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ORIGINAL REPORT

PERCEIVED IMPACT OF STROKE SIX YEARS AFTER ONSET, AND CHANGES IN IMPACT BETWEEN ONE AND SIX YEARS

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Objective: **To examine the perceived impact of stroke between 1 and 6 years after stroke using the Stroke Impact Scale 3.0 (SIS).**

Design: **A prospective longitudinal study.**

Methods: **A total of 100 individuals were assessed using the SIS 3.0 at 1 and 6 years after onset of stroke and clinically meaningful changes were explored. Changes in domain scores were calculated over time in relation to age, sex and stroke severity.**

Results: **The most impacted SIS domains after 6 years were Participation, Strength, Hand function, and Stroke recovery. Participants with moderate/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. Almost half of the participants had a clinically meaningful change in the domain Participation between 1 and 6 years. Those with moderate/severe stroke and the older age group experienced more negative clinically meaningful changes in several domains in comparison with those with mild stroke and the younger age group.**

Conclusion: **The long-term perceived impact of stroke highlights the importance of appropriate rehabilitation interventions within several areas to reduce the long-term negative impact in everyday life.**

Key words: stroke; Stroke Impact Scale; longitudinal study; rehabilitation.

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A stroke is a serious event with a number of consequences after onset. Even though progress has been made regarding diagnostics, treatment, care and rehabilitation, a stroke still has a major negative impact on a person's everyday life (1). Stroke is the cause of the highest number of days at Swedish hospitals and the costs for society are great (2).

Most rehabilitation interventions focus on the first 3 months after stroke. However studies show that a stroke still negatively impacts health-related quality of life, activities of daily living (ADL) (3), hand function, strength (4–6), and participation (3, 6) 1 year or more after stroke. Furthermore, the need for rehabilitation is not always perceived to be fulfilled 12 months after stroke (7), in particular among people with moderate or severe stroke (8, 9). Granted that there are a number of long-term follow-ups after stroke, there are limited numbers of published studies reporting on participation and quality of life (10, 11). Most long-term studies regarding post-stroke do not continue after a 2-year time-point (4, 12, 13). Although 6 years after stroke is not a noteworthy time-point, a recently published qualitative study has shown the in-depth impact of stroke, 10 years after the event (14). Therefore, studies taking into account different variables of importance to the individual and from a more "lifetime" perspective post-stroke are greatly needed.

The perceived impact of stroke can be measured with the Stroke Impact Scale (SIS) (15), which focuses on physical, emotional and everyday life aspects. A Swedish study exploring changes in SIS scores between 3 and 12 months after stroke showed that participants rated their perception of recovery better at 12 months compared with 3 months post-stroke (6). The study also showed lower perceived impact, indicating fewer problems, in strength and emotional life at 12 months compared with 3 months post-stroke. The greatest clinically meaningful changes (i.e. a change of ≥15 points (16)), both positive and negative, between 3 and 12 months were seen in the areas of perceived participation and recovery after stroke (6).

Swedish legislation has recognized the need for persons' involvement in decision-making in their own care (17). This is an aspect of person-centred care and focuses on the health-seeker's personal resources, needs and values. Person-centred care distances itself from the idea that the patient is passive, but instead strives towards the patients' agreement and planning of healthcare and rehabilitation (18). Patients who are active participants in their care are more likely to improve in their self-care, their sense of security, their knowledge of their own health and to perceive an increase in satisfaction with their care (19). Hence, to provide person-centred rehabilitation, it is important to determine persons' perceptions of difficulties in activities and situations in everyday life and what they want to prioritize in their rehabilitation (20).

Knowledge of an individual's perceived impact of stroke over time is important when developing rehabi-

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litation interventions to meet the individual's specific needs, expectations and values and could contribute to the optimal allocation of healthcare resources. However, research has tended to focus on evaluating the impact of stroke at a single point in time rather than examining how people with stroke perceive the long-term impact and longitudinal perspectives. Thus, the overall aim of this study was to examine the perceived impact of stroke between 1 and 6 years after stroke.

METHODS

The data used in this study was collected within the study "Life After Stroke phase 1" (LAS-1) (21) a study of the rehabilitation process 1 year after stroke including a 6-year follow up. All patients with a stroke diagnosis who were admitted to the stroke units at Karolinska University Hospital during the period 15 May 2006 to 15 May 2007, were asked to participate in the study. Of the 349 persons included at stroke onset in LAS-1, 121 people agreed to participate in the 6-year follow-up. The participants were informed both orally and in writing and were included after informed consent. The study was approved by the regional ethics committee in Stockholm, Sweden.

Data collection

Data were collected with valid and reliable instruments in the participants' home, nursing home or in the location that the person had their rehabilitation, by trained occupational therapist or physiotherapists who were not involved in the participant's rehabilitation. Medical data relating to diagnosis were extracted from the medical records at study inclusion. Baseline data regarding sociodemographic information, such as level of education, living alone or cohabiting, were collected through interviews. Post-stroke, participants received services and rehabilitation according to usual practice, e.g. inpatient or outpatient rehabilitation, rehabilitation in primary healthcare, home rehabilitation or no rehabilitation interventions.

Instruments

At baseline, the Barthel Index (BI) was used to assess severity of stroke, categorized as severe stroke: scores ≤ 14, moderate stroke: 15–49, or mild stroke: ≥ 50 (22). Cognitive function was assessed with the Mini-Mental State Examination (MMSE) (23). Speech production was categorized according to the Scandinavian Stroke Scale: "no aphasia", "limited vocabulary", "more than yes/no", or "only yes/no or less" (24).

Signs of depression were assessed 6 years post-stroke with the depression subscale of the Hospital Anxiety and Depression Scale (25). A cut-off of 4, which has been recommended for persons who have had a stroke (26), was used.

At 1 and 6 years after stroke, the SIS 3.0 was used to assess the perceived impact of stroke. The instrument is a self-report measure developed from the perspective and input of both patient, caregiver and health professional with stroke expertise (15). The SIS comprises 59 different items representing 8 domains; Strength, Memory and thinking, Emotions, Communication, ADL/IADL (instrumental activities of daily living), Mobility, Hand function, and Participation. The person with stroke scores the items in all domains on a scale from 1 to 5. Aggregated scores are generated using an algorithm (=[mean –1/5–1] × 100) (4), and the lesser the score (0–100) the greater the impact, i.e. more perceived problems in everyday life. Thus, the concept of impact refers to a negative influence on the person's everyday life after stroke. The SIS also includes one question to assess the person's perception of his or her global recovery after stroke, rated with a visual analogue scale ranging from 0 (no recovery) to 100 (full recovery) (15). The SIS has been extensively tested for validity and proven to have high internal consistency in all 8 domains (16). Concurrent (16) and construct validity (27) have also been established. A ceiling effect has been found for persons with mild stroke in the domains Strength, (15, 16) Emotion, Communication and Memory (15). Another limitation of the SIS is its ability to detect minimal change in the physical domains; a person has to reach 24.0 on Strength, 17.3 on ADL/IADL, 15.1 on Mobility, and 25.9 on Hand function to indicate a true improvement (28). The SIS proxy version was selected if participants' communication or cognitive impairments ruled out self-report (29).

Statistical analysis

If a participant responded to less than 50% of the items within a SIS domain, the domain score was considered as "missing" (16). Since the number of participants having moderate or severe stroke were few, these 2 groups were merged in the analyses.

Descriptive statistics were used to describe the participants and their responses on the SIS at 1 and 6 years. The data concerning the SIS did not have a normal distribution; thus non-parametric statistics were used. For longitudinal analyses of the whole sample, the Wilcoxon matched-pairs test was used to explore changes in domain scores between 1 and 6 years. The Mann–Whitney U test was used in cross-sectional analyses to examine differences in SIS scores at the 6-year follow-up with regard to stroke severity, sex and age.

Descriptive statistics were used to describe the participants' clinically meaningful changes between 1 and 6 years. In line with previous recommendations (6, 16) the participants were sorted into 3 groups according to changes in their SIS domain scores between 1 and 6 years: clinically meaningful positive change (+15 points or more); clinically meaningful negative change (–15 and less); and no change (–14 to +14). Differences between these groups were analysed in relation to stroke severity, sex and age, using the χ^2 test when the number of frequencies allowed, and the Fisher's exact test when the number of expected frequencies was lower than 5. The significance level was set at $p = 0.05$, with no adjustment for multiple comparisons. Software used for the analyses was Statistica 13.2.

RESULTS

The characteristics of the 100 persons with stroke included in the present study are described in Table I. Of the 349 persons included in LAS-1 at onset, 121 participated in the 6-year follow-up (166 had died, 44 declined and 18 could not be reached). Of the 121 participants, 21 had missing or incomplete SIS-data; thus 100 persons were included in the present study. For 10 persons (9 women, 1 man) the impact of stroke was reported with the SIS proxy version by a significant other (4 partners, 1 sister, 2 daughters, 2 sons) and one by the patient and the staff together. The mean age at

Table I. Baseline characteristics

Variables	*n* = 100
Male/female, *n* (%)	59 (57)/41 (43)
Age, years, mean (SD)	62 (14)
Civil status, *n* (%)	
Married/cohabitating	64 (64)
Living alone	36 (36)
Education, *n* (%)	
Compulsory school, 7– 16 years old	31 (34)
Upper secondary school, 16–19 years old	27 (29)
University	34 (37)
Employment, *n* (%)	
Yes	46 (46)
No	53 (54)
Previous stroke/TIA, *n* (%)	23 (24)/5 (5)
Type of stroke, *n* (%)	
Haemorrhagic	14 (14)
Ischaemic	86 (86)
Stroke severity	
Mild	83 (83)
Moderate	11 (11)
Severe	6 (6)
Speech, *n* (%)	
No aphasia	73 (74)
Limited vocabulary	15 (15)
More than "yes/no", but no longer sentences	5 (5)
Only "yes/no" or less	5 (5)
Country of origin	
Foreign born	16 (16)
Born in Sweden	83 (84)
Cognition, *n* (%)	
MMSE < 24	10 (12)
MMSE ≥ 24	72 (88)

SD: standard deviation; MMSE: Mini-Mental State Examination; TIA: transient ischaemic attack.

stroke onset was 62 years and 57% were men (Table I). At 6 years, 38% had signs of depression.

Table II shows that the domains Strength, Hand function, Participation and Stroke recovery showed the highest perceived impact (i.e. the lowest scores) at both 1 and 6 years. Communication had the lowest impact (i.e. the highest scores) at both time-points. Significant changes in scores between 1 and 6 years with higher reported impact at 6 years were seen in 4 domains; Strength, ADL/IADL, Mobility, and Hand function.

At 6 years after stroke there were significant differences in SIS scores between persons with mild compared with moderate/severe stroke in most domains; those with moderate/severe stroke reported higher impact than those with mild stroke (Table III). However, regarding perceived Hand function and Stroke recovery no significant differences were seen between those with mild compared with moderate/severe stroke. Persons ≥ 65 years reported higher impact in Memory and thinking than those < 65 years. No differences were found with regard to sex (Table III).

Table II. Perceived impact of stroke at 1 and 6 years, and *p*-values for changes in Stroke Impact Scale (SIS) domain scores

SIS domain	1 year Mean (SD, range)	6 years Mean (SD, range)	Changes between 1 and 6 years, *p*-value
Strength	77 (23, 13–100)	72 (26, 0–100)	0.007
Memory & thinking	85 (17, 29–100)	84 (20, 18–100)	0.771
Emotions	80 (17, 14–100)	77 (21, 6–100)	0.285
Communication	87 (18, 25–100)	84 (23, 10–100)	0.088
ADL/IADL	87 (18, 28–100)	80 (27, 0–100)	< 0.001
Mobility	87 (18, 19–100)	80 (25, 0–100)	< 0.001
Hand function	78 (30, 0–100)	73 (34, 0–100)	0.008
Participation	77 (24, 6–100)	75 (23, 0–100)	0.199
Stroke recovery	74 (19, 21–100)	70 (26, 0–100)	0.114

ADL: activities of daily living; IADL: instrumental activities of daily living; SD: standard deviation.

Statistically significant changes in SIS scores between 1 and 6 years were found within subgroups of stroke severity, sex and age. Participants with mild stroke reported significantly higher impact at 6 years than at 1 year in the domains Strength ($p = 0.032$), ADL/IADL ($p < 0.001$), Mobility ($p = 0.002$) and Hand function ($p = 0.022$). Participants with moderate/severe stroke reported significantly higher impact of stroke at 6 years than at 1 year in Communication ($p = 0.019$), ADL/IADL ($p = 0.013$), Mobility ($p = 0.017$), and Stroke recovery ($p = 0.048$). Furthermore, men reported a higher impact at 6 years in Strength ($p = 0.034$), ADL/IADL ($p < 0.001$), Mobility ($p < 0.001$), Hand function ($p = 0.008$), and Participation ($p = 0.040$) compared with at 1 year. Women reported a higher impact at 6 years in the domains ADL/IADL ($p = 0.004$) and Mobility ($p = 0.047$). In the younger age group a significantly lower impact at 6 years compared with 1 year was reported regarding Memory and thinking ($p = 0.010$), while a significantly higher impact was

Table III. Stroke Impact Scale (SIS) domain scores at 6 years after stroke onset with regard to stroke severity, age and sex and *p*-values for differences within the groups

		Stroke severity			Sex			Age		
SIS domains	*n*	Mild Mean (SD)	Moderate/Severe Mean (SD)	*p*-value	Male Mean (SD)	Female Mean (SD)	*p*-value	< 65 years Mean (SD)	≥ 65 years Mean (SD)	*p*-value
Strength	100	78 (22)	43 (24)	< 0.001	75 (26)	69 (26)	0.155	79 (23)	65 (27)	0.273
Memory & thinking	100	89 (15)	62 (27)	< 0.001	81 (24)	88 (14)	0.555	90 (14)	78 (24)	0.045
Emotions	99	80 (19)	64 (24)	0.010	76 (22)	77 (19)	0.539	81 (20)	73 (21)	0.807
Communications	100	89 (15)	57 (34)	0.015	84 (23)	84 (22)	0.486	90 (15)	78 (27)	0.213
ADL/IADL	100	86 (20)	51 (37)	0.002	81 (28)	78 (26)	0.646	85 (24)	75 (29)	0.579
Mobility	99	84 (20)	59 (33)	< 0.001	82 (24)	77 (25)	0.742	86 (21)	74 (27)	0.147
Hand function	99	78 (30)	45 (41)	0.085	74 (35)	70 (34)	0.649	76 (32)	69 (36)	0.790
Participation	100	80 (19)	49 (25)	< 0.001	77 (24)	71 (22)	0.114	78 (21)	71 (26)	0.533
Stroke recovery	98	74 (23)	50 (30)	0.399	71 (25)	70 (25)	0.558	73 (25)	69 (27)	0.253

ADL: activities of daily living; IADL: instrumental activities of daily living; SD: standard deviation.

Table IV. Changes in the Stroke Impact Scale (SIS) domains between 1 and 6 years and distribution of participants in the 3 groups: positive, negative and no clinically meaningful changes

SIS domains	*n*	Range	Positive change *n* (%)	Negative change *n* (%)	No change *n* (%)
Strength	100	−50 to +50	13 (13)	27 (27)	60 (60)
Memory & thinking	100	−64 to +54	11 (11)	13 (13)	76 (76)
Emotions	97	−65 to +33	11 (11)	14 (14)	72 (74)
Communication	100	−81 to +29	7 (7)	14 (14)	79 (79)
ADL/IADL	100	−60 to +25	2 (2)	22 (22)	76 (76)
Mobility	99	−85 to +28	6 (6)	25 (25)	68 (69)
Hand function	98	−90 to +40	9 (9)	23 (23)	66 (67)
Participation	100	−78 to +81	18 (18)	28 (28)	54 (54)
Stroke recovery	98	−65 to +60	15 (15)	21 (21)	62 (63)

ADL: activities of daily living; IADL: instrumental activities of daily living.

reported for ADL/IADL ($p=0.012$). In the older age group a higher perceived impact was reported in all domains at 6 years compared with 1 year (Strength, $p=0.005$, Memory and thinking, $p=0.004$, Emotions, $p=0.006$, Communication, $p=0.035$, ADL/IADL, $p<0.001$, Mobility, $p<0.001$, Hand function, 0.051, Participation, 0.027), but regarding Stroke recovery no significant change was found.

The highest proportion of positive clinically meaningful changes between 1 and 6 years post-stroke was found in the domain Participation (18%), as seen in Table IV. On the other hand, 28% of the participants had a negative clinically meaningful change in this domain. The second largest negative clinically meaningful change was seen in the domain Strength (27%).

No statistically significant differences were found when comparing groups of positive or negative clinically meaningful changes with those with no clinically meaningful changes regarding sex (Table V). The group of people with moderate/severe stroke had significantly higher proportions of negative clinically meaningful changes than those with mild stroke in the domains Memory and thinking, Communication, ADL/IADL and Participation. In addition, the older age group had significantly higher proportions of negative clinically meaningful changes than the younger group in the domains Emotions, Communication, Mobility, and Participation (Table V).

Table V. Number of people in groups with regard to stroke severity, sex, age and *p*-values for differences between the groups with positive and negative clinically meaningful change, compared with the group with no change

	Positive change, *n*	*p*-value	Negative change, *n*	*p*-value	No change
Stroke severity, Mild/Moderate-severe					
Strength	11/2	1.000	22/5	0.832	50/10
Memory & thinking	10/1	1.000	6/7	<0.001	67/9
Emotions	9/2	1.000	11/3	0.437	62/10
Communication	7/0	1.000	7/7	<0.001	69/10
ADL/IADL	1/1	0.219	14/8	0.003	68/8
Mobility	5/1	0.554	18/7	0.059	60/8
Hand function	8/1	1.000	19/4	1.000	55/11
Participation	14/4	0.101	19/9	0.008	50/4
Stroke recovery	14/1	0.681	16/5	0.429	52/10
Sex, male/female					
Strength	6/7	0.251	15/12	0.492	38/22
Memory & thinking	5/6	0.437	10/3	0.234	44/32
Emotions	4/7	0.196	10/4	0.552	43/29
Communication	6/1	0.231	10/4	0.380	43/36
ADL/IADL	2/0	0.510	13/9	0.920	44/32
Mobility	2/4	0.397	17/8	0.352	39/29
Hand function	3/6	0.285	16/7	0.312	38/28
Participation	8/10	0.168	17/11	0.842	34/20
Stroke recovery	10/5	0.471	13/8	0.662	35/27
Age, <65/≥65 years					
Strength	7/6	0.767	9/18	0.031	35/25
Memory & thinking	8/3	0.332	3/10	0.071	40/36
Emotions	8/3	0.335	3/11	0.039	39/33
Communication	4/3	1.000	3/11	0.022	44/35
ADL/IADL	1/1	1.000	8/14	0.118	42/34
Mobility	3/3	0.681	7/18	0.006	41/27
Hand function	3/6	0.298	12/11	0.844	30/60
Participation	11/7	0.783	9/19	0.030	31/23
Stroke recovery	8/7	0.827	8/13	0.146	35/27

ADL: activities of daily living; IADL: instrumental activities of daily living.

DISCUSSION

This is the first study to describe the perceived impact of stroke 6 years post-stroke, according to the SIS, and the change in impact between 1 and 6 years after onset. The most impacted domains after 6 years were Participation, Strength and Hand function as well as Stroke recovery. In general, the participants with moderate and severe stroke experienced a higher impact (more problems) in all domains compared with those with mild stroke, with the exception of Hand function and Stroke recovery. Almost half of the participants had either a positive (18%) or negative (28%) clinically meaningful change in the domain Participation between 1 and 6 years. Those with moderate/severe stroke as well as the older age group experienced more negative clinically meaningful changes in several domains in comparison with those with mild stroke and the younger age group.

Perceived impact of stroke

The domains that showed the highest impact after 6 years were Strength, Hand function and Participation, as well as Stroke recovery. This is consistent with results at 3 and 12 months from studies based on the same participants (6, 30) and with other studies that used the SIS in follow-ups at 3, 9 and 12 months after stroke (5, 31–33). Those with moderate/severe stroke reported a higher impact than those with mild stroke in all domains, but with the exception of Hand function and Stroke recovery. This implies that even persons with a mild stroke experience a negative impact on everyday life even up to 6 years post-stroke. One explanation might be a difference in the adaptation process between persons with mild and moderate/

severe stroke, i.e. those with mild stroke may have greater expectations on recovery compared with those with moderate/severe stroke.

The same participants, in a previous study, reported a higher level of recovery at 12 months than at 3 months (6) and a higher level of recovery at 3 and 6 months, compared with scores at 1 month after stroke onset. Similar results were also shown by Duncan et al. (16). This trend does not continue in the present study and no change in Stroke recovery was reported between 1 and 6 years post-onset. This result indicates a need for long-term rehabilitation and follow-up, since people perceive that they do not continue to recover in the long-term. A recent study demonstrated an association between low-rated recovery and experience of unmet rehabilitation needs (9). The perceptions of recovery in persons after stroke has been shown to reflect being able to resume the same activities as before stroke onset (34).

There was a higher perceived impact (more problems) at 6 years compared with 1 year in the whole group and in all subgroups in the domain ADL/IADL. ADL has previously been shown to be a domain where many experience problems 1 year after stroke (35). The Swedish national guidelines for stroke show that ADL training in the home has a strong level of evidence to increase the ability to perform daily activities (36). ADLs have also been shown to have a major impact on life satisfaction, based on experiences of what a person wants to do and actually does (35) and predicts perceived levels of participation after stroke (30). Based on this knowledge, it is important to consider the findings in this study. If healthcare workers, homecare staff and personal assistants focus on improving or maintaining ADL ability even in a long-term perspective, we should be able to diminish the perceived impact of stroke on everyday functioning. Long-term, person-centred rehabilitation interventions may enhance participation in daily activities of the person's choice, as well as satisfaction with life.

Clinically meaningful changes

As the SIS has proven to identify important factors in people's perceptions of the impact of stroke (6, 21), the SIS can be used in designing more person-centred care and rehabilitation. For several of the domains, changes in the present study were seen between time-points for the group as a whole and in respect to stroke severity, sex and age, although low in absolute numbers. Over 40% of the participants had either a positive or negative clinically meaningful change in Participation between 1 and 6 years after stroke onset. In an earlier study, those with a negative clinically meaningful change in Participation between 3 and 12 months after onset were older and had more severe strokes than the group without a clinically meaningful change (6). The present study shows that the negative change in Participation in these subgroups is also present between 1 and 6 years. The high proportions of clinically meaningful change in the domain Participation has previously been linked to the domain's sensitivity to change in the impact of stroke over time (6). Bringing aspects of participation in the planning of rehabilitation interventions should therefore be a central part of the long-term perspective, and also an important part of providing more person-centred rehabilitation. Since the results show both positive and negative changes in Participation, future research should concentrate on determining which persons are most vulnerable and run the risk of participation restrictions in the long-term.

It is interesting that the positive clinically meaningful change found in the domain Hand function in this study has not been seen before. This may indicate that there are further opportunities for improvement, even in the long-term. Degree of impact on Hand function has previously been shown to be important for perceived recovery after stroke after 12 months for people aged 65 years or younger (32). The results of this study may suggest that this could also apply to the older group in the long-term perspective. Another explanation could be that younger people have more intensive training after stroke and receive more rehabilitation at day rehabilitation clinics after discharge from inpatient care (32). This may mean that these people achieve better results in the first months of rehabilitation compared with the older group. Another explanation could be that older people need more time to achieve better hand function regardless of the amount of rehabilitation offered. This finding is also important, since impact in the domain Hand function has been shown to be associated with unfulfilled needs for rehabilitation 12 months post-stroke (9).

Study limitations

There are some concerns regarding the study sample that might limit the generalizability of the study results to the population of all individuals with stroke. The mean age at onset of stroke was 63 for men and 64 for women in those participating in this 6-year follow-up compared to a mean age of 70 for those participating in the 1-year follow-up (7). One reason for this difference in age is that the older individuals in the sample had deceased to a higher extent. The low mean age at stroke onset in the study sample is lower than the mean age at onset in the Swedish population, which is 76 years (37). The low number of participants with severe

stroke prevented separate statistical analyses of this group; thus our results may not be valid for individuals with severe stroke. Furthermore, the analysis did not include adjustment for multiple comparisons, which should be considered when interpreting the results. At 6 years, 38% of subjects had signs of depression. This is consistent with previous studies showing that post-stroke depression occurs in approximately one-third of individuals (38). The presence of depression in slightly more than one-third of the participants, although representative numbers in the general stroke population, might have a negative impact on the perception of stroke recovery. The SIS is sensitive to change over time; however, to the best of our knowledge there are no studies that have used the SIS over a 6-year time span. As having stroke increases the risk of having a new stroke the participants in the study might also have had new strokes and other heart or vascular disorders over the 6 years, which might also have impacted their ratings on the SIS. However, the study's design is a strength; the 6-year follow-up after stroke onset and the examination of the perceived impact of stroke over this time period. Furthermore, data collection was conducted via structured face-to-face interviews performed by specially trained research assistants, which made it possible for persons with difficulties reading and writing to participate in the study.

Conclusion

This study shows a diversity of results regarding the different domains in the SIS in both long-term as well as longitudinal perspectives. These results lend support to 2 main theses within rehabilitation science. The first shows the importance of measuring the perceived impact of stroke, including perceived recovery in the long-term, in all individuals with stroke, regardless of stroke severity, age or sex. Secondly, this study shows the need for rehabilitation interventions to reduce long-term negative impacts of stroke in everyday life and provide knowledge regarding appropriate rehabilitation interventions over time.

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