broad perspective, measuring 4 domains of QoL.

The following limitations should be taken into account. The first assessment of QoL took place at 2 months post stroke; therefore, we did not have information about changes in QoL in the first 2 months post stroke. Furthermore, about 80% of the patients in this study suffered a minor stroke, which limits the validity of our results for this population. Consequently, a lower number of patients in this study were part of the patient group dependent in ADL in the acute phase post stroke, making it more difficult to find significant changes over time for this patient group.

Conclusion

In general, most improvement in QoL takes place up to 6 months post stroke and shows different patterns for the specific QoL domains and for patients with and without

dependency in ADL in the first week post stroke. It is therefore important to differentiate between the courses of these different QoL domains when the long-term perspective is considered. Furthermore, patients dependent in ADL consistently scored lower on all QoL domains and did not reach the level of QoL of patients independent in ADL.

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Disclosure Statement

The authors declare that they have no conflict of interest.

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