

ORIGINAL REPORT

CHANGES IN PERCEIVED IMPACT OF STROKE ON EVERYDAY LIFE OVER FIVE YEARS IN A REHABILITATION SAMPLE THAT RECEIVED AN ACTIVITY OF DAILY LIVING INTERVENTION: A FOLLOW-UP STUDY

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Objective: To compare changes in the perceived impact of stroke on everyday life over time in a rehabilitation sample that received a client-centred activities of daily living (CADL) intervention or usual ADL (UADL) intervention.

Design: Longitudinal follow-up of a randomized controlled trial.

Methods: A total of 145 persons with stroke were assigned into CADL or UADL. Groups were assessed using the Stroke Impact Scale (SIS) at 3 months, 12 months and 5 years post-intervention. Changes in SIS domain scores over time were compared within and between groups.

Results: Changes in the impact of stroke over time were not related to which intervention the groups received. There were no significant differences in the SIS domains or stroke recovery between groups at the 3-month, 12-month and 5-year follow-ups. Despite an increased impact of stroke over time in some domains in both groups, both groups perceived a decreased impact of stroke in the Participation domain at 12 months. Perceived participation was sustained at the same level at 12 months as at 5 years in both groups.

Conclusion: These findings stress the importance of access to follow-up rehabilitation interventions 1-year post-stroke to enable participation in daily activities. Such follow-up and enablement would support the use of self-management strategies in the performance of persons' valued activities, which might be difficult to perform, due to, for example, impact on hand function or mobility. The results of this study emphasize the importance of prioritizing participation in activities that are meaningful from a personal perspective.

Key words: stroke; participation; everyday life; daily activities; rehabilitation; occupational therapy; follow-up studies; longitudinal studies.

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LAY ABSTRACT

In this study, perceived impact of stroke on everyday life over time was compared among 145 persons with stroke who received the client-centred or usual activities of daily living intervention. They were followed up at 3, 12 months and 5-years post-stroke. No differences were found in the impact of stroke over time between groups. Despite increased impact of stroke (indicating more problems) over time in some areas, the groups perceived decreased impact of stroke (less problems) in their participation at 12 months. Perceived participation was sustained at the same level at 12 months as at 5 years in both groups. Findings stress the importance of access to follow-up rehabilitation interventions one-year post-stroke to enable participation in daily activities, and to support the use of self-management strategies to facilitate participation in valued and meaningful activities that might be difficult due to person's functional limitations.

Stroke is one of the common leading causes of disability worldwide (1), and impacts individuals' functioning and participation in everyday life (2–5). The long-term consequences of stroke might also affect individuals' life satisfaction (5–7). Previous research shows that a large number of individuals (> 50%) in a hospital-based sample 1-year post-stroke still experienced restrictions in participation in daily activities (8). Rehabilitation interventions are mostly recommended in the first 3 months post-stroke, due to the importance of this time-period in plasticity-enhancing mechanisms and significant stroke recovery (9). Previous studies, however, suggest that, in 1 year or longer post-stroke, strength and hand function (10–12), activities of daily living (ADL), health-related quality of life (10, 13) and participation (12, 13) are still severely impacted. Moreover, the needs for rehabilitation 1 year post-stroke are not always considered to be met (14), particularly among persons who have had a moderate-to-severe stroke (8, 15). This indicates an essential need for developing effective rehabilitation interventions targeting participation in everyday life and exploring individuals' needs over time. Moreover, sustaining participation

is of great importance and priority. A few studies in various contexts have focused on the perceived impact of stroke at different time-points (12, 16–20) assessed using the Stroke Impact Scale (SIS 3.0). This scale includes 8 domains: Strength; Memory and thinking; Emotions; Communication; Mobility; Activities of daily living (ADL) and Instrumental ADL (IADL); Hand function; and Participation (21). Strength, Hand function, and Participation were the domains in SIS 3.0 that were most affected at 3 months post-stroke (12, 22). Furthermore, the ADL and IADL domains, and the Mobility domain, were also impacted at 3 months post-stroke (22). The Strength and Hand function domains (10–12, 19) and the Participation domain (12, 13, 19) were found to be the most affected at 1 year post-stroke (12, 19). Previous long-term follow-ups post-stroke mostly explored the impact of stroke up to 2 years (10, 23, 24). A follow-up study 6 years post-stroke (19) identified the most impacted SIS domains as: Participation, Strength, Hand function, and Stroke recovery. Those with moderate-to-severe stroke experienced a higher impact in all domains, except Hand function and Stroke recovery, indicating more problems in everyday life, compared with those with mild stroke. A recent follow-up study (20) showed that the perceived consequences of stroke were more severe after 5 years compared with at 1 year. Strength, Emotion and Participation were the areas most affected, along with restrictions in social life and autonomy indoors. The perceived impact of stroke could therefore become more prominent with time, even for persons with mild-to-moderate stroke, highlighting the need for long-term support for persons with stroke. The level of dependency at discharge from hospital was found to be of importance in self-perceived impacts 5 years post-stroke in another follow-up study (25). For those who were functionally independent, non-modifiable factors, e.g. age, sex and type of stroke, were significant predictors of a better outcome. However, for the functionally dependent persons, modifiable factors, such as feeling depressed, cardiovascular risk factors, and recurrent stroke, were significant predictors of unfavourable outcome (25). Previous research has made a great effort in describing the consequences of stroke over time. However, there is still limited knowledge regarding how individuals who have received rehabilitation interventions perceive the long-term impacts of stroke on everyday life. Rehabilitation interventions are mostly focused on the first 3 months post-stroke. To be able to plan and deliver appropriate long-term rehabilitation interventions and follow-ups that are individually adapted (26),

perceived changes over time post-stroke need to be explored among persons with stroke who are in need of rehabilitation. Changes after rehabilitation need to be compared among groups that have received different intervention programmes.

A client-centred ADL intervention (CADL) was developed (27) to be applied among persons with stroke (16) and further compared with usual ADL interventions (UADL) in phase 2 of the Life After Stroke study (LAS II) (16). The interventions were evaluated in a randomized controlled trial (RCT) and changes between groups were compared at 3, 6, 12 months, and 5 years after inclusion (16–18). No differences were found in the participation outcome between the 2 groups at the 3-month follow-up (16), 6-month and 1-year follow-ups (17) and 5-year follow-up (18). However, in the 3-month follow-up a significant difference was found in the SIS domain of Emotion in favour of the CADL intervention (16). The 1-year follow-up, including the whole sample who received CADL and UADL, showed no statistically significant differences between the groups regarding perceived Participation (17). Nevertheless, a positive trend was observed regarding a clinically meaningful positive change in the CADL group on perceived Participation measured by SIS (domain 8).

The 5-year follow-up study showed that perceived Participation (SIS domain 8) improved over time for all participants, regardless of whether they received the CADL or UADL intervention (18). The completed RCT study, comparing 2 groups that received different rehabilitation interventions, provided the opportunity to study the perceived impact of stroke over time. However, in an ageing group of people, many incidents in everyday life can occur in such a long period as 5 years. As such, one should be aware that the type of rehabilitation received might have limited influence regarding the perceived impact of stroke.

Longitudinal studies that focus on the consequences of stroke are crucial to understand the impact of stroke on people's everyday life and how the impact of stroke might change over time. This knowledge is scarce. In our previous study the impact on the domain Participation was reported at 5 years post-stroke (17). Understanding the impact people perceive on their everyday functioning, beyond participation, over the 5 years since stroke onset, is essential to further develop rehabilitation interventions that meet individual needs. The overall aim of this study was therefore to compare changes in the perceived impact of stroke on everyday life over time in a rehabilitation sample who have received either the CADL or UADL intervention.

METHODS

Design and participants

The study was designed as a longitudinal 5-year follow-up of a RCT. The methodology, inclusion criteria, recruitment procedure, and results of the original trial (16, 17, 28) and the 5-year follow-up study (18) are described fully in earlier publications. Briefly, in the original trial (16), 16 rehabilitation units in 3 Swedish county councils were included and randomized to provide the CADL intervention and UADL intervention as intervention and control groups, respectively. Persons with stroke admitted to these units between 6 October 2009 and 7 September 2011 were recruited as participants. In the 5-year follow-up study, the recruitment occurred between 2014 and 2016. All the participants from the original trial who were alive, verified by the Swedish population registry, were contacted first by telephone, and then by letter if there was no response from the person. Information about the study was provided and, in case the person was interested in participation, a date was booked for data collection in participant's home, and informed consent was given. In this follow-up study 145 persons with stroke were recruited and gave their informed consent.

The mean duration of rehabilitation was 40 days (range 7–120 days) for these persons who had been admitted to the participating units for 1 year. Baseline characteristics of the participants in the 2 groups (CADL or UADL) are shown separately in Table I.

The original trial (ClinicalTrials.gov NCT01417585) and the 5-year follow-up received ethics approval from the Regional Ethical Review Board in Stockholm with the reference numbers 2009/727-31/1 and 2014/996-32.

Data collection

Persons with stroke who met the inclusion criteria and agreed to take part in the RCT after giving their informed consent were assessed over time, i.e. at 3 months, 12 months and 5 years, by the same data collectors, who were blinded to the group allocation. More details about the data collection procedure are provided in previous publications (16–18). In this study the data collected from the following outcome measures are used:

- the Stroke Impact Scale 3.0 (SIS) (21, 29) was used to assess the perceived impact of stroke on 8 various domains of Strength, Memory and thinking, Emotions, Communication, Mobility, ADL/IADL, Hand function, and Participation. The SIS comprises 59 items with scores ranging from 0 to 100, where a higher score reflects a smaller impact. Furthermore, the SIS includes 1 item, Stroke recovery, which was assessed with a visual

analogue scale, ranging from 0 (no recovery) to 100 (full recovery). For those participants who were not able to respond to the questions, a proxy version (30) was used.

- the Mini-Mental State Examination (MMSE) (31) was used to assess cognitive function, ranging from 0 to 30 scores.
- the Barthel Index (BI) (32) was used to assess independence in ADL. The BI scores, ranging from 0 to 100, were also used to determine stroke severity (33) and assign the participants into 3 groups of mild stroke (50–100), moderate stroke (15–49), and severe stroke (less than 14).

Data analysis

Descriptive statistics were used to present the characteristics of the participants at baseline.

Baseline variables were compared between the 2 groups (CADL and UADL) using independent *t*-test for continuous variables and χ^2 for categorical variables. Linear mixed models of analysis of variance (ANOVA) were used to examine differences in the change in impact of stroke, as verified by SIS recovery and SIS domain scores 1–8. After inclusion in the RCT, this

Table I. Baseline characteristics of the participants in client-centred activities of daily living (CADL) intervention or usual ADL (UADL) intervention groups (*n* = 145)

Characteristics	CADL	UADL
<i>n</i>	71	74
Age, years		
Mean (SD)	71 (9)	68 (9)
Sex, <i>n</i> (%)		
Male	41 (58)	48 (65)
Female	30 (42)	26 (35)
Education, <i>n</i> (%)		
Elementary school	32 (45)	30 (41)
High school	17 (24)	23 (31)
University	22 (31)	21 (28)
Living status, <i>n</i> (%)		
Living alone	44 (62)	49 (66)
Living with someone	27 (38)	25 (34)
Type of stroke, <i>n</i> (%)		
Infarct	52 (73)	53 (72)
Haemorrhagic	11 (15)	12 (16)
Unspecified	8 (11)	9 (12)
Hemisphere lesion, <i>n</i> (%)		
Left	33 (46)	32 (43)
Right	36 (51)	39 (53)
Unspecified	2 (3)	3 (4)
Stroke severity, <i>n</i> (%)		
Mild (BI = 50–100)	55 (78)	70 (95)
Moderate (BI = 15–49)	15 (21)	4 (5)
Severe (BI < 15)	1 (1)	0 (0)
Independence in ADL (Barthel Index = 0–100)		
Mean (SD)	66 (23)	78 (18)
Cognitive function (MMSE = 0–30)		
Mean (SD)	25.4 (5.8)*	26.5 (4.4)*
Stroke Impact: recovery (SIS = 0–100)		
Mean (SD)	33 (22)	41 (23)

CADL: client-centred activities of daily living; UADL: usual activities of daily living; BI: Barthel index; MMSE: Mini-Mental State Examination; SIS: Stroke Impact Scale.

*Missing data = 2.

change in impact was measured within and between each group of CADL and UADL over different time-points of 3 months, 12 months and 5 years. Pair-wise comparisons were adjusted for multiple comparisons using Bonferroni correction to further explore the changes between different time-points. Moreover, the measures of SIS recovery and SIS domains 1–8 were compared for each time-point between the CADL and UADL groups using analysis of covariance (ANCOVA). Covariates included in the statistical analyses were age, sex, stroke severity (BI score), independence in ADL (BI score) and stroke recovery (SIS score) at baseline.

A *p*-value < 0.05 was set as statistically significant. The analyses were conducted using the SPSS program version 27.0 (Statistical Package for the Social Sciences, Armonk, NY: IBM Corp).

RESULTS

Baseline data for participants in the 5-year follow-up are shown in Table I. The results of Pearson’s χ^2 analysis to compare categorical variables at baseline did not demonstrate any significant differences between frequency of sex (*p* = 0.4; χ^2 = 0.78), education (*p* = 0.93; χ^2 = 0.64) and living status (*p* = 0.61; χ^2 = 0.28) in the 2 groups. The only exception in this comparison was stroke severity (*p* = 0.004; χ^2 = 9.11), which showed that the number of persons with mild stroke was higher in the UADL group than in the CADL group. The results of the independent *t*-tests to compare the mean values of continuous variables in 2 groups

at baseline did not show any significant differences for age (*p* = 0.08) and cognitive function verified by MMSE score (*p* = 0.2). However, there were significant differences in the mean BI total score (*p* = 0.001) and SIS recovery (*p* = 0.04) scores between the 2 groups at baseline. These results showed a higher mean value for independence in ADL and stroke recovery in the UADL group compared with the CADL group (see Table I).

The findings of the ANOVA mixed models comparing change in the impact of stroke as verified by SIS domains 1–8 and recovery scores between 3 months, 12 months, and 5 years post-stroke within each group of CADL and UADL are shown in Tables II–III.

In the pairwise comparisons of the mean values between different time-points in the CADL group, statistically significant changes were found in the domains of: (i) Communication between 3 months and 5 years, and 12 months and 5 years post-stroke with an increased impact of stroke; (ii) Mobility between 12 months and 5 years post-stroke with an increased impact of stroke; (iii) Hand function between 12 months and 5 years with an increased impact of stroke, and, finally; (iv) Participation between 3 and 12 months, and 3 months to 5 years post-stroke with a decreased impact of stroke in both time-periods (see Table II).

In the pairwise comparisons of the mean values between different time-points in the UADL group, statistically significant changes were found in domains of: (i) Emotion between 3 months and 5 years post-stroke with a decreased impact of stroke; (ii) Mobility between 12 months and 5 years with an increased impact of stroke; (iii) Hand function between 3 and 12 months post-stroke

Table II. Comparing changes in the impact of stroke between different time-points post-stroke in the client-centred activities of daily living (CADL) group using linear mixed models of analysis of variance (ANOVA) (*n* = 71)

SIS domains Mean (SD)	3 months (T1)	12 months (T2)	5 years (T3)	Changes within CADL group <i>p</i> -value	F (df, error df)	Pairwise comparisons of mean values between different time-points (<i>p</i> -value)		
	CADL	CADL	CADL			T1-T2 (3–12 months)	T1-T3 (3 months – 5 years)	T2-T3 (12 months – 5 years)
SIS 1 Strength	60.2 (21.6)	57.8 (22.8)	57.9 (24.0)	0.520	F (2, 130) = 0.658	0.864	1.000	1.000
SIS 2 Memory/thinking	85.3 (16.6)	84.6 (15.6)	80.5 (20.6)	0.022	F (2, 132) = 3.948	1.000	0.113	0.068
SIS 3 Emotion	74.6 (15.3)	73.1 (14.2)	74.2 (17.2)	0.611	F (2, 130) = 0.494	0.857	1.000	1.000
SIS 4 Communication	84.9 (20.8)	86.0 (15.2)	80.2 (20.9)	0.005	F (2, 130) = 5.513	1.000	0.035 (II)	0.009 (II)
SIS 5 ADL/IADL	73.4 (18.4)	75.8 (17.1)	72.9 (22.9)	0.298	F (2, 130) = 1.222	0.307	1.000	0.455
SIS 6 Mobility	76.5 (21.9)	77.1 (20.2)	69.8 (25.8)	0.002	F (2, 130) = 6.323	1.000	0.058	0.003 (II)
SIS 7 Hand function	49.5 (33.9)	52.5 (33.7)	45.3 (36.5)	0.027	F (2, 128) = 3.719	0.715	0.359	0.033 (II)
SIS 8 Participation	56.8 (20.9)	66.5 (20.5)	68.5 (20.8)	< 0.001	F (2, 130) = 11.522	< 0.001 (DI)	< 0.001 (DI)	1.000
SIS Recovery	53.8 (21.7)	57.7 (22.9)	57.7 (24.9)	0.241	F (2, 128) = 1.438	0.359	0.515	1.000

T: time post-stroke; DI: decreased impact of stroke; II: increased impact of stroke.

Higher scores present/reflect smaller impact of stroke.

Bold numbers present significant differences as verified by *p*-value less than 0.05.

Table III. Comparing changes in the impact of stroke between different time-points post-stroke in the usual activities of daily living (UADL) group using linear mixed models of analysis of variance (ANOVA) ($n = 74$)

SIS items Mean (SD)	3 months	12 months	5 years	Changes within UADL group	F (df, error df)	Pairwise comparisons of mean values between different time-points (p value)		
	(T1)	(T2)	(T3)			T1-T2	T1-T3	T2-T3
	UADL	UADL	UADL	p-value		(3-12 months)	(3 months - 5 years)	(12 months - 5 years)
SIS 1 Strength	62.4 (24.4)	64.5 (24.8)	67.5 (26.8)	0.056	F (2, 136) = 2.952	0.865	0.093	0.437
SIS 2 Memory/thinking	84.6 (16.2)	86.1 (15.7)	83.6 (15.9)	0.269	F (2, 136) = 1.326	1.000	1.000	0.144
SIS 3 Emotion	73.6 (14.5)	76.3 (13.9)	78.7 (16.3)	0.009	F (2, 136) = 4.910	0.204	0.021 (DI)	0.400
SIS 4 Communication	88.1 (14.9)	88.4 (11.9)	85.8 (17.4)	0.127	F (2, 136) = 2.083	1.000	0.467	0.177
SIS 5 ADL/IADL	78.9 (19.6)	82.3 (17.8)	79.9 (22.8)	0.072	F (2, 134) = 2.683	0.09	1.000	0.487
SIS 6 Mobility	82.2 (19.9)	82.9 (17.6)	78.3 (21.9)	0.012	F (2, 134) = 4.567	1.000	0.102	0.014 (II)
SIS 7 Hand function	62.8 (36.5)	67.8 (34.0)	64.2 (35.1)	0.044	F (2, 132) = 3.208	0.037 (DI)	1.000	0.202
SIS 8 Participation	64.7 (21.4)	71.6 (20.5)	75.5 (21.0)	< 0.001	F (2, 140) = 9.839	0.007 (DI)	0.001 (DI)	0.318
SIS Recovery	59.9 (23.2)	68.3 (22.0)	64.5 (27.2)	0.005	F (2, 138) = 5.484	0.001 (DI)	0.351	0.383

T: time post-stroke; DI: decreased impact of stroke; II: increased impact of stroke.

Higher scores present/reflect smaller impact of stroke.

Bold numbers present significant differences as verified by p -value less than 0.05.

with a decreased impact of stroke; (iv) Participation between 3 and 12 months, and 3 months and 5 years post-stroke with a decreased impact of stroke in both time-periods, and, finally; (v) Recovery between 3 and 12 months post-stroke with a decreased impact of stroke (see Table III).

Table IV presents a comparison of the changes in the impact of stroke regarding measures of SIS domains 1–8 and stroke recovery between the 2 groups of CADL and UADL over the 5 years post-stroke using the analysis of covariance (ANCOVA). The results show that these changes were not related

to which intervention participants received in the CADL or UADL groups.

DISCUSSION

This longitudinal study aimed to compare changes in the perceived impact of stroke in a rehabilitation sample that received CADL and UADL intervention between 3 different time-points of 3 months, 12 months, and 5 years post-intervention. This study made it possible to explore the perceived impact of stroke on people in different time-points over a period of 5 years, which was

Table IV. Comparing changes in the impact of stroke between 2 groups of client-centred activities of daily living (CADL) intervention or usual ADL (UADL) over time post-stroke using analysis of covariance (ANCOVA) ($n = 145$)

SIS domains Mean (SD)	3 months			12 months			5 years		
	CADL	UADL	p-value	CADL	UADL	p-value	CADL	UADL	p-value
SIS 1 Strength	60.2 (21.6)	62.4 (24.4)	0.930	57.8 (22.8)	64.5 (24.8)	0.903	57.9 (24.0)	67.5 (26.8)	0.578
SIS 2 Memory/thinking	85.3 (16.6)	84.6 (16.2)	0.580	84.6 (15.6)	86.1 (15.7)	0.894	80.5 (20.6)	83.6 (15.9)	0.744
SIS 3 Emotion	74.6 (15.3)	73.6 (14.5)	0.213	73.1 (14.2)	76.3 (13.9)	0.738	74.2 (17.2)	78.7 (16.3)	0.869
SIS 4 Communication	84.9 (20.8)	88.1 (14.9)	0.606	86.0 (15.2)	88.4 (11.9)	0.683	80.2 (20.9)	85.8 (17.4)	0.460
SIS 5 ADL/IADL	73.4 (18.4)	78.9 (19.6)	0.157	75.8 (17.1)	82.3 (17.8)	0.600	72.9 (22.9)	79.9 (22.8)	0.318
SIS 6 Mobility	76.5 (21.9)	82.2 (19.9)	0.151	77.1 (20.2)	82.9 (17.6)	0.772	69.8 (25.8)	78.3 (21.9)	0.355
SIS 7 Hand function	49.5 (33.9)	62.8 (36.5)	0.445	52.5 (33.7)	67.8 (34.0)	0.683	45.3 (36.5)	64.2 (35.1)	0.858
SIS 8 Participation	56.8 (20.9)	64.7 (21.4)	0.379	66.5 (20.5)	71.6 (20.5)	0.959	68.5 (20.8)	75.5 (21.0)	0.503
SIS recovery	53.8 (21.7)	59.9 (23.2)	0.437	57.7 (22.9)	68.3 (22.0)	0.548	57.7 (24.9)	64.5 (27.2)	0.699

SIS: Stroke Impact Scale; CADL: client-centred activities of daily living; UADL: usual activities of daily living.

a unique possibility and, to our knowledge, not studied previously. However, when we conducted the study, we were aware that many things could happen that might affect the lives of people at older ages over the years. On this basis, we reasoned that the type of rehabilitation intervention received earlier might not have the most significant effect on everyday life at long-term follow-up. The study results aligned with this reasoning showing that changes in the impact of stroke (SIS) for participants at 3-month, 12-month and 5-year follow-ups were not related to which intervention they received, as no significant differences were found between the CADL and UADL groups in the SIS domains. These results are in line with previous follow-ups carried out at 3 (16) and 12 months (17).

The CADL group demonstrated a significant decreased impact of stroke in the domain of Participation between follow-ups at 3 months and 12 months, and 3 months to 5 years. This indicates that they perceived that their participation in everyday life was enhanced. Most clinically meaningful changes, both negative and positive, were found in the Participation domain in a previous study (12), indicating that this domain is sensitive at follow-ups. However, there was no difference in Participation between 12 months and 5 years, indicating that perceived participation was enhanced in the first year and maintained 4 years later. Interestingly, despite less impact on Participation, the CADL group had a significantly increased impact of stroke (more problems) on Communication, Mobility, and Hand function at the 12-month and 5-year follow-ups, which might be considered to be reflected in the participation score sustained at the decreased 12-month level. This is in line with the results of a recent study that found no significant differences between the perceived impact of stroke on participation between 1 and 6 years post-stroke, even if the impact of stroke significantly increased in Strength, ADL/IADL, Mobility and Hand function domains between these 2 time-points (19). Another previous study showed that an increased impact of stroke was found in Strength, Emotion, Communication, Mobility and even Participation domains after 5 years. The UADL group had similar perceptions of their Participation, even if a significant increased impact of stroke was found on their Mobility between follow-ups at 12 months and 5 years. Previous research (20), however, showed that the perceived impact of stroke was more severe after 5 years compared with at the first years. Strength, Emotion and even Participation were the areas most affected. One possible reason for the finding in the current study might be that the participants in both groups had found a way to deal with the consequences implied by stroke through management strategies they developed over time. Despite slightly lower body function after a stroke, they

could solve problems in their doings to improve their participation in everyday life. It might also be that the participants had adapted to a declined activity repertoire at an older age. Even if the stroke had affected their ability to participate in their usual activities, it can be assumed that they could participate in activities that, to them, were both meaningful and helped provide purpose in life (6). In line with that, perhaps better perceived participation resulted from participants stopping activities that did not work for them and, rather, continuing activities that were meaningful to them. These findings emphasize that the perceived impact of stroke could become more prominent over time. However, Emotion, Participation and Stroke recovery could be enabled even if other domains show restrictions and deterioration. Future research should therefore focus on identifying how to better enable participation in meaningful activities considering individuals' personal strategies and perspectives.

It is notable that the participants estimated the impact of their stroke at approximately the same level after 5 years as at the 3-month follow-up in most of the SIS domains. Thus, the participants are approximately "in the same place" regarding their perceived impact of stroke at 5 years as at shortly after their stroke, but, despite this, they perceived that their participation had enhanced. These findings are clinically important in stroke rehabilitation and stress the importance of prioritizing the enablement of participation in everyday life, rather than focusing mostly on body functions and impairments. From an occupational perspective, these findings are also important. Prioritizing participation in activities that are meaningful from a personal perspective is the basis for providing a client-centred rehabilitation (34). Another clinical implication of the findings is that it is important to consider and evaluate the need for rehabilitation over time among persons with stroke and their need to have longer contact and the opportunity to be offered a new rehabilitation period to receive the support they need.

A decreased impact of stroke over time (indicating fewer problems) in the domains of Emotions, Hand function, and Stroke recovery was found in the UADL group. These results were not found in the CADL group (see Tables II and III). One possible reason for these differences between the 2 groups could relate to the lower severity of stroke, higher independence in ADL, and higher perceived Stroke recovery at baseline in the UADL group. Given that no group differences were detected in previous follow-ups (16–18), a possible explanation is that the interventions in the experimental and control groups might have been too similar. As discussed previously (18), it is plausible that the UADL intervention might have comprised client-centred components due to occupational therapists' long history and experiences of applying a client-centred approach

in clinical practice (35). Previous qualitative research exploring occupational therapists' experiences in the context of providing a client-centred ADL intervention identifies important elements/characteristics, such as responsibility and ownership of the rehabilitation process among persons with stroke (36). These characteristics could also be found in usual occupational therapy interventions, making it difficult to differentiate between the effects of the interventions provided to the CADL and UADL groups in this study.

Study limitations

It is important to reflect on the generalizability of the results of this study to the population of people who have had stroke worldwide. In this study 78% of the CADL group and 95% of the UADL group in the sample had had a mild stroke. Moreover, there was only 1 person with a severe stroke in the CADL group and no subjects with a severe stroke in the UADL group. The significantly higher number of persons with a mild stroke in the UADL group than the CADL group might have affected the results. Furthermore, since the majority of the total sample ($n = 125$) were diagnosed with a mild stroke, the generalizability of the results to a broader group of people with stroke, and especially to those with severe stroke with serious problems in ADL, might be limited. Future studies are therefore needed to explore the changes in impact of stroke in this group. Another reflection on the generalizability of the results might be that this study set out to compare changes in the perceived impact of stroke over time in a rehabilitation sample who have received either the CADL or UADL intervention, and thus may provide limited knowledge that can be generalized to a wider stroke population. Another limitation in the study is the lack of power, since the drop-out analysis showed that more vulnerable persons with stroke who were in a poorer position had dropped out of the study. This situation, however, was evenly distributed across the 2 groups.

Addressing the impact of stroke over 5 years is challenging. One might assume that, in an ageing group of people, many incidents in everyday life can occur in such a long period as 5 years, and that the type of rehabilitation received might have limited influence regarding the perceived impact of stroke. It is therefore reasonable to consider the normal ageing process as a factor. This may be reflected in several domains of the SIS, such as mobility, memory and thinking, and hand function, where an impact of ageing rather than stroke alone can be expected.

In conclusion, despite the increased impact of stroke in some domains in the 2 groups over time, the participants in both groups perceived decreased impact of stroke on

the domain of Participation at 12 months. In both groups the perceived participation was sustained at the same level at 12 months as at 5 years. This result is clinically important, as there seems to be a need to prioritize the enablement of participation in daily activities in the long-term, after 12 months post-stroke among persons with stroke, rather than focusing mostly on body functions and impairments. There might be a need for access to follow-up rehabilitation interventions, even years post-stroke, to support the use of self-management strategies in the performance of persons' valued activities in everyday life. The results of this study emphasize the importance of prioritizing participation in activities that are meaningful from a personal perspective, in order to provide client-centred rehabilitation over a longer period of time.

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