The long term consequences of stroke

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Chapter 3

Patient reported outcomes of hand function three years after stroke

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Abstract

Objective: To comprehensively describe hand function and associated factors among stroke survivors by means of the Michigan Hand Outcomes Questionnaire (MHQ; 6 domains; score 0–100, worst–best).

Methods: In this cross-sectional study, stroke patients were invited to complete a set of questionnaires on hand function, socio-demographic characteristics, mental functioning, daily activities, quality of life, and caregiver strain. Stroke characteristics were collected retrospectively from medical records. Multiple linear regression analysis adjusted for age, sex, and duration of follow-up was used to identify factors associated with MHQ score.

Results: 207 out of 576 eligible patients responded (36%); mean age 63.8 years (SD14.2), 125 males (60.4%). Mean time since stroke was 36.3 months (SD9.9). In 85% of the patients, the MHQ Total score was less than 100 points (median 79.9, IQR 63.0–95.8). The median scores of the domains were: overall hand function 75.0, daily activities 90.5, work 85.0, pain 100, appearance 93.8, and satisfaction with hand function 83.3. A lower MHQ Total score was significantly associated with a lower Barthel Index at hospital discharge, a lower level of education, a supratentorial stroke and with unfavorable outcomes regarding physical and mental functioning, quality of life, and caregiver strain.

Conclusion: Patients can perceive limitations on several domains with respect to hand function 2–5 years after stroke. Problems related to the appearance of the hand and satisfaction with hand function can be relevant and should be considered accordingly. Persistent hand problems after stroke are related to a more severe, supratentorial stroke in lower educated patients.

Introduction

Annually, 15 million people worldwide suffer a stroke. Of these, 5 million die and another 5 million are left permanently disabled, placing a burden on family and community.[1] These numbers are increasing, as is the overall global burden of stroke.[2]

Motor impairment, including hand function problems, after stroke affects about 80% of patients.[3] On hospital admission, more than two-thirds of the stroke patients have impairment of upper extremity function; after 3 months, 20% still have hand function problems, varying from mild to severe.[4] Of the patients with initially impaired motor function of upper and lower extremity some improvement in arm function was seen in 38%, [6] months after stroke.[5] In a study of Norlander et al., using a telephone interview in 145 patients, 35.4% mentioned limitations in upper extremity functioning 10 years post stroke.[6] In a selected population of 54 stroke patients with initial arm impairment, 50% had problems with arm function four years post stroke as measured with performance tests.[7] A remarkable finding in this latter study was that many patients, even those with moderate to good Fugl-Meyer motor scores, still reported the loss of function in an arm to be a major problem. The same observation was made in a study of 84 stroke patients deemed recovered after 3 months; stroke still affected their hand function significantly according to the Stroke Impact Score, compared to a control group of 246 community-dwelling elderly.[8] In a recent study, it was demonstrated that hand function was one of the domains with the highest perceived impact 6 years after stroke.[9]

According to the International Classification of Functioning, Disability and Health (ICF) problems after stroke reach out to several domains of health, including emotional aspects, sensory aspects, pain, activities of daily living, work, and leisure.[10] Hand function assessments used in the abovementioned studies addressed only some of these domains.[11] In addition, performance tests are generally costly and time consuming, requiring a trained professional and adequate equipment, whereas a self-reported questionnaire is relatively easy to administer in a larger population and provides important information about the perceived impact of stroke.[9]

The consequences of hand function problems after stroke are complex since many domains may be affected. Information on the prevalence of hand function problems and their resulting impact on all aspects of daily life in the chronic phase after stroke is essential to understand the needs of stroke patients in this respect, and may be important to explain health care usage.

However, research on this subject is scanty and inconsistent.[9] The Michigan Hand Outcomes Questionnaire (MHQ), a multidimensional questionnaire that was previously validated in stroke patients provides detailed information on several domains of hand function, e.g. pain, function, daily activities, satisfaction, and appearance.[12] The goal of our study was, therefore, to comprehensively describe the impact of hand function problems by means of the MHQ 2–5 years after stroke and to examine to what extent these are related to patient and stroke characteristics.

Methods

Design

This cross-sectional study was executed at the Haaglanden Medical Center (HMC), a large teaching hospital in The Hague, The Netherlands. This hospital has a comprehensive stroke center with vascular neurologists, neuro-interventionalists and vascular neurosurgeons.

Data were collected by means of a set of pen-and-paper questionnaires. Additional medical information was extracted retrospectively from the participants' medical records. The study was judged to fall outside the remit of the Medical Research Involving Human Subjects Act by the Medical Ethics Review Committee South West Netherlands, and a written exemption from ethical approval was obtained. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2013.[13] Informed consent was obtained from all patients for participation in the study.

Patients

All patients hospitalized for a stroke between January 2008 and December 2010 were identified from the HMC hospital registry. From patients who had been hospitalized for a stroke more than once during the study period, only the first hospitalization was taken into account. Of all potentially eligible patients, the hospital and town council registries were checked to identify any deceased patients. Then, a further selection was done using the following inclusion criteria: (a) first-ever ischemic or hemorrhagic stroke; (b) age 18 years or older at the time of hospitalization. Exclusion criteria were: (a) traumatic brain injury, cerebral neoplasms or transient ischemic attack (TIA); (b) medical condition not allowing participation (patients in a vegetative state).

Patients were invited by their treating physician to participate by means of a letter and an information leaflet. Participation concerned the completion of a questionnaire on paper about their current health status and of a questionnaire by their spouse or other caregiver, if applicable. They were asked to return the questionnaires and a signed informed consent form using a prestamped envelope. In case of no response, patients were contacted by telephone by a research nurse. Of the non-responders, the age, sex, and date of stroke were registered.

Hand function: the Michigan Hand Outcomes Questionnaire

The MHQ is a self-administered, 57-item questionnaire covering 6 domains: overall hand function, activities of daily living, pain, work performance, aesthetics, and patients' satisfaction with hand function (http://sitemaker.umich.edu/mhq/overview).[14] It has been validated for hand function problems in stroke patients, rheumatoid arthritis, metacarpal phalangeal joint arthroplasty, carpal tunnel syndrome, hand injury, and distal radius fractures.[12,14–19] The Dutch version of the MHQ was developed and validated in patients with rheumatoid arthritis.[20] In a previous study among stroke patients, the internal consistency of the MHQ was high (Cronbach's α 0.97); the MHQ total score correlated significantly with hand function performance tests ($p < 0.01$) as an indication of a good construct validity; the test–retest ICC was 0.97.[12] It covers several ICF categories to describe the effect of stroke on hand function.[10] The function of the left and right hand is recorded separately (except for the domains pain and work performance). Examples of questions of the 6 domains are: How was the strength in your left hand? (Overall hand function); How difficult was it for you to pick up a coin with your right hand? (activities of daily living); How often did you have to take it easy at your work because of problems with your hand(s)/ wrist(s)? (work performance); how often did the pain in your right hand(s)/ wrist(s) interfere with your sleep? (pain); the appearance (look) of my right hand sometimes made me uncomfortable in public (aesthetics); how is your satisfaction with the overall function of your left hand? (patients' satisfaction with hand function). Each item is scored on a 1–5 scale, with the domain scores ranging from 0 to 100, a higher score indicates better hand function. The pain scale is reversed (100 – pain score) to obtain a range from worst (0) to best (100). The total score (the average of all domains) ranges from 0 to 100, higher scores indicating better hand function. For domains with ≤ 50% missing items within an individual patient, the average of the existing scale items for the individual patient was imputed for the missing items. If > 50% of the items are missing, the domain was not scored. The MHQ total score was not computed if scores for > 2 domains were missing. Completing of the questionnaire takes 15 min.

Stroke-related characteristics

The following data were collected from the medical record: type of stroke (hemorrhagic/ischemic), lateralization (left hemisphere/right hemisphere/vertebrobasilar), receiving rt-PA thrombolysis or not, functioning after admission to the hospital and at discharge from hospital (Barthel Index – BI;[21] score range 0–20; higher score indicates less dependent in daily care) and duration of hospital stay (Length of Hospitalization – LOS; days).

Patient-related characteristics

The survey comprised questions on the following socio-demographic items: educational level (Low: up to and including lower technical and vocational training; medium: up to and including secondary technical and vocational training; and high: up to and including higher technical and vocational training and university), and living alone or not (social situation).

Physical and mental functioning

The FAI (Frenchay Activity Index) describes the level of activities and participation. This inventory scores 15 activities on a 4-point scale (range 0–3, never–frequently). The maximum score is 45 points and represents the highest level of functioning.[22,23]

Anxiety and depression were measured by means of a Dutch version of the Hospital Anxiety and Depression Scale (HADS) which contains two 7-item scales, one for anxiety and one for depression, both with a score range of 0–21.[24,25] A higher score means higher level of depression or anxiety. A HADS depression score of 8 points and above is an indicator of clinically relevant depressive symptoms.[24]

Health-related quality of life

The SF-36 is a generic instrument with 36 items covering eight domains (physical function, role physical, bodily pain, general health, vitality, social function, role emotional, and mental health). The SF-36 subscale scores range from 0 to 100, with a higher score indicating better health status. From these, a physical and a mental summary scale can be computed. Scoring of the summary scales is undertaken by weighting and summing the original eight dimensions. These weights are gained from factor analysis of data from a general population. The SF-36 has been translated and validated by Aaronson et al. into a Dutch version.[26]

The EuroQol classification system (EQ5D) was administered, consisting of 5 questions on mobility, self-care, usual activities, pain/discomfort, and anxiety/depression.[27] From the

EQ5D classification system, the EQ5D utility index was calculated. The five 3-point Likert questions of the EQ5D yield a summary score ranging from –0.329 (no health) to 1 (full health).

Caregiver strain

Caregiver strain was measured using the caregiver strain index (CSI). Participants were instructed to ask their caregiver (partner, child, other family member or friend) to fill the CSI, if applicable. This questionnaire consists of 13 items (yes/no) to assess the subjective care load of the caregiver, the CSI total score ranges from 0 to 13; higher score means more caregiver strain.28 A score of seven or more indicates a high level of strain. The CSI was validated in a Dutch stroke population.[29]

Analysis

Descriptive statistics were used for the stroke-related and patient characteristics, the MHQ scores and the outcome measures (mean [SD] or median [inter quartile range; IQR]).

The unpaired T-test and chi-square test were used to analyze differences between the responders and non-responders with respect to age and sex.

Univariate linear regression analysis was used to determine which stroke characteristics, patient characteristics and health outcome measures (independent variables) were associated with hand function (MHQ total score; dependent variable). Adjustment was made for age, sex, and duration of follow-up as confounding factors. Results were reported as β with 95% Confidence Intervals (95%-CI) and corresponding p-values.

Patient and stroke-related characteristics that were significantly associated with hand function (univariate, $p < 0.05$) were entered in a multivariable linear regression model. In the first block confounding factors were entered (age, sex, and follow-up), in the second block the independent variables were entered. Subsequently, variables that did not contribute to the explained variance were removed from the equation by means of backward elimination. Results were reported as β with 95% Confidence Intervals (95%-CI) and corresponding p-values. Statistical analyses were performed using IBM SPSS statistics, version 22. For all analyses, $p < 0.05$ (2-tailed) is considered the criterion for statistical significance.

Results

A total of 576 patients met the inclusion criteria of the study, of whom 207 (36%) gave informed consent and completed the questionnaires (Figure 1). There were no significant differences between responders and non-responders with respect to sex ($p = 0.11$) and age ($p = 0.13$).

The general results are shown in Table 1. Mean age of the responders was 63.8 years (SD 14.2) at time of stroke, 60.4% were male. The median duration of hospital stay was 7 days (IQR 7). During admission, the median Barthel Index (BI) improved from 14 (IQR 11) to 19 (IQR 8) at discharge, with 77 of 174 (44.3%) having the maximal Barthel score (20 points). The majority of the patients was discharged to their homes (53.6%); others were transferred to another hospital, a rehabilitation clinic or a nursing home.

Most patients (181 of 207, 87.4%) had had an ischemic stroke. The stroke location was predominantly supratentorial (164 patients, 79.2%), 43 (20.8%) were cerebellar or brainstem lesions. One patient had bilateral cerebral lesions. The mean time of follow-up was 36.3 months (SD 9.9; range 21–57 months). At follow-up, most patients were living together (135 of 204 patients, 66.2%).

Of the patients, 38 (22.2%) had a FAI score lower than 15, indicating a serious level of dependence.[30] Clinically relevant depressive symptoms (HADS-D ≥ 8) were reported by 67 patients (34.2%).

Results of Michigan Hand Outcomes Questionnaire

The median score of the MHQ total was 79.9 (IQR 63.0–95.8, Figure 2). In 85% of the patients, the MHQ Total score was less than 100 points, indicating that a majority of the patients experienced hand problems to some extent. Patients with a Barthel Index < 20 points at discharge from the hospital had significantly lower scores on the MHQ Total compared to those with maximal Barthel Index (20 at discharge): 68.8 (SD 24.3) and 83.9 (SD 18.3), respectively (T-test, $p < 0.05$).

The domains that contributed to the MHQ total were all more or less relevant for the patients. Hand function as such was rated lower than limitations related to ADL or work. Appearance and satisfaction scored less than maximal in a majority of the patients (55 ± 6.9% and 63 ± 6.7%, respectively (95% CI). Pain was an issue in a minority of the patients, 43 ± 6.8% (95% CI).

The associations between the patient and stroke characteristics and measures of current health status on the one side and the MHQ scores on the other side are shown in Table 2, adjusted for age, sex, and follow-up. In a univariate regression analysis, lower education, longer hospitalization, lower Barthel Index after admission and at discharge, discharge to another institution and a supratentorial stroke were related to a worse outcome on the MHQ Total. Worse outcomes on daily activities, mood, anxiety and quality of life, and a higher caregiver strain were significantly associated with a lower MHQ Total score.

In order to understand the association of patients' and stroke characteristics with overall hand function as perceived by the patients, hierarchical multiple regression analysis was performed (based on complete data of 156 patients). Lower education (β 6.88, CI 3.00–10.77), a lower Barthel Index at discharge (β 1.62, CI 1.07–2.17), and a supratentorial location (β 9.72, CI 1.84–17.60) were related to a significantly lower MHQ Total score after 2–5 years, adjusted for age, sex, and follow-up (R^2 0.28).

Discussion

The MHQ is a validated, multidimensional tool that efficiently can describe outcome of hand function in larger stroke populations. In this cross-sectional hospital-based study 2 to 5 years after stroke, patients used the MHQ to report on hand function, ADL, work, pain, appearance, and satisfaction with hand function. A majority of the patients experienced at least some limitations; pain was less often mentioned as a problem compared to the other domains. The MHQ Total score was closely related to other health outcomes such as activity level, mood, quality of life, and caregiver strain. Patients with a more severe stroke, a lower education, and a supratentorial stroke location had significantly lower outcomes on the MHQ.

Patients in our study were included regardless of their initial impairment. This resulted in a relatively high MHQ Total compared to studies in patient populations with specific hand function problems as an inclusion criterion. In the present study, the MHQ Total of the subgroup with submaximal Barthel score at discharge (< 20) was 68.8 points (SD 24.3). This is in line with the results of other patient categories, such as rheumatoid patients[20,31] and patients with carpal tunnel syndrome.[19]

In literature, lower percentages of hand function problems are mentioned in unselected stroke cohorts.[4,6] This can be explained by the way hand function is defined and measured.[8] The Action Research Arm Test (ARAT) is frequently used; patients with mild hand function problems can be missed because of the ceiling effect of the ARAT.[11,32] Patients with seemingly good recovery could still experience relevant problems in hand function.[7,8] The MHQ seems to be able to discern the milder hand function problems stroke patients may perceive.

Stroke patients can suffer from complaints other than an impaired function with respect to the hand. The broad range of items that was included in the ICF Core set for stroke reflects the large variety of impairments, limitations, and restrictions of activities and participation involved, as well as the interactions with environmental factors.[10] Other validated assessment tools that comprise hand-related questions are the Stroke Impact scale (SIS) and the Abilhand.[33,34] The SIS focuses on strength and daily activities, the Abilhand on daily activities;[35] they cover a limited range of ICF items compared to the MHQ. In the present study, other domains were at least as important as pain. Of these domains, appearance of the hand and satisfaction with hand function have drawn little attention to date.

Our results indicate that a lower Barthel score at discharge, a lower educational level, and a supratentorial stroke contribute independently to a lower MHQ outcome 2–5 years after stroke. In line with our results, a higher Barthel score was related to a better hand function in a community-based stroke population.[36] The explanation of educational level as a contributor to the MHQ outcome is not unexpected. It is generally accepted that social inequality has effect on the outcome of chronic diseases, partly because of differences in exposure to behavioral risk factors.[37]

The relevance of stroke location for hand function is not fully understood yet. Several aspects could be of importance, e.g. cognition, sensibility, or compensation options for a loss of dexterity after a supratentorial stroke.[38,39] Schiemanck et al. found that at one year post-stroke lesions of the internal capsule were associated with a significantly lower probability of return of isolated hand motor function than lesions of the cortex, subcortex, and corona radiata; only patients with middle cerebral artery strokes were included.[40] Additional research is warranted to understand the influence of stroke location on hand function.

Limitations

Causal relations are difficult to infer due to the cross-sectional design of the study. A selection bias is imminent because not all patients responded to the questionnaire, especially if cognitive or language impairments are present; on the other hand, the non-responders were comparable with respect to age and sex, and the resultant study population was comparable to other hospital-based populations with respect to Barthel Index and health-related outcomes (depression, FAI, quality of life).[6,41,42,43]

Data regarding the volume and content of rehabilitation activities after stroke were not collected and therefore could not be used as a determinant for post-stroke hand function in this study. Objective measurements of hand function were not available, but from earlier research it is known that the MHQ is a valid method to assess post-stroke hand functioning compared with other objective and instrumented measurements.

Conclusions

By means of the MHQ, a multidimensional description of hand function and related aspects in a population of stroke survivors is provided. Apart from known items such as function, ADL, work, and pain, also items regarding appearance and satisfaction can be relevant for stroke patients and should be included in the evaluation of the effect of interventions. A more severe, supratentorial stroke and a lower level of education are associated with the risk of persistent impairments regarding the hand. Future research has to reveal whether interventions that aim to improve hand function in specific domains are effective.

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Figure 1. Characteristics of responders and non responders.

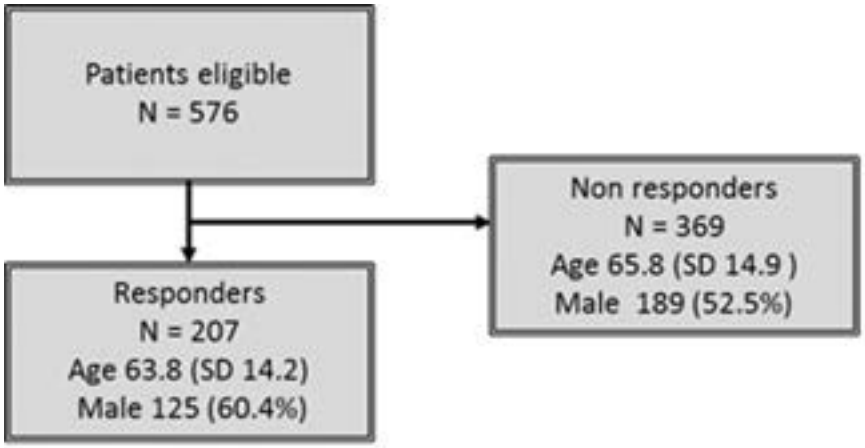

Figure 2. Median scores and IQR of the MHQ Total and the MHQ domains.

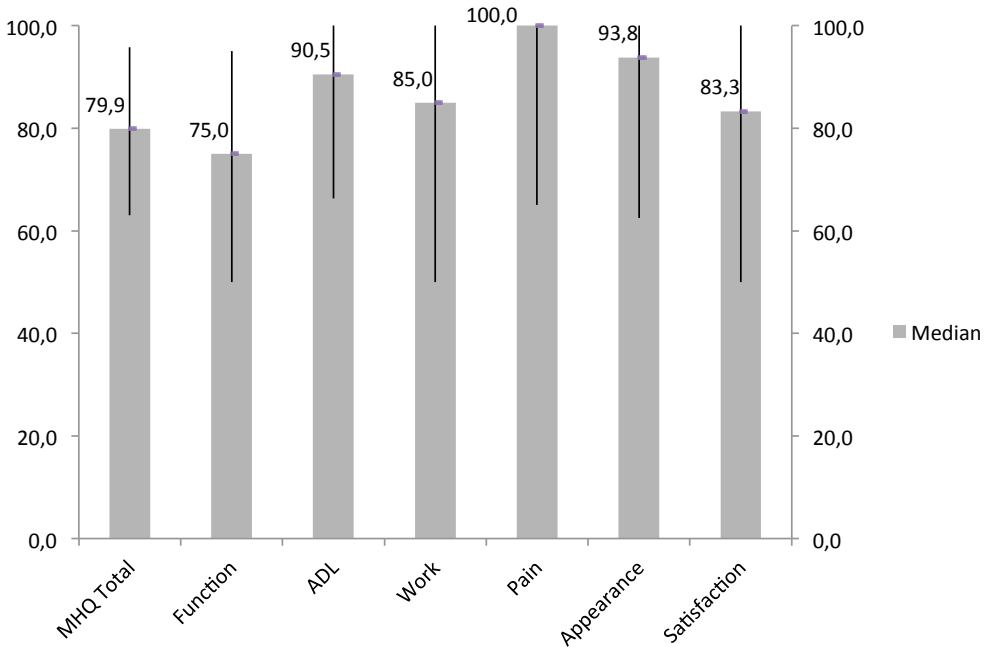

Table 1. Patients' characteristics and stroke characteristics; current health status.

Patients' characteristics		**N total**	
Mean age at stroke, years (SD)		207	63.8 (14.2)
Sex:	- male N (%)	207	125 (60.4)
	- female N (%)		82 (39.6)
Mean duration of follow-up; Months (SD)		207	36.3 (9.9)
Educational level, number:	- Low N (%)	207	72 (36.2)
	- Middle N (%)		72 (36.2)
	- High N (%)		55 (27.6)
Social situation:	- living together N (%)	204	135 (66)
	- living alone N (%)		69 (34)
Stroke characteristics		N total	
Type of stroke:	- ischemic N (%)	207	181 (87.4)
	- haemorragic N (%)		26 (12.6)
Lesion; Number N (%)			
	- Supratentorial	207	164 (79.2)
	- left		97 (46.9)
	- right		66 (31.9)
	- bilateral		1 (0.5)
	- Vertebrobasilar		43 (20.8)
Thrombolysis:	- Yes N (%)	204	49 (23.7)
	- No N (%)		156 (76.3)
Length of hospital stay, days; median (IQR)		207	7 (7)
Barthel Index (0-20; worst – best); Median (IQR)			
	- at admission	174	14 (11)
	- at discharge	174	19 (8)
Discharge:			
	- home N (%)	178	98 (56.3)
	- other institution N (%)		80 (46.4)
Current health status		N total	Mean (SD)
FAI total (Score 0-45; worst-best)		171	23.19 (10.82)
HADS			
	- Anxiety (Score 0-21; best-worst)	195	5.41 (4.71)
	- Depression (Score 0-21; best-worst)	196	5.57 (4.93)
SF 36			
	- PCS (Score 0-100; worst-best)	186	41.49 (13.57)
	- MCS (Score 0-100; worst-best)	186	46.44 (12.53)
EQ5D (Score -0.321-1; worst-best)		195	0.73 (0.25)
CSI (Score 0-13; best-worst)		133	4.46 (3.71)

Abbreviations:, SD = standard deviation, IQR = interquartile range, Abbreviations: SD = standard deviation, IQR = interquartile range, FAI = Frenchay Activity Index, HADS = Hospital Anxiety and Depression scale, EQ5D = EuroQol, CSI = caregiver strain index

Table 2. Patient characteristics, stroke characteristics and outcomes of current health status of stroke patients in relation to the MHQ total (univariate regression analysis, corrected for age, sex and follow-up).

Patients' characteristics	**mean MHQ total**	**N total**	**β (95% CI)**	**p level**
Educational level:		191	6.87 (2.83 – 10.92)	0.001
- Low	69.9			
- Medium	75.3			
- high	83.3			
Social situation:		195	-0.46 (-7.19 – 7.10)	0.990
- living together	75.5			
- living alone	75.7			
Stroke characteristics		N total		
Type of stroke:		196	-0.78 (-10.52 – 8.95)	0.874
- ischemic	75.8			
- haemorragic	74.4			
Stroke lesion		196	12.73 (4.80 – 20.65)	0.002
- Supratentorial	73.1			
- Vertebrobasilar	85.3			
Thrombolysis		194	3.59 (-3.59 –10.77)	0.325
-Yes	74.5			
-No	76.2			
Length of hospital stay		196	-0.69 (-1.07 – -0.31)	<0.001
Barthel Index				
- at admission		165	1.33 (0.83 – 1.84)	<0.001
- at discharge		165	1.74 (1.17 – 2.30)	<0.001
Discharge destination:		175	11.25 (4.51 – 18.00)	0.001
- Home	81.0			
- other institution	69.5			
Current health status		N total		
FAI total (Score 0-45; worst-best)		166	1.55 (1.30 – 1.80)	<0.001
HADS				
- Anxiety (Score 0-21; best-worst)		188	-2.27 (-2.92 – -1.61)	<0.001
- Depression (Score 0-21; best-worst)		189	-2.64 (-3.22 – -2.06)	<0.001
SF 36:				
- PCS		180	1.23 (1.05 – 1.42)	<0.001
- MCS		180	0.77 (0.51 – 1.04)	<0.001
EQ5D* (Score -0.321-1; worst-best)		188	6.18 (5.21 – 7.14)	<0.001
CSI (Score 0-13; best-worst)		129	-3.77 (-4.73 – -2.82)	<0.001

** EQ5D data were multiplied by 10 in this analysis; the B and CI are based on the decile score of the EQ5D which is more comprehensible to interpret*