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Title

Activity among long-term stroke survivors. A study based on an ICF-oriented analysis of two established ADL and social activity instruments

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Abstract

Purpose: To describe activity in different aspects of daily life among long-term stroke survivors, and conceptualize the content of the Barthel Index (BI) and the Swedish extended and modified Frenchay Activities Index (mFAI) using the ICF framework.

Method: Assessments were performed by means of the BI and the mFAI at a ten-year follow-up of 145 consecutive stroke survivors from Lund Stroke Register, Sweden. After linking the two instruments to the ICF core set for stroke, data were analyzed and presented in terms of activity-specific domain-scores for the total sample and sub-groups according to gender and age.

Results: Together the two instruments covered 69 % of the Activities and participation component of the ICF core set for stroke. Two activity-specific domains were identified within the BI and six within the mFAI. Most participants reported a high overall activity level. Inactivity was most common among those ≥80 years. Men and women participated in different types of activities and used different modes of transport.

Conclusions: Long-term stroke survivors have a high activity level in daily life, though individual variation is considerable. The structure provided by linking instruments to the ICF core set for stroke can be used for more fine-tuned descriptions of activity.

Introduction

In Sweden, each year approximately 30,000 people experience a stroke (1). Even though the majority survives the acute phase, many survivors face different types of physical or cognitive impairments (2). Stroke is a primary cause of adult disability that often leads to dependence on relatives and caregivers to manage daily life, as well as restrictions in activity and participation (3). Not only the individual and his/her family are affected but there are also societal consequences in terms of long-term costs for healthcare and social support (4). Additionally, in the coming years a growing number of people ageing with the effects of stroke can be expected as a result of declining mortality rates and a higher incidence of stroke among younger people (5).

Remaining physically and socially active throughout the life span is a protective factor for physical and mental health as well as for survival (6-8). Thus activity limitations may pose a serious threat to the health of people ageing with stroke. Although several studies have been conducted in the early rehabilitation setting, research is scarce concerning the long-term life situation for those ageing with stroke, especially regarding different types of activities. Consequently, there is lack of knowledge on how rehabilitation should be provided to meet the needs of long-term stroke survivors.

The research much needed to reduce this knowledge-gap is challenging to undertake. Not the least because of inconsistent definitions of activity as well as variations between assessment instruments regarding what types of activities they cover (9, 10). Considering that the benefits of activity on health and survival may differ in relation to the type of activity (11) and in relation to

gender and age (8, 12), it is important that results are presented with sufficient detail. Moreover, instruments used to assess activity post stroke are commonly presented in terms of total scores even though this may not be adequate for multidimensional scales (13). Two examples of such assessment instruments are the Barthel Index (BI) (14) and the Frenchay Activities Index (FAI) (15). There have been previous attempts to group the items of the FAI using factor analysis, though no consensus exists regarding the number or composition of its domains (16). The BI has on the other hand been regarded as a one-dimensional scale (17) even though the variety of its items suggests that it targets not only different activities but also body functions.

Hence, to enable comparisons and interpretation of research findings it is essential that the content of evaluation instruments is clearly defined and that a common language is used. For this purpose, linking instruments to the International Classification of Functioning, Disability and Health (ICF) has proved useful (18). The ICF (19) is the state-of-the art conceptual framework used to describe the consequences of different diseases and injuries and comprises four components; Body functions and structures, Activities and participation, Environmental factors, and Personal factors. Activity is defined as "the execution of a task or action by and individual" (19). A stroke-specific core set of the ICF has been developed (20) and is recommended for use in assessments after stroke to ensure that important aspects are addressed (21). However, many of the instruments commonly used in stroke trials and clinical assessments have not yet been linked to the ICF core set for stroke.

Therefore the aim of this study was twofold. The first aim was to describe to what extent ten-year stroke survivors execute different types of activities, with special respect to gender- and age-related differences, based on data gathered with the BI and a Swedish extended and modified

version of the FAI (based on Wendel et al. (22), see also Appendix 1). To create a conceptually sound base for this description, the second aim was to clarify what specific aspects of activity the two instruments cover by linking them to the Activities and participation component of the ICF core set for stroke, and to group the items of the instruments into activity-specific domains in accordance with the ICF.

Methods

Participants and procedure

The present study was based on activity assessments performed during a comprehensive ten-year follow-up of 145 persons with stroke included in the Lund Stroke Register. The Lund Stroke Register is a population-based stroke register that covers the catchment area of Skåne University Hospital in Lund, Sweden, including eight municipalities with a total of approximately 235,000 inhabitants (as of December 31, 2001). The 145 participants were the survivors from an original sample of 416 persons with first-ever stroke consecutively included during a one-year period starting March, 1, 2001. The ten-year follow-up was approved by the Regional Ethical Review Board in Lund, no. 2011/278. Apart from 17 participants who did not give their consent or dropped out early in the study period, all survivors participated at the ten-year follow-up (for participant characteristics see table 1.) Methods for the detection and registration of participants with first-ever stroke during the study period, as well as participant characteristics at baseline and previous follow-ups, have been described in previous publications (23, 24).

TABLE 1 IN HERE

The participants were followed-up ten years after stroke onset by the same researcher (AJ) who had also performed the previous assessments. The majority of the ten-year follow-ups were performed at a hospital outpatient clinic (n=106) or clinical ward (n=9), and the rest in special housing (n=12) or by phone (n=18). If participants had difficulties in replying to the questions because of cognitive or communicative problems they were assisted by a relative or caregiver (n=27). The ten-year follow-up included project-specific questions as well as well-established assessment instruments (24). The participants' activity levels ten years after stroke were assessed by means of the BI (14) and a Swedish extended and modified FAI (based on Wendel et al. (22), see also Appendix 1).

Instruments

The BI is one of the most commonly used instruments in stroke trials and clinical practice (18, 25). It was designed for assessment of dependence level in activities of daily living (ADL), and has good reliability and validity for stroke populations (25, 26). For the present study the original 10-item version (14), with a maximum score of 100, was used. These items included feeding, bathing, grooming, dressing, bowel control, bladder control, toilet use, transfers bed to chair, mobility on level surface and stair climbing. The amount of support needed by the individual in each activity was rated on ordinal scales, with the highest score indicating independence.

The FAI has been recommended as a complement to the BI to capture a wider range of activities (27, 28). It is a 15-item questionnaire used to gather self-reported information about performance of activities within and outside the home including hobbies and social activities (15). The reliability, validity and sensitivity of the FAI have been established for stroke populations (29,

30). However, this instrument has been criticized for not recognizing some common activities of older people (31). Therefore, a Swedish extended and modified version was developed that includes an additional item related to telephone use and an extension of the mobility items. For the present study the 16 items of that extended version, which have been tested with acceptable reliability (22), were used. All items were rated on ordinal scales ranging from 0-3 (max score 48). A minor change to the response options of items 12 and 13 improved conformity by allowing all item scores to be based on frequency of performance. This modified FAI used in the present study, hereinafter referred to as mFAI, is illustrated in Appendix 1. Using the principle established for the original FAI, total score cut-off levels were used to differentiate between participants who were inactive (total score = 0-16), moderately active (total score = 17-32) or highly active (total score = 33-48) (32).

ICF linking and item grouping of the BI and the mFAI

Linking to the ICF core set for stroke

To establish to what extent the BI and the mFAI cover the Activities and participation component of the ICF core set for stroke, both instruments were linked to the core set following the methodology described in the most recent ICF linking rules (33). The ICF core set for stroke is a subset of the ICF intended to reflect stroke-relevant aspects of functioning and disability (20). It has been validated for stroke survivors of various ages and in different phases after stroke (34, 35). The Activities and participation component consists of 51 second-level categories that represent different types of activities organized within nine chapters: Learning and applying knowledge; General tasks and demands; Communication; Mobility; Self-care; Domestic life; Interpersonal interactions and relationships; Major life areas; Community, social and civic life.

All content of the BI and the mFAI, including questions and response options, was linked to one or several of the 51 ICF categories depending on their meaning. The linking was validated in three steps. First two of the authors (AN, AJ) independently linked the content of the two instruments, followed by discussion. Any disagreements that remained were settled with the aid of a third researcher experienced with instrument development and knowledgeable with the ICF (SI).

Grouping items into activity-specific domains

To create a conceptually well-defined base for the presentation of activity-data gathered by means of the BI and the mFAI, the items of the two instruments were grouped into activity-specific domains. The grouping of items was done in accordance with the nine chapters of the Activities and participation component of the ICF core set for stroke. Items related to more than one of the chapters were classified according to their principal meaning. Items that did not concern Activity and participation were excluded. The terms *activity-specific domains* or *domains* refer to these groups of items created within the two instruments. The domains that emerged within the BI and the mFAI were named using the terminology of the corresponding ICF chapters. Since both instruments contained items related to the ICF chapter Mobility, to avoid confusion, these domains were given unique names (BI: Basic mobility, mFAI: Outdoor mobility). Finally, domain scores were calculated by summing the scores for the items included in each domain. Validation of the grouping of items was done in the same manner as for the linking.

Statistical analysis

The data collected with the BI and mFAI were presented in terms of total scores and activity-specific domain scores. In addition non-parametric statistical analysis of sub-group differences according to gender and age were performed. For analysis of median scores the Mann-Whitney U test was used to study differences between men and women and the Kruskal-Wallis test to study differences between age groups. To determine where such differences occurred, post-hoc analyses using the Mann-Whitney U test with Bonferroni correction for multiple comparisons were applied. The IBM SPSS Statistics 21 program was used for the data analyses. Unless otherwise stated, p-values <0.05 were considered statistically significant.

Results

ICF core set coverage and activity-specific domains of the BI and the mFAI

The content of the BI was linked to 14 unique categories within the Activities and participation component of the ICF core set for stroke (27 % coverage), all representing the ICF chapters Mobility or Self-care. The content of the mFAI was linked to 26 unique categories (51 % coverage) representing the ICF chapters Learning and applying knowledge; General tasks and demands; Communication; Mobility; Domestic life; Major life areas; or Community, social and civic life. There was an overlap between the BI and the mFAI consisting of four categories related to Mobility. Accordingly, the two instruments together covered 69 % of all categories of the Activities and participation component of the core set. Notably, together the BI and the mFAI covered all categories of the ICF core set-chapters Mobility; Domestic life; and Community, social and civic life. On the contrary, no links were made to the chapter Interpersonal interactions and relationships (table 2).

TABLE 2 IN HERE

The items of the BI were grouped into two activity-specific domains; Basic mobility (3 items) and Self-care (5 items). Two items, "Bowel control" and "Bladder control", were excluded since they were related to the ICF component Body functions rather than to Activities and participation (resulting in a maximum total score of 80 for the remaining eight items). The items of the mFAI were grouped into six activity-specific domains; Learning and applying knowledge (1 item); Communication (1 item); Outdoor mobility (8 items); Domestic life (8 items); Major life areas (1 item); and Community, social and civic life (3 items). The grouping of BI and mFAI items is presented in table 3.

TABLE 3 IN HERE

Activity level among ten-year stroke survivors

At the ten-year follow-up the majority of the participants reported a high level of activity related to Self-care and Basic mobility (total score median 80, range 0-80). In total 75 % of the participants were independent in Basic mobility, and 72 % were independent in Self-care (i.e. obtained the maximum domain score). Over two thirds (69 %) obtained the maximum score for both domains of the BI. There were no significant gender differences in any of the domains. Between age groups, statistically significant differences were found for Self-care as well as Basic mobility ($p<0.001$). The post-hoc analysis revealed a significantly lower activity among those 80 years or older compared to the younger age groups ($p<0.017$) (table 4).

The overall activity level based on the mFAI total score varied considerably between participants with individual scores ranging from 0 to 46 (median 32). Close to half (48 %) of the participants were classified as highly active, 29 % as moderately active and 23 % as inactive (figure 1). The highest activity was found for the domains Communication, Domestic life, Community social and civic life and Outdoor mobility, whereas the participants reported lower activity concerning Learning and applying knowledge and Major life areas (table 4).

FIGURE 1 IN HERE

There was no statistically significant difference between men and women regarding overall activity level as assessed by the mFAI total score, nor for the activity-specific domains (table 4). Individual item scores however revealed gender differences for specific types of activities. Compared to men, women more often prepared main meals ($p<0.001$), washed clothes ($p<0.001$) and carried out light housework ($p=0.010$). Though men and women seemed to travel out of home to the same extent they used different modes of transport. The women more often travelled as passengers in private car/taxi ($p<0.001$), whereas men had higher scores for driving a car/motorcycle ($p<0.001$) and going by bicycle/moped ($p=0.006$).

Between age groups there were significant differences in overall activity level ($p<0.001$) as well as in all activity-specific domains of the mFAI except for Learning and applying knowledge (table 4). The post-hoc analyses revealed a significantly ($p<0.017$) lower activity among participants aged ≥80 years compared to the younger age groups for the domains Domestic life, Community social and civic life and Communication. Those younger than 65 years more often participated in activities related to Outdoor mobility, and Major life areas compared to the older

age groups (table 4). Analysis on item level also revealed age related differences regarding the mode of transportation used, for example those ≥80 years used special transport services and powered wheelchairs to a greater extent than the younger age groups.

TABLE 4 IN HERE

Discussion

In the present study we applied a novel ICF-oriented approach to analyze and present data on activity collected with established assessment instruments. By using the ICF as a framework we conceptualized the content of the BI (14) and the mFAI (22), and were thereby able to describe activity among long-term stroke survivors within activity-specific domains rather than just using total scores. Using this approach, sub-group differences according to gender and age were also highlighted.

Our results confirm that the BI and the mFAI complement each other in a purposeful way. Even though both instruments have a mobility domain they capture different aspects of mobility, the BI being focused on basic indoor mobility while the mFAI covers outdoor mobility, including use of manual and motorized vehicles as well as public transport. It should be noted that concerning the ICF-chapters Mobility; Domestic life; and Community, social and civic life, the two instruments together fully represent the ICF core set for stroke. However, complementing assessments are needed to ensure a full coverage of the Activities and participation component of the core set, especially regarding Interpersonal interactions and relationships.

Though the BI showed ceiling effects in our sample, by means of the mFAI we found that the individual variations in activity level among the participants were considerable. There were also differences between sub-groups, regarding total scores as well as activity-specific domains. Analysis on item level revealed more detailed gender-related variations. The differences found related to age and gender were consistent with those seen among stroke survivors at earlier time points post stroke (13, 31), and in the general population (36). Based on our results it seems that ten years after stroke men and women are equally active on an overall level, but participate in different types of activities. Significant differences between men and women were found for individual items, and there was also a trend for women to report higher activity for the domain Domestic life, whereas men more often participated in activities related to Community, social and civic life (table 4). Previous studies have demonstrated that men and women may benefit from different types of activities, even in terms of survival (8), which makes it important to further explore these differences. In clinical practice, detailed information concerning each individual is important to provide tailored interventions.

It should be noted that the differences in activity level between age groups cannot with certainty be explained by age itself, but may be a result of other factors such as socioeconomic situation, earlier habits, gender, disability level or housing situation. For example, the gender distribution was not the same in the three age groups, with the highest percentage of women in the oldest group. Also, women had more disabilities and more often lived alone compared to men. Multivariate statistical analyses are needed to determine predictors of long-term participation in activities after stroke, which was beyond the scope of the present study.

To our knowledge no Swedish population-based long-term follow-up of stroke survivors that includes activity assessments has previously been reported. The few European studies that could be considered for comparison consist of long-term follow-ups in Norway (37), England (38) and the Netherlands (39) with high loss to follow-up. In these studies two different versions of the BI (scored 0-20 or 0-100) and the FAI (scored 0-45 or 15-60) were used, making comparisons difficult. The proportion of stroke survivors rated as independent in basic ADL, based on BI total scores, varied between 49 - 90 %, compared to 73 % in our sample (24). FAI scores indicated inactivity for 18 - 30 % of the stroke survivors, compared to 23 % in our study (figure 1). The impact of gender and age on activity has not gained much attention except in the study from England, where inactivity was found to increase with age and was higher among men throughout the study period (38).

Bearing in mind the challenges of comparing different studies, and the individual variations among participants, our results imply that long-term stroke survivors are more active compared to stroke survivors assessed one year after stroke onset (13, 31). Part of the explanation may be that ten years after stroke onset the oldest and those with the most disability at baseline were deceased (24). The long-term survivors may also have adapted to their life situation and developed compensatory strategies that allow them to be active despite functional limitations. Considering that previous activity patterns predict activity later in life (12) and are related to long-term health and survival (8, 40), it is possible that a high pre-stroke activity level contributed to their survival. Unfortunately, since detailed data on activity performance was not available for this sample prior to the ten-year follow-up we were not able to explore such explanations empirically. Not to be forgotten, several of the participants were classified as inactive at the time of the ten-year follow-up. To be able to provide adequate support for those at risk of activity limitations, an increased

understanding of factors that can be obstacles or facilitators for activity long-term after stroke is needed.

Turning to methodological considerations, in this study we used a Swedish extended and modified version of the FAI published in 2013 (22), which is not yet used widely. Observing the fact that the item "Using the telephone" obtained the highest score of all items, adding this item to the instrument seems relevant for this population. Regarding transportation, our results show that many of the participants frequently used other modes of transport than those included in the original item (driving a car/travel on bus), and thus the extension seems appropriate to more accurately capture participation in out of home activities.

Concerning the ICF linking, the ICF core set for stroke (20) is relevant for the stroke population and was feasible to use. As of yet, similar studies for comparison are scarce. There are prior studies linking several outcome measures used in stroke trials and rehabilitation, including the BI and the FAI, to the ICF (18, 41). However, in these studies the content of individual instruments was not reported, nor did they apply the ICF core set for stroke. Still, we did identify one study where the BI was linked to the ICF core set for stroke (42), and another were the BI was linked to the ICF core set for early post-acute rehabilitation (43). These two studies reported similar though not identical results to ours. The mFAI has not previously been linked to the ICF or to the ICF core set for stroke. The closest comparison is a study by Schepers et al. (10) where the BI as well as the original FAI was linked to the full version of the ICF (19). Comparing the results of Schepers et al. to ours demonstrated that the added item of the mFAI (Using the telephone) improved the coverage of the Activities and participation component of the ICF, by means of links related to Communication. The extended mobility-items did however not yield any

additional links to the ICF but provided more detailed information on outdoor mobility. The somewhat differing results between studies suggest that there may be validation issues in the ICF-linking procedure. Efforts to ensure the quality of the linking in the present study included using the competence of a multidisciplinary team of researchers and describing the procedure in a transparent way.

In addition to the linking we also grouped the items of the BI and the mFAI into activity-specific domains using the ICF as a conceptual framework. This approach has not previously been undertaken in any studies that we know of. We argue that it provides a better and more generally applicable base for the presentation of BI and mFAI data compared to grouping of items using factor analysis which has yielded different results for different samples (16).
To clearly demonstrate how the domains were derived, we chose to label the activity-specific domains of the BI and mFAI in accordance with the chapters of the Activities and participation component of the ICF. However, it should be noted that the BI and mFAI domain scores only reflect some aspects of those chapters.

Finally, a reflection regarding the distinction between activity and participation is needed. In the ICF activities and participation are joined in one component indicating the close relationship between the two concepts. However, since the launch of the ICF several studies have addressed the challenges regarding the definition and operationalization of activity and participation (see e.g. references 44, 45), highlighting that the two concepts might be better evaluated separately. Even though the BI as well as the FAI traditionally have been considered as measures on the activity level (9), the FAI has also been used as a measure of participation (46). Aware of this challenge regarding definitions, we nevertheless chose to describe our results solely in terms of

activity. Hence, even though execution of an activity also implies some degree of participation, the broader concept of participation was not targeted in the present study.

Strengths and limitations

One of the strengths of this study is the population based cohort with an efficient case ascertainment method as described in previous publications (23, 47). One limitation is the relatively low number of participants in the cohort, and more long-term studies in different regions and countries are needed to confirm our results. Even though the methodology including both conceptual and descriptive analyses strengthens the study and allowed for a detailed presentation of different types of activities, it should be kept in mind that assessments using the mFAI only provide information about the frequency of activity performance and may fail to reflect self-perceived activity limitations. Furthermore, no longitudinal inferences on changes in activity level post stroke could be made since mFAI data were not available prior to the ten-year follow-up.

Conclusions

Linking the BI and the mFAI to the ICF core set for stroke allowed for a more fine-tuned description of activity among long-term stroke survivors. The results show that ten years after a first-ever stroke, most survivors were independent in self-care and basic mobility and regularly participated in activities of daily living including social activities. Persons over the age of 80 are likely at the highest risk for inactivity, but individual variations as well as gender- and age-related differences deserve consideration. To increase the knowledge of factors that predict and facilitate participation in activities post stroke the methodological approach presented in this study can be useful. Further studies applying multivariable regression analyses are necessary and should also

address aspects related to interpersonal interactions and relationships. Future research along these lines may guide the development of tailored activity-promoting interventions for long-term stroke survivors.

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Declaration of interest

The authors report no declarations of interest.

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Table 1. *Participant demographics at the ten-year follow up (N = 145).*

	Men n = 86	Women n = 59
Mean age, years (range)	75 (28-97)	78 (55-96)
Stroke type, n (%)		
Cerebral infarction	74 (86)	52 (88)
Intracerebral hemorrhage	9 (11)	1 (2)
Subarachnoid hemorrhage	3 (3)	5 (8)
Undefined	0 (0)	1 (2)
Disability level (mRS score), n (%)		
No disability (0-1)	53 (62)	25 (42)
Slight to moderate disability (2-3)	20 (23)	25 (43)
Moderately severe to severe disability (4-5)	13 (15)	9 (15)
Mobility devices, n (%)		
None	55 (64)	26 (44)
Walking device	16 (18)	22 (37)
Walking device and wheelchair	4 (5)	3 (5)
Wheelchair	11 (13)	8 (14)
Living alone	30 (35)	32 (54)
Housing and care situation, n (%)		
Ordinary housing, no home care	65 (76)	34 (58)
Ordinary housing, with homecare	12 (14)	19 (32)
Special housing	9 (10)	6 (10)

mRS: modified Rankin Scale

Table 2. *Categories of the Activities and participation component of the ICF core set for stroke, and links to the BI and the mFAI*

ICF core set for stroke	BI	mFAI
1. LEARNING AND APPLYING KNOWLEDGE		
d115 Listening	-	X
d155 Acquiring skills	-	-
d160 Focusing attention	-	X
d166 Reading	-	X
d170 Writing	-	X
d172 Calculating	-	-
d175 Solving problems	-	-
2. GENERAL TASKS AND DEMANDS		
d210 Undertaking a single task	-	X
d220 Undertaking multiple tasks	-	-
d230 Carrying out daily routine	-	-
d240 Handling stress and other psychological demands	-	-
3. COMMUNICATION		
d310 Communicating with – receiving - spoken messages	-	X
d315 Communicating with - receiving - nonverbal messages	-	-
d325 Communicating with – receiving – written messages	-	X
d330 Speaking	-	X
d335 Producing non-verbal messages	-	-
d345 Writing messages	-	X
d350 Conversation	-	X
d360 Using communication devices and techniques	-	X
4. MOBILITY		
d410 Changing basic body position	X	-
d415 Maintaining a body position	X	-
420 Transferring oneself	X	-
d430 Lifting and carrying objects	-	X
d440 Fine hand use	X	X
d445 Hand and arm use	X	X
d450 Walking	X	X
d455 Moving around	X	-
d460 Moving around in different locations	X	X
d465 Moving around using equipment	X	X
d470 Using transportation	-	X
d475 Driving	-	X
5. SELF-CARE		
d510 Washing oneself	X	-
d520 Caring for body parts	X	-
d530 Toileting	X	-
d540 Dressing	X	-
d550 Eating	X	-
d570 Looking after one´s health	-	-
6. DOMESTIC LIFE		
d620 Acquisition of goods and services	-	X
d630 Preparing meals	-	X
d640 Doing housework	-	X
7. INTERPERSONAL INTERACTIONS AND RELATIONSHIPS		
d710 Basic interpersonal interactions	-	-
d750 Informal social relationships	-	-
d760 Family relationships	-	-
d770 Intimate relationships	-	-
8. MAJOR LIFE AREAS		
d845 Acquiring, keeping and terminating a job	-	-
d850 Remunerative employment	-	X
d855 Non-remunerative employment	-	-
d860 Basic economic transactions	-	X
d870 Economic self-sufficiency	-	-
9. COMMUNITY, SOCIAL AND CIVIC LIFE		
d910 Community life	-	X
d920 Recreation and leisure	-	X
Total 51 categories	14 (27 %)*	26 (51 %)*

BI: Barthel Index. mFAI: Swedish extended and modified Frenchay Activities Index.
* Number of linked categories and coverage (%) of the Activities and participation component of the ICF core set for stroke.

Table 3. *BI and mFAI items grouped based on activity type, in accordance with the chapters of ICF Activity and participation.*

	ICF chapters						
	Learning and applying knowledge	Communication	Mobility*	Self-care	Domestic life	Major life areas	Community social and civic life
BI items (n=8)[1]			8. Transfers 9. Mobility 10. Stairs	1. Feeding 2. Bathing 3. Grooming 4. Dressing 7. Toilet use			
mFAI items (n=22)[2]	14. Reading books	16. Using the telephone	8 A. Walking outside > 15 min 8 B. Manual wheelchair outside > 15 min 10 A. Driving a car/motorbike 10 B. Going by bus or train 10 C. Going by bicycle or moped 10 D. Powered wheelchair 10 E. Passenger private car/taxi 10 F. Special transport service		1. Preparing main meals 2. Washing up after meals 3. Washing clothes 4. Light housework 5. Heavy housework 6. Local shopping 12. Gardening outside 13. Household maintenance	15. Gainful work	7. Social occasions outside the home 8. Actively pursuing hobby 11. Travel outing/car ride

BI: Barthel Index. mFAI: Swedish extended and modified Frenchay Activities Index. ICF: International Classification of Functioning, Disability and Health.

[1] Two items of the BI were excluded (bowel and bladder function), since they were not linked to ICF Activity and participation.

[2] Sixteen extended items based on Wendel et al, 2013 (24).

*Both instruments contained items related to ICF Mobility, though the instrument domains were given unique names (BI: "Basic mobility", mFAI: "Outdoor mobility").

Table 4. *BI and mFAI activity-specific domain scores and total scores (median values) for all participants and according to gender and age.*

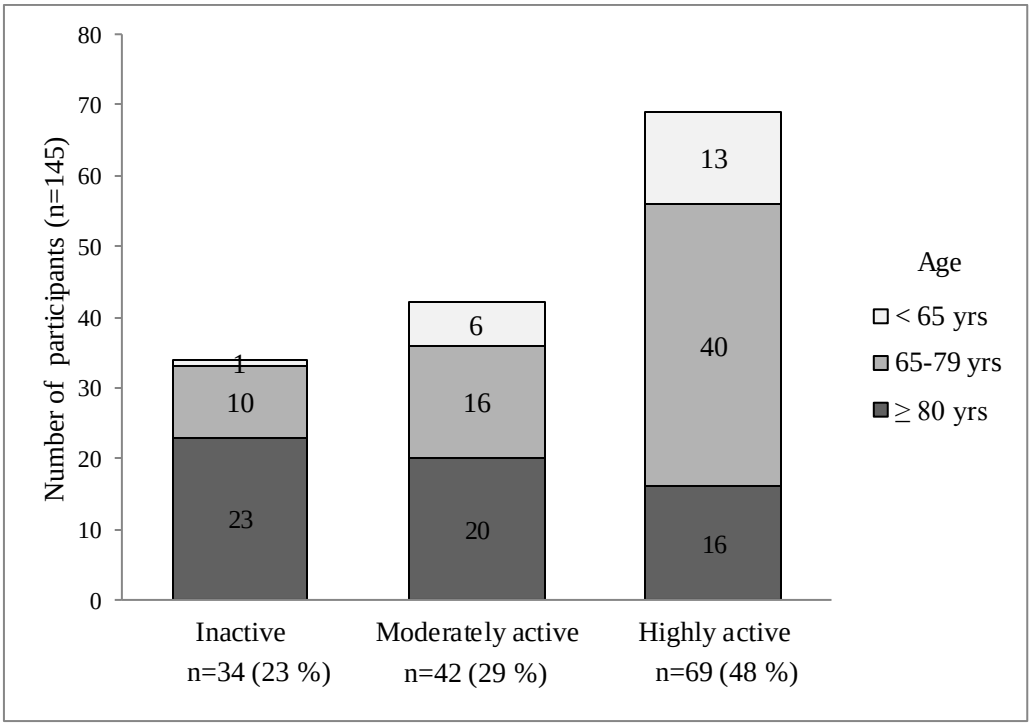
Instrument domains (n items)	Max. score	All N=145	Men n=86	Women n=59	*p*-value*	< 65 yrs n=20	65-79 yrs n=66	≥ 80 yrs n=59	*p*-value†
The BI		*Md (Q_1-Q_3)*				*Md (Q_1-Q_3)*			
Basic mobility (3)	40	40 (35-40)	40 (40-40)	40 (35-40)	0.516	40 (40-40)	40 (40-40)	40 (25-40)	<0.001 [b,c]
Self care (5)	40	40 (35-40)	40 (35-40)	40 (35-40)	0.738	40 (40-40)	40 (40-40)	40 (20-40)	<0.001 [b,c]
Total score (8)[1]	80	80 (70-80)	80 (74-80)	80 (70-80)	0.554	80 (80-80)	80 (80-80)	75 (45-80)	<0.001 [b,c]
The mFAI									
Domestic life (8)	24	17 (8-21)	16 (7-20)	19 (11-21)	0.052	18 (14-23)	20 (13-22)	12 (0-19)	<0.001 [b,c]
Community social and civic life (3)	9	5 (3-7)	6 (3-8)	4 (1-7)	0.052	6 (4-8)	6 (4-8)	4 (1-6)	0.001 [b,c]
Outdoor mobility (2)[2]	6	6 (3-6)	6 (4-6)	5 (3-6)	0.101	6 (4-6)	6 (5-6)	5 (2-6)	0.006 [a,b]
Learning and applying knowledge (1)	3	1 (0-2)	1 (0-2)	1 (0-2)	0.871	1 (2-0)	1 (2-0)	0 (2-0)	0.370
Major life areas (1)	3	0 (0-0)	0 (0-0)	0 (0-0)	0.173	2 (0-3)	0 (0-0)	0 (0-0)	<0.001 [a,b]
Communication (1)	3	3 (2-3)	3 (2-3)	3 (2-3)	0.087	3 (3-3)	3 (2-3)	2 (2-3)	0.018 [c]
Total score (16)[2]	48	32 (20-38)	31 (19-37)	34 (21-39)	0.345	36 (27-40)	35 (27-39)	23 (8-34)	<0.001 [b,c]

BI: Barthel Index. mFAI: Swedish extended and modified Frenchay Activities Index. Q_1-Q_3: First-third quartile.
* The Mann-Whitney U test for differences between two groups (statistical significance: $p<0.05$).
† The Kruskal-Wallis test for differences between three groups (statistical significance: $p<0.05$).
[1] Two items of the BI (bowel and bladder function) were excluded as they were not linked to ICF Activity and participation.
[2] The single highest rating within each of the extended items (8 A-B and 10 A-F) was used when calculating the Outdoor mobility domain score and the total mFAI score.
Post-hoc analysis: Letters denote significant difference between age groups using Bonferroni corrected p-value <0.017.
[a] <65 yrs vs. 65-79 yrs.
[b] <65 yrs vs. ≥80 yrs.
[c] 65-79 yrs vs. ≥80 yrs.

Appendix 1. The Swedish extended and modified version of the Frenchay Activities Index used in the present study, based on Wendel et al. 2013 (22).

In the last **3** months how often have you undertaken:	
1. Preparing main meals 2. Washing up	0 = Never 1 = Less than once a week 2 = 1-2 times per week 3 = Most days
3. Washing clothes 4. Light housework 5. Heavy housework 6. Local shopping 7. Social outings 8A. Walking outdoors > 15 min 8B. Wheelchair outdoors > 15 min 9. Pursing active interest in hobby 10A. Driving a car/motorbike 10B. Going by bus or train 10C. Going by bicycle or moped 10D. Powered wheelchair 10E. Passenger private car/taxi 10F. Special transport service	0 = Never 1 = 1-2 times in 3 months 2 = 3-12 times in 3 months 3 = At least weekly
In the last **6** months how often have you undertaken:	
11. Outings/car rides 12. Gardening* 13. Household/car maintenance*	0 = Never 1 = 1-2 times in 6 months 2 = 3-12 times in 6 months 3 = At least weekly
14. Reading books	0 = None 1 = 1 in 6 months 2 = Less than 1 in 2 weeks 3 = More than 1 every 2 weeks
15. Gainful work	0 = None 1 = Up to 10 hours/week 2 = 10-30 hours/week 3 = Over 30 hours/week
16. Using the telephone/text-phone	0 = Never 1 = Less than once a week 2 = 1-2 times per week 3 = Most days

*Modified response options compared to Wendel et al. 2013 (22).



Inactive = mFAI total score 0-16; Moderately active = 17-32; Highly active = 33-48.
Cut-off levels based on Patel et al. 2006 (32).

Figure 1. *Activity level among the ten-year stroke survivors, based on the Swedish extended and modified Frenchay Activities Index (mFAI) total score.*