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Quality of life after stroke rehabilitation discharge: a 12-month longitudinal study

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ABSTRACT

Purpose: To analyse trends in quality of life (QoL) development among older stroke patients within the first year after rehabilitation discharge, and to investigate the impact of including proxy interviews in research and practice.

Methods: A prospective cohort study with follow-up at 3, 6, and 12 months with 411 patients and proxy respondents was conducted. The EUROHIS-QOL 8-item index was used to assess QoL. By performing descriptive analyses, QoL development over time was compared among subgroups. Linear mixed models were calculated to estimate mean changes from baseline to 12-month follow-up. The effects of patient characteristics and time on QoL were investigated using comprehensive mixed models.

Results: One year after rehabilitation discharge, the majority of patients had neither maintained nor regained their initial QoL. Proxy respondents reported significantly lower QoL (22.6–29.5 points, $p < 0.001$). Characteristics associated with lower QoL were stroke severity, depression, and pain. Having a small social network was negatively associated with QoL (–1.66 points, 95%CI: –2.84/–0.48, $p = 0.006$).

Conclusions: Quality of life scores reported at the time of rehabilitation discharge are often not lasting. Including severely impaired patients via proxies reduces the risk of overestimating QoL outcomes. Outpatient's characteristics should be taken into account when planning therapy strategies to maintain previously achieved health goals. Regular re-assessments are required.

IMPLICATIONS FOR REHABILITATION

There should be an awareness that improvements in quality of life (QoL) achieved during rehabilitation are not sustainable.

Regularly re-assessing pain status, psychological burden, and social network size could help clinicians to determine treatment strategies for maintaining and improving rehabilitation achievements.

Conducting proxy interviews is required to assess disease burden of patients with severe stroke (e.g., non-linguistic patients).

KEYWORDS

Stroke; quality of life; social networks; patient-reported outcome measures; proxy

Introduction

Stroke prevalence and the complex nature of its treatment mean that stroke is one of the major challenges facing healthcare systems, both today and in the future [1–3]. Patients with stroke suffer from its suddenness, potential severity, and long duration of their disease. After primary acute care in a stroke unit, inpatient rehabilitation is often required. One-third of all patients need additional outpatient follow-up care in order to further minimise functional, cognitive, or communicative impairments and regain independence [4–8]. Stroke treatment and recovery are often complemented by assessing clinical and patient-reported outcomes with health-related quality of life (QoL) being an important outcome for demonstrating progress. Patient-reported outcomes are well-established tools for evaluating patients' progress after acute events such as a stroke [9–11]. Self-reported insights into patients' health status are crucial to evaluate outcomes of completed treatment or to organise additional care. Currently, patient-focused outcomes are used too rarely in therapy. In particular, systematic monitoring of patients health status is reported rarely in outpatient follow-up care.

Current state of knowledge on post-stroke QoL

Compared to the general population, QoL is lower in post-stroke patients. It differs between age groups and may decline over time due to the effects of age-related conditions [12]. Analysing patient-reported QoL in a longitudinal study requires an awareness of potential reconceptualisation of QoL [13]. Frequently reported post-stroke QoL predictors are the patients pre-stroke and current functional status, sociodemographic and socioeconomic status (e.g., marital status, income) [14], living situation (alone or cohabiting), education [15] as well as depression [16–19]. The impact of psychological factors on post-stroke health-related QoL has not yet been conclusively determined [20,21]. Stroke incidents increase the risk of social isolation, leading to a lower QoL [12]. Study findings indicate positive effects of social support and participation on health-related QoL in stroke patients [22–25], although the type or source of support is rarely specified [22]. Mediation effects in cases where low social support is an indicator of depressive symptoms affecting QoL are also addressed [26,27]. Post-stroke pain is also reported as a cause of reduced QoL in short-term observations [28]. Sex differences in prevalence, incidence, acute care, medication, and rehabilitation are factors for deviating outcomes in QoL. It still seems vague whether such differences exist or whether they are artefacts of latent mechanisms [12,29–33]. The consistency and impact of the above-mentioned factors influencing post-stroke QoL are currently under discussion [30,31,34,35].

Typical trajectories for post-stroke QoL have not yet been presented, although some initial attempts have been made and it is certainly predicated on the patients' characteristics [12,21,36,37]. Previous studies reported a non-uniform development of patient QoL after stroke. There is evidence for an increase in QoL within the first 3–24 months after stroke [36,37], along with a decline in QoL over a period of three years [12]. It is important to note that QoL rises after sufficient inpatient treatment in hospital and rehabilitation centres. However, a decline in individual domains can occur after discharge [8,38].

Groups of stroke patients who have been severely affected and impaired by the disease are regularly excluded from surveys based on patient-reported outcomes [25,39]. Some efforts are being made to involve these groups and overcome selection bias, but it is still difficult to assess the impact on study results [40–42]. In order to adequately represent all patient groups, the present study conducted interviews with both patients and proxies.

The purpose of this longitudinal study was to assess changes in QoL among older stroke patients, starting at the end of inpatient rehabilitation and continuing up to 3, 6, and 12 months after discharge. The study

would make it possible to compare changes in QoL after discharge for specific subgroups and to identify influencing factors which could then be considered in future therapy planning. The study also aimed to investigate the impact of including proxy interviews in research and practice.

Methods (data and statistical analysis)

Data source

The present research is based on a prospective cohort study [43]. The purpose of the study was to survey the transsectoral health situation of older patients with mild to severe stroke. Patients were recruited at a major rehabilitation hospital which specialises in neurological rehabilitation (n¼ 411). The survey was conducted between 2010 and 2012.

Participants

Primary inclusion criteria were a main diagnosis of stroke and an age of at least 65 years. The ICD-10 codes I60–I64, I69 and G45 were included (International Statistical Classification of Diseases and Related Health Problems). Proxies – next of kin or legally authorised representatives – were recruited if patients were unable to participate directly due to the severity of their stroke [43]. The study was approved by the ethics committee at the Charite – Universitaetsmedizin Berlin, Germany (approval number EA1/172/09).

Assessments and included variables

Patients and proxies were surveyed just before rehabilitation discharge in a face-to-face interview (t0), and then by telephone at 3 (t1), 6 (t2), and 12 (t3) months after discharge. Health-related QoL, the primary outcome, was measured using the EUROHIS-QOL 8item index, which is a short form of the WHOQOL-BREF [44] questionnaire [45–49]. The index is a generic instrument and cross-culturally validated. It is composed of two single items (overall QoL and general health) and four short scales that assess patients' physical and psychological health, social relationships, and environment. The responses to each item are aggregated to produce a total score (range from 8 to 40 points). Higher scores indicate higher health-related QoL. The EUROHIS-QOL 8-item index showed good internal consistency (Cronbach's α 0.71–0.81) across countries [49,50]. The study questionnaire also addressed basic sociodemographic and socioeconomic information, risk factors (alcohol consumption, body mass index), and additional patient-reported outcomes such as information regarding size of social network. Social network size was assessed by asking patients for the number of people who were important to them and with whom they had regular contact (e.g., colleagues, neighbours, friends, acquaintances, and members of the household). The researchers split the sample into three equal-sized groups based on frequency statistics about the network sizes and defined three network sizes: small (<5 people), medium (5–10 people), and large (>10 people).

Depression screening was conducted using the validated short form of the Patient Health Questionnaire-2 (PHQ-2), a two-item screener for major depression and anhedonia [51]. The original questionnaire has been applied to stroke patients in previous research [52,53]. The total score can range from 0 to 6. A score 3 indicates that the patient may have depression [51]. To measure stroke severity, elements of the Stroke Impact Scale (SIS), a 59-item self-report assessment, were used [54,55]. A scale ranging from 18 to 90 was developed by selecting 18 items on clinical experience from the original scale (items 1.a–d, 7.b–e, 2.a–d, 4.a–f). A higher score indicates higher severity. A cut-off value at the median of 30 points was used for the bivariate study analysis. The Barthel Index (BI) [48,56,57] was used to assess the patients' functional status. The index covers 10 basic aspects of daily life. The BI scores range from 0 to 100, and lower scores indicate greater care dependency. Since patients with a score of 0–70 have major support needs, a cut-off value of BI 70 points was defined for this analysis [7,21,29]. Current pain status was measured using elements of

the Brief Pain Inventory (BPI) [58–60]. Five items were selected on the basis of being the most relevant according to clinical experience: general activity, mood, walking ability, sleep, and enjoyment of life (questions 9, 10, 11, 14, 15). The scores ranged from 5 to 25, with a higher score indicating a higher pain burden. The cut-off value was set at 12 points (median).

Statistical analyses

First, descriptive statistics for the baseline sample at discharge were presented separately for men, women, and interview format. They included absolute and relative frequencies for categorical variables, means, and standard deviations for continuous variables. Chi-square test and Student's t-test were used to compare normally distributed variables at baseline, and the Mann–Whitney U test to compare non-parametric continuous variables.

Second, the researchers calculated means and standard deviations of QoL for specific patient characteristics (Table 2) for each time point of the observation. To estimate mean changes, linear mixed models (random intercept models) were calculated for QoL with repeated measurements (at discharge and 3, 6, and 12 months) as level-one units nested within individuals who were level-two units. Estimated mean changes in QoL from baseline to 12-month follow-up were shown as model-based post hoc estimates (mean, 95% CI). The interaction time patient characteristics assessed whether the slopes of the curves differed between subgroups. Additionally, the models were adjusted for severity of stroke (continuous SIS with updated values at each time point) and age at baseline (discharge) (continuous).

Third, three different linear mixed models (random intercept models) were used to analyse the effect of patient characteristics and time on QoL as the outcome variable. The first model included the variables sex (male/female), age, stroke severity (SIS adapted), type of interview (self-assessment or proxy interview), and time (continuous, in days). In the second model, sociodemographic aspects (income group, cohabitation status (yes/no), and comorbidities (0–2 vs. >2)) were added. In the third model, clinical scores (BI, PHQ-2, BPI adapted) were included. The MuMIn package in R was used to calculate the marginal and conditional R^2 for the variance explanation [61–63]. All other calculations were performed with SPSS 25 (SPSS Inc., Chicago, IL). A two-sided significance level of $\alpha = 0.05$ was used.

Results

Baseline sample characteristics

The baseline sample ($n = 411$) declined to 393 (t1), 362 (t2), and 339 (t3) patients within the survey period due to deaths and nonresponses. Eighty-nine proxy respondents were included at baseline. Mean age was 75 years (SD 5.8) (Table 1). Forty-eight percent of the participants were female ($n = 197$). Women stated a lower socioeconomic status and more frequently a dependent-care status before the stroke incident (17.1% vs. 13.3%). More women reported living alone than men (53.3% vs. 15.0%). In total, 26.1% of patients reported having access to a social network of more than 10 people. This applied to 20.5% of women, and 31.1% of men (Table 1). The researchers had complete data (all four time points) in the target variable (QoL) for 281 patients. Patients in need of proxy interviews were more frequently dependent on care before stroke, tended to have smaller social networks, and had more severe functional impairments (SIS). They were also more likely to be dependent on care (BI), showed a higher probability of depression (PHQ-2), and reported more severe pain (BPI) post-stroke.

Differences in QoL at baseline

Means and standard deviations of QoL values for specific patient characteristics at all available time points are reported in Table 2. Patients with higher disease severity according to their SIS (mean 25.6 vs. 32.0), BI (mean 22.9 vs. 29.7), and BPI scores (mean 24.3 vs. 29.1) reported markedly lower QoL levels (Table

2). Women had lower baseline levels compared to men (mean 27.4 vs. 29.1). Those with lower income reported lower levels of QoL (low: 27.3, medium: 28.2, high: 29.8). Patients living alone reported lower QoL scores than those not living alone (mean 26.9 vs. 29.0), and those with smaller social networks reported lower QoL than those with larger social networks (mean QoL, small: 27.0, medium: 28.3, large: 29.9) (Table 2).

Differences in QoL across follow-ups

The course of QoL and estimated mean differences in changes in QoL over time are reported for several subgroups in Table 2. On average, QoL decreased within the first year after rehabilitation discharge (Figure 1) and did not regain baseline QoL levels. Women reported two points lower QoL at baseline compared to men (Figure 1; Table 2). A difference in QoL between women and men remained over the study period, but decreased somewhat. The estimated mean change in QoL for men over 12 months was -1.5 points (95% CI: $-2.2/-0.8$, $p < 0.001$, adjusted for age and SIS) (Table 2).

Considerable differences also existed regarding social network size. Although a loss in QoL was estimated for each of the subgroups, the decline was less pronounced among those with larger social networks. For patients with a network of less than five people, a mean change in QoL of -1.2 points was estimated (95% CI: $-2.1/-0.3$, $p = 0.011$).

Patients with higher disease severity according to SIS, BI, PHQ2, and BPI had lower QoL scores at baseline and larger decreases in QoL over time compared to those with a less severe stroke. However, subgroup time interactions were not statistically significant, meaning there was no indication of substantial differences between subgroups in the way QoL developed over time. Living situation was the only area with a significant interaction with time: patients who did not live alone reported a decrease in QoL over time (mean at baseline vs. 12 months: 29.0 vs. 27.4), while those who lived alone reported almost no change. This resulted in a smaller gap between both groups at the end of the study. Certain subgroups with initially higher QoL scores (patients living with someone, those with higher income, and those >80 years) demonstrated larger decreases over time than other patient subgroups (Table 2). Compared to patients surveyed via proxy interviews, those who completed self-assessments reported higher QoL at each time point, although their QoL decreased over time (mean difference -1.2 , 95% CI: $-1.8/-0.5$, $p < 0.001$).

Factors affecting QoL

The last stage of the study involved performing a multiple mixed model analysis for QoL values to adjust for all possible confounders, including all available time points. The first model (M1) included the variables sex, age, SIS, interview type, and time. M1 revealed the following: women had lower QoL than men (-1.18 points, 95% CI: $-1.99/-0.37$, $p = 0.004$, see Table 3); patients younger than 80 years had lower QoL than those older than 80 years; patients with higher SIS had lower QoL; and QoL decreased slightly over time (change per month: -0.08 , 95% CI: $-0.12/-0.04$, $p < 0.001$). In addition, proxy respondents reported a significantly reduced QoL for their patients. The second model (M2) contained the M1 variables plus income, living situation, and comorbidities. Age below 80 years was associated with lower QoL compared to patients that are 80 years or older. Additionally, the presence of three or more comorbidities was associated with lower QoL (-0.97 , 95% CI: $-1.81/-0.12$, $p < 0.025$). Within M2, differences in QoL between men and women were smaller than in the unadjusted model (mean difference women–men: -0.60 , 95% CI: -1.52 to 0.32 , $p = 0.202$). QoL significantly differed with regard to the interview type, with proxy estimates being lower (-0.93 , 95% CI: $-1.76/-0.01$, $p < 0.028$). In the full model (M3, only calculated for subsample), age below 80 years was still associated with lower QoL compared to age of 80 years or older. M3 contained the M2 variables plus BPI, PHQ-2, and size of social network. Patients with higher disease severity according to their BPI, PHQ2, and SIS scores had lower QoL estimates than participants with lower disease

severity. QoL estimates for patients indicating a network of less than five people were significantly lower (−1.66, 95%CI: −2.84/−0.48, $p=0.006$) than for patients with a network of more than 10 people. Patients with 5–10 people in their network still had a significantly lower QoL predicted than the reference group (−1.29, 95%CI: −2.34/−0.23, $p=0.017$). Within the full model, differences between interview types were minor.

Discussion

Main findings

The purpose of this study was to outline the development of QoL among older stroke patients during the first year after rehabilitation discharge. The study allows a characterisation of patients with a higher QoL and to identify patients who are at a higher risk of experiencing a decline in QoL. Compared to reference values for the general population, post-stroke participants reported lower rates of QoL at rehabilitation discharge and after 12 months [45,48]. The positive trajectories described in reference studies could not be confirmed for the present sample [21,36,37]. It is noticeable that the initial QoL score at rehabilitation discharge could be neither maintained nor regained within the outpatient treatment setting. Lower levels of QoL over time were associated with smaller social networks, more severe pain, and a positive depression screening. Next to these key findings, further mechanisms for decline could be suggested. Lower QoL is probably associated with less professional (family) care after discharge and the need for adaptations at home (e.g., because of communicative impairments [42] and physical limitations [12]), and unmet medical needs which are less common in an inpatient environment.

Proxy respondents

One reason why these findings deviate from other research could be the inclusion of proxy respondents for patients whose stroke-induced functional and cognitive impairments were so severe that they could not provide information themselves. Studies rarely incorporate proxies because the patients' inaccessibility significantly increases the recruitment efforts. However, including severely impaired patients via proxies reduces the risk of overestimating QoL outcomes in patients with stroke, and should therefore be considered in any future study design. Haley et al. reported a significant decline in physical health-related QoL for a sample of mildly affected stroke patients with at least one informal caregiver [12]. The present study confirmed this for mildly affected patients and patients with severe stroke, regardless of the availability of an informal caregiver. For a slightly smaller sample ($n=85$), Hopman and Verner also found a decline in QoL [8]. However, they only observed patients for a period of six months after stroke incident and did not include any proxies. The present study covered a much longer period after rehabilitation discharge and included patients irrespective of the severity of their impairments [8].

Gender and age differences in QoL

Particularly worthy of note are the different trajectories in QoL among male and female patients. Men showed a higher QoL at baseline, but reported a longer-lasting decrease up to six months, accompanied by a higher risk of diminishing QoL over time. This risk is described less specifically for higher QoL values in the literature [12]. Women presented lower QoL rates at baseline, but reported positive progress after three months. Significant differences in QoL between the sexes diminished over time and statistically disappeared after 12 months. Women in the study sample were more likely to report severe pain and a higher psychological burden, which could explain their lower QoL and longer recovery time. Given that the differences between the sexes disappeared with adjustment for confounders, biological differences do not encourage inequalities in QoL. This confirms the findings of Bushnell et al. [30,31]. Sex differences are also observed in reference populations, with women experiencing more frequent chronic pain conditions,

higher age, and more severe strokes [35,48]. Patients older than 80 years reported a higher QoL after discharge from rehabilitation compared to other age groups. Earlier studies partly reported similar results, as patients older than 80 complained less about their impairments, found comfort in religious beliefs and maintained good social relationships [64]. Further studies reported a declining prevalence of mood-anxiety disorders with age, which had a positive effect on QoL [65,66]. Other studies noted a higher pain burden and therefore lower QoL in older patients [67]. The present study observed a larger decrease in QoL over time for patients older than 80 years, which rather supports the picture that these patients are particularly vulnerable. The effect of age within our sample was not clear and needs additional research efforts.

Social support and QoL

The beneficial effect of social support has previously been examined to some extent [22–24]. Hilari and Northcott found that network size correlated with QoL in female post-stroke patients with aphasia [68]. The present study specifically reported significant effects on QoL with social networks of <5 people, 5–10 people, and >10 people for men and women. One group of patients had a smaller social network and were probably more socially isolated with fewer social resources such as nearby people who offered counselling or gave solace. This vulnerable group is more likely to be female and has a lower probability of improving QoL over 6 or 12 months post-rehabilitation. Larger network size seems to improve patients' resilience. Relatives, for example, are important for organising professional support or guidance after discharge [69,70]. The impact of patients' living situations remains unclear. Patients living alone reported lower QoL, but patients living with others demonstrated a significantly larger decline over time. It is important to emphasise that presumed social support in these cases may work antithetically. Silverstein et al. report that a high level of support can be harmful [71] and that relationships might harbour the risk of abuse or violence [72].

Baseline level of QoL

This study found that patients with a higher QoL at rehabilitation discharge were at higher risk of a regression in attained health goals over the next 12 months. Van Mierlo et al. showed that most functional recovery and improvement in QoL takes place within the first six months after stroke incident. After that, patients (with and without care dependency) reach a kind of plateau with no further changes in QoL [36]. Due to the later and prolonged observation time, the present study supplements van Mierlo's findings by adding QoL data of the time period after rehabilitation discharge where QoL frequently decreases.

Depression, pain, and QoL

A high current pain score and positive depression screening are associated with lower QoL and adverse trajectories of development [12,16,17,73]. Since the impact of psychological burden has yet to be determined conclusively [20,21], it is important to provide complementary data. Van Mierlo et al. [21] found that poststroke depression is highly associated with adverse QoL trajectories in mildly affected patients. The present study confirmed these results for patients with mild to severe stroke. More extensive investment in coping strategies might help to stabilise and improve QoL outcomes post-stroke [27], and self-management or caregiver programmes could help patients to cope better within the outpatient setting [74,75].

Practical implications

From an individual and societal perspective, it is necessary to stabilise the goals achieved during inpatient rehabilitation. Patients obviously need support to ensure therapeutic success in the long term. Given present

and future financial strain in the healthcare systems, resources should be handled with care and foresight. Initial attempts to research and pilot face-to-face re-assessments of stroke patients after discharge from hospital or inpatient rehabilitation should be considered to be extended for longer periods of time and large samples [7]. Regularly re-assessing patients could assist clinicians and therapists with changing or adding treatment strategies. Next to face-to-face re-assessments, the use of tele-rehabilitation interventions could help to monitor patients' progress and complement conventional face-to-face therapy [76,77].

Limitations

One limitation of this study is that it risked selection bias due to the monocentric design with patient recruitment from a single rehabilitation hospital. Additionally, including proxies might be a limitation since external assessments could differ from self-assessments. Conducting proxy interviews is therefore controversial, and it is hard to assess the impact on the results. Previous studies have found that, for patients with severe aphasia, proxy assessments are an important addition to avoid overestimating QoL [42]. However, other studies found that proxies were more likely to report health problems and dysfunction than patients were [40,41]. A stratification for stroke severity among the patients is missing, but would be helpful for interpretation. Caregivers' current health status could also affect their assessments as proxies. For instance, proxies showing depressive symptoms tend to underestimate pain in stroke patients [78]. Using the EUROHISQOL 8-item index to measure QoL via caregivers might lead to an underestimation of QoL compared to self-rating in cases of patients with dementia [79]. In general, proxy assessments are considered more reliable for stroke patients than for dementia patients [80]. Previous findings also suggest that patient-proxy agreement is higher in a post-acute context, e.g., six months after stroke [80]. To sum up, the present study results confirm previous findings that proxy interviews help to provide information about a highly vulnerable and often disregarded group of patients. The researchers therefore recommend testing and adjusting for respondent type effects within calculated models. A further limitation of this study is that some characteristics measured by the Patient Health Questionnaire – such as depression – are by definition associated with QoL since they measure partly similar dimensions. Therefore, associations between these characteristics and QoL must be interpreted with caution.

Conclusions

Most stroke patients reported a decline in QoL during the first year following rehabilitation discharge. These lower levels of QoL over time were associated with a small social network, more severe pain and positive depression screening. Further research is needed to characterise patients who are able to improve their QoL even in an outpatient setting, and those who are vulnerable to regression and in need of additional support. Future research should consider how findings are associated with the interview format. With lower QoL, there could be components of impaired self-awareness in self-rated QoL, and negative spread in proximated QoL. Regular re-assessments could indicate stagnation within health progression or identify patients who are unable to organise therapists for themselves. It should be investigated and determined in how far the healthcare system fails to establish an outpatient setting that stabilises or even improves reasonable outcomes achieved during inpatient treatments. Once patients make health gains, they must be able to sustain them; this is desirable both from an individual and a societal (economic) perspective.

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Disclosure statement

The authors declare no conflicts of interest.

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Table 1. Comparison of cohort characteristics at discharge from rehabilitation clinic (baseline) by sex and interview format.

Characteristics	Total	Female	Male	p Value	Self-assessment	Proxy interview	p Value
Participants, n (%)	411 (100)	197 (47.9)	214 (52.1)		322 (78.3)	89 (21.7)	
Age, n, mean (SD)	411, 75.2 (5.8)	197, 76.1 (6.0)	214, 74.3 (5.6)	0.002	322, 75.1 (5.9)	89, 75.4 (5.5)	0.612
School education, n (%)				<0.001			0.069
Lower secondary education	220 (54.9)	123 (63.7)	97 (46.6)		180 (57.0)	40 (47.1)	
Secondary education	111 (27.7)	52 (26.9)	59 (28.4)		79 (25.0)	32 (37.6)	
University entrance qualification	70 (17.5)	18 (9.3)	52 (25.0)		57 (18.0)	13 (15.3)	
Occupational education, n (%)				<0.001			0.053
No further education	51 (12.6)	41 (21.1)	10 (4.7)		35 (10.9)	16 (19.0)	
Vocational training	203 (50.0)	123 (63.4)	80 (37.7)		159 (49.4)	44 (52.4)	
University degree	152 (37.4)	30 (15.5)	122 (57.6)		128 (39.8)	24 (28.6)	
Income, n (%)				<0.001			0.387
<1250 EUR/month	161 (43.4)	107 (59.8)	54 (28.1)		132 (45.1)	29 (37.2)	
1251–1750 EUR/month	104 (28.0)	43 (24.0)	61 (31.8)		78 (26.6)	26 (33.3)	
>1751 EUR/month	106 (28.6)	29 (16.2)	77 (40.1)		83 (28.3)	23 (29.5)	
Living situation, n (%)				<0.001			0.464
With someone	272 (66.7)	91 (46.7)	181 (85.0)		216 (67.5)	56 (63.6)	
Alone	136 (33.3)	104 (53.3)	32 (15.0)		104 (32.5)	32 (36.4)	
Size of social network, n (%)				0.052			0.022
<5 people	136 (34.2)	70 (36.8)	66 (31.7)		105 (32.9)	31 (39.2)	
5–10 people	158 (39.7)	81 (42.6)	77 (37.0)		121 (37.9)	37 (46.8)	
>10 people	104 (26.1)	39 (20.5)	65 (31.3)		93 (29.2)	11 (13.9)	
Care status preadmission, n (%)				0.021			0.008
Not dependent on care	277 (87.4)	126 (82.9)	151 (91.5)		239 (89.5)	38 (76.0)	
Dependent on care	40 (12.6)	26 (17.1)	14 (13.3)		28 (10.5)	12 (24.0)	
Stroke type, n (%)				0.412			<0.001
Ischemic	322 (78.3)	155 (78.7)	167 (78.0)		268 (83.2)	54 (60.7)	
Haemorrhagic	54 (13.1)	28 (14.2)	26 (12.1)		32 (9.9)	22 (24.7)	
TIA	5 (1.2)	1 (0.5)	4 (1.9)		5 (1.6)	0 (0.0)	
Other, not specified	30 (7.3)	13 (6.6)	17 (7.9)		17 (5.3)	13 (14.6)	
Body mass index, n, mean (SD)	402, 27.2 (5.0)	191, 27.7 (5.9)	211, 26.8 (3.9)	.061	320, 27.5 (4.5)	82, 26.2 (6.6)	0.049
Alcohol use, n (%)				<0.001			0.017
Never	164 (48.8)	92 (56.4)	72 (41.6)		134 (46.9)	30 (60.0)	
Occasionally	145 (43.2)	68 (41.7)	77 (44.5)		132 (46.2)	13 (26.0)	
Frequently	27 (8.0)	3 (1.8)	24 (13.9)		20 (7.0)	7 (14.0)	
Number of medications, n (%)				0.379			0.053

No pharmaceuticals	12 (2.9)	5 (2.5)	7 (3.3)		6 (1.9)	6 (6.7)	
1–6 pharmaceuticals	147 (35.8)	67 (34.0)	80 (37.4)		116 (36.0)	31 (34.8)	
>6 pharmaceuticals	252 (61.3)	125 (63.5)	127 (59.4)		200 (62.1)	52 (58.4)	
Number of comorbidities, n (%)				0.719			0.779
0–2 comorbidities	137 (33.8)	67 (34.7)	70 (33.0)		110 (34.2)	27 (32.5)	
>2 comorbidities	268 (66.2)	126 (65.3)	142 (67.0)		212 (65.8)	56 (67.5)	
Clinical measures, n, median (IQR)							
Stroke Impact Scale (SIS adapted)	330, 29 (22–43)	152, 29 (22–45)	178, 29 (22–42)	0.683	286, 27 (22–36)	44, 70 (56–82)	<0.001
Barthel Index (BI)	383, 95 (75–100)	179, 90 (75–100)	204, 95 (75–100)	0.047	317, 95 (85–100)	66, 35 (10–80)	<0.001
Patient Health Questionnaire (PHQ-2)	395, 1 (0–2)	189, 1 (0–2)	206, 1 (0–2)	0.004	320, 0.5 (0–2)	75, 3 (2–4)	<0.001
Brief Pain Inventory (BPI adapted)	145, 11 (8–16)	74, 13.5 (9–16)	71, 10 (7–15)	0.033	126, 10 (7–15)	19, 16 (13–20)	0.001
EUROHIS-QOL-8, n, mean (SD)	381, 28.3 (6.0)	183, 27.4 (5.8)	198, 29.1 (6.1)	0.005	317, 29.5 (5.4)	64, 22.6 (5.5)	<0.001
Type of interview (baseline), n (%)				0.315			
Self-assessment	322 (78.3)	152 (77.2)	170 (79.4)				
Proxy interview	89 (21.7)	45 (22.8)	44 (20.6)				
Number of patient deaths, n (%)	38 (9.2)	13 (6.6)	25 (11.7)	0.065	18 (5.6)	20 (22.5)	<0.001

Note: For detailed information on the adaption of the Stroke Impact Scale (SIS) and Brief Pain Inventory (BPI), see the Methods section.

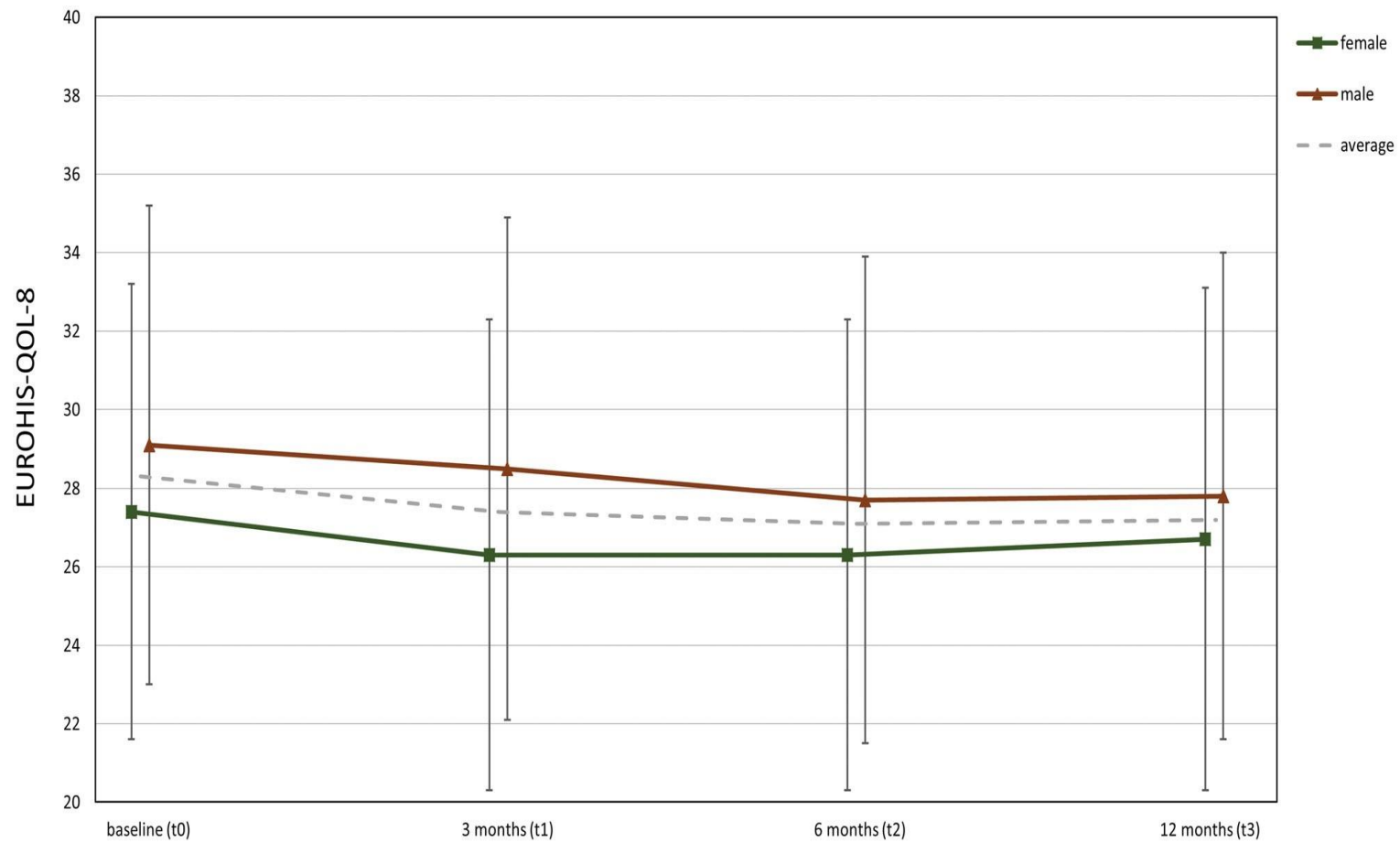


Figure 1. Development of quality of life after rehabilitation discharge (EUROHIS-QOL-8 [mean, standard deviation], n(t0) = 411).

Table 2. Development of quality of life (EUROHIS-QOL-8) over time for selected subgroups

EUROHIS-QOL-8	Baseline		3 months		6 months		12 months		Mean change from BL to 12 months (95% CI) ^a		p Value interaction time x group
	M (SD)	N	M (SD)	N	M (SD)	N	M (SD)	N	p Value		
Sex											0.175
Female	27.4 (5.8)	183	26.3 (6.0)	163	26.3 (6.0)	154	26.7 (6.4)	146	-0.4 (-1.2 to 0.3)	0.249	
Male	29.1 (6.1)	198	28.5 (6.4)	174	27.7 (6.2)	176	27.8 (6.2)	154	-1.5 (-2.2 to -0.8)	<0.001	
Age											0.403
<70	29.0 (6.0)	83	28.7 (5.7)	69	28.0 (6.0)	75	28.8 (6.0)	71	-0.3 (-1.3 to 0.7)	0.554	
70–74	28.0 (5.6)	120	26.8 (6.8)	111	27.1 (6.5)	101	26.6 (6.7)	99	-1.1 (-2.0 to -0.2)	0.016	
75–79	27.6 (6.1)	103	26.9 (6.5)	92	25.6 (5.9)	90	26.8 (6.0)	76	-0.8 (-1.9 to 0.2)	0.119	
80	29.0 (6.3)	75	27.9 (5.6)	65	28.0 (5.9)	64	26.9 (6.3)	54	-1.9 (-3.1 to -0.8)	0.001	
Income											0.662
1251–1750 EUR/month	28.2 (5.8)	100	27.7 (5.8)	90	28.1 (5.4)	84	27.3 (6.8)	80	-1.0 (-2.0 to 0.03)	0.056	
>1751 EUR/month	29.8 (6.3)	100	28.6 (6.5)	90	28.1 (6.3)	89	28.6 (6.4)	81	-1.2 (-2.2 to -0.3)	0.013	
Living situation											0.015
Alone	26.9 (5.9)	123	26.5 (6.0)	109	26.5 (6.3)	105	26.9 (5.9)	95	0.2 (-0.7 to 1.1)	0.627	
With someone	29.0 (6.0)	256	27.9 (6.4)	227	27.3 (6.1)	225	27.4 (6.5)	205	-1.5 (-2.1 to -0.9)	<0.001	
Size of social network											0.595
<5 people	27.0 (6.0)	124	26.3 (6.3)	140	25.9 (6.1)	144	25.6 (6.7)	113	-1.2 (-2.1 to -0.3)	0.011	
5–10 people	28.3 (6.1)	150	27.3 (6.0)	126	27.1 (6.4)	123	28.0 (5.9)	133	-0.8 (-1.7 to -0.04)	0.040	
>10 people	29.9 (5.4)	102	30.1 (6.0)	70	29.8 (4.9)	62	28.8 (5.9)	54	-0.6 (-1.7 to 0.5)	0.311	
Care status preadmission											0.374
Not dependent on c	29.5 (5.7)	260	28.6 (5.9)	232	27.9 (6.0)	234	28.2 (6.0)	215	0.3 (-1.5 to 2.2)	0.707	
Dependent on care	25.2 (4.9)	37	23.7 (5.7)	33	24.4 (5.4)	30	24.5 (5.2)	23	-1.0 (-1.6 to -0.4)	0.001	
Alcohol use											0.220
Never	28.4 (5.8)	155	27.2 (6.1)	135	26.5 (6.1)	134	26.8 (5.9)	118	-1.3 (-2.1 to -0.5)	0.002	
Occasionally	29.5 (5.4)	140	28.6 (6.0)	130	28.5 (5.7)	126	29.0 (5.9)	118	-0.4 (-1.1 to 0.4)	0.356	
Frequently	27.4 (8.2)	24	27.2 (7.5)	22	27.3 (6.4)	22	26.4 (6.9)	17	-2.4 (-4.6 to -0.3)	0.026	
Brief Pain Inventory (dichotomised) (BPI)											0.142
<12	29.1 (4.7)	74	28.9 (5.5)	54	28.9 (5.2)	50	27.4 (5.8)	50	-0.3 (-1.7 to -0.9)	0.573	
12	24.3 (5.7)	71	23.9 (5.2)	81	23.1 (5.2)	93	24.1 (5.2)	93	-0.9 (-2.2 to 0.3)	0.129	
Barthel Index (dichotomised) (BI)											0.063
<70	22.9 (5.4)	76	22.1 (5.4)	72	21.5 (5.1)	63	21.7 (5.2)	59	-2.4 (-3.6 to -1.0)	0.000	
70	29.7 (5.3)	291	29.2 (5.4)	238	28.5 (5.6)	252	28.8 (5.6)	216	-0.6 (-1.2 to -0.1)	0.031	
Stroke Impact Scale (dichotomised) (SIS)											0.490

<30	32.0 (5.5)	170	31.4 (5.0)	139	31.3 (4.6)	128	31.2 (4.8)	129	-0.9 (-1.7 to -0.2)	0.015	
30	25.6 (5.2)	149	24.5 (5.4)	150	24.2 (5.3)	163	24.3 (5.7)	149	-1.6 (-2.3 to -0.8)	<0.001	
Patient Health Questionnaire (dichotomised), PHQ-2											0.468
<3	29.8 (5.3)	305	29.6 (5.3)	243	29.4 (5.1)	234	29.3 (5.4)	217	-0.8 (-1.3 to -0.2)	0.010	
3	22.4 (4.7)	73	22.0 (5.2)	88	21.5 (4.8)	95	21.8 (5.2)	81	-0.9 (-2.2 to 0.3)	0.142	
Type of interview											0.272
Self-assessment	29.5 (5.4)	322	28.7 (5.6)	292	28.3 (5.7)	270	28.8 (5.5)	247	-1.2 (-1.8 to -0.5)	<0.001	
Proxy interview	22.6 (5.5)	89	21.9 (6.2)	101	21.9 (5.5)	92	21.1 (5.8)	92	-0.1 (-1.3 to 1.1)	0.870	

M: mean; SD: standard deviation; N: number of cases.

^a Mean changes and 95%CI of QoL from baseline to 12-month follow up were calculated as model-based post hoc estimates from linear mixed models (random intercept models), adjusted for SIS (severity), age, time, and interaction-term for time.

Table 3. Characteristics associated with quality of life over 12 months after discharge from rehabilitation clinic (EUROHIS-QOL-8), linear mixed models.

	Model 1			Model 2			Model 3		
	Number of individuals: n = 372 Number of measures: n = 1072			Number of individuals: n = 338 Number of measures: n = 985			Number of individuals: n = 190 Number of measures: n = 371		
	Estimate	CI	p Value	Estimate	CI	p Value	Estimate	CI	p Value
Fixed-effects estimates									
Intercept	38.77	37.35 to 40.19	<0.001	40.37	38.65 to 42.10	<0.001	34.59	31.58 to 37.60	<0.001
Sex (female)	-1.18	-1.99 to -0.37	0.004	-0.60	-1.52 to 0.32	0.202	-0.58	-1.9 to 0.78	0.401
Age <70	-1.24	-2.50 to 0.01	0.054	-1.69	-3.07 to -0.31	0.016	-2.41	-4.34 to 0.47	0.015
70–74	-1.01	-2.16 to 0.15	0.087	-1.35	-2.61 to 0.09	0.035	-1.67	-3.37 to -0.01	0.049
75–79	-1.59	-2.77 to -0.39	0.009	-1.82	-3.11 to -0.52	0.006	-2.13	-3.89 to -0.37	0.018
80 Income	ref.			ref.			ref.		
<1250 EUR/month				-0.99	-2.16 to 0.17	0.095	-1.54	-3.16 to 0.07	0.061
1251–1750 EUR/month				-0.55	-1.69 to 0.59	0.340	-0.89	-2.44 to 0.66	0.256
>1751 EUR/month				ref.			ref.		
Living situation (alone)				-1.07	-2.16 to 0.01	0.051	-0.38	-1.98 to 1.23	0.645
Comorbidities (>2)				-0.97	-1.81 to -0.12	0.025	-0.62	-1.84 to 0.60	0.315
Brief Pain Inventory (adapted)							-1.18	0.30–2.06	0.009
Patient Health Questionnaire							-2.61	1.59–3.63	<0.001
Stroke Impact Scale (adapted)	-0.23	-0.25 to -0.21	<0.001	-0.23	-0.26 to -0.21	<0.001	-0.16	-0.20 to -0.12	<0.001
Size of social network									
<5 people							-1.66	-2.84 to -0.48	0.006
5–10 people							-1.29	-2.34 to -0.23	0.017
>10 people							ref.		
Proxy (dummy)	-0.81	-1.59 to -0.03	0.041	-0.93	-1.76 to -0.10	0.028	-0.60	-1.93 to 0.74	0.383
Time (months)	-0.08	-0.12 to -0.04	<0.001	-0.06	-0.11 to 0.02	0.008	0.02	-0.05 to 0.11	0.507
Estimates of covariance									
Parameters									
Residual	9.30	8.37 to 10.33	<0.001	9.27	8.31 to 10.34	<0.001	7.94	6.42 to 9.81	<0.001
Random intercept estimates	11.16	9.15 to 13.61	<0.001	11.22	9.11 to 13.83	<0.001	10.42	7.49 to 14.49	<0.001
R ² marginal	0.43			0.44			0.42		
R ² conditional	0.74			0.75			0.75		

CI: confidence interval (95%).