## ORIGINAL REPORT

# APPLYING THE COMPREHENSIVE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH CORE SETS FOR STROKE FRAMEWORK TO STROKE SURVIVORS LIVING IN THE COMMUNITY

Markku Paanalahti, MSc<sup>1,2</sup>, Åsa Lundgren-Nilsson, PhD¹, Anton Arndt, PhD<sup>2,3</sup> and Katharina S. Sunnerhagen, MD, PhD¹

From the <sup>1</sup>Rehabilitation Medicine, Institute for Neuroscience and Physiology, Sahlgrenska Academy, University of Gothenburg, Gothenburg, <sup>2</sup>Institution CLINTEC, Karolinska Institutet and <sup>3</sup>Swedish School of Sport and Health Sciences, Stockholm, Sweden

Objective: The aims of this study were to explore the perspective of functioning in community-dwelling people with prior stroke and to confirm, if possible, the Comprehensive International Classification of Functioning, Disability and Health (ICF) Comprehensive Core Set for stroke.

Methods: Qualitative interviews were analysed (using the content analysis method and established ICF linking rules) from 22 persons following stroke (age range 59–87 years), as well as their spouses/partners, where relevant.

Results: Ninety-nine (76%) of 130 second-level ICF categories in the existing Comprehensive ICF Core Set for stroke were confirmed: 31 categories (of 41) in the component of body functions, 38 categories (of 51) in the component of activities and participation, 26 (of 33) in the component of environmental factors and 4 (of 5) in the component of body structures. Eleven additional ICF categories and one personal factor, a coping style of "I take it as it comes" were also identified in the transcribed text.

Conclusion: The Comprehensive ICF Core Set for stroke was largely confirmed.

*Key words:* stroke; qualitative study; ICF. J Rehabil Med 2013; 45: 331–340

Correspondence address: Katharina Sunnerhagen, Rehabilitation Medicine, Institute for Neuroscience and Physiology, University Göteborg, Per Dubbsgatan 14 3rd Floor, SU/Sahlgrenska, SE-413 45 Göteborg, Sweden. E-mail: KS.Sunnerhagen@neuro.gu.se

Accepted Oct 12, 2012; Epub ahead of print Feb 6, 2013

# INTRODUCTION

The term stroke refers to a clinical syndrome of presumed vascular origin typically identified by rapidly developing signs of focal or global disturbance of cerebral functions lasting more than 24 h or leading to death (1). In Sweden, stroke is a rapidly increasing public health problem, the most common cause of disability in the adult population, and one of the main causes of death (2). Approximately 30,000 persons suffer stroke in Sweden annually, and the total cost of stroke care in the country is estimated at 1.5 billion Euro per year (3). The prevalence of

stroke is estimated at over 100,000 stroke survivors, of whom the majority lives at home (4).

Problems with functioning are an essential concern for persons with prior stroke, since they affect social reintegration and activities of daily living (5). Requirement for home-help services, assistive devices or home modifications are common after stroke (6). In Sweden home-help services and home modifications for people with disabilities are required by law in order to make it possible for people to remain in their homes. Most elderly care is funded by taxes, and the healthcare costs to be paid by elderly people themselves are subsidized and based on certain rate schedules (7, 8).

The importance of the person perspective is evident (9) because health is related to one's functional status in association with personal and environmental factors (10, 11). The person perspective assists the multidisciplinary team in recognizing who the person is and what type of support they need (12). Personal factors are seldom understood (13, 14), however, and there is no agreement on how person-centred rehabilitation (15) should be planned or evaluated from this perspective (16). Evidence is still lacking for the concepts to be taken into account when addressing stroke (17), and this can lead to inefficient or ineffective rehabilitation services that are not based on problems experienced by persons with stroke (18). In a 2010 study in Sweden, community-dwelling persons with prior stroke frequently reported that they had not received enough individual support or rehabilitation (19). In 2009, the Cochrane systematic review acknowledged the home environment as a growing arena for stroke rehabilitation, where evaluation of the effectiveness of outpatient services is of key importance to the delivery of efficient evidence-based stroke care (17). The home environment has thus become the natural rehabilitation setting for communitydwelling people living with a prior stroke, and it is a challenge to the multidisciplinary team to develop efficient person-centred stroke care (19, 20). The Comprehensive International Classification of Functioning, Disability and Health (ICF) Core Set for stroke is intended to guide multidisciplinary assessments in persons with stroke (21) and to define what to measure, e.g. what are the important aspects of functioning and health for a person with stroke (22). Since its publication, several studies have shown that using the ICF can enhance person-centred care

(23–25). Altogether, 130 ICF categories are included in the Comprehensive ICF Core Set for stroke, with 41 categories from the component body functions, 51 from activities and participation, 33 from environmental factors and 5 from body structures (21).

The aims of the study were: to explore the perspective of functioning in community-dwelling people living with a prior stroke; and to confirm, if possible, the Comprehensive International Classification of Functioning, Disability and Health (ICF) Comprehensive Core Set for stroke. A qualitative design was chosen in order to understand the experiences of life after a stroke; to explore the subjects' point of view, i.e. experiences, attitudes, feelings and the world they live in, in their natural settings by interpreting meaning or phenomena from text data that adheres to naturalistic paradigm (26, 27) suggesting that "reality is socially constructed" (28).

#### **METHODS**

A qualitative study was performed, using individual interview methodology (27) to gather information from persons with prior stroke living in the community. A directed content analysis approach (29) was employed to analyse the manifest (the visible, literally present and the obvious) components of the transcribed text (30). This approach was used to help to confirm or extend conceptually a pre-existing theoretical framework (29) using inductive analysis of text data that was later linked to a pre-existing framework, i.e. the ICF. Established ICF linking rules (31) were used in linking the concepts of functioning identified to the Comprehensive ICF Core Set for stroke.

#### Participants

Thirteen women and 9 men were included in the study (Table I). Three women and 6 men lived in a pair relationship. Six women and 7 men lived alone. The mean age of the participants was 72.2 years (age range

58–87 years). The time from first stroke ranged from 8 months to 23 years, with a mean of 5.3 years. Twenty-one of the participants were retired, of whom 4 had retired early due to stroke. One participant worked part-time. All participants were community-dwelling as well as native Swedes.

The study was approved by the ethics committee at Umeå University. Written information describing the study and a guarantee of confidentiality were given to each participant. Written informed consent was obtained from all participants according to the Declaration of Helsinki 1996.

#### Data collection procedure

Participants were recruited by the first author, who worked as a physiotherapist in the municipality's multidisciplinary homecare team. The first author also conducted the interviews during a period of 3 months. A purposeful sampling strategy was chosen in order to study community-dwelling person's with prior stroke and to be in contact with the multidisciplinary homecare team. Each person with stroke, a total of 21 persons at the healthcare districts Hoting and Backe in the municipality of Strömsund, was contacted and asked whether they wanted to participate. They all fulfilled the following inclusion criteria; main diagnosis stroke; a minimum 6 month's poststroke, with lasting neurological symptoms; Swedish speaking; able to give written informed consent; living at home; and in contact with the multidisciplinary homecare team. One declined, as he felt that participation was not going to help improve his health. Two additional persons who fulfilled the inclusion criteria from another healthcare district independently contacted the author and wanted to participate in the study. Both were included because they improved the heterogeneity of the sample.

The participants were asked if they would participate in a face-to-face interview that would be recorded. They were also asked to complete a questionnaire Case Record Form (CRF) for patients (in Ludwig Maximilians University of Munich – World Health Organization (WHO) Collaboration Project). The CRF comprises demographic information, condition-specific information, the stroke impact scale in

Table I. Characteristics of the participants reported in the Case Record Form

			Persons	Investigators		Does		Need for	Need for	Home-	
		Affected	perspective	perspective		comorbidity		assistive	assistive	help,	
Sex/age	, Event of	side of	on recovery	on disability		limit your	Type of	devices	devices	times a	Living
years	Stroke	the body	(0-100)	(mRS 0-6)	Comorbidity	activities?	comorbidity	indoors	outdoors	week	situation
M/75	1989/2006	R	50	1	Yes	No	High BP	None	Walking aid	0	Alone
M/58	1997	L	60	3	No	_	_	Walking aid	Walking aid	Daily	Alone
M/71	1994/2006	L	0	3	Yes	No	High BP	None	Walking aid	0	Spouse
F/76	1996	L	70	2	Yes	Yes	Heart disease	None	Walking aid	1	Alone
M/68	1997	L/R	50	2	Yes	No	Diabetes	None	Walking aid	0	Spouse
M/62	2000	R	30	4	No	_	_	Wheelchair	Wheelchair	Daily	Alone
M/85	2006	R	50	2	Yes	Yes	Osteoarthritis	None	Walking aid	0	Spouse
M/78	1996	L	80	3	Yes	Yes	Depression	Walking aid	Walking aid	Daily	Alone
M/76	1984	L	40	4	Yes	No	Diabetes	Walking aid	Wheelchair	Daily	Alone
M/75	1997/2006	L/R	40	3	Yes	No	Heart disease	Walking aid	Walking aid	0	Spouse
F/60	2004	L	40	1	Yes	No	High BP	None	Walking aid	1	Alone
F/66	2004	R	90	1	Yes	No	Diabetes	None	Walking aid	0	Spouse
F/72	2004	L	60	3	Yes	No	Heart disease	None	Walking aid	0	Spouse
M/77	2004	R	30	2	Yes	No	Heart disease	Walking aid	Walking aid	Daily	Alone
F/85	2006	L	50	1	Yes	No	High BP	None	Walking aid	Daily	Alone
F/85	2001	R	30	3	Yes	No	Heart disease	Walking aid	Walking aid	Daily	Alone
M/78	1999	L/R	40	4	Yes	Yes	Heart disease	Walking aid	Walking aid	1	Spouse
F/87	2005	L/R	40	2	Yes	Yes	Heart disease	None	Walking aid	Daily	Alone
F/65	1995	L	50	4	Yes	No	Heart disease	Wheelchair	Wheelchair	Daily	Spouse
M/73	2000/2006	L/R	70	1	Yes	Yes	Diabetes	None	Walking aid	0	Spouse
F/63	2005	R	40	1	Yes	No	High BP	None	None	0	Alone
M/64	1997	R	80	2	Yes	No	Heart disease	None	None	0	Alone

mRS: modified Ranking Scale; R: right; L: left; BP: blood pressure.

Table II. Qualitative data analysis scheme

Transcription	Meaning unit	ICF category
Interviewer: If you think about your body, what functional problems do you have?		
Participant A: I have a memorising problem, because if I for example read something and should go on with reading and remember what I read at the first place I don't, it is like, the biggest problem.  Interviewer: If you think about your daily life, what are your biggest	A memorising problem	b144 Memory functions
problems? Participant B: When I walk it goes well but if I start to look around and admire the nature or something I suddenly start to walk crooked and not straight.	Problem with looking around while walking	b140 Attention functions 450 Walking

The transcription undergoes qualitative analysis to derive a meaning unit that is then linked to an International Classification of Functioning, Disability and Health (ICF) category.

Swedish, the self-administered co-morbidity questionnaire (32), the Short Form-36 (SF-36) health survey and the modified Ranking Scale (mRS). The interviews were conducted at the participants' homes 2–4 weeks after completion of the CRF.

Each interview began with an open conversation about how the person had experienced his or her life after stroke, before the open-ended interview questions that followed the structure were asked as follows:

- Body Functions: If you think about your body, what functional problems do you have?
- Body Structures: If you think about your body, where are your biggest problems?
- Activities and Participation: If you think about your daily life, what are your biggest problems?
- Environmental Factors: If you think about your environment, factors in your surroundings, and your living conditions, what do you find helpful or supportive? What do you find problematic?

The open-ended questions were intended to stimulate the interviewee to reflect on the different aspects of functioning at home. After every question, participants were also encouraged to speak freely about their perspective of functioning after stroke. Each interview was taperecorded and lasted between 40 and 60 min. After the interviews were conducted, another meeting was organized in their homes (2–4 weeks after the interview) to present the results and ask them whether their perspective of functioning at home had been correctly understood.

The spouses of participants who lived in a pair relationship were present during the interviews and were asked to comment and give additional information on the functioning of the interview person at home. Two of the participant's had aphasia; one was supported by their partner during the interview and the other did not need support during the interview.

#### Data analysis

When all the interviews were completed and transcribed verbatim, the text was first read several times by the first and the second authors to get an overview of the data. Each interview was considered a separate unit of analysis (30). Secondly, the meaning units, i.e. words or sentences that contained the interviewed person's perspective of functioning at home, were identified from each unit of analysis. This was first done

by the first author, then the second author investigated the identified meaning units from all unit of analysis. The concepts of functioning from the meaning units were then linked to the second-level categories, in the existing comprehensive ICF Core Set for stroke, independently by the first and the second author. One concept of functioning could be linked to 1 or more ICF categories, depending on the number of topics contained in it. The scheme of the qualitative data analysis and the structure of ICF are presented in Tables II and III.

The second author, an ICF expert, then analysed the results of the process from above in each unit of analysis and determined the ICF categories to which the identified concepts of functioning should be linked. Both investigators agreed completely on the concepts of functioning identified from the transcribed text. The agreement on linking to the second-level ICF categories ranged from 55% to 100% (Table IV). Finally, the identified ICF categories were compared with the existing categories in the comprehensive ICF Core Set for stroke. An ICF category of the Comprehensive ICF Core Set for stroke was regarded as confirmed if the identical or a similar concept of functioning emerged from the transcribed text.

## RESULTS

The results from the CRF confirmed that the main cause of functioning problems at home was stroke. Fourteen participant's with comorbidities (Table I) reported that comorbidity did not limited their activities. None of the 4 participants who reported in the CRF that comorbidity limited their activities mentioned it during the interviews.

#### Data saturation

The saturation of data was defined as when the collection of new data does not shed any further light on the issue under investigation (33). The saturation of data was studied in the analysis of the transcribed text and was considered to have been reached when 3 consecutive interviews did not reveal any new personal

Table III. Structure of different levels of the International Classification of Functioning, Disability and Health (ICF)

ICF Component	Chapter level	Level 2 ICF category	Level 3 ICF category	Level 4 ICF category	Title of ICF component, chapter or category
b					Body function
	b2				Chapter 2. Sensory functions and pain
		b280			Sensation of pain
			b2801		Pain in body part
				b28010	Pain in head and neck

perspectives of functioning at home. The 19<sup>th</sup> interview was the last interview in which new concepts of functioning that could be linked to ICF categories were identified (Fig. 1).

Another meeting that was organized with the participants to present the results from the interview did not raise any new concepts of functioning, and this supports that the saturation of data was reached.

Comprehensive ICF Core Set for stroke as an interpreter of personal perspective of functioning at home

A total of 313 meaning units that contained participants' perspectives of functioning at home were identified from the transcribed text. From these meaning units, the identified concepts of functioning were linked to 99 (76%) of 130 second-level ICF categories in the existing Comprehensive ICF Core Set for stroke, 31 categories (of 41), in the component of body functions, 38 categories (of 51), in the component of activities and participation, 26 (of 33), in the component of environmental factors and 4 (of 5) in the component of body structures (Tables V, VI, VII and VIII). The following additional categories were also confirmed from the transcribed text: b230 hearing functions, b235 vestibular functions, b255 smell functions, b780 sensations related to muscle and movement functions, e140 products and technology for culture, recreation and sport, e215 population, e225 climate, e 560 media systems, services and policies, d110 watching, d660 assisting others and d720 complex interpersonal interactions.

Perspectives that were linked to ICF component body functions

Seventeen of the participants reported problems with ability to recall events. These problems were linked to the second-level ICF category b144 memory function that classifies the problems with remembering and recalling recent and remote memory.

"The memory, a lot of it is gone, I like to do crosswords and the other day when I wanted to continue to solve the one I was working with I couldn't find it! I didn't remember where I had put it! That is not normal for me."

Sixteen of the participants reported problems in proprioceptive functions when moving around indoors and outdoors. They

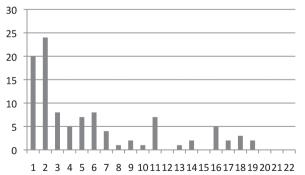


Fig. 1. The number of new concepts (y) of functioning identified and linked to International Classification of Functioning, Disability and Health (ICF) categories per interview (x interview number).

often expressed this as a problem with the balance function. The balance problems were classified with the category b260 proprioceptive function that describes the sensing of the relative position of body parts and with the category b235 vestibular functions.

"The balance is quite poor, I can't walk like I want to, I need a walker, I can fall backwards you know, I have to be careful. This with the balance is the worst thing (after stroke)."

Fifteen of the participants reported functioning problems that had to do with different problems in neuromusculoskeletal and movement-related functions.

"I have a problem with my left leg, when I try to lift the leg up the shoe falls back to the ground."

This problem was linked to category b730 muscle power functions, which are functions related to the force generated by the contraction of a muscle or muscle groups.

Perspectives that were linked to ICF component activities and participation

Difficulties in walking and moving (10 of 22) and carrying, moving and handling objects when doing housework (8 of 22) were frequently reported activities and participation problems.

"I have difficulties when I wash the dishes and do things like that, it's hard to take down or lift up the plates and cups. It's hard for me to turn my left hand in and out and pick up things."

This difficulty was linked to the categories d640 doing housework, d445 hands and arm use and d440 fine hand use.

Nine of the participants reported problems in participating in community life or in recreation and leisure.

Table IV. The agreement between 2 investigators on linking the identified concepts of functioning (CoF) to the second-level International Classification of Functioning, Disability and Health (ICF) categories in the Comprehensive ICF Core Set for stroke

Interview	Identified CoF, n	Agreement, %
1	11	55
2	13	85
3	19	84
4	7	57
5	12	83
6	13	82
7	8	100
8	11	73
9	6	83
10	18	56
11	6	67
12	10	90
13	10	90
14	27	93
15	21	90
16	15	87
17	10	80
18	14	77
19	9	89
20	14	93
21	12	92
22	15	93

Table V. International Classification of Functioning, Disability and Health (ICF) second-level categories<sup>a</sup> included in the component (b) body functions in the existing Comprehensive ICF Core Set for stroke

ICF second-level category	ICF category title	Confirmed by the investigators
b110	Consciousness functions	Confirmed
b114	Orientation functions	
b117	Intellectual functions	
b126	Temperament and personality functions	Confirmed
b130	Energy and drive functions	Confirmed
b134	Sleep functions	Confirmed
b140	Attention functions	Confirmed
b144	Memory functions	Confirmed
b152	Emotional functions	Confirmed
b156	Perceptual functions	
b164	Higher-level cognitive functions	Confirmed
b167	Mental functions of language	Confirmed
b172	Calculation functions	
b176	Mental function of sequencing complex movements	
b180	Experience of self and time functions	
b210	Seeing functions	Confirmed
b215	Functions of structures adjoining the eye	Confirmed
b260	Proprioceptive function	Confirmed
b265	Touch function	Confirmed
b270	Sensory functions related to temperature and other stimuli	Confirmed
b280	Sensation of pain	Confirmed
b310	Voice functions	Confirmed
b320	Articulation functions	Confirmed
b330	Fluency and rhythm of speech functions	Confirmed
b410	Heart functions	Confirmed
b415	Blood vessel functions	
b420	Blood pressure functions	
b455	Exercise tolerance functions	Confirmed
b510	Ingestion functions	Confirmed
b525	Defecation functions	Confirmed
b620	Urination functions	
b640	Sexual functions	Confirmed
b710	Mobility of joint functions	Confirmed
b715	Stability of joint functions	Confirmed
b730	Muscle power functions	Confirmed
b735	Muscle tone functions	Confirmed
b740	Muscle endurance functions	Confirmed
b750	Motor reflex functions	
b755	Involuntary movement reaction functions	Confirmed
b760	Control of voluntary movement functions	Confirmed
b770	Gait pattern functions	Confirmed

<sup>&</sup>lt;sup>a</sup>If a concept that emerged from the interviews was linked to an ICF category in the existing Comprehensive ICF Core Set for stroke it was regarded as confirmed.

"When I was well I used to go hunting and fishing all the time, before this happened. Yes, I was very interested in hunting and fishing. Now I can't do either one of them because I can't move around like before."

"It's hard for us to take part in different activities because he can't drive a car (after stroke) and it is 20 kilometres to town."

These perspectives were linked to category d920 recreation and leisure.

Perspectives that were linked to ICF component environmental factors (barrier and facilitators)

"Earlier I had my mailbox out in the porch just beside the front door, but they (the post office) decided to move it away from the door. Now I can't get my mail myself (the interviewed person sat in a wheelchair and did not have sufficient muscle power to drive up the ramp after visiting the mail box)."

This barrier was linked to category e535 communication services, systems and policies, and to category e120 products and technology for personal indoor and outdoor mobility and transportation (as well as to category d940 human rights).

"It's really difficult to walk outdoors without a walker; I just don't go outdoors without it."

The walker was experienced primarily as a facilitator by 17 of the participants and was also linked to category e120. Two of the participants used a wheelchair indoors and outdoors (e120). One of the participants used a wheelchair outdoors and a walker at home. Sixteen of the participants used a walker as a

Table VI. International Classification of Functioning, Disability and Health (ICF) second-level categories<sup>a</sup> included in the component (d) activities and participation in the existing Comprehensive ICF Core Set for stroke

ICF second-level categories	ICF category title	Confirmed by the investigators
d115	Listening	
d155	Acquiring skills	
d160	Focusing attention	Confirmed
d166	Reading	Confirmed
d170	Writing	Confirmed
d172	Calculating	
d175	Solving problems	
d210	Undertaking a single task	Confirmed
d220	Undertaking multiple tasks	Confirmed
d230	Carrying out daily routine	Confirmed
d240	Handling stress and other psychological demands	Confirmed
d310	Communicating with – receiving – spoken messages	Committee
d315	Communicating with – receiving – non-verbal messages	
d325	Communicating with – receiving – written messages	Confirmed
d330	Speaking	Confirmed
d335	Producing non-verbal messages	Commined
d345	Writing messages	Confirmed
d350	Conversation	Confirmed
d360	Using communication devices and techniques	Commined
d410	Changing basic body position	Confirmed
d415	Maintaining a body position	Confirmed
d420	Transferring oneself	Confirmed
d430	Lifting and carrying objects	Confirmed
d440	Fine hand use	Confirmed
d445	Hand and arm use	Confirmed
d450	Walking	Confirmed
d455	Moving around	Confirmed
d460	Moving around in different locations	Confirmed
d465	Moving around using equipment	Confirmed
d470	Using transportation	
d475	Driving	Confirmed
d510	Washing oneself	Confirmed
d520	Caring for body parts	Confirmed
d530	Toileting	Confirmed
d540	Dressing	Confirmed
d550	Eating	Confirmed
d570	Looking after one's health	Confirmed
d620	Acquisition of goods and services	Confirmed
d630	Preparing meals	Confirmed
d640	Doing housework	Confirmed
d710	Basic interpersonal interactions	Confirmed
d750	Informal social relationship	Confirmed
d760	Family relationships	Confirmed
d770	Intimate relationships	Confirmed
d845	Acquiring, keeping and terminating a job	Confirmed
d850	Remunerative employment	
d855	Non-remunerative employment	
d860	Basic economic transactions	
d870	Economic self-sufficiency	
d910	Community life	Confirmed
d920	Recreation and leisure	Confirmed

<sup>&</sup>lt;sup>a</sup>If a concept that emerged from the interviews was linked to an ICF category in the existing Comprehensive ICF Core Set for stroke it was regarded as confirmed.

walking aid outdoors. Seven of the participants used a walker indoors. Nine of the participants had home-help services on a daily basis and 3 had home-help services once a week. These were experienced by all of them as an important facilitator and were linked to category e340 personal care providers and personal assistants.

"I wouldn't be able to manage without home care, I can't manage to take a shower by myself, they come every Thursday and help me."

Home modifications that facilitated functioning had been made for 10 of the participants and were linked to category

Table VII. International Classification of Functioning, Disability and Health (ICF) second-level categories<sup>a</sup> included in the component (e) environmental factors in the existing Comprehensive ICF Core set for stroke

ICF second-level categories	ICF category title	Confirmed by the investigators
e110	Products or substances for personal consumption	Confirmed
e115	Products and technology for personal use in daily living	Confirmed
e120	Products and technology for personal indoor and outdoor mobility and transportation	Confirmed
e125	Products and technology for communication	Confirmed
e135	Products and technology for employment	
e150	Design, construction and building products and technology of buildings for public use	Confirmed
e155	Design, construction and building products and technology of buildings for private use	Confirmed
e165	Assets	
e210	Physical geography	
e310	Immediate family	Confirmed
e315	Extended family	Confirmed
e320	Friends	Confirmed
e325	Acquaintances, peers, colleagues, neighbours and community members	Confirmed
e340	Personal care providers and personal assistants	Confirmed
e355	Health professionals	Confirmed
e360	Health-related professionals	Confirmed
e410	Individual attitudes of immediate family members	Confirmed
e420	Individual attitudes of friends	Confirmed
e425	Individual attitudes of acquaintances, peers, colleagues, neighbours and community members	Confirmed
e440	Individual attitudes of personal care providers and personal assistants	Confirmed
e450	Individual attitudes of health professionals	
e455	Individual attitudes of health-related professionals	
e460	Societal attitudes	
e515	Architecture and construction services, systems and policies	Confirmed
e525	Housing services, systems and policies	Confirmed
e535	Communication services, systems and policies	Confirmed
e540	Transportation services, systems and policies	Confirmed
e550	Legal services, systems and policies	Confirmed
e555	Associations and organizational services, systems and policies	
e570	Social security services, systems and policies	Confirmed
e575	General social support services, systems and policies	Confirmed
e580	Health services, systems and policies	Confirmed
e590	Labour and employment services, systems and policies	Confirmed

<sup>&</sup>lt;sup>a</sup>If a concept that emerged from the interviews was linked to a ICF category in the existing Comprehensive ICF Core Set for stroke it was regarded as confirmed.

e155 design, construction and building products and technology of buildings for private use. These included various individual solutions, such as stationary ramps that facilitated mobility (with a wheelchair or with a walker), grab bars for support in the shower, thresholds that were removed in order to facilitate mobility or toilet rails and raised toilet seats, etc.

Concepts as time-related aspects, quality of life in general, aspects related to health and age, such as "I'm not getting any younger and it is normal that my health is not so good anymore" or desire to have company were classified as not defined (nd)

or health condition (hc). The need for assistance from one or two persons was identified twice in the transcribed text and was classified as not covered (nc) by the ICF.

A personal factor, a coping style with a theme (I just take it as it comes), was identified in 9 of the interviews. The participants described their feelings as follows:

"Well, after some time it becomes an ordinary part of everyday life, I have learnt to cope with it (stroke)."

"The most important thing is that I can stay at home so I think I just have to find a way to do it, so I just take it as it comes."

Table VIII. International Classification of Functioning, Disability and Health (ICF) second-level categories<sup>a</sup> included in the component (s) body structures in the existing Comprehensive ICF Core set for stroke

ICF second-level categories	ICF category title	Confirmed by the investigators
s110	Structure of brain	Confirmed
s410	Structure of cardiovascular system	
s720	Structure of shoulder region	Confirmed
s730	Structure of upper extremity	Confirmed
s750	Structure of lower extremity	Confirmed

<sup>&</sup>lt;sup>a</sup>If a concept that emerged from the interviews was linked to an ICF category in the existing Comprehensive ICF Core Set for stroke it was regarded as confirmed.

"I find a way to go to outside and rest in peace and quiet when I want to do it. No, it doesn't help to grumble but to take it as it comes."

## DISCUSSION

The aim of this study was to explore the perspective of functioning in community-dwelling people with prior stroke and to use this information to confirm the ICF Comprehensive Core Set for stroke.

The interviews conducted reached saturation, and thus the first aim of exploring functioning was reached. Most of the categories from the Comprehensive ICF Core Set for stroke were also confirmed by the face-to-face interviews, thus it can be assumed to address the perspective of functioning (barriers and facilitators) of a person living at home. Three of the 11 additional ICF categories that could not be linked to the comprehensive ICF Core Set for stroke – b230 hearing functions, b235 vestibular functions, d110 watching – are included in the extended version of the comprehensive ICF Core Set for stroke (23). This finding supports the idea of using the extended version of the ICF Core Set for stroke in multidisciplinary practice, since the functioning problems among persons with stroke are usually complex and heterogeneous (22). The results of this study also support Stucki's statement (34) that the ICF Core Sets can be used to define what to measure, and the researchers could use this information in selecting the most appropriate outcome measures for the intervention applied. The ICF Core Set might be a guide for multidisciplinary assessments in the home rehabilitation setting to enhance person-centred stroke care.

Problems with memory function were common among the participants and the statement "I have a memory problem" was presumably also used to describe different kinds of hidden functional disabilities (35) and a variety of circumstances that influence coping with problems and emotions.

The importance of the modifications (6) made to the homes of 10 of the participants was only partly revealed in the transcribed text, perhaps because the modifications were experienced as a normal part of the environment and the interviewer had only inquired about the present perspective of functioning at home. The immediate family, assistive devices and homehelp services were reported by almost all the participants to be important facilitators, which emphasizes' the importance of including the environmental factors as a legitimate part of planning and evaluating person-centred home rehabilitation (36, 37).

The coping style identified "I take it as it comes" could not be classified with current ICF components, but was classified as a personal factor according to the ICF linking rules (31). Nine of the participants in this study reported different problems in terms of participation that had more of a social quality than a medical one. They simply wished to be able to meet other people and to take part in community life (38) in the same way as they had done before the stroke. Traditionally, the multidisciplinary team is not responsible for reporting or working with problems that are not directly a part of the

patient's health condition. The improvement in recovery from stroke is still measured primarily in terms of regaining physical function (39). The challenge is how to plan and evaluate a person-centred home rehabilitation programme when the person's needs are more social than medical. The ICF classification gives the tools to clarify the boundaries between medical and social "rehabilitation" at the body, person and societal levels (24, 15).

## Discussion of the method

The interviews took place at the homes of the participants, where they were able to physically demonstrate facilitators and barriers on functioning in the natural setting if necessary. This was an advantage and gave a further dimension to the interview situation. The spouses of participants who lived in a pair relationship were present during the interviews. This approach gave more data and made the interview situation more natural in the home setting. A possible weakness in the interview-based approach was that persons having lived with a prior stroke often suffer from the common phenomenon of unawareness (35). Many of the participants reported problems in memory and attention functions that might have had an effect on their judgement about functioning at home (39). The open ICF interview approach (40) was considered most suitable for this particular group of persons because it was assumed that they might fatigue easily in the interview situation and the ICF-based approach (40) was considered more exhaustive way of conducting the interviews at home. Using this approach problems in defecation, urination and sexual functions were not specifically discussed with the participants during the interviews and it is possible that not all functioning problems in these categories were identified (40). Both men and women of different ages and in varying post-stroke phases were interviewed, which gave a broad condition-specific perspective on participants functioning at home and strengthened the credibility (30) of the results. A selection bias in the study was that only persons with stroke in contact with the multidisciplinary homecare team were contacted as well as that all the participants were native Swedes. However, this particular group of persons is commonly seen in the multidisciplinary homecare teams in Sweden, and therefore is an important factor to study when developing person-centred care (18, 19). The fact that that all the participants were native Swedes reflects the demographic situation in that community (only 5% of the population in the municipally were born outside Sweden in the ages 45 years and above). That the interviewer had taken part in the participants' rehabilitation process might have influenced how they chose to answer the interview questions. It is also possible that the participants did not want to discuss topics such as health professionals' or other care providers' attitudes towards people with stroke because the interviewer (the first author) belonged to that group of professionals. However, the interview method was assumed to be authentic and simulates the situation in which health professionals can use the ICF in person-centred clinical practice and document personal preferences, beliefs and values (14). The directed manifest

content analysis method was found to be easy to comprehend and use when identifying the (manifest) concepts of functioning from the transcribed text. However, as seen in Table II, different health professionals may identify different aspects of functioning, and thus a consensus meeting is needed when conclusions are drawn from the content of the transcribed text, which always contains multiple meanings (30).

In conclusion, since stroke is one of the major disease groups in Sweden and a common cause of disability, the perspective, of the person living with a prior stroke, of problems in functioning at home, is important for developing public health services that will ensure a good quality of life. Using the Comprehensive ICF Core Set for stroke can provide a broader perspective of, and a systematic coding system for, the needs of persons with stroke who live at home. ICF therefore has the potential to be used as a framework to provide structure, clarify team roles and demonstrate clinical reasoning in multidisciplinary stroke rehabilitation at home, which could lead to a more patient-centred practice.

#### **ACKNOWLEDGEMENTS**

The study was financed by the FoU-Jämt – a research and development organization in the county of Jämtland in Sweden.

## REFERENCES

- World Health Organization. Stroke 1989. Recommendations on stroke prevention, diagnosis, and therapy. Report of the WHO task force on stroke and other cerebrovascular disorders. Stroke 1989; 20: 1407–1431.
- Hallström B, Jönsson AC, Nerbrand C, Norrving B, Lindgren A. Stroke incidence and survival in the beginning of the 21st century in Southern Sweden: comparisons with the late 20th century and projections in to the future. Stroke 2008; 39: 10–15.
- Ghatnekar O, Ljungberg A, Wirestrand LE, Svensson A. Cost of stroke in Sweden; an incidence estimate. Int J Technol Assess Health Care 2004; 20: 375–380.
- The Swedish Stroke Register. [Annual report 2010 from the Swedish Stroke register], p. 10. Available from: http://www. riks-stroke.org/index.php?content=&lang=eng&text=#informati on col (in Swedish).
- Jansen HE, Schepers VP, Visser-Meily JM, Post MV. Social activity one and three years' post-stroke. J Rehabil Med 2012; 44: 47–50.
- Algurén B, Lundgren-Nilsson Å, Sunnerhagen KS. Facilitators and barriers of stroke survivors in the early post-stroke phase. Disabil Rehabil 2009; 31: 1584–1591.
- SFS, 1982: 763. [Health and Medical Act]. In: Swedish statute book. Liber AB: Stockholm; 2009 (in Swedish).
- 8. SFS, 2001: 453. [Social Service Act]. In: Swedish statute book. Liber AB: Stockholm; 2009 (in Swedish).
- Jones F, Mandy A, Partridge C. Reasons for recovery after stroke: a perspective based on personal experience. Disabil Rehabil 2008; 30: 507–516.
- Weigl M, Cieza A, Andersen C, Kollerits B, Amann E, Stucki G. Identification of relevant ICF categories in patients with chronic health conditions: a Delphi exercise. J Rehabil Med 2004; Suppl 44: 12–21.
- Stucki G, Reinhardt JD, Grimby G, Melvin J. Developing "human functioning and rehabilitation research" from the comprehensive perspective. J Rehabil Med 2007; 39: 665–671.

- 12. Prigatano GP. The importance of the patient's subjective experience in stroke rehabilitation. Top Stroke Rehabil 2011; 18: 30–34.
- Banja JD. Stroke rehabilitation and the phenomenological experiences of persons with acquired brain injury. J Rehabil Med 2008; 40: 89–95.
- Eriksson A, Park M, Tham K. Belonging: a qualitative, longitudinal study of what matters for persons after stroke during one year of rehabilitation. J Rehabil Med 2010; 42: 831–838.
- Ekman I, Swedberg K, Taft C, Lindseth A, Norberg A, Brink E, et al. Person-centered care- ready for prime time. Eur J Cardiovasc Nurs 2011; 10: 248–251.
- Reed MC, Wood V, Harrington R, Paterson J. Developing stroke rehabilitation and community services: a meta-synthesis of qualitative literature. Disabil Rehabil 2012; 34: 553–563.
- Outpatient Service Trialists. Therapy-based rehabilitation services for stroke patients at home. Cochrane Database of Systematic Reviews 2003, Issue 1. Art. No.: CD002925. DOI: 10.1002/14651858. CD002925.
- 18. Tistad M, Ytterberg C, Tham K, von Koch L. Poor concurrence between disabilities as described by the patients and established assessment tools three months after stroke: a mixed method approach. J Neurol Sci 2012; 313:160–166.
- The National Board of Health and Welfare. [National Assessment 2011 – Stroke Care. County Council Assessment – Summary] (in Swedish). Summary available in English from: http://www.socialstyrelsen.se/publikationer2011/2011-11-3.
- Lund A, Michelet M, Kjeken I, Wyller TB, Sveen U. Development of a person centered life-style intervention for older adults following a stroke or a transient ischemic attack. Scand J Occup Ther 2011; 19: 1–10.
- 21. Geyh S, Cieza A, Schouten J, Dickson H, Frommelt P, Omar Z, et al. ICF Core set for stroke. J Rehabil Med 2004; Suppl 44: 135–141.
- 22. Geyh S, Kurt T, Brockow T, Cieza A, Ewert T, Omar Z, et al. Identifying the concepts contained in outcome measures of clinical trials on stroke using the international classification of functioning, disability and health as a reference. J Rehabil Med 2004; Suppl 44: 56–62.
- Algurén B, Lundgren-Nilsson Å, Sunnerhagen KS. Functioning of stroke survivors – a validation of the ICF core set for stroke in Sweden. Disabil Rehabil 2010; 32: 551–559.
- 24. Rentsch H, Buchner P, Nyffler I, Wolf C, Hefti H, Fluri E. The implementation of the international classification of functioning disability and health (ICF) in daily practise of neurorehabilitation: an interdisciplinary project at the Kantonsspital of Lucerne, Switzerland. Disabil Rehabil 2003; 25: 411–421.
- Goljar N, Burger H, Vidmar G, Leonardi M, Marincek C. Measuring patterns of disability using the international classification of functioning disability and health in the post-acute stroke rehabilitation settings. J Rehabil Med 2011; 43: 590–601.
- Lincoln YS, Cuba EG. Naturalistic Inquiry. Thousand Oaks, CA: Sage Publications; 1985.
- Kvale S, Brinkman S. Interviews. Learning the craft of qualitative research interviewing. 2nd ed. Thousand Oaks, CA: Sage Publications; 2008.
- 28. Denzin NK, Lincoln YS. The Sage handbook of qualitative research. 4th edn. Thousand Oaks, CA: Sage Publications; 2011.
- 29. Hsiu-Fang H, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res 2005; 15: 1277–1287.
- Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse Educ Today 2004; 24: 105–112.
- Cieza A, Geyh S, Chatterji S, Kostansjek S, Ustun B, Stucki G. ICF linking rules: an update based on lesson learnt. J Rehabil Med 2005; 37: 212–218.
- 32. Sangha O, Stucki G, Liang MH, Fossel AH, Katz JN. The self-administered comorbidity questionnaire: a new method to assess comorbidity for clinical and health services research. Arthritis

- Rheum 2003; 49: 156-163.
- 33. Glaser BG, Strauss AL. The discovery of grounded theory. Strategies for qualitative research. Chicago: Aldine; 1967.
- Stucki G. International Classification of Functioning, Disability, and Health (ICF): a promising framework and classification for rehabilitation medicine. Am J Phys Med Rehabil 2005; 84: 733–740.
- 35. Allet L, Bruge E, Monnin D. ICF: Clinical relevance for physiotherapy? A critical review. Adv Physioter 2008; 10: 127–137.
- Kuipers P, Foster M, Smith S, Fleming J. Using ICF-Environment factors to enhance the continuum of outpatient ABI rehabilitation: an exploratory study. Disabil Rehabil 2009; 31: 144–151.
- 37. Robinson J, Wiles R, Ellis-Hill C, McPehrsson K, Hydman D, Ashburn A. Resuming previously valued activities post-stroke: who or what helps? Disabil Rehabil 2009; 31: 1555–1566.
- 38. Gubrium JF, Rittman MR, Williams C, Young ME, Boylstein CA. Benchmarking as everyday functional assessment in stroke recovery. J Gerontol B Psychol Sci Soc Sci 2003; 58: 203–211.
- 39. Fish J, Manly T, Emslie H, Evans J, Wilson BA. Compensatory strategies for acquired disorders of memory and planning. Differential effects of a paging system for patients with brain injury of traumatic versus cerebrovascular aetiology. J Neurol Neurosurg Psychiatry 2007; 26: 2–13.
- 40. Coenen M, Cieza A, Stamm TA, Amann E, Kollerits B, Stucki G. Validation of the International Classification of Functioning, Disability and Health (ICF) Core Set for rehaumatoid arthritis from the patient perspective using focus groups. Arthritis Research & Therapy 2006; 8: Available from: http://arthritis-reasearch.com/content/8/4R84.

