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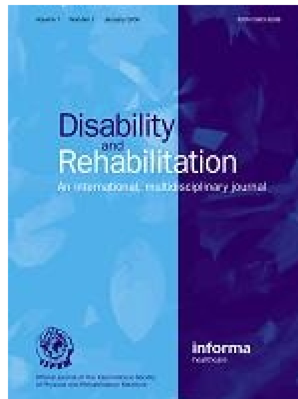

Patient- and proxy-perceptions on functioning after stroke rehabilitation using the 12-item WHODAS 2.0: a longitudinal cohort study

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IMPLICATIONS FOR REHABILITATION

- Stroke survivors´ functioning improved significantly during the 9-50 months follow-up after subacute inpatient stroke rehabilitation.
- Stroke survivors perceived slightly less difficulties in their functioning compared to evaluations by proxies.
- Strong correlation between patient- and proxy-perceptions on stroke survivors functioning strengthened from subacute to chronic phase of stroke recovery.
- The 12-item WHODAS 2.0 seems to be a valuable patient- and proxy-reported outcome measure to assess longitudinal changes in stroke survivors' functioning after stroke.

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Patient- and proxy-perceptions on functioning after stroke rehabilitation using the 12-item WHODAS 2.0: a longitudinal cohort study

Abstract

Purpose: To analyse longitudinally patient- and proxy-perceptions on stroke survivors'(SSs') functioning using the 12-item WHO Disability Assessment Schedule 2.0 (WHODAS) after subacute inpatient stroke rehabilitation.

Methods: Sixty-five SSs and their significant others(proxies) responded to WHODAS questionnaire at discharge and 9 to 50 months later. Self-WHODAS ratings were compared with corresponding proxy-perceptions and informal ratings on self-reported functional recovery.

Results: On average, SSs' functioning improved after discharge, except according to self-WHODAS ratings of those with severe stroke. Individual changes were, however, notable. Association between time and change was statistically insignificant. SSs perceived greatest improvements in walking, household tasks, community life and working ability. The only items showing slight deterioration were emotions and relationships. In parallel, proxies rated all items except emotions and relationships improved. At discharge, proxies rated SSs´ functioning more impaired than SSs themselves, mostly regarding those with severe stroke. Still, inter-rater reliability was very strong and increased significantly with time (ICC 0.799 vs. 0.979 at follow-up). Ninety percent of SSs with improved functioning according to self-WHODAS reported better functioning also in the informal questionnaire.

Conclusion: WHODAS showed improvements in SSs' functioning 9-50 months after discharge from subacute stroke rehabilitation. Improvements were in line with proxy-perception and self-reported functional recovery.

Keywords: stroke, functioning, disability, rehabilitation, patient-reported outcome measure, WHODAS 2.0

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Introduction

Stroke is the leading cause of long-term disability in adult population worldwide [1]. Although the incidence of stroke is diminishing, the prevalence of stroke survivors is increasing due to longevity and medical advancements [2]. Stroke survivors need long-term support in coping with the consequences of stroke [3-6]. However, there is only scarce evidence on longitudinal changes in stroke survivors' self- and proxy-perceived functioning.

Previous studies show both positive and negative changes in stroke survivors' self-perceived functioning over time. Positive changes in mobility, life activities (e.g. working ability), participation, autonomy, and even complete recovery have been reported in two thirds of stroke survivors four to five years after stroke [7-9]. On the other hand, gradual deterioration in functioning has been reported up to 10 years post-stroke [4-6], as well as deterioration starting from 3 years post-stroke [10].

A variety of outcome measures have been used to assess subjective changes in stroke survivors' functioning, including e.g. Frenchay Activity Index, Short Form-36, Patient Competency Rating Scale, London Handicap Scale [9], Utrecht Scale for Evaluation of Rehabilitation-Participation [3], WHODAS [7], and Impact on Participation and Autonomy [8] as well as informal questionnaires [4-6].

In this study, WHODAS was used, as it is a valid and reliable measure in stroke population [11-12] and is based on the International Classification of Functioning, Disability and Health (ICF) [13]. WHODAS considers both activity and participation components of functioning in several domains. It has a full 36-item, and a brief 12-item versions. Application of the brief version has been recommended in several diagnostic groups in addition to stroke [14-18].

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WHODAS allows both self- and proxy-assessments [19] enhancing patient-and family-centred processes in stroke rehabilitation [20-22]. It can also predict institutionalization [23-24] and return to work [22].

Several studies using WHODAS in a stroke population have been published. Among them we found only one assessing longitudinal change in functioning using the full 36-item version [7]. Besides earlier work from Tarvonen-Schröder et al. [20,24], only one study utilized both self- and proxy-WHODAS questionnaire to assess stroke survivors' functioning [12], even if family-centred rehabilitation processes would require the involvement of significant others.

The purpose of this study was to analyse longitudinally patient- and proxy-perceptions on stroke survivors' functioning using the 12-item WHODAS after subacute inpatient stroke rehabilitation. This is the first study applying the brief version of WHODAS at two time points to compare self- and proxy-perceptions in a stroke population.

Methods

Study design and participants

This is a longitudinal cohort survey. Participants were first-time stroke survivors admitted into a university hospital specialized rehabilitation unit, and their proxies (Figure 1). The baseline data was collected at the time of discharge from the rehabilitation unit between 8/2015-3/2019 from all voluntary consecutive stroke survivors (n=229), mean age 62.1 years at stroke onset (56% men), and their significant others (proxies). Stroke survivors and their proxies were asked to fill in a WHODAS questionnaire blinded from each other. A neurologist assisted participants if needed. If the patient was unable to respond reliably because of aphasia or cognitive deficits, only proxy response was gathered. The follow-up data was collected through postal survey between 10/2019-3/2020 as a follow-up appointment

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3 at the rehabilitation unit was not possible. Questionnaires (self- and proxy-WHODAS and the informal questionnaire) were sent to all available 214 stroke survivors living in a community or long-term facility.

Exclusion criteria for stroke survivors at baseline were age under 16 years at stroke onset, previous stroke, current major medical or psychotic condition, previous disability causing dependence on others, brain injury without radiological findings, and medical reasons for interrupted rehabilitation. At follow-up, the only exclusion criteria was living abroad. The time interval of 9 to 50 months from discharge was set after the final data collection according to the participating stroke survivors. Finally, stroke survivors who had both self- and proxy-WHODAS responses at discharge and at follow-up available, were included in the analyses.

[Figure 1 near here]

Outcome variables

The main outcome, functioning, was assessed with the 12-item WHODAS 2.0. Proxies were included as the agreement between two evaluators may shed light to the reliability of WHODAS in this patient population. It is a fairly seldom used perspective in stroke research and disability studies that could enhance family-centred rehabilitation process and decision making. This is especially important in stroke survivors with severe aphasia, cognitive problems or other reasons preventing subjective assessment.

WHODAS is a generic patient-reported outcome measure that includes also a version for proxies. It identifies burden during the past 30 days caused by different mental and physical health conditions. [19,25-26.] WHODAS is based on the framework of the International

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Classification of Functioning, Disability and Health (ICF) covering *six life domains* in two components: (A) Activities including *mobility* (standing and walking long-distances), *self-care* (washing oneself and getting dressed) and *cognition* (learning and concentration); and (B) Participation including *getting along* (dealing with strangers and maintaining friendships i.e. relationships), *life activities* (household tasks and working), and *social participation* (community life and emotions). [19]

In the baseline assessment, the stroke survivors and their proxies were asked to rate *the current state* of stroke survivors' functioning instead of the past 30 days, as functioning is usually rapidly evolving during subacute inpatient rehabilitation. Functioning status at the follow-up was rated according to the ordinary instructions. Each WHODAS item was rated with a five-point Likert scale, the qualifiers being *no difficulty* (0), *mild difficulty* (1), *moderate difficulty* (2), *severe difficulty* (3), and *extreme difficulty/cannot do* (4). The 12-item WHODAS sum score is ranging from 0 to 48 and was further categorized as follows: 0 = no disability, 1-4 = mild disability, 5-9 = moderate disability, and 10-48 = severe disability [27].

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Independent outcome variables retrieved from the hospital register were age at stroke onset, gender, acute stroke severity, and time from discharge. Acute stroke severity was classified by a neurologist with the 11-item National Institutes of Health Stroke Scale (NIHSS) at 24 hours from hospitalization. NIHSS total score 0-42 was categorized as follows: 0-5 = mild stroke, 6-14 = moderate stroke, and 15-42 = severe stroke [28].

Functional dependence at discharge was assessed with the modified Rankin Scale (mRS) by a neurologist and the Functional Independence Measure® (FIM®) by a nurse, trained and accredited as a FIM® rater using the electronic FIM® version 5.2, Uniform Data System for

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Medical rehabilitation, Amherts, NY, USA. mRS is a rough measure incorporating the ICF components of body functions, activity and participation. It encompasses seven levels from total independence without residual symptoms (0) to death (6) [28]. FIM® describes the degree of independence in 18 items focusing on motor and cognitive function. Each item is rated on a 7-point scale (1= <25% independence to 7=100% independence), the total score ranging from 18 to 126. FIM® motor subscore refers to a sum score for self-care, sphincter control, mobility, and locomotion (scale 13-91). FIM® cognitive subscore refers to a sum score for communication, psychosocial adjustment, and cognitive function (scale 5-35). [29-30]

In addition to WHODAS, an informal study-specific semi-structured questionnaire on self-reported functional recovery was completed by the stroke survivors at the follow-up. The informal questionnaire was addressed only for the stroke survivors for comparison with WHODAS responses and to describe other perspectives of self-perceived functioning. The questionnaire was based on the professional insights of the research group and approved by two external rehabilitation professionals. The questionnaire included following categorical questions reported in table 1 and/or 5: *What is your living status?... working status? Have you had recurrent stroke(s)? Any other health conditions that affect your functioning? Have you fallen during the past 12 months? Are you receiving rehabilitation at the moment? If yes, what kind? How well does the situation meet your needs?* The following five-point Likert-scale questions modified into three categories are presented in table 1 and/or 5: *How much do you need assistance in self-care? How would you rate your upper extremity function? ...mobility? How would you rate your functioning compared to the status at discharge?...participation compared to the time before stroke?*

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Statistical analysis

Data was analysed with relevant descriptive, correlational and comparative statistics using the IBM SPSS Statistics for Macintosh, Version 25.0. Continuous variables were described using medians and interquartile ranges with range of values. Categorical variables were described using frequencies and percentages. Cronbach's alfa was used to assess the reliability of self- and proxy-WHODAS. Change in stroke survivors' functioning (self- and proxy-WHODAS sum score, component scores and item scores) were tested by Wilcoxon Signed Ranks Test. *P*-values <0.05 (2-tailed) were considered statistically significant.

Associations between continuous variables were tested with Spearman's Correlation Coefficients. Linear regression analysis was applied to test the association between time and change in self- and proxy-WHODAS. Intraclass correlation (ICC) was calculated at both baseline and follow-up to estimate the agreement of self- and proxy-WHODAS sum score. Correlations of 0-0.29 were considered as weak, 0.30-0.49 as moderate, 0.50-0.69 as strong, and 0.70-1.00 as very strong.

Ethical considerations

This study was approved by the Ethics Committee of the University of Turku and Turku University Hospital (19.5.2015, 73/2015). The ethical standards of the World Medical Association Declaration of Helsinki 1975 (revised 1983) and the Finnish National Board on Research Integrity 2019 were followed. Participation was voluntary throughout the study. All participants gave written informed consent prior inclusion in the study. The data was handled confidentially and used only for the study purposes. Some of the participants have been involved in previous studies of Tarvonen-Schröder et al. [20,24,31-34].

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Results

Participants

Sixty-five stroke survivors (30% out of the eligible 214), median age 62.7 years at stroke onset (range 16-83) and 60% of women, who had both self- and proxy-WHODAS responses from baseline and follow-up available, were included in the analyses (Figure 1). The occurrence of right, left, bilateral, and posterior stroke in severity subgroups were: *mild* n=4 (25%), n=6 (38%), n=5 (31%), n=1 (6%), *moderate* n=14 (47%), n=11 (37%), n=1 (3%), n=4 (13%), and *severe stroke* n=5 (26%), n=10 (53%), n=1 (5%), n=3 (16%), respectively. Subarachnoid haemorrhage (SAH) occurred only in stroke survivors with mild stroke, and they all had bilateral radiological findings. Aphasia occurred at admission to the rehabilitation unit in 35% (n=23) of SSs, mostly mild (n=19). Remaining few cases with more severe aphasia had all improved significantly and were able to respond at discharge. The same applied to neglect, which was present at admission in 63% (n=41) of stroke survivors, mostly mild (n=29) and improved during the rehabilitation. More demographic and clinical data of the sample are presented in Table 1.

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Proxies had many roles in relation to the stroke survivors and not all of them were living in the same household. About half of the proxies were either spouses or partners. One fifth were other relatives such as offspring, siblings, and parents. Another 20% did not report their role. Remaining 10% were personal assistants or close friends.

[Table 1 near here]

Change in stroke survivors' functioning after discharge

Both self- and proxy-WHODAS sum scores decreased indicating statistically significant improvement (p=0.004 and p<0.0001) in stroke survivors' functioning 9-50 months from

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discharge (Table 2). Participation component score decreased slightly more than activities component. Nevertheless, about half of the stroke survivors were still categorized with severe disability (sum score 10-43 out of 48) according to both self- and proxy-WHODAS responses (Table 1) [27]. Association between time and change in both self- and proxy-WHODAS sum scores were statistically insignificant. The improvement in functioning seemed to be slightly less in stroke survivors with longer time from discharge (Figure 2).

[Table 2 near here]

[Figure 2 near here]

Because of the small sample size, we could not analyse subgroup differences statistically. Those who showed deterioration in functioning after discharge according to WHODAS were mostly 65 years or older with severe stroke (Table 3). More difficulties in functioning reflected also to restricted participation, walking difficulties, incidence of falls, and unilateral upper extremity function. Eighty percent of the stroke survivors whose functioning deteriorated were 65 years and older and reported falls during the past 12 months.

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Self-reported functional recovery was well in line with self- and proxy-WHODAS sum score change (Table 4). Ninety percent of the stroke survivors who showed improvement in functioning according to self-WHODAS sum, reported better functioning in the informal questionnaire as well. Majority (79%) of the stroke survivors reported less difficulties in functioning at follow-up, and 71% according to self-WHODAS sum score (Table 3).

Although stroke survivors' functioning mostly improved, nearly 60% experienced more participation restrictions compared to the time before stroke. At present, about 40% of the

stroke survivors reported having access to rehabilitation. The most common form of rehabilitation was physiotherapy (73%) followed by speech therapy (36%), occupational therapy (33%), and neuropsychological counselling (15%). Nearly 40% of the stroke survivors reported unmet rehabilitation needs at follow-up.

[Table 3 near here]

[Table 4 near here]

Correlation between self- and proxy-perception on functioning

To overcome a fairly small sample size, proxy-WHODAS and the informal questionnaire were used beside self-WHODAS. Stroke survivors perceived slightly less difficulties in functioning than their proxies (Figure 3), except for those with mild stroke (Table 1). At discharge, the difference between self- and proxy-WHODAS was statistically significant in sum score (p=0.001) and in all other item scores except emotions, concentration, and walking. At follow-up, there were no statistically significant differences between self- and proxy-WHODAS sum or items scores. Reliability of the 12-item WHODAS for both stroke survivors (α = 0.859) and their proxies (α = 0.841) was acceptable [35].

Correlation between self-WHODAS sum score change and proxy-WHODAS sum score change was strong (*r*=0.623). Strong item change correlations were found in standing (*r*=0.627), household tasks (*r*=0.624), walking (*r*=0.690), and working ability (*r*=0.644), and moderate correlations in all other items (*r*=0.489-0.361). All correlations were significant at the 0.01 level (2-tailed). Intraclass correlation coefficient (ICC) between self-WHODAS and proxy-WHODAS sum score was very strong and improved significantly with time (at discharge 0.799 vs. at follow-up 0.979).

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[Figure 3 near here]

Discussion

This is the first study using the 12-item WHODAS 2.0 longitudinally to analyse patient- and proxy-perceptions on stroke survivors' functioning after subacute inpatient stroke rehabilitation. In overall, both self- and proxy-WHODAS sum scores diminished statistically significantly after discharge denoting better functioning, except for self-WHODAS of those with severe stroke. Approximately 70% of the stroke survivors perceived less difficulties in functioning 9 to 50 months after discharge from the rehabilitation hospital. Individual differences were, however, notable.

On WHODAS item level, the greatest improvements occurred in walking, household tasks, community life and working ability. The only items showing deterioration were emotions, dealing with strangers, and maintaining friendships demonstrating slight increase in self-WHODAS item scores. However, the latter two items (i.e. relationships) were the least impaired already at discharge. In parallel, proxies reported improvements in stroke survivors' functioning with significant change in all items except for emotions and relationships.

Our results regarding positive changes in stroke survivors' mobility, participation, and life activities are in line with the only earlier longitudinal WHODAS-study investigating an age matching stroke population over four years [7]. On the contrary, significant deterioration has been found in self-care and household tasks, but maintained social roles, during the 2 to 4 years follow-up in another rehabilitant population [39]. In a population-based study among stroke survivors with moderate stroke severity, self-perceived restrictions in social life were

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3 one of the most affected areas [40]. In the present study, the stroke survivors perceived slight
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5 deterioration in emotions and relationships.
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10 In our stroke population, the greatest disability at follow-up was found in mobility (standing
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12 and walking), working ability (life activities), and emotions (social participation). This is
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14 supported by previous population-based studies showing the greatest disability in mobility,
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17 physical independence, working ability, and leisure activities five years post-stroke in stroke
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19 survivors with somewhat better functional status compared to our population [9,41-42].
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24 Some other population-based studies in stroke survivors with somewhat better functioning
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26 support the fact that 60-80% of stroke survivors (mean age 67-76 years) have no disabilities
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28 five years post-stroke [9,43-44]. In a four-year follow-up study, only one third of stroke
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31 survivors (mean age 67 years) perceived participation restrictions [45]. In our study, less than
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33 20% of the stroke survivors perceived no disabilities and 60% had more participation
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35 restrictions compared to the time before stroke. These differences might be explained by a
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38 less severe stroke population (60-65% mild stroke cases vs. our 25%) [43,45]. The difference
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40 between our results and other studies might also be explained by the fact that our sample was
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42 highly selected and in need of intensive subacute inpatient rehabilitation, but also because of
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45 different outcome measures used.
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49 In the present study, the stroke survivors with mild and moderate stroke recovered better than
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51 those with severe stroke according to self-WHODAS, whereas by the proxies, all the stroke
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54 severity subgroups improved. Increasing stroke severity [4] and age [4,7,9,45] have been
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56 found to have a negative impact on stroke survivors´ functional recovery, even if those with
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58 severe stroke and disability have a possibility to improve more than those with less
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disabilities [46]. One explanation to this discrepancy could be that those with more severe stroke may have had less insight of the consequences of stroke at discharge with overestimation of their functioning, thus showing less improvement at follow-up. In addition, the participants with severe stroke were some years older than those with milder stroke.

Younger stroke survivors seemed to recover better than older stroke survivors. It is possible that there has been a leverage combined effect with severe stroke and older age, as 63% of the stroke survivors with severe stroke were 65 years and older compared to 38%, and 43% in those with mild, and moderate stroke. Worse recovery among the older stroke survivors may also be related to lesser access to rehabilitation after discharge compared to the working aged stroke survivors. This, however, was not analysed in the present study.

Association between time and change in stroke survivors' functioning was statistically insignificant although improvements were found to be slightly less in those with longer follow-up. Kwon et al. (2016) found improvements in stroke survivors' functioning until three years after stroke, but deterioration thereafter [11]. It must be noted though that their study design was cross-sectional, limiting the solidity of the results.

Our results provide tentative evidence about validity and reliability of the 12-item WHODAS 2.0 in stroke population supporting earlier findings [11,12]. Correlation between self- and proxy-WHODAS sum scores, and sum score change was strong to very strong, supporting the inter-rater reliability of the 12-item WHODAS 2.0 to assess longitudinal change in stroke survivors' functioning. We compared self-WHODAS sum score change also with stroke survivors' self-reported functional recovery (informal questionnaire), because the minimal clinically important difference score for the 12-item WHODAS sum has not been established

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[26]. Ninety percent of the stroke survivors who showed improvement in functioning according to self-WHODAS sum, reported better functioning also in the informal questionnaire.

In our study, proxies perceived slightly more difficulties in stroke survivors` functioning than stroke survivors themselves, particularly at discharge. This disagreement could be partly due to lack of the stroke survivors' insight in the consequences of stroke at early phase of recovery, especially in patients with severe stroke and cognitive deficits. In turn, depression could cause underestimation of self-perceived functioning at any phase of recovery. Still, we did not find any significant disagreement between self- and proxy-perceptions like Björkdahl et al. (2012) [36]. Obviously, personal perspectives and environmental factors influence the experience of disability and difficulty levels [13]. However, those factors were not the target of our study.

The inter-rater reliability in the 12-item WHODAS 2.0 appeared to be good, as there were very strong correlations between self- and proxy-perceptions both at discharge and follow-up. Strong agreement has been found also in a previous study using ICF-based activity and participation items [37] or WHODAS in a stroke population [20,38] and in other neurological patient populations [14-18].

Strengths and limitations

This study has several strengths. The study design allowed us to explore patient- and proxy-perceptions on stroke survivors' functioning longitudinally. The study setting was natural, and stroke survivors living in long-term facilities at follow-up were also included. A wide variety of sociodemographic characteristics and functional consequences of stroke were presented.

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The follow-up sample was versatile, representing well the baseline population as the age at stroke onset, stroke severity, functional independence and functioning at discharge varied in a large scale.

The study has also limitations to be considered. First, the baseline population was carefully selected for intensive subacute stroke rehabilitation in a university hospital specialized rehabilitation unit, subject to selection bias. This led to a greater portion of younger stroke survivors and higher intensity rehabilitation compared to an ordinary primary health care setting and could explain the high survival rate (94%), and better improvements in functioning with time. The follow-up sample was somewhat younger and more women were included compared to the baseline population. The follow-up participants had also less severe stroke and were more independent at discharge indicating better stroke outcomes than among the non-participants.

Second, there is a possibility of type I error due to the small sample size. Third, the follow-up data was collected in much shorter time period than the baseline data restricting the power to detect the relationship between time and functional recovery. The results are not as robust as they would be, if the follow-up data had been collected at a set time-point from all of the stroke survivors. All of these facts limit the generalization of the results and can lead to possible biases. Studies with bigger sample sizes are needed to confirm our results.

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Conclusions

Stroke survivors´ functioning improved significantly according to both patient- and proxy-perceptions after subacute inpatient stroke rehabilitation. Still, over half of the stroke survivors were rated with severe disability 9 to 50 months after discharge according to WHODAS. Patient- and proxy-perceptions resembled each other very strongly although stroke survivors perceived slightly less difficulties in their functioning than proxies. Correlation between self- and proxy-WHODAS sum score change was also strong. The 12-item WHODAS 2.0 seems to be a valuable measure to assess stroke survivors' functioning, also longitudinally.

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Disclosure statement

The authors report no conflicts of interest to declare.

Data availability statement

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Tables

Table 1. Characteristics of the participants in total and according to stroke severity by NIHSS.

Table 2. Change in self- and proxy-WHODAS sum score, component scores, and item scores between discharge and follow-up using Wilcoxon Signed Ranks Test.

Table 3. Self-WHODAS sum score change in SSs with more difficulties, no change, and less difficulties at follow-up according to self-WHODAS sum, and associating factors.

Table 4. SSs' self-reported change in functioning according to informal questionnaire (n=63) versus self- and proxy-WHODAS sum score change.

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Figures

Figure 1. Flow of the participants from discharge to follow-up.

Figure 2. Self- and proxy-WHODAS sum score change by time

Figure 3. Comparison of self- and proxy-WHODAS item score means at discharge and 9-50 months from discharge.

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Table 1. Characteristics of the participants in total and according to stroke severity by NIHSS.

Characteristics	All (*n*=65)	Mild stroke (*n*=16)	Moderate stroke (*n*=30)	Severe stroke (*n*=19)
At hospital				
Md (IQR) (range)				
Age at stroke onset (y)	62.7 (16.9) (16-83)	59.2 (20.3) (32-76)	60.6 (14.4) (38-83)	68.8 (22.9) (16-83)
NIHSS at 24 hours	9.0 (10.0) (0-35)	3.5 (4.0) (0-5)	9.0 (5.0) (6-13)	18.0 (7.0) (15-35)
Days in inpatient rehabilitation	22.0 (23.5) (3-102)	11.0 (9.3) (3-32)	21.5 (21.0) (7-61)	34.0 (31.0) (13-102)
mRS at discharge from rehab	3 (2) (2-5)	2 (0) (2-3)	3 (1) (2-4)	4 (1) (2-5)
FIM® at discharge from rehab				
Total	115 (20) (45-126)	123 (6) (115-125)	115 (14) (63-126)	86 (40) (45-125)
Motor	84 (19) (25-91)	89 (3) (85-91)	83 (14) (34-91)	57 (34) (25-91)
Cognition	32 (5) (16-35)	33 (4) (25-35)	32 (4) (23-35)	28 (8) (16-35)
Age group at stroke onset				
< 65 years (younger) *n* (%)	34 (52)	10 (63)	17 (57)	7 (37)
≥ 65 years (older)	31 (48)	6 (38)	13 (43)	12 (63)
Gender				
Women	39 (60)	11 (69)	17 (57)	11 (58)
Men	26 (40)	5 (31)	13 (43)	8 (42)
Type of stroke				
Ischemic	40 (62)	9 (56)	19 (63)	12 (63)
Haemorrhage, ICH	20 (31)	2 (13)	11 (37)	7 (37)
Haemorrhage, SAH	5 (8)	5 (31)	0 (0)	0 (0)
Self-WHODAS at discharge				
Md (IQR) (range)	15.0 (14) (0-41)	12.0 (14) (1-26)	12.5 (11) (0-41)	21.0 (8) (4-32)
Proxy-WHODAS at discharge	20.0 (22) (0-48)	9.5 (10) (1-27)	16.5 (18) (0-48)	30.0 (11) (7-45)
At follow-up				
Self-WHODAS	9.0 (18) (0-40)	2.5 (8) (0-17)	6.0 (12) (0-39)	22.0 (21) (0-40)
Proxy-WHODAS	10.0 (21) (0-43)	1.5 (7) (0-14)	10.0 (17) (0-42)	21.0 (20) (0-43)
Time from discharge (mo.)	32.2 (22.2) (9-50)	32.8 (24.7) (11-49)	29.5 (25.4) (11-50)	33.0 (18.2) (9-48)
Time since stroke (mo.)	34.7 (22.7) (11-54)	34.8 (25.1) (12-51)	31.1 (24.2) (13-53)	36.7 (18.6) (11-54)
Informal questionnaire				
Comorbidities (n=62)				
Yes *n* (%)	23 (37)	5 (33)	13 (46)	5 (26)
No	39 (63)	10 (67)	15 (54)	14 (74)
Recurrent stroke (n=63)				
Yes	3 (5)	0 (0)	1 (3)	2 (11)
No	60 (95)	15 (100)	28 (97)	17 (89)
Living status (n=64)				
Single at home	18 (28)	4 (25)	9 (31)	5 (26)
With family at home	40 (63)	12 (75)	19 (66)	9 (47)
In long-term facility	6 (9)	0 (0)	1 (3)	5 (26)
Dependence in self-care (n=64)				
None (< 5%)	35 (55)	13 (81)	18 (62)	4 (21)
Minor to moderate (5-49%)	19 (30)	3 (19)	7 (24)	9 (47)
High to total (50-100%)	10 (16)	0 (0)	4 (14)	6 (32)
Upper extremity function (n=64)				
Unilateral	28 (44)	1 (6)	11 (38)	16 (84)
Bilateral	36 (56)	15 (94)	18 (62)	3 (16)
Mobility outdoors (n=64)				
Walking without devices	38 (59)	16 (100)	18 (62)	4 (21)
Walking with assistance	12 (19)	0 (0)	8 (28)	4 (21)
Wheelchair users	14 (22)	0 (0)	3 (10)	11 (58)
Number of fallers* (n=61)	26 (43)	3 (20)	13 (46)	10 (56)
Working status				
Working/studying	12 (19)	6 (38)	4 (13)	2 (11)
Unemployed	1 (2)	0 (0)	1 (3)	0 (0)
Retiree	32 (49)	9 (56)	13 (43)	10 (53)
Unable to work	20 (31)	1 (6)	12 (40)	7 (37)

NIHSS=National Institutes of Health Stroke Scale categories at 24 hours from hospitalization: mild stroke (0-5/42), moderate stroke (6-14/42), severe stroke (15-42/42); *n*=frequency; *Md*=median; *IQR*=interquartile range; y=years; mo.=months; mRS=modified Ranking Scale; FIM®=Functional Independence Measure®; WHODAS=12-item World Health Organization Disability Assessment Schedule 2.0; ICH= intracranial haemorrhage; SAH=subarachnoid haemorrhage, * past 12 months

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Table 2. Change in self- and proxy-WHODAS sum score, component scores, and item scores between discharge and follow-up using Wilcoxon Signed Ranks Test.

	Self-WHODAS				Proxy-WHODAS			
	Md (IQR)	min	max	*p*	Md (IQR)	min	max	*p*
Sum score change	-5 (9)	-21	29	0.004*	-6 (14)	-33	15	<0.00001**
Component scores change								
Activities	-2 (7)	-13	18	0.026*	-2 (7)	-18	9	<0.001**
Participation	-2 (6)	-13	11	0.003**	-4 (7)	-16	7	<0.00001**
Item score change								
1 Standing	0 (1)	-4	4	0.084	0 (1)	-4	4	0.003**
2 Household tasks	0 (2)	-4	3	0.002**	-1 (2)	-4	3	<0.00001**
3 Learning	0 (2)	-4	4	0.820	0 (1)	-3	2	0.007**
4 Community life	0 (1)	-4	3	0.035*	-1 (2)	-4	2	<0.001**
5 Emotions	0 (2)	-4	3	0.580	0 (1)	-3	3	0.075
6 Concentration	0 (1)	-4	4	0.102	0 (1)	-4	4	0.028*
7 Walking	0 (2)	-4	3	0.004**	0 (2)	-4	4	<0.001**
8 Washing oneself	0 (1)	-4	4	0.697	0 (1)	-4	3	0.038*
9 Dressing oneself	0 (1)	-2	3	0.797	0 (1)	-3	2	0.045*
10 Dealing with strangers	0 (0)	-2	4	0.393	0 (1)	-2	2	0.395
11 Maintaining friendships	0 (1)	-3	2	0.248	0 (2)	-4	3	0.242
12 Working / studying	-1 (2)	-4	3	<0.00001**	-2 (3)	-4	1	<0.00001**

Md=median; IQR=interquartile range; *p*=p-value for Wilcoxon Signed Ranks Test; **=significant at 0.01 level; *=significant at 0.05 level.

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Table 3. Self-WHODAS sum score change in SSs with more difficulties, no change, and less difficulties at follow-up according to self-WHODAS sum, and associating factors.

Self-WHODAS sum score change		All	More difficulties	No change	Less difficulties
	n (%)	65 (100)	15 (23)	4 (6)	46 (71)
Self-WHODAS sum score					
Total change	*Md(IQR) (min, max)*	-5.0 (9) (-21, 29)	10.0 (7) (1, 29)	0.0 (0) (0, 0)	-7.0 (9) (-21, -1)
Change in activities*		-2.0 (7) (-13, 18)	5.0 (4) (0, 18)	0.0 (2) (-2, 0)	-3.0 (6) (-13, 2)
Change in participation#		-2.0 (6) (-13, 11)	4.0 (4) (-4, 11)	0.0 (2) (0, 2)	-4.0 (5) (-13, 1)
Stroke severity at 24 hours					
Mild	*n* (%)	16 (25)	1 (7)	1 (25)	14 (30)
Moderate		30 (46)	5 (33)	2 (50)	23 (50)
Severe		19 (29)	9 (60)	1 (25)	9 (20)
Age at stroke onset					
< 65 years (younger)		34 (52)	3 (20)	3 (75)	28 (61)
≥ 65 years (older)		31 (48)	12 (80)	1 (25)	18 (39)
Informal questionnaire					
Comorbidities (n=62)		23 (37)	8 (57)	2 (50)	13 (30)
Yes		39 (63)	6 (43)	2 (50)	31 (70)
No					
Recurrent stroke (n=63)					
Yes		3 (5)	0 (0)	0 (0)	3 (7)
No		60 (95)	15 (100)	4 (100)	41 (93)
Self-reported functional recovery (n=63)					
More difficulties		9 (14)	6 (40)	0 (0)	3 (7)
No change		4 (6)	3 (20)	0 (0)	1 (2)
Less difficulties		50 (79)	6 (40)	4 (100)	40 (91)
Change in participation after stroke (n=64)					
Restricted		38 (59)	15 (100)	1 (25)	22 (49)
No change		12 (19)	0 (0)	2 (50)	10 (22)
Improved		14 (22)	0 (0)	1 (25)	13 (29)
Mobility outdoors (n=64)					
Walking without devices		38 (59)	3 (20)	4 (100)	31 (69)
Walking with assistance		12 (19)	5 (33)	0 (0)	7 (16)
Wheelchair user		14 (22)	7 (47)	0 (0)	7 (16)
Falls past 12 months (n=61)					
Yes		26 (43)	11 (79)	1 (25)	14 (33)
No		35 (57)	3 (21)	3 (75)	29 (67)
Upper extremity function (n=64)					
Unilateral		28 (44)	13 (87)	1 (25)	14 (32)
Bilateral		36 (56)	2 (13)	3 (75)	31 (68)
Present access to rehabilitation (n=64)					
Yes		25 (39)	8 (53)	0 (0)	17 (38)
No		39 (61)	7 (47)	4 (100)	28 (62)
Unmet rehabilitation needs (n=47)					
Unsatisfied		17 (37)	6 (50)	0 (0)	12 (33)
Neither nor /neutral		7 (15)	4 (33)	0 (0)	3 (9)
Satisfied		23 (49)	2 (17)	1 (100)	20 (59)

Md=median; *IQR*=interquartile range; *= WHODAS items 1, 3, 6-9; # = WHODAS items 2, 4-5, 10-12.

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Table 4. SSs' self-reported change in functioning according to informal questionnaire (n=63) versus self- and proxy-WHODAS sum score change.

Functioning	Much worse (n=3)	Worse (n=6)	Same (n=4)	Better (n=17)	Much better (n=33)
Self-WHODAS change					
Md (IQR) (min,max)	12.0 (-) (-1,25)	2.5 (17) (-6,14)	9.0 (33) (-14,29)	-2.0 (12) (-16,19)	-6.0 (12) (-21,11)
Proxy-WHODAS change					
	13.0 (-) (11,15)	3.5 (12) (-5,10)	2.0 (17) (-14,6)	-7.0 (12) (-33,9)	-8.0 (12) (-23,5)

WHODAS=12-item World Health Organization Disability Assessment Schedule 2.0.

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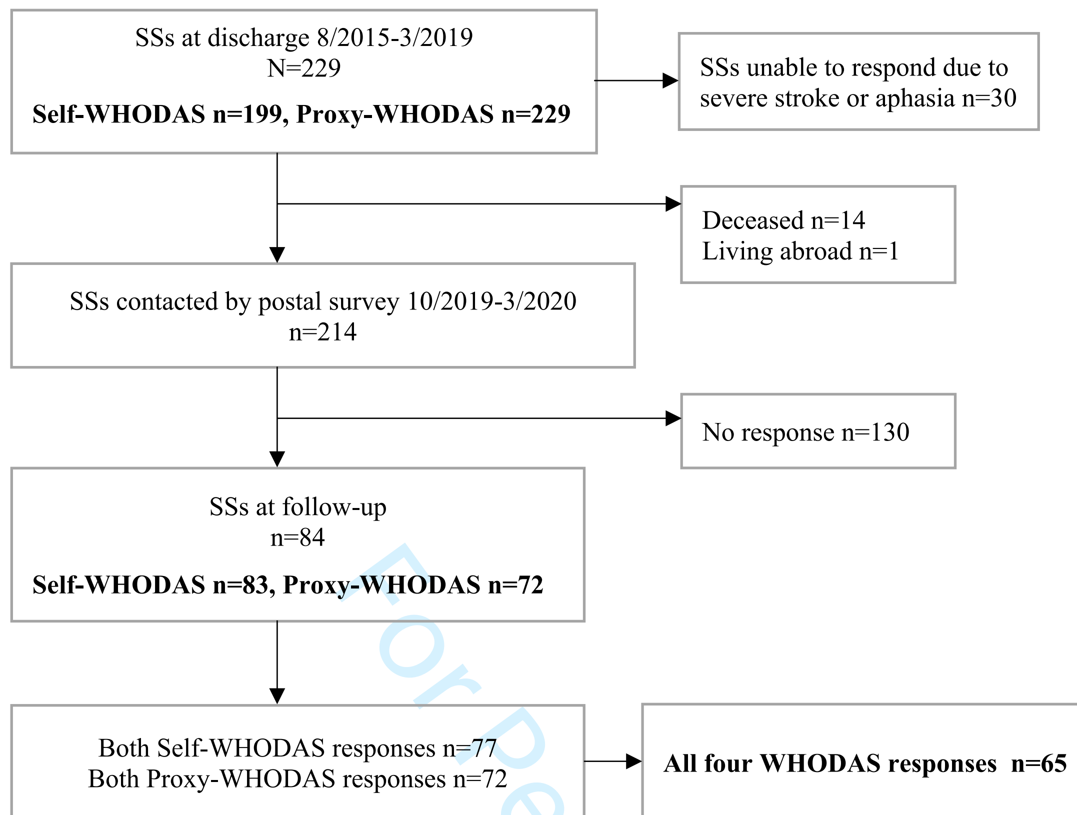

Figure 1. Flow of the participants from discharge to follow-up.

SSs=stroke survivors; WHODAS=12-item World Health Organization Disability Assessment Schedule 2.0.

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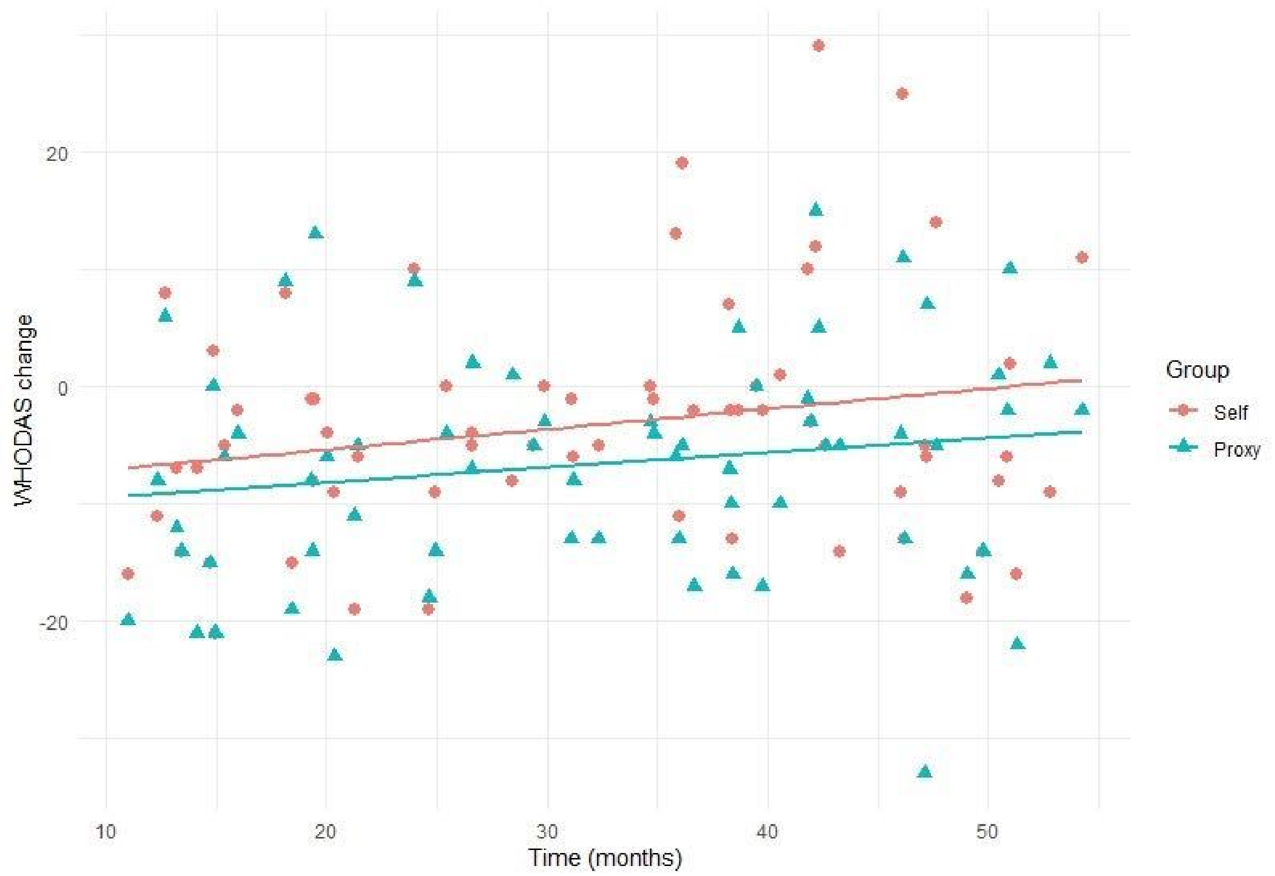

Figure 2. Self- and proxy-WHODAS sum score change by time.

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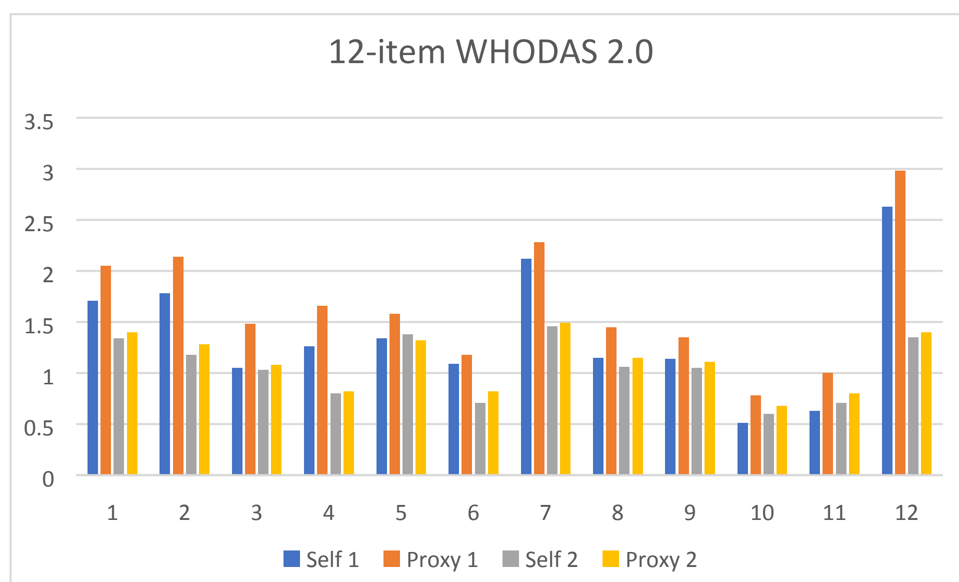

Figure 3. Comparison of self- and proxy-WHODAS item score means at discharge and 9-50 months after discharge.

WHODAS=World Health Organization Disability Assessment Schedule; self/proxy 1=WHODAS at discharge; self/proxy 2=WHODAS at follow-up; X-axis: 1=standing, 2=household tasks, 3=learning, 4=community life, 5=emotions, 6=concentration, 7=walking, 8=washing oneself, 9=getting dressed, 10=dealing with strangers, 11=maintaining friendships, and 12=working ability; Y-axis: item score value 0=no difficulty, 1=mild difficulty, 2=moderate difficulty, 3=severe difficulty, 4= extreme difficulty/cannot do.

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Table 1. Characteristics of the participants in total and according to stroke severity by NIHSS.

Characteristics	All (*n*=65)	Mild stroke (*n*=16)	Moderate stroke (*n*=30)	Severe stroke (*n*=19)
At hospital				
Md (IQR) (range)				
Age at stroke onset (y)	62.7 (16.9) (16-83)	59.2 (20.3) (32-76)	60.6 (14.4) (38-83)	68.8 (22.9) (16-83)
NIHSS at 24 hours	9.0 (10.0) (0-35)	3.5 (4.0) (0-5)	9.0 (5.0) (6-13)	18.0 (7.0) (15-35)
Days in inpatient rehabilitation	22.0 (23.5) (3-102)	11.0 (9.3) (3-32)	21.5 (21.0) (7-61)	34.0 (31.0) (13-102)
mRS at discharge from rehab	3 (2) (2-5)	2 (0) (2-3)	3 (1) (2-4)	4 (1) (2-5)
FIM® at discharge from rehab				
Total	115 (20) (45-126)	123 (6) (115-125)	115 (14) (63-126)	86 (40) (45-125)
Motor	84 (19) (25-91)	89 (3) (85-91)	83 (14) (34-91)	57 (34) (25-91)
Cognition	32 (5) (16-35)	33 (4) (25-35)	32 (4) (23-35)	28 (8) (16-35)
Age group at stroke onset				
< 65 years (younger) *n* (%)	34 (52)	10 (63)	17 (57)	7 (37)
≥ 65 years (older)	31 (48)	6 (38)	13 (43)	12 (63)
Gender				
Women	39 (60)	11 (69)	17 (57)	11 (58)
Men	26 (40)	5 (31)	13 (43)	8 (42)
Type of stroke				
Ischemic	40 (62)	9 (56)	19 (63)	12 (63)
Haemorrhage, ICH	20 (31)	2 (13)	11 (37)	7 (37)
Haemorrhage, SAH	5 (8)	5 (31)	0 (0)	0 (0)
Self-WHODAS at discharge				
Md (IQR) (range)	15.0 (14) (0-41)	12.0 (14) (1-26)	12.5 (11) (0-41)	21.0 (8) (4-32)
Proxy-WHODAS at discharge	20.0 (22) (0-48)	9.5 (10) (1-27)	16.5 (18) (0-48)	30.0 (11) (7-45)
At follow-up				
Self-WHODAS	9.0 (18) (0-40)	2.5 (8) (0-17)	6.0 (12) (0-39)	22.0 (21) (0-40)
Proxy-WHODAS	10.0 (21) (0-43)	1.5 (7) (0-14)	10.0 (17) (0-42)	21.0 (20) (0-43)
Time from discharge (mo.)	32.2 (22.2) (9-50)	32.8 (24.7) (11-49)	29.5 (25.4) (11-50)	33.0 (18.2) (9-48)
Time since stroke (mo.)	34.7 (22.7) (11-54)	34.8 (25.1) (12-51)	31.1 (24.2) (13-53)	36.7 (18.6) (11-54)
Informal questionnaire				
Comorbidities (n=62)				
Yes *n* (%)	23 (37)	5 (33)	13 (46)	5 (26)
No	39 (63)	10 (67)	15 (54)	14 (74)
Recurrent stroke (n=63)				
Yes	3 (5)	0 (0)	1 (3)	2 (11)
No	60 (95)	15 (100)	28 (97)	17 (89)
Living status (n=64)				
Single at home	18 (28)	4 (25)	9 (31)	5 (26)
With family at home	40 (63)	12 (75)	19 (66)	9 (47)
In long-term facility	6 (9)	0 (0)	1 (3)	5 (26)
Dependence in self-care (n=64)				
None (< 5%)	35 (55)	13 (81)	18 (62)	4 (21)
Minor to moderate(5-49%)	19 (30)	3 (19)	7 (24)	9 (47)
High to total (50-100%)	10 (16)	0 (0)	4 (14)	6 (32)
Upper extremity function (n=64)				
Unilateral	28 (44)	1 (6)	11 (38)	16 (84)
Bilateral	36 (56)	15 (94)	18 (62)	3 (16)
Mobility outdoors (n=64)				
Walking without devices	38 (59)	16 (100)	18 (62)	4 (21)
Walking with assistance	12 (19)	0 (0)	8 (28)	4 (21)
Wheelchair users	14 (22)	0 (0)	3 (10)	11 (58)
Number of fallers* (n=61)	26 (43)	3 (20)	13 (46)	10 (56)
Working status				
Working/studying	12 (19)	6 (38)	4 (13)	2 (11)
Unemployed	1 (2)	0 (0)	1 (3)	0 (0)
Retiree	32 (49)	9 (56)	13 (43)	10 (53)
Unable to work	20 (31)	1 (6)	12 (40)	7 (37)

NIHSS=National Institutes of Health Stroke Scale categories at 24 hours from hospitalization: mild stroke (0-5/42), moderate stroke (6-14/42), severe stroke (15-42/42); *n*=frequency; *Md*=median; *IQR*=interquartile range; y=years; mo.=months; mRS=modified Ranking Scale; FIM®=Functional Independence Measure®; WHODAS=12-item World Health Organization Disability Assessment Schedule 2.0; ICH= intracranial haemorrhage; SAH=subarachnoid haemorrhage, * past 12 months

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Table 2. Change in self- and proxy-WHODAS sum score, component scores, and item scores between discharge and follow-up using Wilcoxon Signed Ranks Test.

	Self-WHODAS				Proxy-WHODAS			
	Md (IQR)	min	max	*p*	Md (IQR)	min	max	*p*
Sum score change	-5 (9)	-21	29	0.004*	-6 (14)	-33	15	<0.00001**
Component scores change								
Activities	-2 (7)	-13	18	0.026*	-2 (7)	-18	9	<0.001**
Participation	-2 (6)	-13	11	0.003**	-4 (7)	-16	7	<0.00001**
Item score change								
1 Standing	0 (1)	-4	4	0.084	0 (1)	-4	4	0.003**
2 Household tasks	0 (2)	-4	3	0.002**	-1 (2)	-4	3	<0.00001**
3 Learning	0 (2)	-4	4	0.820	0 (1)	-3	2	0.007**
4 Community life	0 (1)	-4	3	0.035*	-1 (2)	-4	2	<0.001**
5 Emotions	0 (2)	-4	3	0.580	0 (1)	-3	3	0.075
6 Concentration	0 (1)	-4	4	0.102	0 (1)	-4	4	0.028*
7 Walking	0 (2)	-4	3	0.004**	0 (2)	-4	4	<0.001**
8 Washing oneself	0 (1)	-4	4	0.697	0 (1)	-4	3	0.038*
9 Dressing oneself	0 (1)	-2	3	0.797	0 (1)	-3	2	0.045*
10 Dealing with strangers	0 (0)	-2	4	0.393	0 (1)	-2	2	0.395
11 Maintaining friendships	0 (1)	-3	2	0.248	0 (2)	-4	3	0.242
12 Working / studying	-1 (2)	-4	3	<0.00001**	-2 (3)	-4	1	<0.00001**

Md=median; IQR=interquartile range; *p*=p-value for Wilcoxon Signed Ranks Test; **=significant at 0.01 level; *=significant at 0.05 level.

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Table 3. Self-WHODAS sum score change in SSs with more difficulties, no change, and less difficulties at follow-up according to self-WHODAS sum, and associating factors.

Self-WHODAS sum score change		All	More difficulties	No change	Less difficulties
	n (%)	65 (100)	15 (23)	4 (6)	46 (71)
Self-WHODAS sum score					
Total change	*Md(IQR) (min, max)*	-5.0 (9) (-21, 29)	10.0 (7) (1, 29)	0.0 (0) (0, 0)	-7.0 (9) (-21, -1)
Change in activities*		-2.0 (7) (-13, 18)	5.0 (4) (0, 18)	0.0 (2) (-2, 0)	-3.0 (6) (-13, 2)
Change in participation#		-2.0 (6) (-13, 11)	4.0 (4) (-4, 11)	0.0 (2) (0, 2)	-4.0 (5) (-13, 1)
Stroke severity at 24 hours					
Mild	*n* (%)	16 (25)	1 (7)	1 (25)	14 (30)
Moderate		30 (46)	5 (33)	2 (50)	23 (50)
Severe		19 (29)	9 (60)	1 (25)	9 (20)
Age at stroke onset					
< 65 years (younger)		34 (52)	3 (20)	3 (75)	28 (61)
≥ 65 years (older)		31 (48)	12 (80)	1 (25)	18 (39)
Informal questionnaire					
Comorbidities (n=62)		23 (37)	8 (57)	2 (50)	13 (30)
Yes		39 (63)	6 (43)	2 (50)	31 (70)
No					
Recurrent stroke (n=63)					
Yes		3 (5)	0 (0)	0 (0)	3 (7)
No		60 (95)	15 (100)	4 (100)	41 (93)
Self-reported functional recovery (n=63)					
More difficulties		9 (14)	6 (40)	0 (0)	3 (7)
No change		4 (6)	3 (20)	0 (0)	1 (2)
Less difficulties		50 (79)	6 (40)	4 (100)	40 (91)
Change in participation after stroke (n=64)					
Restricted		38 (59)	15 (100)	1 (25)	22 (49)
No change		12 (19)	0 (0)	2 (50)	10 (22)
Improved		14 (22)	0 (0)	1 (25)	13 (29)
Mobility outdoors (n=64)					
Walking without devices		38 (59)	3 (20)	4 (100)	31 (69)
Walking with assistance		12 (19)	5 (33)	0 (0)	7 (16)
Wheelchair user		14 (22)	7 (47)	0 (0)	7 (16)
Falls past 12 months (n=61)					
Yes		26 (43)	11 (79)	1 (25)	14 (33)
No		35 (57)	3 (21)	3 (75)	29 (67)
Upper extremity function (n=64)					
Unilateral		28 (44)	13 (87)	1 (25)	14 (32)
Bilateral		36 (56)	2 (13)	3 (75)	31 (68)
Present access to rehabilitation (n=64)					
Yes		25 (39)	8 (53)	0 (0)	17 (38)
No		39 (61)	7 (47)	4 (100)	28 (62)
Unmet rehabilitation needs (n=47)					
Unsatisfied		17 (37)	6 (50)	0 (0)	12 (33)
Neither nor /neutral		7 (15)	4 (33)	0 (0)	3 (9)
Satisfied		23 (49)	2 (17)	1 (100)	20 (59)

Md=median; *IQR*=interquartile range; *= WHODAS items 1, 3, 6-9; #= WHODAS items 2, 4-5, 10-12.

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Table 4. SSs' self-reported change in functioning according to informal questionnaire (n=63) versus self- and proxy-WHODAS sum score change.

Functioning Md (IQR) (min,max)	Much worse (n=3)	Worse (n=6)	Same (n=4)	Better (n=17)	Much better (n=33)
Self-WHODAS change	12.0 (-) (-1,25)	2.5 (17) (-6,14)	9.0 (33) (-14,29)	-2.0 (12) (-16,19)	-6.0 (12) (-21,11)
Proxy-WHODAS change	13.0 (-) (11,15)	3.5 (12) (-5,10)	2.0 (17) (-14,6)	-7.0 (12) (-33,9)	-8.0 (12) (-23,5)

WHODAS=12-item World Health Organization Disability Assessment Schedule 2.0.

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