

Community dwelling person's perspective on functioning after stroke

**-Applying Comprehensive International Classification of Functioning Disability and
Health (ICF) Core Set for stroke**

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Dedicated to Elena and Arleena

Some people regard disability simply as a form of discrimination, thereby locating it entirely as something that society does to people who are different from the majority.

What is disability? DisabilityInformation.com.

Abstract

Background: Stroke is the second most common cause of death worldwide after ischaemic heart disease and the most common cause of long-term disability in adults. Disability following stroke results from the interaction between persons with impairments and environmental barriers that hinder full participation in society. The International Classification of Functioning, Disability and Health (ICF) is intended to record a wide range of information about health-related states and to standardize the assessment of functioning of individuals in everyday life. To facilitate the use of the ICF in clinical practice, purpose specific category-lists such as Comprehensive ICF Core Sets for stroke have been developed.

Aim: This research project explored whether the Comprehensive ICF Core Set for stroke could serve as a basis for understanding persons with previous stroke's perspective on functioning problems in daily activities. The thesis is comprised of four studies. The face validity of the Comprehensive ICF Core Set for stroke was explored in studies I and II. The construct validity of the Comprehensive ICF Core Set for stroke was explored in study III. In study IV the influence of personal factors (PF) age, gender, place of residence and time since onset of stroke on self-perceived functioning was explored using the Comprehensive ICF Core Set for stroke as a framework.

Participants: A total of 357 community-dwelling persons (45 % women) with previous stroke.

Methods: Studies I and II. Qualitative interviews in Sweden (n=22) and in Finland (n=22). The participants' perspective on functioning in everyday life was linked to ICF categories. Study III. A cross-sectional study (n=242). The distribution of item scores from the Stroke Impact Scale with respect to the ICF category scores were analysed using descriptive statistics, Chi-square test for independence with Yates continuity correction, phi coefficient, percent of agreement, Kappa statistics and odds ratio.

Study IV. Cross-sectional study (n=243). Regression analysis of 4 selected PF's was used to explore their influence on perceived functioning and environmental factors, using the Comprehensive ICF Core Set for Stroke as a framework. **Results:** In Study I. 99 (76%) of 130 in the first version and in Study II. 115 (68%) of 166 2nd level ICF categories in the second version of the Comprehensive ICF Core Set for stroke were validated. Study III. Construct validity of 22 of 31 ICF categories linked to SIS items was supported by the findings. The number of patient-reported problems in the SIS domains emotional and social participation was evidently higher than number of health-professionals assessed problems in ICF categories linked to these domains. Study IV. The selected personal factors had statistically significant predictive values for almost all the categories, domains and components of functioning and environmental factors examined. **Conclusion:** The results support the assumption that the categories included in the Comprehensive ICF Core Set for stroke represent the typical spectrum of functioning problems among people with previous stroke. The face validity of the Comprehensive ICF Core Set for stroke was largely confirmed by individual interviews. All categories included in the Comprehensive ICF Core Set for stroke were validated in study III. The construct validity of ICF categories linked to SIS items was partly validated. The influence of selected personal factors on self-perceived functioning and environmental factors was confirmed in study IV. In conclusion, the use of the Comprehensive ICF Core Set for stroke can provide a wider perspective of and a systematic coding system for understanding the needs of persons with previous stroke and has the potential to be used in the development of measures used in the assessment of stroke related functioning problems and stroke rehabilitation ultimately leading to better person centred care and outcomes.

Populärvetenskaplig sammanfattning

Stroke är den näst vanligaste dödsorsaken i världen och den vanligaste orsaken till funktionsnedsättning inklusive rörelsehinder för vuxna. Funktionsproblem efter stroke är resultat av interaktionen mellan problem i kroppsfunktioner och omgivningsfaktorer som utgörs av den fysiska, sociala och attitydsmässiga omgivning en person lever i. ICF bygger på en kombination av den medicinska och den sociala begreppsmodellen och använder en ”biopsykosocial” inriktning för att beskriva hälsa och hälsorelaterade tillstånd. ICF Core Sets är ett standardurval (core sets) av kategorier i syfte att konstruera en bred bild av individens funktionstillstånd/ funktionshinder och hälsa och kan användas för att minska risken för individen viktiga livsområden förbises inom hälso-och sjukvården. Syftet med forskningsprojektet var att undersöka om ICF Core Set för stroke skulle kunna tjäna som grund för att ge ökad förståelse av personer med stroke och deras perspektiv på funktionsproblem i dagliga aktiviteter. Avhandlingen består av fyra delstudier. Uppenbar validitet av ICF Core Set för stroke undersöktes genom intervjuer av personer med stroke i studie I och II i Sverige och i Finland. Begreppsvaliditet av ICF Core-Set för stroke undersöktes i studie III genom att undersöka sambandet mellan resultatet för en stroke specifik mätinstrument Stroke Impact Scale (SIS) och ICF Core Set för stroke. I studie IV undersöktes påverkan av utfallet av ICF core sets från ålder, kön, bostadsort och tid sedan insjuknandet i stroke på funktionstillstånd/ funktionshinder. I de olika studierna deltog totalt 357 personer (45 % kvinnor) med stroke. I arbetet användes olika metoder: I studie I och II undersöktes deltagarnas perspektiv på funktionstillstånd/funktionshinder i dagliga aktiviteter med hjälp av individuella intervjuer och därefter kvalitativ analys.

I de två andra studierna användes kvantitativ metodik. I studie III gjordes sambandsanalyser mellan patientrapporterade problem i SIS och vårdpersonalens rapporterade problem i ICF Core Set för stroke.

I studie IV undersöktes 4 personliga faktorer (ålder, kön, bostadsort och tid sedan insjuknandet i stroke) påverkan på resultatet av ICF core sets, med hjälp av regressionsanalys. Resultaten från studie I och II visar att de flesta kategorier inkluderad i ICF Core-Set för stroke kunde validerades med hjälp av personernas berättelser. Sambandet mellan patientrapporterade problem i SIS och vårdpersonal rapporterade problem i Core Set för stroke kunde till viss del styrkas i studie III. I studie IV visades de studerade 4 PF hade prediktiv influens på nästan alla ICF kategorier, domäner och komponenter inkluderad i ICF Core Set för stroke. Sammanfattningsvis visar arbetena i avhandlingen att de flesta kategorier inkluderade i ICF Core-Set för stroke har uppenbar validitet. Begreppsvaliditeringen kunde visas i 22 av 31 ICF kategorier som ingår i ICF Core-Set för stroke. PFs inverkan på ICF core sets har också visats.

Avhandlingen styrker användningen av ICF Core-Set för stroke och att dessa kan ge ett bredare perspektiv på funktionstillstånd/funktionshinder och omgivningsfaktorer. ICF Core-Set för stroke kan användas för att öka förståelsen av person med stroke perspektiv på funktionstillstånd/funktionshinder i vardagen och i utveckling av bedömningsinstrument och person-centrerad stroke rehabilitering.

LIST OF ORIGINAL PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals.

- I. Markku Paanalahti, Åsa Lundgren-Nilsson, Anton Arndt and Katharina S. Sunnerhagen. Applying the Comprehensive International Classification of functioning, disability and health Core Sets for Stroke framework to Stroke survivors living in the community. *J Rehabil Med.* 2013 Apr; 45(4):331-40.
- II. Markku Paanalahti, Margit Alt-Murph, Åsa Lundgren-Nilsson and Katharina S. Sunnerhagen. Validation of the Comprehensive ICF Core Set for stroke by exploring the patient's perspective on functioning in everyday life: a qualitative study. *Int J Rehabil Res.* 2014 Jul 17, [Epub ahead of print], PMID 25035909.
- III. Markku Paanalahti, Åsa Lundgren-Nilsson, Guna Berzina, Anton Arndt and Katharina S. Sunnerhagen. Association of item scores in patient-reported Stroke Impact Scale (SIS) with respect to scores in health professionals assessed Comprehensive International Classification of Functioning, Disability and Health (ICF) Core Set for stroke. Manuscript.
- IV. Guna Berzina, Markku Paanalahti, Åsa Lundgren-Nilsson, Katharina S. Sunnerhagen. Exploration of some personal factors with the International Classification of Functioning, Disability and Health Core Set for stroke. *J Rehabil Med* 2013; 45: 609–615.

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CONTENTS

LIST OF ORIGINAL PAPERS.....	9
CONTENTS	10
ABBREVIATIONS	13
PREFACE.....	14
1 INTRODUCTION	15
1.1 Stroke	15
1.2 Epidemiology of stroke.....	16
1.3 Consequences of stroke.....	17
1.4 Person perspective on functioning in daily activities after stroke	18
1.5 Rehabilitation	20
1.6 Stroke rehabilitation in the community.....	20
2 THEORETICAL AND METHODOLOGICAL FRAMEWORK	22
2.1 International Classification of Functioning, Disability and Health (ICF)	23
2.2 ICF background	24
2.3 ICF framework for the description of functioning and disability	25
2.4 ICF Core Sets	27
2.5 ICF Core Sets for stroke.....	27
2.6 Qualitative research design, exploring the person perspective of functioning	29
3 AIM OF THE THESIS	30
4 METHODS	31
4.1 Study designs and population	31
4.2 Assessment methods	33
4.3 Procedures and data collection (studies I-IV)	37
4.3.1 Qualitative design in studies I and II	37
4.3.2 Cross-sectional design in studies III and IV	43
4.3.3 Ethical Considerations	48
5 RESULTS	49
5.1 Results in qualitative studies I and II.....	49
5.2 Results in studies III and IV.....	61
6 DISCUSSION.....	73
7 CONCLUSION	90
8 FURTHER RESEARCH	90

ACKNOWLEDGEMENT	91
APPENDIX 1.	95
REFERENCES	103

ABBREVIATIONS

b	Body Functions in the ICF
CI	Confidence Interval
CRF	Case Record Form
d	Activities and Participation in the ICF
e	Environmental Factors in the ICF
ICD	International Classification of Diseases and Related Health Problems
ICD-10	International Classification of Diseases and Related Health Problems 10 th Revision
ICF	International Classification of Functioning, Disability and Health
ICIDH	Classification of Impairments, Disabilities and Handicaps
mRS	Modified Rankin Scale
PF	Personal Factors
SCQ	Self-administered Comorbidity Questionnaire
SIS	Stroke Impact Scale
SPSS	Statistical Packages for Social Sciences
WHO	World Health Organization

PREFACE

Disability is part of the human condition that concerns almost everyone permanently or temporarily at some point in life and as we get older we will commonly experience increasing difficulties in functioning. Disability results from the interaction between persons with functional limitations and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others (1). Article 26 of the United Nations Convention on the Rights of People with Disabilities emphasises the need for comprehensive rehabilitation services and programs to aid people with disabilities to attain and maintain maximum independence and full inclusion and participation in all aspects of life. Article 26 also states that disability should clearly be seen as the result of the interaction between a person and his/her environment (2). Fundamental to advancing the knowledge of disability and its impact on individual lives and society as a whole is the ability to communicate with one another and to speak in a common language that is understood across related professional fields and disciplines and also by the people with disabilities (3-5). Unifying a conceptual model and taxonomy of human functioning is consequently required for the successful development of rehabilitation practice and research. An general and widely accepted theoretical framework such as the International Classification of Functioning, Disability and Health (ICF) (6) could act as a roadmap permitting all stakeholders to talk the same language and strive for the same goals. Greater understanding of the rehabilitation process by both the rehabilitation practitioner (7) and persons with previous stroke can ultimately lead to better outcomes (8, 9).

To facilitate the use of the ICF in clinical practice, purpose specific category-lists such as Comprehensive ICF Core Set for stroke (10) have been developed. This research project explored whether the Comprehensive ICF Core Set for Stroke (10) could serve as a basis for systematic documentation and understanding of the person perspective and add knowledge for development of person centred stroke rehabilitation and measures used in the assessment of stroke related functioning problems.

1 INTRODUCTION

1.1 Stroke

The word stroke is used to refer 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 hours or leading to death with no apparent cause other than of vascular origin” (11). Stroke was first catalogued as apoplexy “struck with violence” by Hippocrates more than 2,000 years ago (12) to denote a disease in which the patient falls to the ground, often suddenly, and lies without sense or voluntary motion. The term cerebrovascular accident was introduced in 1928 when the apoplexy was divided into categories based on the cause of the blood vessel problem (haemorrhage or obstruction). This led to the terms stroke or "cerebrovascular accident" (13, 14). In the 1970s the World Health Organization (WHO) defined stroke as a "neurological deficit of cerebrovascular cause that persists beyond 24 hours or is interrupted by death within 24 hours"(15) as the disruption of blood flow to the brain is not an accident, but is caused by diseases of the circulatory system.

1.2 Epidemiology of stroke

Stroke is the second most common cause of death worldwide (16, 17) and the most common cause of long-term disability in adults (18). The predicted increase of stroke frequency (16) along with other non-communicable diseases in the future means that disability is also a growing problem, especially in rapidly developing regions (1, 19).

In Sweden, stroke is one of the main public health problems and the most common cause of disability in the adult population as well as one of the main causes of death (20).

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 Euros per year (21). In Sweden the mean age at first-ever stroke for women is 77, 5 and for men 73, 6 years (22). The stroke incidence has increased relatively more among young < 65 (23) and in old > 75 persons (1995-2008) compared to the intermediate age group, but higher frequency of strokes in the older group leads to the higher mean age (24). In Finland, the annual stroke incidence has increased from 10,225 to 10,763 first-time strokes (1999-2007), the stroke prevalence is estimated at 82 000, or 1.5% of the national population (25, 26). The reports of growing stroke incidence among younger persons in the developed countries (24, 27) and of increasing stroke related disability in the low- and middle-income countries (19) stress the need to expand stroke rehabilitation further than the acute management of stroke. The persons with previous stroke ability to manage activities of daily living and full participation in community life should be prioritized in stroke rehabilitation when the acute phase of stroke is over (27-29).

1.3 Consequences of stroke

Stroke is a multifaceted and complex disease and no stroke is the same. The problems facing survivors of stroke are usually complex and heterogonous (30, 31) and people's experiences of disability are extremely varied (32, 33). At least 40% of stroke incidences cause persistent neurological impairments that affect functional abilities and participation (34, 35), thus stroke has severe consequences for the individual, the family and health care (20, 36).

The sequel after a stroke may include motor, sensory, perceptual or cognitive deficits which may exacerbate any stroke-related disability leading to various functioning problems and physical inactivity (37, 38). The presence of depressive mood symptoms post stroke is common (39-41) as is pain, although this does not necessarily affect the health-related quality of life (42).

Decline in mobility is an essential concern for the person with previous stroke since it might lead to dependency in activities of daily living and affect social reintegration (29, 43).

Limitations in the ability to participate and feelings of frustration "not recognized as the person I am" (44) as well as feelings of uncertainty and confusion are shared after stroke (45, 46). Previously taken-for-granted activities like taking a shower, dressing, eating, bed making and vacuuming, are associated with considerably greater energy requirements post stroke. The energy cost of walking after stroke can be up to twice that of able-bodied persons (47).

Today more persons with a previous stroke also live alone compared to 1995, which has led to an increased demand for municipal home-help services in Sweden (24). Half of the persons with previous stroke living at home 3 months after stroke reported that they were partly or entirely dependent on support by next-of-kin (48).

There is evidence that the dependency on the support from next-of-kin has increased and that when available spouses provide all, or some, of the service needed (24, 49). There is also a growing awareness of the necessity to include not only the person with previous stroke but also the immediate family as clients to be able to systematically assess the social environment and to provide services in accordance with needs (36). Thus the home environment can be considered as a natural health-care setting for community dwelling people with previous stroke (34, 50).

1.4 Person perspective on functioning in daily activities after stroke

When the ability to engage in valued activities in everyday life is interrupted because of stroke, there is a question of how emotions, expectations and meaning of life are shaped and reshaped over time. In the early rehabilitation process functional abilities such as levels of independency in activities of daily living, e.g. manageability in self-care, are prominent (51). In the long term, acceptance of life changes (46, 52), engagement in new roles and activities and social support appear to be key factors in post-stroke adjustment (44-46, 53, 54).

For the long term stroke survivors the social and personal context of long-term recovery and adjustment to disability beyond physical functioning (55), as well as participation in valued activities are associated with enhanced quality of life (46).

However, the person perspective is still rarely understood (44, 56, 57) nor taken into account when planning relevant health care interventions (58) because the comprehensive understanding of the needs of persons with previous stroke is still incomplete (59).

In a 2010 study in Sweden, community-dwelling persons with previous stroke frequently reported that they had not received enough individual support or rehabilitation (60). In a study from Finland in 2010 the authors stated that the facts concerning the functional level of persons with previous stroke in terms of activities of daily living are unknown (25). Several studies report differences in the prevalence of participation restrictions among people with previous stroke (28, 59, 61-63). These findings indicate that the multidimensional concept concerning participation and many other aspects of the phenomenon of disability among people with previous stroke remain inaccessible or incomprehensible to us (64).

The correlation between disability and well-being is not fully understood (63, 65-68) and the progress in recovery from stroke is still viewed primarily as a matter of regaining physical functioning in which the burden of recovery is on the person (40, 56, 69).

It can be argued that the central reason for this discrepancy is the lack of comprehensive understanding of human functioning, current limitations in rehabilitation research (3, 70, 71) and that the health care professionals and leaders still have dissimilar understanding of structures, goals, processes and end results of the health care and how it should be organized (72-74). Also the large varieties of discipline specific measures currently in use for neurological conditions refer to an enormous variety of concepts and different aspects of functioning measures (9, 75, 76). The everyday lives of people with previous stroke are affected in a variety of ways not easily captured by these often discipline specific measures (9, 75, 77).

The absence of consensus of the concepts to be taken into account when addressing stroke (78) can lead to ineffective rehabilitation services if they are not based on problems experienced by the person with previous stroke (55, 56, 64).

Indeed, after stroke, “inability to occupy one’s time in a manner appropriate to one’s age, sex, and background is by far the most problematic of all areas assessed” (79).

1.5 Rehabilitation

According to the WHO “Rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels” and “rehabilitation provides disabled people with the tools they need to attain independence and self-determination” (80).

This bio-psychosocial integrative model (6, 70) of rehabilitation includes recovery of body structures and functions and facilitation of activities and participation by including environmental- and personal factors as components in comprehensive rehabilitation. The acknowledgement of the integrative model of rehabilitation has widened the scope of rehabilitation from treatment designed to facilitate the process of recovery from injury or disease to promote performance in everyday life (2) as well as to protect human rights (81). Consequently stroke rehabilitation is a process to achieve functionality, independence and participation in society to the maximum for meaningful life after stroke (82).

1.6 Stroke rehabilitation in the community

The community life after stroke includes the physical and social environment of the person with previous stroke where she or he lives including a nursing home or residential care home if it is the patient’s long-term accommodation.

Community rehabilitation is a process that centrally involves the person with previous stroke in making plans and setting goals that are important and relevant for themselves (83, 84). The home environment offers professionals working in multidisciplinary teams opportunities to enable persons with previous stroke to influence their rehabilitation process and implement an individualized rehabilitation program that varies in duration, content and frequency (69, 85).

This means that in the community health care health professionals, social workers and home help services (i.e. the team of people who can assess and help with most problems commonly faced by persons with previous stroke) go beyond simply working together and setting goals discipline by discipline but that the goals are set according to the needs and goals of the person with previous stroke (65). The challenge in the community health care is that professionals, who are generally not specialized in stroke rehabilitation (86) need to recognize rehabilitation needs and provide appropriate rehabilitation interventions and support for the person with previous stroke. The needs of people with previous stroke also continue to change over time and these should be reviewed regularly so that they can adapt to these changes (52, 53).

In Sweden stroke rehabilitation is commonly a multidisciplinary chain of care from the stroke unit at the hospital to the delivery of community health care services after returning home.

The rehabilitation process in community involves health professionals (with or without specialized knowledge of stroke rehabilitation), home- help services (including home modifications for people with disabilities), and social workers in order to make it possible for people to return to their homes. Although Swedish stroke care is continually improving (48, 87, 88) there are still many patients that do not have access to dedicated stroke units and an unchanged proportion of persons with previous stroke state that the support they have received from health care and community is insufficient (48).

Most health care is still structured around acute episodes and the patients often must adapt to the customs and usual procedures of health care organizations and professionals, rather than receiving care designed to focus on the needs, preferences and values of persons with previous stroke over a period of years or even decades (41, 58, 89).

Much effort is required to develop services that are responsive to the needs of persons with previous stroke enabling them to live healthier and fuller lives as well as help them to integrate back into the community life (90-92). The individual alone can no longer be considered responsible for managing their disability as there is also a societal responsibility for removing barriers to full participation (4, 6, 65). The evaluation of the effectiveness of outpatient services is of key importance to the delivery of efficient evidence-based stroke care and it relies on the comprehensive understanding and awareness of the people with previous stroke needs (32, 34, 44, 55).

2 THEORETICAL AND METHODOLOGICAL FRAMEWORK

Obtaining the perspective of persons with previous stroke concerning perceived functioning problems in daily activities is a key component for the development of measures used in the assessment of stroke related function problems, effective stroke rehabilitation and to support health care decisions that are important to the persons with previous stroke, caregivers and clinicians (58, 93, 94).

A growing body of evidence indicates that patients do better with a well-organized, multidisciplinary approach to rehabilitation that can cut healthcare costs by reducing length of stay at hospital and by preventing functioning problems in daily activities (31, 32, 84, 95-97). As a universal framework, the integrative approach of the ICF could be used for the development of the multidisciplinary approach to rehabilitation by enhancing broader understanding of the person with previous stroke functioning problems in daily activities across related professional disciplines ultimately leading to better outcomes (6, 98-100).

2.1 International Classification of Functioning, Disability and Health (ICF)

To advance the understanding of disablement in a comprehensive manner the ICF of the WHO was developed as a common framework to understand health and to describe the impact of health condition on an individual's functioning (6). The competing conceptual models of disability i.e. the medical model versus the social model of disability are combined in the ICF in a bio-psychosocial model (3, 70), which provides the basis for the new approach to understanding disability and health (6). The aims of the ICF are: to establish a common language to improve communication across disciplines and sectors; to provide a systematic coding scheme for health care information systems; to provide a scientific basis for understanding health and health-related states, outcomes and determinants; to enable data comparison across different countries, health care systems, services and among health conditions (6).

2.2 ICF background

The increase in the phenomenon of chronicity in the late 1960s made the WHO aware of the inadequacy of the International Classification of Diseases (ICD) for rehabilitation and compensation purposes (101). ICD provides a classification system for diseases, disorders, and injuries but does not take into consideration the realities experienced by persons with chronic disabilities when the acute phase of the illness is over. Consequently the curative medical model is incomplete and the necessity of understanding the needs of people living with chronic functional and social consequences of diseases and traumas was acknowledged (101-103).

For that purpose the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (79) was developed by WHO in 1980 to classify the consequences of health conditions and trauma but was also found incomplete because it advocates biomedical tradition i.e. disease, disorder or injuries as a cause of the disability (104, 105).

This led to revision of the ICIDH and the new classification ICF was officially endorsed by all 191 WHO Member States in 2001. The origin of the ICF lies in the Nagis Disablement model (5, 102, 103), further conceptualized in the “Disablement process” by Verbrugge and Jette (5). In accordance with the Nagi’s Disablement Model (103), the ICF framework (6) attempts to provide a coherent bio-psychosocial view of health states from a biological, personal, and social perspective (4, 105).

2.3 ICF framework for the description of functioning and disability

As the international standard for health and disability information, the ICF intends to cover all human functioning and treats disability as a continuum rather than categorizing people with disabilities as a separate group. I.e. disability is a matter of “more or less”, not “yes or no” and the ICF therefore, recognises the complex interaction between a person’s health condition and contextual factors. The ICF has a comprehensive bio-psychosocial view on functioning in terms of interaction between the individual and environment. ICF organises information in two parts. Part 1 includes components of body functions (b) and structures (s) and activities and participation (d), and Part 2 contextual factors, components of environmental (e) and personal factors (pf) (Figure 1).

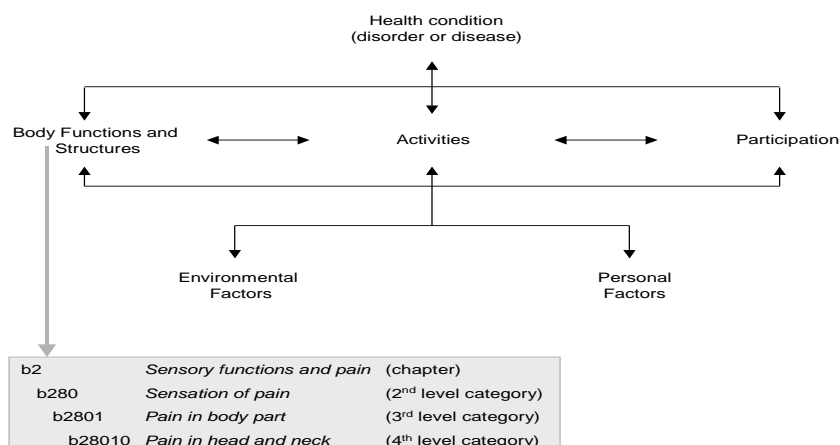


Figure 1. Current understanding of the framework of the ICF. The functioning of an individual in a specific domain reflects an interaction between the health condition and the contextual: environmental and personal factors. The ICF is a hierarchical classification. The information coded at the 4th level of the classification is preserved at the 2nd level, as well.

The term disability describes the consequences of *impairments* in body functions and structures, *limitations* in activities and *restrictions* in participation on functioning (Part 1.) always in interaction with the environmental and personal factors (Part 2.). Environmental factors can either facilitate or build barriers on the person's functioning in the physical, social and attitudinal environment in which people live and conduct their lives. Personal factors (e.g. age, sex, lifestyle, habits, coping etc.) which can have a positive or negative influence on disability and functioning, are included in the conceptual framework and their development is on-going (106, 107) but they are not yet classified due to the large individual differences that exist. The term health condition is used as an umbrella term for disease, disorder, injury/trauma and can be coded using International Classification of Diseases (ICD) -10 (6).

To evaluate the extent of a person's problems in each ICF category, the qualifier scale proposed by the WHO can be used. This scale has 5 response categories for body functions and activities and participation ranging from 0 to 4: 0 = no problem; 1 = mild problem; 2 = moderate problem; 3 = severe problem; 4 = complete problem.

For body structures the qualifier scale has 9 response categories that are used to indicate the nature of the change in the respective body structure: 0 no change in structure, 1 total absence, 2 partial absence, 3 additional part, 4 aberrant dimensions, 5 discontinuity, 6 deviating position, 7 qualitative changes in structure, including accumulation of fluid, 8 not specified and 9 not applicable. For environmental factors, the qualifier scale also has 9 response categories: 0 (no barrier or facilitator), 1 to 4 (mild/moderate/severe/complete barrier), and +1 to +4 (mild/moderate/severe/complete facilitator). In addition, there are the response options 8 (not specified) and 9 (not applicable).

The drawback of the ICF is that it contains 1424 categories that make it difficult to use in clinical situations and in research. There is also criticism towards the use of personal factors as defined in the ICF because at the present time there is no taxonomy of codes and no guidelines how it should be used (108). The reliability of the ICF qualifier scale has also been found to be inconsistent (109, 110) and should be further investigated (111).

2.4 ICF Core Sets

The ICF Core Set project began in 2001 to improve the feasibility of the ICF from the user perspective (112, 113) by developing purpose specific category-lists, the ICF Core Sets, for 12 health conditions (10, 113-115). The ICF Core Sets are aimed to structure the needs of an individual in a systematic way and reduce risk for missing important aspects of functioning taken into account in clinical practice and research (115, 116). The ICF Core Sets are used in a comprehensive or in brief versions (112). The Comprehensive ICF Core Sets are intended to be used in multidisciplinary rehabilitation settings and the Brief ICF Core Sets are aimed to provide the minimal a standard for assessment of health and functioning in any clinical setting. The further development and validation of the ICF Core Sets for various applications is an ongoing process (116).

2.5 ICF Core Sets for stroke

The Comprehensive ICF Core Set for stroke (10) is assumed to include the typical spectrum of problems in functioning of people with previous stroke (7).

Altogether, 130 second level ICF categories were included in the first version of the Comprehensive ICF Core Set for stroke in 2004 (10) including 41 categories from the component body functions, 5 from the component body structures, 51 from the component activities and participation, and 33 from the component environmental factors. In 2005 the Comprehensive ICF Core Set for stroke was extended with 36 ICF categories from the Core Sets for persons with neurological conditions in the acute and early post-acute phases to enable its use in all clinical situations (117-119). Therefore the term “extended version” of the Comprehensive ICF Core Set for stroke including 166 categories (Appendix 1) at the second-level of the classification, 59 categories of body functions, 11 categories of body structures, 59 activities and participation categories and 37 environmental factors (120) is also used in the literature. The large set of ICF categories included in the Comprehensive ICF Core Set for stroke (10) reflects how the stroke affects nearly all aspects of functioning and health.

The brief ICF Core Set for stroke comprises 18 second level ICF categories, which represent 14% of the 130 2nd level categories from the Comprehensive ICF Core Set (109) for stroke including 6 categories from the component body functions, 2 categories from body structures, 7 from activities and participation and 3 from environmental factors.

The Comprehensive ICF Core Set for stroke has been content validated from the perspective of international physicians, occupational therapist, physical therapist, among chronic stroke outpatients in three Brazilian rehabilitation facilities and using focus groups in Germany (120-124). In Sweden the Comprehensive ICF Core Set for stroke has been assessed in the first 3 months and 1 year post stroke (51, 125, 126).

The content validity of the Comprehensive ICF Core Set for stroke has been largely supported in the previous studies.

In this thesis the terms first-, or second version of the Comprehensive ICF Core Set are used when relevant. At the time of this thesis the ICF Research Branch, ICF Core Set project, a partner of the WHO Collaborating Centre for the Family of International Classifications (WHO-FIC) in Germany has not yet published the final version of the Comprehensive ICF Core Set for stroke (127).

2.6 Qualitative research design, exploring the person perspective of functioning

Qualitative methodology is increasingly accepted in health and in rehabilitation research often included in mixed-methodology-studies together with quantitative methods (128, 129).

Qualitative methodology provides access to the experiences of the person with previous stroke to better understand their perspective on disability and functioning to be able choose the assessment methods and interventions suited to the needs experienced by the person with previous stroke as well as to be able to support the person before, during and after the evaluation (54, 63, 130). Qualitative study has its origins in the holistic tradition and aim to explore, describe, understand and interpret the participants' experiences/views of a phenomenon and to gain increased understanding of a problem (131) as the reality is regarded as a construct created by humans, partly through social interactions in contrast to the positivist assumption that the reality is governed by universal laws. Qualitative research methods involve systematic collection of the subjective experiences of participants through interviews and observation and interpretation of a textual material. Interpretation of interview transcripts is an inductive process i.e. people's attitudes, needs, thoughts and motivation which might influence the course of disability and certainly rehabilitation outcomes, are explored through interviews to better understand what matters for a person with a previous stroke.

3 AIMS OF THE THESIS

The objective of this thesis was to validate the Comprehensive ICF Core Set for stroke by exploring the person with previous stroke perspective on functioning in everyday life. Aims of this thesis were: to investigate the face validity of the Comprehensive ICF Core Set for stroke from the perspective of persons with previous stroke in different environments (studies I and II); to investigate the construct validity of the Comprehensive ICF Core Set for stroke by exploring the association between the patient-reported item scores in the Stroke Impact scale (SIS) and the ICF category scores assessed by health professionals (study III) and to investigate the influence (criterion validity) of personal factors (PF) age, gender, place of residence and time since onset of stroke on self-perceived functioning and environmental factors using the Comprehensive ICF Core Set for stroke as a framework (Study IV).

The specific aims were:

Study I. The aims of this study were to explore the perspective of functioning in community-dwelling people with previous stroke and to validate, if possible, the Comprehensive ICF Core Set for stroke.

Study II. The purpose of this study was to validate the Comprehensive ICF Core Set for stroke by exploring the patient's living at home and receiving outpatient rehabilitation perspective on functioning in everyday life.

Study III. To investigate the construct validity of the Comprehensive ICF Core Set for stroke by exploring the association of patient-reported SIS scores with respect to the scores in the ICF categories linked to these items assessed by health professionals.

Study IV. The aim of this study was to explore the influence of PF's (i.e. age, gender, place of residence and time since onset of stroke) on self-perceived functioning and environmental factors, using the Comprehensive ICF Core Set for stroke as a framework.

4 METHODS

4.1 Study designs and population

The study population was comprised of 357 participants with previous stroke who were recruited in Sweden and in Finland between 2005 and 2007. Study I (n=22) was conducted in the municipality of Strömsund in Sweden. Twenty two persons with previous stroke were interviewed at their homes. Study II (n=22) was conducted at the Helsinki University Hospital in Finland. The participants were interviewed at the hospital's rehabilitation department. The participants in both studies I and II were people with previous stroke living at home and in contact with the municipality's multidisciplinary rehabilitation team (study I) or with the hospitals multidisciplinary rehabilitation team (study II). Study III (n=242) was a cross-sectional study, conducted in Gothenburg and in Strömsund in Sweden. The study IV (n=243) was also a cross-sectional study, conducted in Gothenburg in Sweden. One hundred and fifty people (41% female) included in studies III and IV were the same individuals. The participants were either former patients of a stroke unit or of a rehabilitation clinic, who were in contact with physical therapists in the community or recruited through a patient organization or in contact with the municipality's multidisciplinary rehabilitation team.

An overview of the study designs and, main analysis methods along with inclusion and exclusion criteria for participants is displayed in Table 1. A summary of demographic and clinical characteristics of participants included in studies I to IV is presented in Table 2. A chart of the study population in different studies is presented in Figure 2.

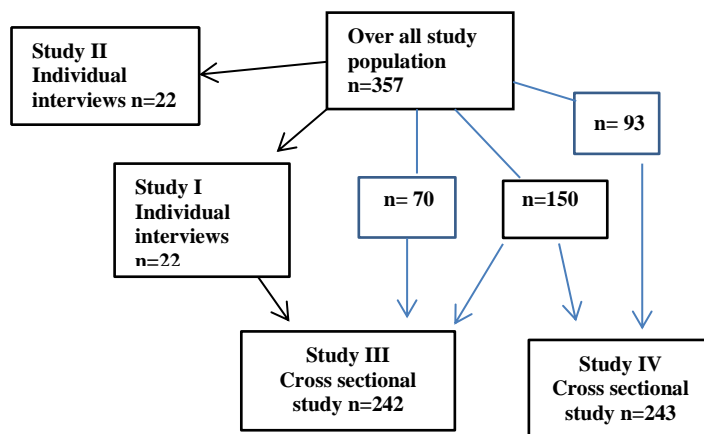


Figure 2. Chart of the study population in different studies.

Table 1. Overview of the study design, samples and, inclusion criteria in studies I-IV.

	Study I	Study II	Study III	Study IV
Design	Individual interviews	Individual interviews	Cross-sectional study	Cross-sectional study
Analysis	Inductive analysis of the transcribed text before deductive category application		Analysis of relationship	Analysis of relationship
Measurement assessed	Content validity	Content validity	Construct validity	Criterion validity
Subjects	Stroke, chronic (n=22)	Stroke, sub-acute and chronic (n=22)	Stroke, sub-acute and chronic (n=242)	Stroke, chronic (n=243)
Recruitment	Purposeful sampling strategy	Purposeful sampling strategy	Convenient sample	Convenient sample
Inclusion criteria	Main diagnosis stroke; a minimum 6 month's post stroke, with lasting neurological symptoms; Swedish speaking; able to give written informed consent; living at home; and in contact with the multidisciplinary homecare team	Prior stroke with lasting neurological symptoms, Finnish speaking, living at home and in contact with the multidisciplinary rehabilitation team.	A diagnosis of stroke ICD-10 codes I60–I67, clinically determined by specialists at stroke units according to WHO criteria (20) and confirmed by computed tomography (CT), an age of at least 18 and an ability to give written informed consent (or consent given by next of kin).	A diagnosis of stroke (ICD-10 codes I60–I67), clinically determined by specialists at stroke units according to WHO criteria (2) and confirmed by computed tomography (CT); age at least 18 years and having given written informed consent (or consent given by next of kin); time from onset of stroke of at least 6 months.

Table 2. Demographic data and clinical characteristics of the participants in all four studies.

	Study I	Study II	Study III	Study IV
Subjects, n	22	22	242	243
Male/Female	13/9	9/13	139/103	128/115
Age, years mean (min-max)	72.2 (58-87)	52.2 (32-60)	66.6 (21-96)	68 (24-95)
Infarct/Hemorrhage, n	19/3	20/2	118/69	155/40
not specified as haemorrhage or infarction	0	0	54	48
Time since stroke, months				
Mean (min-max)	64 (8-276)	12 (2.4-47)	40.6 (1-320)	33.3 (6–157)
Affected side of body				
none/ right/left/both	0/8/9/5	0/6/15/1	15/88/123/16	20/79/118/13 (no data 13)
Modified Rankin scale, n (%)				
0 – no disability	0	0	1	10
1 – no significant disability	6	2	44	55
2 – slight disability	6	7	70	68
3 – moderate disability	6	6	63	55
4 – moderately severe disability	4	6	58	50
5 – severe disability	0	1	2	3
No data	-	-	4	2

4.2 Assessment methods

Comprehensive ICF Core Set for stroke

In this thesis the perspective of persons with previous stroke on problems in daily activities was assessed by linking the reported problems to the ICF framework i.e. the Comprehensive ICF Core Set for stroke using ICF linking rules (132) in studies I to II. In studies III and IV the health professionals assessed the participants reported problems using the second version of the Comprehensive ICF Core Set for stroke as a reference during the semi-structured interviews. In study III the second version of the Comprehensive ICF Core Set for stroke was used as a framework to study the association between SIS item scores and ICF category scores.

In study IV the influence of 4 selected PF's on reported functioning problems in different domains and components of the ICF was assessed using the second version of the Comprehensive ICF Core Set as a framework. It is assumed that the integrative ICF model (6) requires the health professionals to document broader categorical functional profiles of individuals than the traditional one, which has concentrated only on the areas of body functions and structure (7).

ICF linking rules

The ICF linking rules (132, 133) were developed to facilitate systematic and standardized linking of concepts of the outcome measures and clinical assessment tools to the domains and categories, as represented by the ICF. The ICF linking process has shown to be a useful way (99) to apply the ICF classification in research but further investigation is required for reaching a standardized linking process when linking interview transcripts and free text to the ICF (99, 134, 135). The linking rules (132) do not clearly describe the process of establishing the meaningful concepts (134, 135) therefore content analysis (136-138) was used together with the linking rules to interpret the manifest components of the transcribed text (138) in studies I and II. This approach was used to help to confirm or conceptually extend a pre-existing theoretical framework (ICF) using first inductive analysis of text data that was later linked to the ICF framework by means of established linking rules (132).

According to the suggested linking rules (132), if the information provided by the meaningful concept was not sufficient for making a decision about the precise ICF category it should be linked to the meaningful concept was classified as not covered by the ICF or personal factor (as defined in the ICF) (6) and could not be linked to the ICF categories. Also meaningful concepts referring to health and to quality of life in general were classified as health condition, not definable-general health, not definable-physical health, not definable-mental health. I.e., not definable by the ICF (132) and could not be linked to the ICF categories.

Linking of the health status measure items to the ICF categories is also seen as an important part to enhance their concurrent use and implementation in clinical practice and research (112, 115, 133).

Stroke Impact scale (SIS)

The participants also filled in the Stroke Impact Scale (139) (Swedish version) to describe the consequences of the stroke except in study II which was conducted in Finland. The stroke-specific outcome measure SIS was developed from the perspective of persons with previous stroke, caregivers and health-professionals (139-141). The SIS version 3.0 includes 59 items and assesses 8 domains; strength (4 items), memory and thinking (7 items), emotion (9 items), communication (7 items), activities of daily living (10 items), mobility (9 items), hand function (5 items), and social participation (8 items) and the rating stroke recovery (139, 141). Each item is rated in a 5-point Likert scale in terms of the difficulty the patient has experienced in completing each item. The SIS has been tested for validity, reliability and sensitivity to change (139-141).

The results in the SIS were used in study III for comparison between the patient-reported problems in the SIS items and by the health professionals assessed problems in the ICF categories linked to the SIS items. The SIS items have previously been linked to ICF categories (75) included in the Comprehensive ICF Core Set for stroke using the suggested linking rules by Cieza et al (132). SIS items are linked to the ICF component of body function and activities and participation. None of the SIS items are linked to the ICF component of body structures or environmental factors (75). Two ICF categories b755 (involuntary movement functions) and d470 (using transportation) previously linked to the SIS items (75) were not included in the data-analysis because the authors of the present study considered that these categories could not be linked to specific SIS items. The SIS item 8g “your ability to control your life as you wish” is classified as not definable by the ICF (132) and was therefore not included in the data-analysis. The SIS item 8h “your ability to help others” was not included in the Swedish version of the SIS during the time of the study and was therefore also not included in the data-analysis.

Case Record Form for patients (studies I-IV)

The participants were asked to complete a Case Record Form (CRF) for patient’s questionnaire that comprises demographic information, condition-specific information, and the self-administered co-morbidity questionnaire (142) which is an instrument to assess comorbidity for clinical and health services research.

Modified Rankin Scale

The modified Rankin Scale (mRS) measures the overall functional independence of stroke patient's and consists of 7 grades (0 No symptom's at all – 6 Death) (143, 144).

The scale was developed by Dr John Rankin in 1957 (145). The interviewers assessed the person with previous stroke according to the modified Ranking Scale (mRS) (144, 146) in all four studies. The mRS results are presented as part of the person with previous stroke condition-specific information.

4.3 Procedures and data collection (studies I-IV)

4.3.1 Qualitative design in studies I and II

In studies I and II an individual interview method was chosen to study the person with a previous stroke perspective of perceived functioning problems in daily activities. Individual interviews (131) with each participant were considered as the most suitable approach to study this specific group of persons. The interviews were tape-recorded and transcribed verbatim before the analyses of the transcriptions. The content analyses method (136, 137) together with the ICF linking rules (132, 133) were used to link the manifest (the visible, literally present and the obvious) content (138) of the transcripts that revealed the person with previous stroke perspective of perceived functioning problems in daily activities to the 2nd level ICF categories from the whole classification in studies I and II.

The qualitative data analysis scheme used in studies I and II is presented in Table 3.

Table 3. Qualitative data analysis scheme.

Transcription (larger meaning unit)	Condensed meaning unit	Meaningful concept	ICF category
<p>Interviewer: If you think about your environment, factors in your surroundings, and your living conditions, what do you find helpful or supportive?</p> <p>Participant A: Right now it is the walker that helps me a lot. I can't walk outdoors without it. I have a poor balance.</p> <p>Interviewer: What do you find problematic? It is difficult to get into the bus with a walker and they (health personal) have said that I should not try to use buses or tram alone yet. That I'm not ready to do it.</p>	<p>The walker helps me to walk outdoors.</p> <p>I can't walk outdoors because of poor balance.</p> <p>Difficult to get into bus with a walker.</p> <p>Health personal / I should not use public transportation alone.</p>	<p>Walker as a facilitator</p> <p>Problem with walking outdoors balance problem</p> <p>Problem using bus</p> <p>Health personal</p> <p>Need of assistance when using a bus</p>	<p>e120 Products and technology for personal indoor and outdoor mobility and transportation</p> <p>d450 Walking, d460(outdoors) balance problem, (not-definable physical health)</p> <p>d 470 Using transportation</p> <p>e355 Health Personal</p> <p>Chapter 3 Support and Relationship</p>

Participants in studies I and II

In study I, 22 persons following stroke as well as their spouses/partners, (when relevant) were interviewed at their homes. Nine women and 13 men were included in the study. They all fulfilled the following inclusion criteria; main diagnosis stroke; a minimum 6 month's post stroke, with lasting neurological symptoms; Swedish speaking; able to give written informed consent; living at home; and in contact with the multidisciplinary homecare team.

In study II, 22 persons following stroke living at home were interviewed at the rehabilitation department at the Helsinki University hospital.

Thirteen women and 9 men were included in the study. They all fulfilled the following inclusion criteria; main diagnosis stroke, with lasting neurological symptoms; Finnish speaking; able to give written informed consent; living at home; and in contact with the hospitals multidisciplinary homecare.

Data collection procedure in studies I and II

In both studies I and II a purposeful sampling strategy was used to recruit both men and women in different ages and with different social situations and levels of impairments. The participants were recruited among people with previous stroke living at home and in contact with the multidisciplinary rehabilitation team during the time of the study. In study I the participants were recruited by the first author, who worked as a physiotherapist in the municipality's multidisciplinary homecare team and in study II by four members (a speech therapist, an occupational therapist, and by two physiotherapists) of the hospitals multidisciplinary rehabilitation team. The participants were contacted and asked if they would participate in a face to-face interview that would be recorded. In study I one declined, as he felt that participation was not going to help improve his health. Two additional persons independently contacted the first author and wanted to participate in study I. Both were included since they improved the heterogeneity of the sample. In study II all persons who were asked participated in the study. The first author conducted the interviews in study I and in study II the interviews were conducted by the four members of the hospitals multidisciplinary rehabilitation team.

Those who conducted the interviews in studies I and II were in regular contact with the participants during the time of the studies. The interviews were conducted after completion of the CRF.

In both studies I and II each interview began with an open conversation about how the person had experienced his or her life after stroke, before the semi-structured interview questions based upon the ICF 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 semi-structured questions were intended to stimulate the participant to reflect on the different aspects of functioning at home. After every question, participants were also encouraged to speak freely about their perspective of perceived functioning problems in daily activities after stroke. Each interview was tape recorded and lasted between 40 and 60 min. In study I, after the interviews were conducted, another meeting (member checking) (147) 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.

In study I the spouses of the 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. In study II the spouses of the participants were not present during the interviews at the rehabilitation department. In study II the member checking (147) was not applied.

Qualitative data analysis in studies I and II

In both studies I and II the data-analysis followed the following procedure. When all the interviews were completed and transcribed verbatim, the text was first read several times to get an overview of the data.

Each interview was considered a separate unit of analysis (138). After this the meaning units, i.e. words or sentences that contained the participant's perspective of perceived functioning problems in everyday life, were identified from each unit of analysis. Then the identified concepts of functioning from the meaning units were linked to 2nd level ICF categories from the whole classification. One functional concept could be linked to 1 or more ICF categories, depending on the number of topics contained within it (Table 3). In both studies I and II investigator triangulation (148, 149) was used in the data-analysis process for the comparison of the identified functional concepts and the linking procedure.

In study I, the functional concepts identified by the first author were first investigated by the second author, an ICF expert, before the first- and the second author independently linked the identified functional concepts to the ICF categories.

The second author did not know or interview the participants. In study II, the four interviewers and the first author performed the identification of the functional concepts and the linking procedure independently in all transcripts.

To further study the accuracy of the identification of the functional concepts and the linking procedure, peer review was used (150) in study II. Five randomly selected transcripts, 22% of the transcribed text, were independently analysed by the second author using the same procedure as the four interviewers and the first author. The first and the second author did not know or interview the participants.

In both studies I and II the first author then discussed the interpretation of the results of the linking procedure with the last co-author, an expert regarding ICF, to reach a consensus for precise linking of the 2nd level ICF categories to the functional concepts in all transcripts.

Finally, the set of linked ICF categories were compared with the categories in the Comprehensive ICF Core Set for stroke.

An ICF category of the Comprehensive ICF Core Set for stroke was regarded as validated if the identical or equal concept of functioning emerged from the transcribed text. Since the ICF categories are arranged in a hierarchical code system, the 2nd level ICF categories were considered confirmed when the corresponding 3rd or 4th level ICF category were identified from the interview transcripts.

Data saturation

Data saturation was defined as when the collection of new data did not shed any further light on the issue under investigation (151). 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 perspectives of functioning at home.

4.3.2 Cross-sectional design in studies III and IV

Participants

People with previous stroke participating in studies III (n=242) and IV (n=243) were recruited in Sweden between 2005- and 2007 and were convenience samples of those with previous stroke from different parts of the country. The inclusion criteria were; a diagnosis of stroke ICD-10 codes I60–I67, clinically determined by specialists at stroke units according to WHO criteria (11) and confirmed by computed tomography (CT), an age of at least 18 and an ability to give written informed consent (or consent given by next of kin). In study III time from onset of stroke was at least 1 month and in study IV at least 6 months. The aim was to include people of different ages, with different social situations and levels of impairments.

Data collection procedure in studies III and IV

The data were collected by semi-structured interviews using the Comprehensive ICF Core Set for stroke as a reference frame during the interviews. Participants were interviewed at home. The interviews were conducted by health professionals experienced in stroke rehabilitation to gather information for background data and to document functioning problems (as reported by the participant) using the Comprehensive ICF Core Set for stroke, and complemented with the interviewer's observation as well as information from the next-of-kin before the data-analysis. All interviewers were trained prior to the study within the scope of the international WHO Collaboration Project to validate ICF Core Sets (152). The duration of the interview varied between 30 minutes and 2 hours depending on the participant's functioning. The interviewer selected the ICF category that best described the participants functioning problem in daily activities and assessed the level of the participant functioning using the ICF qualifiers. The interviews were conducted after completion of the CRF.

Data analysis in study III

Using information from 242 patient-reported SIS forms the construct validity of the ICF categories linked to the SIS items was investigated by examining the association between the patient-reported SIS item scores with respect to the ICF category scores, as assessed by health professionals.

Statistical analysis in study III

Statistical analysis was carried out using SPSS version 21. Descriptive statistics were used for demographic and clinical characteristics of the study population. The SIS item scales and the qualifier scale of the ICF categories were dichotomized into a yes (1) and no (0) problem to be able to investigate the distribution of the patient-reported item scale scores with respect to the ICF category scores assessed by the health professionals. SIS 5-point Likert scale scores were dichotomized and recoded as; Not difficult at all 5 = 0 (no problem), A little difficult 4 = 1 (problem), Somewhat difficult 3 = 1, Very difficult 2 = 1 and Could not do at all 1 = 1.

For the ICF categories the qualifier 0 (no problem) was maintained. The qualifiers 1–4 were re-coded to 1 (problem), response option 8 (not specified) was treated as missing, and response option 9 (not applicable) was re-coded to 0 (no problem). For facilitators of environmental factors, qualifiers 1–4 (facilitators) recoded as 1, 0 (neither/nor) were maintained, response option 8 (not specified) was treated as missing, and response options 9 (not applicable). For barriers of environmental factors, qualifiers –1 to –4 (barriers) recoded as 1, 0 (neither/nor) was maintained, response option 8 (not specified) was treated as missing, and response option 9 (not applicable) was re-coded as 0 (neither/nor).

The problems were counted under different patient-reported SIS domains and ICF components of functioning, and facilitators and barriers were counted according to the domains of environmental factors included in the second version of the Comprehensive ICF Core Set for Stroke assessed by health professionals.

The association between the patient-reported item scores with respect to the health professionals assessed scores in the linked ICF categories was calculated using descriptive statistics, the Chi-square test (χ^2) for independence with Yates Continuity Correction including Phi correlation coefficient (phi) to measure the strength of the association. The phi value can range from 0 to 1 with higher values indicating stronger association between the two variables. Phi value .10 is considered for small effect, .30 for medium and .50 for large effect (153).

The inter-rater agreement between the problems reported by patients and assessed by the health professionals was explored by percent of agreement (PA) and by Kappa statistics (154, 155). The Kappa value can range from 0 to 1 with higher values indicating stronger agreement between raters. Kappa value < 0.00 is considered poor (less than chance agreement), 0.01 to 0.20, slight agreement, 0.21 to 0.40, fair agreement, 0.41 to 0.60, moderate agreement, 0.61 to 0.80, substantial agreement and 0.81 to 0.99, almost perfect agreement.

The Odds Ratio was calculated to explore the likelihood of a participant who reported problems in the SIS items being classified as having a problem in the linked ICF categories assessed by the health professionals.

Data analysis in study IV

Regression analysis of four personal factors (age, gender, place of residence and time since onset of stroke) was used to explore the influence on different components, domains and categories of functioning and environmental factors evaluated using the Comprehensive ICF Core Set for stroke.

Statistical analysis in Study IV

Statistical analyses were carried out using SPSS (version 21.0). Descriptive statistics were used for demographic and clinical characteristics of the study population. The qualifier scale of the ICF categories was dichotomized using the same procedure as in study III to avoid analysing data that would not represent actual changes in components of the ICF.

The problems were counted under different components of functioning, and facilitators and barriers were counted according to the domains of environmental factors included in the second version of the Comprehensive ICF Core Set for Stroke. The same independent variables were used in both the standard multiple regression analysis and the direct logistic regression analysis: age, gender, place of residence (rural or city) and time since onset of stroke. Preliminary analyses were conducted to assess the assumptions of normality, linearity, multicollinearity and homoscedasticity, to ensure that they were adequately fulfilled.

Standard multiple regression was used to assess the ability of selected factors to predict the number of problems in functioning (in the components of body functions and activities and participation) and the number of barriers and facilitators in environmental factors divided into 5 domains (“products and technology”; “natural environment and human rights”; “support and relationships”; “attitudes”; and “services, systems and policies”). Direct logistic regression was used to assess the impact of PF on the perception of selected components of activities and participation and environmental factors in the context of the ICF: moving around in different locations (d469), toileting (d530), dressing (d540), doing housework (d640), recreation and leisure (d920), physical geography (e210) and immediate family (e310).

These domains were selected on the basis of their properties for reflecting the need for assistance, previous reports of their being common problems (8, 77, 126), and according to clinical judgment.

4.3.3 Ethical Considerations

Study I was approved by the ethics committee at Umeå University Dnr 07-011M. Study II was approved by the Ethics at the Helsinki University Hospital and Helsinki Healthcare District ref. 108/E9/07 and studies III and IV by the ethics committee of the University of Gothenburg numbers T129-05/Ad 419-04 and 390-05. In both studies I and II written information describing the study and a guarantee of confidentiality were given to each participant. Oral and written informed consent was obtained from all participants or their next of kin prior to entry into all studies in compliance with the ethical principles set forth in the Helsinki Declaration 1996. Participation in the studies was voluntary and the participants knew their right to withdraw from the research anytime. No specific risks of participating in these studies were identified.

5 RESULTS

Altogether 357 people (45.5% women) with previous stroke participated in studies I to IV and infarct was the most common cause for stroke. The mean age of the participants was 67.5 years (age range 24–95 years). There was considerable spread of time since stroke among the participants, with the shortest taking place 1 month after the stroke and the longest 26 years after the onset of stroke with an average of 3.4 years (Table 2).

5.1 Results in qualitative studies I and II

The results from the CRF confirmed that the main cause of functioning problems at home was stroke in both studies. All participants in study I were community-dwelling as well as native Swedes and in study II native Finns. In study I the mean age of the participants was 72.2 years (age range 58–87 years) and in study II 52.2 years (age range 32–60). Time since onset of stroke ranged from 8 to 276 months (mean 5.3 years) among the participant in study I and from 2.4 to 47 months (mean 1 year) in study II (Table 4).

In study I 21 of the participants were retired, of whom 4 had retired early due to stroke, 3 women and 6 men lived in a pair relationship and 6 women and 7 men lived alone. One participant worked part-time. Two of the participant's had aphasia; one was supported by their partner during the interview and the other had milder speech disorder and did not need support during the interview.

Twenty participants reported comorbidities: depression (1), diabetes (4), heart disease (9), high blood pressure (5) and osteoarthritis (1). Two of six who reported in the CRF that comorbidity limits their activities mentioned this during the interviews (Table 4). Two of the participants used wheelchairs in- and outdoors, 7 of the participants used walking aid indoors and 18 of the participants needed walking aid outdoors. Nine of the participants had home-help services daily (Table 4).

In study II 13 of the participants were retired due to stroke, 7 men and 8 women lived in a pair relationship and 3 men and 6 women lived alone. During the time of the interviews, nine of the participants had applied for early retirement or disability pension but had not yet received the decision. Two participants had a mild speech disorder (aphasia) but did not need support during the interview. Nineteen participants reported comorbidities: celiac (1), depression (3), diabetes (2), epilepsy (2), heart disease (4), high blood pressure (6) and osteoarthritis (1). One of six who reported in the CRF that comorbidity limits their activities mentioned it during the interview (Table 4). One of the participants used wheelchair in- and outdoors and 3 of the participants needed wheelchair only outdoors. Ten of the participants used walking aid in- and outdoors and two needed walking aid only outdoors. Four of the participants had home-help services daily (Table 4).

Table 4. Characteristics of the participants (CRF) in study I (second row from the left) and in study II (third row from the left) ^{a,b}.

M/F	Affected side of the body	Age range, years (mean)	Time since onset of stroke, months (mean yrs.)	^a mRS 0-6 ^b (nr.)	Does Comorbidity limit your activities?	Need for assistive devices indoors	Need for assistive devices outdoors	Home-help times a week ^b (nr.)	Living situation
13/9	left 9 right 8 both 5	58-87 (72.2)	8 to 276 (5.3)	1 (2) 2 (7) 3 (6) 4 (6) 5 (1)	yes 6 no 16	yes 9 no 13	yes 20 no 2	7 (9) 1 (3) 0 (14)	alone 13 spouse 9
9/13	left 15 right 6 both 1	32-60 (52.2)	3 to 47 (1)	1 (2) 2 (7) 3 (6) 4 (6) 5 (1)	yes 6 no 16	yes 11 no 11	yes 13 no 9	7 (4) 0 (18)	alone 7 spouse 15

^a Investigators perspective on disability, mRS: modified Ranking Scale. ^b nr: number of participants with different mRS grades and Home-help times a week, M (male), F (female).

Data saturation

In study I the 19th and in study II the 18th interview was the last interview in which new concepts of functioning that could be linked to ICF categories were identified (Figure 3).

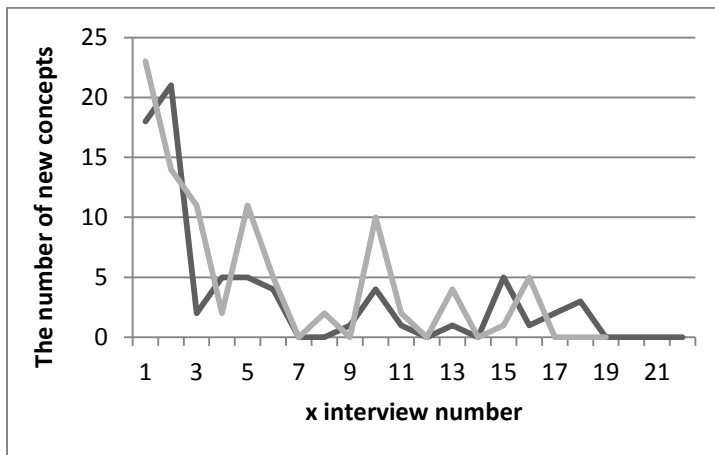


Figure 3. The number of new concepts (y) of functioning identified and linked to ICF categories per interview in studies I and II.

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

A total of 313 (study I) and 372 (study II) meaning units that contained participants' perspectives of functioning problems in daily activities were identified from the transcribed text. From these meaning units, the identified functional concepts were linked to 103 (76%, study I) and to 107 (83%, study II) of 130 second-level ICF categories included in the first version of the Comprehensive ICF Core Set for stroke. In study I 4 (11 %) and in study II 8 (22 %) of 36 categories added to the second version of the Comprehensive ICF Core Set for stroke in 2005 were also validated.

Validated second level ICF categories in the component of body functions

In the component of body functions, 31 (75.6%) and 33 (80.5 %) of 41 categories included in the first version of the Comprehensive ICF Core Set for stroke (10) were validated in studies I and II respectively. In study I 2 and in study II, 5 of the 18 categories added to the component of body functions in the second version of the Comprehensive ICF Core Set for stroke were also validated (Table 5).

The most common problems in the component of body functions were primarily classified as problems in memory- (b144) or in attention functions (b140). Seventeen of the 22 participants in study I and 18 in study II reported various problems with remembering and recalling recent and remote memory. Fifteen of the participants in study I and 16 in study II reported functioning problems that related to various problems in neuromusculoskeletal and movement-related functions such as muscle power (b730), muscle tone (b735) or gait functions (b770) that affected their daily activities. Sixteen of the participants in study I and 5 in study II reported balance problems when moving around indoors and outdoors.

These problems were classified as proprioceptive functions (b260) or as vestibular functions (b235) or as sensations associated with hearing and vestibular function (b240).

Table 5. Validated 2nd level ICF categories ^a included in the component (b) body functions in the Comprehensive ICF Core Set for stroke in studies I and II.

ICF Chapter and 2 nd level ICF categories	Study		Example of functional concepts linked to ICF categories
	I	II	
Chapter 1: Mental functions			
b110 Consciousness functions	Yes	Yes	I can't think clearly its foggy
b114 Orientation functions	No	Yes	Difficulties to find a way even that knows the place well
b117 Intellectual functions	No	Yes	My brain capacity is lower
b126 Temperament and personality functions	Yes	Yes	I have become quite edgy, irritated
b130 Energy and drive functions	Yes	Yes	My appetite has become a problem
b134 Sleep functions	Yes	Yes	I sleep but do not get rest
b140 Attention functions	Yes	Yes	I go and get something and forget what it was
b144 Memory functions	Yes	Yes	I don't remember telephone numbers
b147 Psychomotor functions	No	No	

b152 Emotional functions	Yes	Yes	I feel so worried
b156 Perceptual functions	Yes	Yes	
b160 Thought functions	No	Yes	To put together things and draw conclusion is difficult
b164 Higher-level cognitive functions	Yes	Yes	I would not dare to make decisions at my work, I don't trust myself yet
b167 Mental functions of language	Yes	No	
b172 Calculation functions	No	Yes	I can't calculate numbers as before
b176 Mental function of sequencing complex movements	No	Yes	I try to dial a telephone number but I get it wrong
b180 Experience of self and time functions	No	Yes	I don't feel as myself
Chapter 2: Sensory functions and pain			
b210 Seeing functions	Yes	Yes	I don't see well (after stroke)
b215 Functions of structures adjoining the eye	Yes	Yes	left eyelid like hangs and the eye waters
b230 Hearing functions	Yes	No	
b235 Vestibular functions	Yes	No	
b240 Sensations associated with hearing and vestibular function	No	Yes	I feel dizzy, I'm falling
b260 Proprioceptive function	Yes	Yes	My foot and leg like I'm not sure if they follow me
b265 Touch function	Yes	Yes	My hand feels numb
b270 Sensory functions related to temperature and other stimuli	Yes	Yes	It hurts even if I just touch something
b280 Sensation of pain	Yes	Yes	The pain in my knees
Chapter 3: Voice and speech functions			
b310 Voice functions	Yes	No	
b320 Articulation functions	Yes	Yes	Difficult to pronounce some words
b330 Fluency and rhythm of speech functions	Yes	Yes	I stutter when I speak
b340 Alternative vocalization functions	No	No	
Chapter 4: Functions of the cardiovascular, haematological, immunological and respiratory systems			
b410 Heart functions	Yes	Yes	I have some heart problems
b415 Blood vessel functions	No	No	
b420 Blood pressure functions	No	Yes	The blood pressure is only a minor problem now
b430 Hematological system functions	No	No	
b435 Immunological system functions	No	Yes	My allergy is troublesome
b440 Respiration functions	No	No	
b450 Additional respiratory functions	No	No	
b455 Exercise tolerance functions	Yes	Yes	I get easily tired when I do household chores
Chapter 5: Functions of the digestive, metabolic and endocrine systems			
b510 Ingestion functions	Yes	Yes	I drool
b515 Digestive functions	No	No	
b525 Defecation functions	Yes	No	
b530 Weight maintenance functions	No	Yes	I put on weight
b535 Sensations associated with the digestive system	No	No	
b540 General metabolic functions	No	No	
b545 Water, mineral and electrolyte balance functions	No	No	
b550 Thermoregulatory functions	No	Yes	It so strange my skin gets so hot
Chapter 6: Genitourinary and reproductive functions			
b620 Urination functions	No	No	
b630 Sensations associated with urinary functions	No	No	
b640 Sexual functions	Yes	No	
Chapter 7: Neuromusculoskeletal and movement-related functions			
b710 Mobility of joint functions	Yes	Yes	My elbow it is hard to bend my arm
b715 Stability of joint functions	Yes	No	
b730 Muscle power functions	Yes	Yes	I don't have enough strength in my left leg
b735 Muscle tone functions	Yes	Yes	My arm is hard and stiff
b740 Muscle endurance functions	Yes	Yes	My left leg becomes tired soon and I start to limp
b750 Motor reflex functions	No	No	

b755 Involuntary movement reaction functions	Yes	No	
b760 Control of voluntary movement functions	Yes	Yes	My hand does not turn as I want to
b770 Gait pattern functions	Yes	Yes	I limp, the leg is so stiff
Chapter 8: Functions of the skin and related structures			
b810 Protective functions of the skin	No	No	
Additional categories not included in the extended ICF Core Set for stroke			
b220 Sensations associated with the eye and adjoining structures	No	Yes	My right eye feels dry
b255 Smell functions	Yes	No	
b765 Involuntary movement functions	No	Yes	The arm is quite shaky
b780 Sensations related to muscles and movement functions	Yes	Yes	My ankles feel stiff and tired while walking
b830 Other functions of the skin	No	Yes	I can start sweating without a reason

^aIf a concept that emerged from the interviews was linked to an ICF category in the Comprehensive ICF Core Set for stroke it was regarded as validated. Categories in **bold** belong to the second version of the Comprehensive ICF Core Set for Stroke.

Validated second level ICF categories in the component of body structures

Four of 5 categories included in the component of body structures in the first version of the Comprehensive ICF Core Set for stroke were validated in both studies I and II. None of the 6 categories added to the component of body structures in the second version of the Comprehensive ICF Core Set for stroke were validated (Table 6).

Table 6. Validated 2nd level ICF categories ^a included in the component (b) body structures in the Comprehensive ICF Core Set for stroke in studies I and II.

ICF Chapter and 2 nd level ICF categories ICF category title	Study	
	I	II
Chapter 1: Structures of the nervous system		
s110 Structure of brain	Yes	Yes
s120 Spinal cord and related structure	No	No
s130 Structure of meninges	No	No
Chapter 4: Structures of the cardiovascular, immunological and respiratory systems		
s410 Structure of cardiovascular system	No	Yes
s430 Structure of respiratory structure	No	No
Chapter 5: Structures related to the digestive, metabolic and endocrine systems		
s530 Structure of stomach	No	No
Chapter 7: Structures related to movement		
s710 Structure of head and neck region	No	No
s720 Structure of shoulder region	Yes	No
s730 Structure of upper extremity	Yes	Yes
s750 Structure of lower extremity	Yes	Yes
s810 Protective functions of the skin	No	No

^a If a concept that emerged from the interviews was linked to an ICF category in the Comprehensive ICF Core Set for stroke it was regarded as validated. Categories in **bold** belong to the second version of the Comprehensive ICF Core Set for stroke.

Validated second level ICF categories in the component of activities and participation

In the component of activities and participation, 38 (74.5%) and 45 (88.2 %) of 51 categories included in the first version of the Comprehensive ICF Core Set for stroke were validated in studies I and II. In study I 2 (25%) and in study II, 3 (37.5%) of the 8 categories added to the component of activities and participation in the second version of the Comprehensive ICF Core Set for stroke were also validated (Table 7).

Ten of 22 participants in study I and 14 in study II reported difficulties in walking, carrying and handling objects and when doing housework. These problems were linked to the categories fine hand use (d440) and/or hand and arm use (d455) or in doing housework (d640). Nine of the participants in study I and 5 in study II reported problems in participating in community life or in recreation and leisure. These perspectives were linked to the category recreation and leisure (d920).

Table 7. Validated 2nd level ICF categories ^a included in the component of activities and participation (d) in the Comprehensive ICF Core Set for stroke in studies I and II.

ICF Chapter and 2 nd level ICF categories	ICF category title	Confirmed Study		Example of functional concepts linked to ICF categories
		I	II	
Chapter 1: Learning and applying knowledge				
d110	Watching	Yes	Yes	Watching films on the TV can be difficult for me
d115	Listening	No	No	
d120	Other purposeful sensing	No	No	
d130	Copying	No	No	
d135	Rehearsing	No	No	
d155	Acquiring skills	No	Yes	
d160	Focusing attention	Yes	Yes	
d166	Reading	Yes	Yes	
d170	Writing	Yes	Yes	
d172	Calculating	No	Yes	
d175	Solving problems	No	Yes	
d177	Making decisions	No	Yes	
Chapter 2: General tasks and demands				
d210	Undertaking a single task	Yes	Yes	
d220	Undertaking multiple tasks	Yes	Yes	
d230	Carrying out daily routine	Yes	Yes	

d240 Handling stress and other psychological demands	Yes	Yes	
Chapter 3: Communication			
d310 Communicating with - receiving - spoken messages	No	Yes	
d315 Communicating with - receiving - nonverbal messages	No	No	
d325 Communicating with - receiving - written messages	Yes	Yes	
d330 Speaking	Yes	Yes	
d335 Producing nonverbal messages	No	No	
d345 Writing messages	Yes	Yes	
d350 Conversation	Yes	Yes	I fear the job interview; I want to manage it without stuttering or saying something wrong
d360 Using communication devices and techniques	No	Yes	
Chapter 4: Mobility			
d410 Changing basic body position	Yes	Yes	
d415 Maintaining a body position	Yes	Yes	
d420 Transferring oneself	Yes	Yes	
d430 Lifting and carrying objects	Yes	Yes	
d440 Fine hand use	Yes	Yes	It's hard for me to turn my left hand in and out and pick up things
d445 Hand and arm use	Yes	Yes	It's hard to take down or lift up the plates and cups.
d450 Walking	Yes	Yes	
d455 Moving around	Yes	Yes	
d460 Moving around in different locations	Yes	Yes	
d465 Moving around using equipment	Yes	Yes	
d470 Using transportation	No	Yes	
d475 Driving	Yes	Yes	
Chapter 5: Self-care			
d510 Washing oneself	Yes	Yes	
d520 Caring for body parts	Yes	Yes	
d530 Toileting	Yes	Yes	
d540 Dressing	Yes	Yes	
d550 Eating	Yes	Yes	
d560 Drinking	No	Yes	
d570 Looking after one's health	Yes	Yes	
Chapter 6: Domestic life			
d620 Acquisition of goods and services	Yes	Yes	
d630 Preparing meals	Yes	Yes	
d640 Doing housework	Yes	Yes	I have difficulties when I wash the dishes and do things like that
Chapter 7: Interpersonal interactions and relationships			
d710 Basic interpersonal interactions	Yes	Yes	
d750 Informal social relationship	Yes	Yes	
d760 Family relationships	Yes	Yes	family relationship have become quite strained after the stroke
d770 Intimate relationships	Yes	No	
Chapter 8: Major life areas			
d845 Acquiring, keeping and terminating a job	Yes	Yes	
d850 Remunerative employment	No	Yes	
d855 Non-remunerative employment	No	Yes	
d860 Basic economic transactions	No	No	
d870 Economic self-sufficiency	No	No	
Chapter 9: Community, social and civic life			
d910 Community life	Yes	Yes	
d920 Recreation and leisure	Yes	Yes	"When I was well I used to go hunting and fishing before this happened. Now I can't
d930 Religion and spirituality	No	No	
d940 Human rights	Yes	No	

^a If a concept that emerged from the interviews was linked to an ICF category in the Comprehensive ICF Core Set for stroke it was regarded as validated. Categories in **bold** belong to the second version of the Comprehensive ICF Core Set for stroke.

Validated second level ICF categories in the component of environmental factors

In the component of environmental factors, 26 (78.8%) and 27 (81.8 %) of 33 categories included in the first version of the Comprehensive ICF Core Set for stroke, were validated in studies I and II. In studies I and II none of the 4 categories added to the component of environmental factors in the second version of the Comprehensive ICF Core Set for stroke in were validated (Table 8).

The walker was experienced as a facilitator by 17 of the participants in study I. Eleven participants in study II reported walking aids and grab bars for support in the shower as important facilitators that make it possible or easier to move around at home and were linked to category products and technology for personal indoor and outdoor mobility and transportation (e120). Sixteen of the participants in studies I and II had home-help services. Home-help services were experienced by all these participants as an important facilitator and were linked to category personal care providers and personal assistants (e340). Also home modifications linked to category design, construction and building products and technology of buildings for private use (e155) were reported as important facilitators by 10 of the participants in study I and by 8 in study II. The same category (e155) was reported as a barrier for wheelchair users and those who needed walking aids as the design and construction of buildings for private use hindered their ability to move around. Also transportation services, systems and policies (e540) were experienced as a barrier by 3 of the participants in study II because they had difficulties climbing in a bus with a walker. The climate (e225) was also reported as a barrier in both studies, e.g., one participant stated *“the icy frozen ground it stops me to walk outside the house”*.

Table 8. Validated 2nd level ICF categories ^a included in the component of environmental factors (e) in the Comprehensive ICF Core set for stroke in studies I and II.

ICF Chapter and 2nd level ICF categories	ICF category title	Study		Example of functional concepts linked to ICF categories
		I	II	
Chapter 1: Products and technology				
e110	Products or substances for personal consumption	Yes	Yes	
e115	Products and technology for personal use in daily living	Yes	Yes	
e120	Products and technology for personal indoor and outdoor mobility and transportation	Yes	Yes	“It’s difficult to walk without a walker (facilitator)”
e125	Products and technology for communication	Yes	Yes	
e135	Products and technology for employment	No	No	
e150	Design, construction and building products and technology of buildings for public use	Yes	Yes	
e155	Design, construction and building products and technology of buildings for private use	Yes	Yes	
e165	Assets	No	No	
Chapter 2: Natural environment and human-made changes to environment				
e210	Physical geography	No	Yes	
e240	Light	No	No	
e250	Sound	No	No	
Chapter 3: Support and relationships				
e310	Immediate family	Yes	Yes	
e315	Extended family	Yes	Yes	
e320	Friends	Yes	Yes	
e325	Acquaintances, peers, colleagues, neighbours and community members	Yes	Yes	
e340	Personal care providers and personal assistants	Yes	Yes	“I wouldn’t be able to manage without home care (facilitator)”
e355	Health professionals	Yes	Yes	
e360	Other professionals	Yes	Yes	
Chapter 4: Attitudes				
e410	Individual attitudes of immediate family members	Yes	Yes	
e415	Individual attitudes of extended family members	No	No	
e420	Individual attitudes of friends	Yes	No	
e425	Individual attitudes of acquaintances, peers, colleagues, neighbours and community members	Yes	Yes	
e440	Individual attitudes of personal care providers and personal assistants	Yes	No	
e450	Individual attitudes of health professionals	No	Yes	
e455	Individual attitudes of health-related professionals	No	No	
e460	Societal attitudes	No	Yes	
e465	Social norms, practices and ideologies	No	No	
Chapter 5: Services, systems and policies				
e515	Architecture and construction services, systems and policies	Yes	Yes	
e525	Housing services, systems and policies	Yes	No	
e535	Communication services, systems and policies	Yes	Yes	Earlier I had my mailbox out in the porch but the post office decided to move it away from the door (barrier)
e540	Transportation services, systems and policies	Yes	Yes	How to climb in to a bus with a walker? (barrier)
e550	Legal services, systems and policies	Yes	Yes	
e555	Associations and organizational services, systems and policies	No	No	
e570	Social security services, systems and policies	Yes	Yes	
e575	General social support services, systems and policies	Yes	Yes	
e580	Health services, systems and policies	Yes	Yes	
e590	Labour and employment services, systems and policies	Yes	Yes	

Additional categories not included in the extended ICF Core Set for stroke			
e215 Population	Yes	No	
e225 Climate	Yes	Yes	
e140 Assistive products and technology for culture, recreation and sports	Yes	Yes	

^aIf a concept that emerged from the interviews was linked to an ICF category in the Comprehensive ICF Core Set for stroke it was regarded as validated. Categories in **bold** belong to the second version of the Comprehensive ICF Core Set for stroke.

Validated additional 2nd level ICF categories

The following additional categories were confirmed from the transcribed text in both studies I and II; sensations related to muscle and movement functions (b780), products and technology for culture, recreation and sport (e140) and climate (e225). Additional categories confirmed in study I; media systems, services and policies (e560), assisting others (d660), complex interpersonal interactions (d720) and population (e215). Additional categories confirmed in study II; smell functions (b255), sensations associated with the eye and adjoining structure (b220), involuntary movement functions (b765), other functions of the skin (b830).

Meaningful concept that could not be linked to ICF categories

Meaningful concepts that could not be linked to the ICF categories were classified as; not covered by the ICF, personal factor, health condition, non-definable mental health or non-definable physical health. Examples of meaningful concepts that could not be linked to the ICF categories are presented in the Table 9.

Table 9. Examples of meaning units that contained meaningful concept (s) that could not be linked to the ICF categories in studies I and II*.

Meaning units	Meaningful concept (s) not linked to ICF	Labeled as	Classified as
There are better days and days when it doesn't work (points her head)	There are better days (when head works) Days when it (head) does not work	Not definable Not definable	nd-mh nd-mh
I just feel like something is missing, in my head	I just feel something is missing in my head	Not definable	nd-mh
It is like struggling with myself in my head	It is struggling with myself In my head	Not definable	nd-mh
I hope that I don't stay like this that it gets better, I can remember (b144) things, but something is missing in my head	I hope I don't stay like this That it gets better Something is missing in my head	Current experience Expectation Not definable	nc nc nd-mh
I have always been mentally strong but now I'm not, not anymore even that I look the same	I have always been mentally strong But now (after stroke) I'm not even that I look the same	Personal factor Current experience	pf nc
I'm missing mental power, more mental than other things (after stroke)	I'm missing mental power (after stroke) More mental than other things (after stroke)	Current experience Not definable	nd-mh nd-mh
Im doing things that my grandma did I called it hazing it like something that is not working very well in my head	Im doing things I call hazing Something is not working in my head	Not definable Not definable	nd-mh nd-mh
My body works worse now, it does not work so well	My body works worse not so well	Not definable	nd-ph
It is just the arm (s730) and the leg (s750)	It is just the arm and the leg	Not definable	nd-ph
I have epilepsy but it is not a problem	Epilepsy / it is not a problem	Diagnoses Current experience	hc nc
I have this depression too	Depression	Diagnoses	hc
In the future when I feel more as myself (b180)	in the future when I feel	The interval of time	nc
I did not have any of these troubles before stroke	I did not have any of these troubles before stroke	past experience The interval of time	nc nc
I just have to get little bit better then, I can walk (d450) better	I just have to get little bit better	Expectation	nc
When I get better I start to seek a job (d845)	When I get better	Expectation	nc
Everything happens in slow motion these days	Everything happens in slow motion These days	Current experience The interval of time	nc nc
I find myself in this it is what it is	I find myself in this It is what it is	Current experience Current experience	nc nc
I go out with my dog every day that is good for me	I go out with my dog every day That is good for me	Habits Current experience	pf pf
I think it is a question of my own ability to rehabilitate myself, that's it	I think it is a question of my own ability to rehabilitate myself That's it	Coping style Current experience	pf nc
I continue to activate myself with things that give me joy	I continue to activate myself With things that give me joy	Habits Current experience	pf pf
I manage if I try hard enough	I manage it I try hard enough	Coping style	pf
I think that I actually have everything I need	I have everything I need	Current experience	pf
Now, all the basic things are going well	Now all the basic things are going well	Current experience	pf
I just have to fine tune some things with my arm (s730)	I have to fine tune some things	Current experience	pf

* nd-mh (not definable mental health), nd-ph (not definable physical health), hc (health condition), nc (not covered by the ICF), pf (personal factor).

5.2 Results in studies III and IV

The 242 participants in study III (43% women) had an average age of 66.6 (age range 21-96) years and the 243 participants in study IV (53% men) 69.4 (age range 24–95) years. The majority of the participants in study III, 159 (67.1%) were outpatients living in city or in the rural area in different parts of Sweden. In study IV, 176 (72.4%) of the participants were outpatients living in the city. In study III the time since onset of stroke varied from 1 months to 26 years (average 40.6 months) and from 6 months to 13 years (average 33.3 months) in study IV. The characteristics of study populations are presented in Table 10.

Table 10. Characteristics of study populations in studies III and IV.

Characteristics	Study III			Study IV		
	Males n=139 (57, 4%)	Females n=103 (42, 6%)	Total n=242 (100%)	Males (n = 129 (53.1%)	Females (n = 114, 46.9%)	Total (n = 243, 100%)
<i>Age, years</i>						
Mean (min-max)	66.2 (21-92)	67.1 (25-96)	66.6 (21-96)	67.7 (31-92)	71.3 (24–95)	69.4 (24–95)
Median	65	68	66	68	74	71
IQR	58-76	60-78	59-76	60.2–77	63–83	62–80
<i>Time since onset of stroke, months</i>						
Mean (min-max)	41.2 (1-320)	39.8 (1-156)	40.6 (1-320)	33.9 (6–144)	32.7 (6–157)	33.3 (6–157)
Median	23	29.5	25	18	12	14
IQR	6-59	5-58.3	6-59	12–42.5	11–46	12–44
<i>Diagnosis, ICD-10, n (%)</i>						
I60	11 (7.9)	11 (10.7)	22 (9.1)	7 (5.4)	7 (6.1)	14 (5.8)
I61	26 (18.7)	15 (14.6)	41 (16.9)	19 (14.7)	7 (6.1)	26 (10.7)
I62	1 (0.7)	5 (4.9)	6 (2.5)	no data	no data	no data
I63	69 (49.6)	49 (47.6)	118 (48.8)	70 (54.3)	85 (74.6)	155 (63.8)
I64	28 (20.1)	18 (17.5)	46 (19)	33 (25.6)	15 (13.2)	48 (19.8)
Other stroke	4 (2.9)	5 (4.9)	9 (3.7)	-	-	-
<i>Affected side of body, n (%)</i>						
None	8 (5.8)	7 (6.8)	15 (6.2)	8 (6.2)	12 (10.5)	20 (8.2)
Right	55 (39.6)	33 (32.0)	88 (36.4)	40 (31.0)	39 (34.2)	79 (32.5)
Left	66 (47.5)	57 (55.3)	123 (50.8)	66 (51.2)	52 (45.6)	118 (48.6)
Both	10 (7.2)	6 (5.8)	16 (6.6)	7 (5.4%)	6 (5.3)	13 (5.3)
No data	-	-	-	8 (6.2)	5 (4.4)	13 (5.3)
<i>Modified Rankin scale, n (%)</i>						
0 - no disability	1 (0.7)	0 (0.0)	1 (0.4)	5 (3.9)	5 (4.4)	10 (4.1)
1 - no significant disability	28 (20.1)	16 (15.7)	44 (18.2)	35 (27.1)	20 (17.5)	55 (22.6)
2 - slight disability	35 (25.2)	34 (33.3)	70 (28.9)	36 (27.9)	32 (28.1)	68 (28.0)
3 - moderate disability	36 (25.9)	27 (26.5)	63 (26.0)	25 (19.4)	30 (26.3)	55 (22.6)
4 - moderately severe disability	35 (25.2)	23 (22.5)	58 (24.0)	25 (19.4)	25 (21.9)	50 (20.6)
5 - severe disability	1 (0.7)	1 (1.0)	2 (0.8)	2 (1.5)	1 (0.9)	3 (1.2)
No data	3 (2.2)	1 (1.0)	4 (1.7)	1 (0.8)	1 (0.9)	2 (0.8)

Number of health professionals assessed problems in the ICF component of body functions and structures and activities and participation in studies III and IV and patient-reported problems in the SIS items linked to the ICF categories

The most common problems in the ICF component of body functions reported by the health professionals were related to neuromusculoskeletal and movement related functions such as muscle power functions and gait pattern functions. Problems in mental functions such as memory and attention were also common as were problems in vestibular functions, exercise tolerance, seeing and pain functions (Table 11). The number of patient-reported problems in the SIS items linked to ICF categories was highest in the SIS domain strength as well as in the SIS domain memory and thinking. The number of patient-reported problems was also large in the SIS domain emotion (Table 11). All 59 2nd level categories in the component of body functions and all 11 2nd level categories in the component of body structures included in the second version of the Comprehensive ICF Core Set for stroke were validated in study III.

Table 11. *The number of problems in the ICF components of body functions and structures assessed by the health professionals in studies III and IV and patient-reported problems in the SIS items linked to ICF categories.

2nd level ICF Category	Reported by Health professionals		SIS domain (items)	Patient-reported
	Study III (n=242)	Study IV (n=243)		Study III (n=242)
Body Functions	Total (n, %)	Total (n, %)		Total (n, %)
<i>Chapter 1 Mental functions</i>				
Consciousness functions b110	48 (20.6)			
Orientation functions b114	64 (27.1)		Memory (2d)	93 (38.4)
Intellectual functions b117	50 (24.0)			
Temperament and personality functions b126	67 (30.3)			
Energy and drive functions b130	91 (42.3)	114 (46.9)		
Sleep functions b134	65 (34.9)	77 (31.7)		
Attention functions b140	99 (43.4)	81 (33.3)	Memory (2e)	81 (33.6)
Memory functions b144	143 (61.1)	125 (51.4)	Memory (2a,b,c)	167 (69.0)
Psychomotor functions b147	55 (27.1)			
Emotional functions b152	69 (33.3)		Emotion (3a to 3i)	133 (55.0)
Perceptual functions b156	57 (27.0)			
Thought functions b160	56 (30.4)		Memory (2f)	148 (61.9)
Higher-level cognitive functions b164	76 (41.3)			

Mental functions of language b167	58 (27.2)		Communication (4a to 4d)	82 (33.8)
Calculation functions b172	56 (28.3)			
Mental functions of sequencing complex movements	73 (33.2)			
Experience of self and time functions b180	42 (18.7)			
<i>Chapter 2 Sensory functions and pain</i>				
Seeing functions b210	87 (40.1)	134 (55.1)		
Functions of structures adjoining the eye b215	29 (14.6)			
Hearing functions b230	29 (14.8)			
Vestibular functions b235	96 (46.0)	76 (31.3)		
<i>Sensations associated with hearing and vestibular functions b240</i>	50 (25.4)			
Proprioceptive function b260	78 (36.4)			
Touch function b265	61 (28.4)			
Sensory functions related to temperature and other stimuli b270	49 (23.7)			
Sensation of pain b280	83 (37.9)	78 (32.1)		
<i>Chapter 3 Voice and speech functions</i>				
Voice functions b310	58 (28.3)			
Articulation functions b320	53 (22.6)			
Fluency and rhythm of speech functions b330	55 (24.3)			
Alternative vocalization functions b340	33 (18.2)			
Heart functions b410	44 (25.6)			
Blood vessel functions b415	41 (25.8)			
Blood pressure functions b420	74 (46.0)			
Haematological system functions b430	15 (10.6)			
Immunological system functions b435	8 (5.6)			
Respiration functions b440	20 (11.7)			
Additional respiratory functions b450	24 (12.8)			
Exercise tolerance functions b455	126 (58.9)	147 (60.5)		
<i>Chapter 5 Functions of digestive, metabolic and endocrine systems</i>				
Ingestion functions b510	28 (14.0)			
Digestive functions b515	17 (10.3)			
Defecation functions b525	26 (14.0)		Activities of daily living (5g)	43 (17.9)
Weight maintenance functions b530	40 (20.7)			
Sensations associated with the digestive system b535	13 (7.4)			
General metabolic functions b540	7 (4.9)			
Water, mineral and electrolyte balance functions b545	7 (4.9)			
Thermoregulatory functions b550	7 (4.4)			
<i>Chapter 6 Genitourinary and reproductive functions</i>				
Urination functions b620	51 (25.4)		Activities of daily living (5f)	75 (31.4)
Sensations associated with urinary functions b630	38 (21.6)			
Sexual functions b640	8 (14.3)			
Mobility of joint functions b710	125 (53.2)	106 (43.6)		
Stability of joint functions b715	95 (41.5)			
Muscle power functions b730	177 (76.3)	165 (67.9)	Strength (1a,b,c,d)	210 (87.5)
Muscle tone functions b735	110 (48.9)	85 (35)		
Muscle endurance functions b740	114 (58.1)	118 (48.6)		
Motor reflex functions b750	73 (35.4)			
Involuntary movement reaction functions b755	72 (33.8)	106 (43.6)		
Control of voluntary movement functions b760	102 (44.5)	98 (40.3)		
Gait pattern functions b770	140 (58.8)	143 (58.8)		
<i>Chapter 8 Functions of skin and related structures</i>				
Protective functions of the skin b810	7 (4.2)			
Body Structures				
<i>Chapter 1 Structures of the nervous system</i>				
Structure of brain s110	157 (92.9)	97 (39.9)		
Spinal cord and related structures s120	1 (0.6)			

Structure of meninges s130	18 (11.3)			
<i>Chapter 4 Structure of the cardiovascular, immunological and respiratory systems</i>				
Structure of cardiovascular system s140	80 (48.5)	54 (22.2)		
Structure of respiratory system s430	15 (9.5)			
<i>Chapter 5 Structures related to the digestive, metabolic and endocrine systems</i>				
Structure of stomach s530	12 (7.6)			
<i>Chapter 7 Structures related to movement</i>				
Structure of head and neck region s710	9 (5.4)			
Structure of shoulder region s720	58 (33.3)	46 (18.9)		
Structure of upper extremity s730	100 (54.1)	68 (28)		
Structure of lower extremity s750	114 (56.3)	78 (32.1)		
<i>Chapter 8 Skin and related structures</i>				
Structure of areas of skin s810	9 (5.5)			

*Categories in **bold** belong to the second version of the Comprehensive ICF Core Set for stroke.

In the component of activities and participation the most common functioning problems reported by the health professionals were related to mobility and problems in domestic life such as doing housework or preparing meals as well as problems in self-care (Table 12). The most common patient-reported problems in the SIS items linked to the ICF categories in the component of activities and participation were in the areas of mobility and domestic life. The number of patient-reported problems was also large in the SIS domain social participation as presented in the table 12. All 59 2nd level categories in the component of activities included in the second version of the Comprehensive ICF Core Set for stroke were validated in study III.

Table 12. *The number of reported problems in the ICF component of activities and participation assessed by the health professionals in studies III and IV and patient-reported problems in the SIS items linked to ICF categories.

	Assessed by health professionals		SIS domain (items)	Patient-reported
	Study III (n=242)	Study IV (n=243)		Study III (n=242)
2 nd level ICF Category	Total (n, %)	Total (n, %)		Total (n, %)
Activities and Participation				
<i>Chapter 1 Learning and applying knowledge</i>				
Watching d110	60 (28.6)			
Listening d115	53 (23.0)			
Other purposeful sensing d120	43 (22.3)			
Copying d130	41 (28.1)			
Rehearsing d135	57 (33.7)			
Acquiring skills d155	74 (39.8)			

Focusing attention d160	106 (50.7)			
Reading d166	78 (37.5)			
Writing d170	111 (51.4)			
Calculating d172	61 (31.1)			
Solving problems d175	94 (49.5)			
Making decisions d177	69 (45.4)			
<i>Chapter 2 General tasks and demands</i>				
Undertaking a single task d210	83 (37.7)			
Undertaking multiple tasks d220	117 (61.6)			
Carrying out daily routine d230	107 (48.0)	153 (63.0)	Memory (2g)	110 (45.5)
Handling stress and other psychosocial demands d240	106 (54.9)	143 (58.8)		
<i>Chapter 3 Communication</i>				
Communicating with-receiving-spoken messages d310	57 (26.1)			
Communicating with-receiving-nonverbal messages d315	38 (20.3)			
Communicating with-receiving-written messages d325	48 (24.5)			
Speaking d330	68 (28.6)			
Producing nonverbal messages d335	40 (19.3)			
Writing messages d345	108 (52.9)			
Conversation d350	91 (40.1)		Communication (4e,f)	114 (49.6)
Using communication devices and techniques d360	55 (24.4)		Communication (4g)	73 (30.5)
<i>Chapter 4 Mobility</i>				
Changing basic body position d410	120 (50.6)		Mobility (6d)	109 (45.0)
Maintaining a body position d415	92 (38.7)		Mobility (6a,b)	141 (58.3)
Transferring oneself d420	125 (53.0)			
Lifting and carrying objects d430	179 (76.5)	147 (60.5)	Hand function (7a)	188 (79.0)
Fine hand use d440	163 (70.3)	132 (54.3)	Hand function (7b,d,e)	177 (74.4)
Hand and arm use d445	153 (65.9)	130 (53.5)	Hand function (7c)	180 (76.3)
Walking d450	186 (78.2)	181 (74.5)	Mobility (6c,e,f)	206 (85.8)
Moving around d455	191 (79.9)	205 (84.4)	Mobility (6g,h)	167 (69.6)
Moving around in different locations d460	168 (71.2)	166 (68.3)		
Moving around using equipment d465	138 (59.5)	159 (65.4)		
Using transportation d470	112 (50.5)			
Driving d475	72 (36.4)	153 (63.0)		
<i>Chapter 5 Self-care</i>				
Washing oneself d510	139 (59.7)		Activities of daily living (5c)	153 (64.3)
Dressing d540	120 (51.7)		Activities of daily living (5b)	95 (39.6)
Caring for body parts d520	156 (56.2)		Activities of daily living (5d)	153 (64.3)
Toileting d530	75 (33.5)		Activities of daily living (5e)	85 (35.4)
Eating d550	91 (31.4)		Activities of daily living (5a)	121 (50.6)
Drinking d560	59 (26.8)			
Looking after one's health d570	78 (36.6)			
<i>Chapter 6 Domestic life</i>				
Acquisition of goods and services d620	87 (38.8)		Activities of daily living (5i)	178 (77.4)
Preparing meals d630	136 (61.6)			
Doing housework d640	175 (77.1)	166 (68.3)	Activities of daily living (5h,j)	187 (77.9)
<i>Chapter 7 Interpersonal interactions and relationships</i>				
Basic interpersonal interactions d710	35 (16.6)			
Informal social relationships d750	53 (25.7)		Social participation 8e	123 (51.5)
Family relationships d760				
Intimate relationships d770	21 (13.5)			
<i>Chapter 8 Major life areas</i>				
Acquiring, keeping and terminating a job d845	21 (11.7)	183 (75.3)		

Remunerative employment d850	35 (17.3)	169 (69.5)	Social participation (8a)	178 (78.1)
Non-remunerative employment d855		154 (63.4)		
Basic economic transactions d860	41 (21.0)			
Economic self-sufficiency d870	47 (24.2)			
<i>Chapter 9 Community, social and civic life</i>				
Community life d910	56 (29.5)			
Recreation and leisure d920	107 (50.5)	130 (53.5)	Social participation (8b,c,d)	202 (84.5)
Religion and spirituality d930	18 (17.4)	-	Social participation (8f)	71 (29.3)
Human rights d940	4 (2.3)			

*Categories in bold belong to the second version of the Comprehensive ICF Core Set for stroke.

The reported barriers and facilitators in the ICF Component of environmental factors in studies III and IV

The most common reported barriers were physical geography (e210) and design, construction and building products and technology of building for public use (e150). Family and friends were the most common reported facilitators as well as food, drink and drugs (e110) and products and technology that facilitated mobility and transportation (Table 13). All 37 2nd level categories in the component of environmental factors included in the second version of the Comprehensive ICF Core Set for stroke were validated in study III.

Table 13. Reported facilitators and barriers in the ICF component of environmental factors in studies III and IV.

2 nd level ICF categories	Reported by Health professionals in study III (n=242)		Reported by Health professionals in study IV (n=243)	
	Facilitator +	Barrier -	Facilitator +	Barrier -
Environmental factors	Total (%)		Total (%)	
<i>Chapter 1 Products and technology</i>				
Products or substances for personal consumption e110	34 (17.4)	10 (5.1)	113 (46.5)	
Products and technology for personal use in daily living e115	66 (30.4)	7 (3.2)		
Products and technology for personal indoor and outdoor mobility and transportation e120	106 (45.9)	7 (3.0)	113 (46.5)	
Products and technology for communication e125	68 (30.3)	5 (2.3)		
Products and technology for employment e135	7 (3.4)	3 (2.5)		
Design, construction and building products and technology of buildings for public use e150	43 (19.3)	29 (13)		23 (9.5)
Design, construction and building products and technology of buildings for private use e155	63 (27.8)	24 (10.6)		20 (8.2)

Assets e165	12 (6.7)	4 (2.2)		
<i>Chapter 2 Natural environment and human-made changes to environment</i>				
Physical geography e210	3 (1.5)	24 (12.0)		23 (9.5)
Light e240	41 (21.0)	8 (4.1)		
Sound e250	10 (5.5)	24 (13.1)		19 (7.8)
<i>Chapter 3 Support and relationships</i>				
Immediate family e310	163 (77.6)	8 (3.8)	193 (79.4)	
Extended family e315	110 (61.1)	9 (5.0)	149 (61.3)	
Friends e320	158 (77.4)	7 (3.4)	173 (71.2)	
Acquaintances, peers, colleagues, neighbours, and community members e325	87 (47.8)	15 (8.2)	118 (48.6)	
Personal care providers and personal assistance e340	107 (47.6)	3 (1.3)		
Health professionals e355	162 (70.7)	16 (7.0)		
Other professionals e360	54 (28.6)	5 (2.6)		
<i>Chapter 4 Attitudes</i>				
Individual attitudes of immediate family members e410	129 (65.8)	16 (8.2)	112 (46.1)	
Individual attitudes of extended family members e415	94 (57.7)	7 (4.3)		
Individual attitudes of friends e420	120 (63.8)	14 (7.4)		
Individual attitudes of acquaintances, peers, colleagues, neighbours, and community members e425	60 (34.7)	21 (12.1)		
Individual attitudes of personal care providers and personal assistance e440	72 (36.4)	13 (6.6)		
Individual attitudes of health professionals e450	106 (53.0)	21 (10.5)		17 (7.0)
Individual attitudes of other professionals e455	67 (38.1)	11 (6.3)		
Societal attitudes e460	40 (23.4)	22 (12.9)		18 (7.4)
Social norms, practices and ideologies e465	30 (19.7)	18 (11.8)		
<i>e5Chapter 5 Services, Systems and Policies</i>				
Architecture and construction services, systems and policies e515	34 (18.4)	19 (10.3)		
Housing services, systems and policies e525	66 (33.3)	7 (3.5)		
Communication services, systems and policies e535	81 (41.5)	7 (3.6)		
Transportation services, systems and policies e540	88 (42.7)	14 (6.8)	106 (43.6)	
Legal services, systems and policies e550	45 (24.9)	7 (3.9)		
Associations and organizational services, systems and policies e555	12 (7.0)	4 (2.3)		
Social security services, systems and policies e570	75 (38.3)	9 (4.6)	106 (43.6)	
General social support services, systems and policies e575	74 (35.9)	8 (3.9)		
Health services, systems and policies e580	110 (52.4)	18 (8.6)	113 (46.5)	
Labour and employment services, systems and policies e590	19 (9.7)	4 (2.0)		

* Categories in bold belong to the second version of the Comprehensive ICF Core Set for stroke.

The association between patient-reported SIS items scores and health professionals assessed ICF category scores in study III

Nine 2nd level categories from the ICF component of body functions and 22 from the ICF component of activities and participation were linked to 57 SIS items covering 20% of the Comprehensive ICF Core Set for stroke (Table 12).

The χ^2 test indicated highly statistically significant ($p < 0.001$) association between 40 and significant ($p < .05$) association between 8 of 57 linked SIS item scale and ICF category scores (Table 14).

In the SIS domain 3; emotion the association between 4 of 9 item scores (3b “feel that there is nobody you are close to”, 3c “feel that you are a burden to others”, 3e “blame yourself for mistakes that you made” and 3f “enjoy things as much as ever”) and linked ICF category emotional functions (b152) scores and in the SIS domain scores was not significant ($p > .10$).

Also in the SIS domain 4; communication the association between 4 of 7 item scores (4a “say the name of someone who was in front of you”, 4b “understand what was being said to you in a conversation”, 4c “reply to questions” and 4d “correctly name objects”) and linked ICF category mental functions of language (b167) scores was not significant ($p > .10$).

As well as in the SIS domain 8; social participation the association between the item 8a (“your work (paid voluntary or other)”) scores and the linked ICF categories remunerative (d850) - and non-remunerative employment (d855) scores was not significant ($p > .10$).

The strength of the association was large ($> .50$) between 12, medium ($> .30$) between 24 and small ($> .10$) between 12 of 48 SIS items and linked ICF category scores (Table 14). The PA between patient-reported and health professionals assessed problems ranged from 70.0 to 84.3 % in 30 and from 50 to 68.4% in 18 of the 48 item-category pairs. The kappa value indicated moderate agreement (κ 0.412 - 0.590) between 21, fair agreement (κ 0.218 - 0.391) between 21 and slight agreement (κ 0.01 to 0.20) between 6 of 48 SIS items and linked ICF category scores (Table 14). The odds ratios indicated that a participant who reported functioning problems in the SIS domains strength, memory, activities of daily living, mobility and hand function had a likelihood of 2.3 to 24 times to be classified as having a problem in the linked ICF categories (Table 14) .

Table 14. The association between patient-reported SIS items scores and health professionals assessed ICF category scores.

SIS domain/item (linked to 2 nd level ICF category)	N	Pearson Chi Sq. value	df	Asymp .sig. (two- sided)	phi	Sig.	% PA	Kappa	Sig κ	Odds Ratio	95% CI for Odds Ratio Lower Upper	
Strength												
1abcd (b730 muscle power functions)	227	53.59	1	.000	.501	.000	83.0	.448	.000	21.09	7.89	56.38
Memory												
2abc (b144 Memory functions)	220	65.69	1	.000	.557	.000	80.3	.556	.000	18.21	8.34	39.75
2d (b114 Orientation functions)	233	24.89	1	.000	.337	.000	70.0	.326	.000	5.61	2.86	11.01
2e (b140 Attention functions)	224	8.63	1	.003	.206	.002	61.7	.196	.003	2.95	1.58	5.50
2f (b160 Thought functions)	180	4.05	1	.044	.163	.029	52.5	.134	.030	2.32	1.09	4.94
2g (d230 Carrying out daily routine)	220	13.90	1	.000	.261	.000	62.3	.243	.001	2.77	1.57	4.88
Emotion												
3a (b152 Emotional functions)	204	6.72	1	.010	.193	.006	50.0	.138	.005	2.68	1.20	5.97
3d (b152)	204	4.77	1	.029	.164	.019	53.6	.138	.020	2.25	1.16	4.36
3g (b152)	204	4.09	1	.043	.152	.030	55.1	.142	.022	1.92	1.02	3.60
3h (b152)	204	10.73	1	.001	.240	.001	60.9	.208	.001	3.04	1.62	5.70
3i (b152)	204	10.10	1	.001	.233	.001	61.8	.213	.002	2.94	1.57	5.50
Communication												
4ef (d350 Conversation)	222	30.71	1	.000	.381	.000	68.4	.365	.000	6.05	3.22	11.38
4g (d360 Using communication devices and techniques)	219	22.37	1	.000	.331	.000	73.5	.333	.000	5.61	2.81	11.20
Activities of daily living												
5a (d550 Eating)	225	73.12	1	.000	.579	.000	77.2	.544	.000	6.05	3.22	11.38
5b (d540 Dressing)	227	83.39	1	.000	.615	.000	78.7	.577	.000	24.50	11.28	53.19
5c (d510 Washing oneself)	225	72.15	1	.000	.576	.000	78.6	.548	.000	16.63	8.11	34.14
5d (d520 Caring for body parts)	219	79.76	1	.000	.613	.000	80.2	.590	.000	21.86	10.15	47.09
5e (d530 Toileting)	219	69.71	1	.000	.574	.000	81.1	.580	.000	16.30	7.93	33.50
5f (b620 Urination functions)	196	42.27	1	.000	.477	.000	78.8	.460	.000	11.30	5.14	24.83
5g (b525 Defecation functions)	182	30.17	1	.000	.428	.000	84.2	.361	.000	12.16	4.56	32.44
5hj (d640 Doing housework)	221	32.59	1	.000	.397	.000	78.7	.391	.000	6.53	3.11	13.72
5i (d620 Acquisition of goods and services)	213	24.01	1	.000	.347	.000	58.3	.262	.000	10.49	3.54	31.07
Mobility												
6a,b (d415Maintaining a body position)	239	26.59	1	.000	.342	.000	64.0	.308	.000	4.33	2.31	8.09
6c,e,f (d450 Walking)	235	14.82	1	.000	.417	.000	84.3	.475	.000	7.97	3.63	17.50
6d (d410 Changing basic body position)	238	27.41	1	.000	.348	.000	67.4	.345	.000	5.05	2.74	9.33
6g,h (d455 Moving around)	233	16.47	1	.000	.277	.000	71.7	.267	.000	5.59	2.59	12.09
6i (d410 Changing basic body position)	227	17.90	1	.000	.290	.006	63.2	.265	.000	3.42	1.19	6.12
Hand function												

7a (d430 Lifting and carrying objects)	226	40.40	1	.000	.435	.000	79.6	.412	.000	10.88	5.01	23.64
7b,d,e (d440 Fine hand use)	224	52.49	1	.000	.439	.000	80.7	.513	.000	13.75	6.42	29.45
7c (d445 Hand and arm use)	222	47.42	1	.000	.471	.000	77.9	.461	.000	16.49	7.07	38.48
Social participation												
8b,c,d (d920 Recreation and leisure)	206	27.45	1	.000	.377	.000	63.2	.256	.000	14.07	4.64	42.61
8e (d760 Family relationships and d750 Informal social relationships)	200	3.89	1	.049	.151	.033	75.1	.145	.017	2.05	1.05	3.97
8f (d930 Religion and spirituality)	238	24.85	1	.000	.339	.000	74.8	.222	.000	12.81	3.99	41.13

*Only items with significant association ($p < .05$) with respect to linked ICF categories are included in the table 14.

The strength of the association was from medium to large and highly significant between 5 of 9 linked ICF categories from the component of body functions (Table 14). The percent of agreement ranged from 70 to 83.4% value between these 5 item-category pairs and kappa values from .326 to .556. The strength of the association was large between SIS items linked to ICF categories muscle power function (b730) and memory functions (b144) (Table 14). The strength of the association was from medium to large and highly significant between 17 of 22 linked ICF categories from the component of activities and participation and linked SIS items. The percent of agreement ranged from 63.2 to 84.3% and kappa value from .222 to .590 between these 17 item-category pairs. The strength of the association was large between SIS items linked to 5 ICF categories from the ICF chapter 5 self-care (Table 14).

The influence of personal factors age, gender, place of residence and time since onset of stroke on self-perceived functioning and environmental factors using the Comprehensive ICF Core Set for stroke framework in study IV

Higher age indicated a greater number of problems in functioning and more restrictions in “activities and participation”. Age also had an influence on most of the areas in the

environmental factors (Tables 15 and 16) (156). Time since onset was found to be a factor that influences “activities and participation” and from “environmental factors”, the perception of attitudes was influenced (Table 15). Living in a rural setting was associated with perceiving more facilitators in “natural environment and human-made changes in the environment” than those who lived in the city. In contrary, those who lived in the city perceived more facilitators in “support and relationships” and “attitudes”. The results of the complete analyses of the regression analyses are shown in tables 15 and 16 (156) where only independent variables with a p-value of less than 0.1 are included. The beta value in Tables 15 and 16 is reported for the model including all 4 PF (156).

Table 15. Results of standard multiple regression analysis.

						Beta	P**				
Sum of problems in body functions		R ²	.045	Males vs. Females		.156	.016				
		p*	.026								
Sum of problems in activities and participation		R ²	.102	Time		.219	.001				
		p*	<.0005	Age		.134	.036				
				Males vs. Females		.110	.077				
		Facilitators				Barriers					
				Beta	P**		Beta	P**			
Environmental factors	Products and technology	R ²	.214	Age	.401	<.0005	R ²	.049	Age	-.137	.036
		p*	<.0005	Males vs. Females	.131	.025	p	.017	Rural vs. City living	-.199	.006
	Natural environment and human-made changes to environment	R ²	.042	Rural vs. City living	-.159	.026	R ²	.053	Age	-.224	.001
		p*	.038				p	.012			
	Support and relationships	R ²	.119	Rural vs. City living	.320	<.0005	R ²	.076	Age	-.274	<.0005
	p*	<.0005				p	.001				
Attitudes	R ²	.094	Time	.194	.005	R ²	.090	Time	.137	.045	
	p*	<.0005	Age	-.199	.002	p	<.0005	Age	-.271	<.0005	
			Rural vs. City living	.127	.068						
Services, systems and policies	R ²	.098	Age	.243	<.0005	R ²	.049	Age	-.189	.004	
	p*	<.0005	Male vs. Females	.152	.016	p	.017				

*Statistical significance of the model; **statistical significance of each variable of the model.

Table 16. Results of direct logistic analysis for seven chosen domains of ICF (five items of ‘activities and participation’ and two of ‘environmental factors’).

ICF code	ICF category title		p*	B	P**	Odds Ratio (OR)	95% CI for OR	
							Lower	Upper
d460	Moving around in different locations		<.0005	Age	.054	.000	1.056	1.031 1.082
d530	Toileting		<.0005	Time	.011	.033	1.011	1.001 1.021
				Age	.047	.002	1.048	1.017 1.080
				Males vs. Females	-.583	.090	.558	.285 1.094
				Rural vs. City living	-.817	.033	.442	.208 .938
d540	Dressing		<.0005	Time	.010	.049	1.010	1.000 1.019
				Age	.036	.003	1.013	1.013 1.062
				Rural vs. City living	-1.038	.003	.354	.177 .709
				Time	.018	.022	1.018	1.003 1.033
d640	Doing housework		<.0005	Age	.036	.003	1.036	1.013 1.060
				Males vs. Females	.660	.043	1.935	1.021 3.669
				Rural vs. City living	-1.036	.013	.241	.078 .740
				Age	.029	.008	1.029	1.007 1.052
d920	Recreation and leisure		<.0005	Rural vs. City living	-1.027	.023	.358	.148 .867
				Age	.029	.008	1.029	1.007 1.052
e210	Physical geography'	Facilitators	.054					
		Barriers	.016	Rural vs. City living	-1.519	.004	.219	.079 .608
e310	Immediate family	Facilitators	.001	Age	.039	.022	1.042	1.040 1.075
				Rural vs. City living	2.110	.000	8.251	2.860 23.801
		Barriers	.470;					

*Statistical significance of the model; **statistical significance of each variable of the model. ICF: International Classification of Functioning, Disability and Health; OR: odds ratio; CI: confidence interval.

6 DISCUSSION

General discussion

The management of limitations in functioning and improving the functioning from the acute rehabilitation settings to the community health care settings is becoming one of the most urgent outcomes in public health planning and implementation of preventative actions (3, 89). These actions are only feasible if the needs of people with disabilities such as stroke are considered when agreement on the scope of concepts to be taken into account (10, 68) in disability assessment is required. Therefore understanding the perspective of people with previous stroke's on functioning becomes crucial for the development of effective outpatient services (3, 34, 157).

The objective of this thesis was to validate the Comprehensive International Classification of Functioning, Disability and Health (ICF) Core Set for stroke by exploring the person with previous stroke perspective on functioning in everyday life.

The data collection in all four studies was done by semi-structured interviews with persons with previous stroke and by observation and information from the next-of-kin when relevant. The perspectives of persons with previous stroke were then translated to the ICF language by linking the reported functioning problems to the 2nd level ICF categories using the Comprehensive ICF Core Set for stroke as a reference. These linked 2nd level ICF categories were then interpreted to represent persons with previous stroke's perspective on functioning problems in daily activities.

The results in studies I and II supported the assumption that the categories included in the first version of the Comprehensive ICF Core Set for stroke (10) largely represented the common functioning problems (33, 125, 126) among persons with previous stroke living in their homes at least 2, 4 months after stroke (10, 33, 120) and who were able to participate in face-to-face interviews. The results presented in study III, which also included persons with previous stroke at least 1 month since stroke (i.e. in the early post-acute phase of stroke were included) supported this inference. However the results also indicated that the validation of the Comprehensive ICF Core Set for stroke is still incomplete.

Studies I and II

The specific aims of studies I and II were to validate the Comprehensive ICF Core Set for stroke by exploring the community-dwelling people with previous stroke's perspective of functioning in two different environments.

In total, 28 of 36 categories added to the Comprehensive ICF Core Set for stroke in 2005 (117-119) were not validated in studies I and II in individuals with stroke living in their homes. Eleven of 18 categories added to the second version of the Comprehensive ICF Core Set for stroke (115) in the component of body functions and 6 of 6 in the component of body structures appeared to belong to the assessment of sensory deficits, motor disturbances, problems with nutrition and swallowing, bowel and bladder dysfunction and cognitive impairments (158, 159) in the acute and early post-acute phases of stroke as described by Ewert et al (119) as well as to not confirmed categories in the component of body structures (117).

Three of the un-validated categories in the component of activities and participation; other purposeful sensing (d120), copying (d130) and rehearsing (d135) are aimed to identify social and behavioural restrictions (158, 159) and can also be seen as important to assess in the acute and early post-acute phases of stroke. The 4 of 4 not validated 2nd level ICF categories in the component of environmental factors; light (e240) and sound (e250) can be a major burden to patients in intensive care units (117) which explains why these categories were important to add to the second version of the Comprehensive ICF Core Set for stroke to enable its use in all clinical situations.

The inclusion of the fourth not validated category religion and spirituality (d930) as well as the category human rights (d940) also included in the second version of the Comprehensive ICF Core Set for stroke is, difficult to motivate with the same postulation, as these categories refer to the potentially restricted privacy or dignity (119). Inclusion of these two categories in the second version of the Comprehensive ICF Core Set for stroke highlights the fact that the requirements for consensus in developing a Core Set are complex (113) and that the ICF Core Sets are a result of a consensus process of different experts' opinions (10, 114, 119). There may still be disparities between these definitions and how people experience their disabilities.

ICF categories added to the second version of the Comprehensive ICF Core Set for stroke can be said to complete the health professional's point of view and enhance systematic documentation of person with previous stroke functioning problems in all clinical situations (117, 119, 120) reducing the risk for missing important aspects of functioning when assessing stroke (114). These assumptions were considered to support the validity of the second version of the Comprehensive ICF Core Set for stroke i.e. what should be assessed in all phases of stroke.

In studies I and II, 11 additionally validated 2nd level ICF categories not included in the second version of the Comprehensive ICF Core Set for stroke underline that problems facing people with previous stroke are usually complex and heterogenous (23) and people's experiences of disability are extremely varied (24, 25). In the previous (second version) of the Comprehensive ICF Core Set for stroke validation study using focus groups in Germany (120), the number of validated additional categories was 31 which is similar with the findings in our studies. It is of importance to note that the following additional categories were validated from the perspective of persons with previous stroke in our studies and in the validation study in Germany (120); sensations associated with the eye and adjoining structure (b220), smell functions (b255), involuntary movement functions (b765), sensations related to muscle and movement functions (b780), other functions of the skin (b830), assisting others (d660), complex interpersonal interactions (d720), population (e215) and climate (e225). Whether these categories should be included in the final version of the Comprehensive ICF Core Set for stroke is open to discussion. These results indicated that the comprehensive understanding of the persons with previous stroke's perspectives on functioning problems in daily activities is still incomplete using the Comprehensive ICF Core Set for stroke as a frame of reference.

Meaningful concepts that could not be linked to the ICF

The participants also raised other topics in the studies I and II that could not be linked to the ICF using the suggested linking rules (132). These topics, e.g. current experiences (not covered by the ICF) or the personal factor, a coping style of "I take it as it comes" identified in the transcribed texts in study I, could not be linked to the ICF categories and therefore the

importance of these topics for the person with previous stroke's functioning was not explored in the scope of this thesis.

Study III

The specific aim of study III was to investigate the construct validity of the Comprehensive ICF Core Set for stroke by exploring the association of patient-reported Stroke Impact Scale (SIS) scores with respect to the scores in the ICF categories linked to these items assessed by health professionals.

Construct validity of the ICF categories linked to the SIS items

In study III the results were considered to support the construct validity of 22 of 31 ICF categories linked to SIS items i.e. the SIS item and the linked ICF category were considered to characterize the same patient-reported problem. Nine of 31 ICF categories linked to SIS items that represented social, communication and emotional aspects of functioning were considered not to represent the patient-reported problems. Whether the ICF categories should be linked to SIS items that express the subjective experience of participation problems (44, 139) should be further studied to enhance the concurrent use of the SIS and the Comprehensive ICF Core Set for stroke in clinical practice and research.

The fact that there is no consensus or clear instructions of the most precise linking of the ICF categories to a single SIS item that is critical (75, 132, 134) for the comparison and generalization of the results in different settings and study populations, may have affected the reliability of the findings in study III.

Comparison of the number of patient-reported (SIS) and health professionals assessed problems in the ICF component of body functions

The number of patient-reported and health-professionals assessed problems in the SIS item – ICF category pairs representing physical functioning and memory functions in the component of body functions were comparable which supported the validity of the ICF categories linked to the SIS items. The difference between the number of patient-reported and health-professionals assessed problems were obvious in the SIS item – ICF category pairs representing emotional and communication problems. These results are somewhat surprising because it is well known that persons with previous stroke often have communication problems (160, 161), express feelings of frustration, uncertainty and confusion, e.g. “not recognized as the person I am” (44-46) and there is evidence that depressive mood symptoms after stroke are common (39-41).

The findings implicated that the improvement in recovery from stroke is still measured primarily in terms of regaining physical function (162) and a dialog between the health professionals and persons with previous stroke is needed if health services are to be based on problems experienced by the people with previous stroke (56).

These results also stress the importance of addressing commonly perceived problems (8, 77, 126) in mental functions in stroke rehabilitation despite the difficulties to introduce mental practice as part of the regular rehabilitation (163). Addressing the problems in mental functions is also an important part of the motor recovery (163) as cognitive deficits may exacerbate any stroke-related disability leading to various functioning problems and physical inactivity (37, 38). More unconventional therapies such as singing in choir (164) are obviously needed to expand the stroke rehabilitation.

Comparison of the number of patient-reported (SIS) and health professionals reported problems in the ICF component of activities and participation

In study III the SIS items linked to the ICF categories in the component of activities and participation identified the same common problems that were also reported in studies I, II and IV i.e. problems related to mobility and problems in domestic life such as doing housework or preparing meals or problems with recreation and leisure. The difference between the number of patient-reported and health-professionals assessed problems were obvious in the SIS item – ICF category pairs representing social participation. E.g., the SIS item 8f. “Your participation in spiritual or religious activities”, that was reported as a problem by 71 participants, was linked to the ICF category religion and spirituality (d930) that was assessed as a problem for 18 participants by the health professionals. These results appear to confirm that for the long term stroke survivors it is the social and personal context and adjustment to disability beyond physical functioning (55) that is associated with enhanced quality of life in the long-term recovery after stroke (46).

The challenge is how to plan and evaluate stroke rehabilitation when the person's needs are more social than medical (57). It can be speculated that professional specialisation, lack of common understanding of disability and the absence of consensus of the concepts to be taken into account when addressing stroke (78) has led to a fragmentation between professions. Professionals in the rehabilitation team might have a tendency to identify problems within their scope of practice, which can hinder team members to look at problems holistically, i.e. to describe the interactions among body functions, body structure, activities and participation, and the related variables of environmental and personal factors (74, 157, 165).

It can be thought whether the reason for the findings in social, communication and emotional aspects of functioning is that these domains are traditionally not seen as a part of the regular rehabilitation process (56, 162). For example according to the Swedish National Stroke Register about 55% of persons with previous stroke who reported speech problems in 2012 have not received speech therapy (166).

The results of study III indicated that the person perspective of functioning problems in physical daily activities (140) was largely captured (44, 56) using the second version of the Comprehensive ICF Core Set for stroke as a reference. I.e. the number of identified functioning problems was comparable between the health-professionals assessed functioning problems in ICF categories (included in the Comprehensive ICF Core Set) and the patient-reported problems in the SIS items. Furthermore all the ICF categories included in the second version of the Comprehensive ICF Core Set for stroke were validated by the semi-structured interviews. These results supported the validity of the second version of the Comprehensive ICF Core Set for stroke.

Study IV

The specific aim of study IV was to explore the influence of personal factors (i.e. age, gender, place of residence and time since onset of stroke) on self-perceived functioning and environmental factors, using the International Classification of Functioning, Disability and Health (ICF) Core Set for stroke as a framework.

The results in study IV supported the criterion validity of the personal factors age, gender, place of residence and time since onset of stroke in evaluation of self-perceived functioning problems and environmental facilitators and barriers as defined in the Comprehensive ICF Core Set for stroke framework.

Personal factors (PF) are not classified in the ICF but it is assumed that PF's can influence disability at any level (6) and are essential determinants in the context of functioning and disability (6). The results of study IV confirmed the importance of PF's in construction of person with previous stroke's functional profiles. The selected PF's had a predictive value for perceived functioning problems and environmental factors in the chronic phase after stroke. These PF's influenced self-perceived functional outcome and environmental factors in terms of being barriers or facilitators. The investigated PF's represent basic background for living with permanent disability and it was possible to categorize and measure them. Better understanding of PF's may therefore facilitate construction of broader functional profiles of the person with previous stroke and lead to improvements in person-centred rehabilitation (107).

Although the model of selected PF's in study IV showed an influence of all the components, domains and categories that were used for the analysis, the influence of each single factor and the interaction of these factors differed widely between different ICF components, domains and categories. This illustrates the complexity of the evaluation of human functioning and the results of this study need to be confirmed in future research.

Environmental factors in studies I to IV

The immediate family, extended family and friends apart from the health professional were important facilitators in the results of studies I to IV.

These findings were in agreement with other studies on the dependency of people with previous strokes on the support from the next-of-kin (48, 49). The support from the immediate family can be said to be mainly facilitator for the persons with previous stroke (126), as the immediate family often provides most of the required service (24). These results supported the idea that not only the person with previous stroke but also the immediate family should be included as clients to be able to systematically assess the social environment and to provide services in accordance with needs (36, 167). In study IV the time since onset of stroke was found to be a factor that influences “activities and participation” and the perceptions of attitudes (environmental factors). This confirms that different patterns of change in functioning take place after stroke (53) in interaction with disabling or enabling environments (168) and this knowledge should serve to help guide person centred rehabilitation (58) and assessment of persons with previous stroke's needs in everyday life during different phases after stroke.

The results in study IV also indicated that the place of residence had a positive or negative effect on reported facilitators and barriers in environmental factors. Human made changes to the environment such as home modifications and transportation services, systems and policies were also reported as important facilitators even though the same categories were also experienced as barriers by some of the participants in all four studies. These results indicated that a supportive environment facilitated functioning among participants and confirmed that modifying environmental factors is important and beneficial for people with previous stroke (51, 126).

Environmental factors (physical, social and attitudinal environment in which people live and conduct their lives) act as modulators of disability being facilitators or barriers (169). To identify the key environmental factors that are necessary to account for in planning and developing stroke rehabilitation and community services is one of the key concepts in supporting the people with previous stroke in performing in the problematic areas of functioning and activities of daily living (8, 50, 124, 170, 171). The need of external home services among stroke survivors in Sweden is increasing (24) which further stresses the importance to include the physical, social and attitudinal environmental factors as part of multidisciplinary stroke assessment.

All categories included in the environmental factors in the second version of the Comprehensive ICF Core Set for stroke were validated in study III which supported the validity of the second version of the Comprehensive ICF Core Set for stroke.

Feasibility of the Comprehensive ICF Core Set for stroke in clinical practise and research

It is debatable how many categories are feasible to manage in clinical practice and in research while at the same time fulfilling the requirements of multi-professional comprehensive assessment of stroke (112). Alguren et al (125) suggested a possible reduction in the number of categories included in the second version of the Comprehensive ICF Core Set for stroke to increase its integration in clinical practice (from the health professionals point of view). However, the final version of the Comprehensive Core Set for stroke should also answer the question what matters for the person with previous stroke (3) i.e. what should be measured when assessing stroke. Therefore, the final version of the Comprehensive ICF Core Set for stroke should include the number of categories required to create a comprehensive functional profile of a person with previous stroke to thus provide a common framework for health outcome measurement (67, 172, 173).

The Comprehensive ICF Core Set for stroke is the largest of the ICF Core Sets developed for the 12 most burdensome chronic conditions (10) reflecting the high burden of stroke (114). To learn to use the Comprehensive ICF Core Set for stroke in clinical practice and research is without a doubt challenging and time-consuming but it can provide a rich functional profile of a person with previous stroke with the additional advantage of being able to describe contextual factors (168, 174).

Methodological discussion

Data saturation

Twelve interviews suffice to reach saturation of data in most cases according to Guest et al, (2006), but more interviews are recommended if the target group is relatively heterogeneous as in the studies presented here. Data saturation was reached in both of the presented qualitative studies and was also confirmed with three consecutive interviews in study I and with four in study II that did not reveal any new concepts that could be linked to new ICF categories.

Limitations and strengths in data collection

That the interviewers in study I and II 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 previous stroke because the interviewers (also in studies III and IV) belonged to that group of professionals.

However, the interviewers in studies I and II had met the participants several times during their post stroke rehabilitation and this relationship can be considered to have helped them to create a relaxed atmosphere during the interviews which led to rich description of the participants perceived functioning problems in daily activities.

In all four studies the interviewers were experienced in stroke rehabilitation and also had good knowledge concerning ICF, which helped them to document the ICF categories that described participants' problems.

A possible weakness in the interview-based approach in studies I and II was that participants who reported problems such as in mental functions as in memory- and attention functions can suffer from the common phenomenon of unawareness (162), and this might have had an effect on their judgement about their perspective of perceived functioning problems in daily activities.

The semi-structured interview guide used in studies I and II helped the interviewers to cover the different dimensions of the ICF but in the open interview approach (175) 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 (175). Several other not confirmed categories, such as intimate relationships (d770) can be difficult to confirm if the topics are not directly addressed in the interview situation. Therefore our results support the use of the ICF based interview approach technique (175) to ensure that as many aspects of functioning as possible are addressed during the interviews (150).

In studies III and IV the interviewers had the Comprehensive ICF Core Set for stroke as reference during the interviews. This made it possible to systematically document the categories that in their opinion best represented the participant's problems. It can't be ruled out that the interviewer mainly chose the categories that presented participants' problems in accordance with his/hers own professional background and experience.

Limitations and strengths of the study population in studies I to IV

People with previous stroke of different ages, with different social situations and levels of impairments were included in the studies which can be said to support the validity of the findings. The strengths in the chosen study population were that both men and women (45.5%) were included and that people with previous stroke living in different environments, in the city and in rural areas and even in different countries (Sweden/Finland) were included in the studies. Furthermore the considerable spread in ages (range 24–95 years) and time since stroke, with the shortest period being 1 month after the stroke and the longest 26 years after the onset of stroke, can be considered as strengths in the chosen study population.

The data collection was based on interviews and observation of the participants who were able to give their perspective on perceived functioning problems in daily activities and fill in surveys. Therefore the identified problems do not necessarily represent the perspective on functioning in daily activities of people with severe impaired cognitive functions.

Another selection bias was that most of the participants in studies I, III and IV were native Swedes and all in study II were native Finns. The number of persons born outside Sweden in studies III and IV was low and insufficient for reliable statistical analysis.

Therefore the results cannot be said to represent the perspective of persons with previous stroke born outside of Sweden. Most of participants included in studies I to IV were people connected to rehabilitation facilities and had received rehabilitation at some time or were still in contact with the members of the multidisciplinary teams.

This is also a limitation because all persons with previous stroke do not come in contact with rehabilitation facilities after stroke and their perspective on functioning after stroke was not studied. The limitations mean that the results in our studies cannot be said to be applicable to all persons with previous stroke.

Limitations and strengths in the data-analysis

In studies I and II the concepts that could not be linked to the ICF were classified as, health condition, time-related aspects, personal factors, not definable or not covered by the ICF according the ICF linking rules (132). This ensured that the manifest content of the transcript interviews was defined to its fullest extent within the context in which the analysts had chosen to read them (138). Investigator triangulation (148, 149) was used in the data analysis of studies I and II to increase the identification accuracy of the functional concepts from the transcriptions and during the linking procedure. In order to increase the accuracy of the data-analysis in study I, another meeting was organized in the participants' homes (2–4 weeks after the interview). In this meeting the results were presented and they were asked whether their perspective of functioning at home had been correctly understood.

A limitation in data-analysis in studies III and IV was that, for the ICF, qualifiers are intended to denote the extent of the problem, but this does not satisfy the criteria for reliable measurement (111).

Therefore the data were dichotomized to avoid analysing data that would not represent actual changes in components of the ICF. The disadvantage of this approach was that the extent of problems among the participants in studies III and IV were not analysed.

In study III the data were dichotomized to yes and no answers and therefore, to explore distribution of the SIS item scale scores with respect to linked ICF category scores to be able to explore the association between two categorical variables by comparing the frequencies of patient-reported problems and those reported by the health professionals. In our opinion this increased the reliability of the findings. A possible bias in the data-analysis in the study III was that the SIS items linked to specific ICF categories do not necessarily represent the same problems. Treating the response option 8 (not specified) as missing, and the response option 9 (not applicable) (as no problem) could have caused bias towards “no problem” in the data-analysis because it is possible that the health professional chose option 8 or 9 when they felt unsure which ICF category should be used.

7 CONCLUSION

The presented results support the assumption that the 2nd level ICF categories included in the second version of the Comprehensive ICF Core Set for stroke portray the common and central problems, barriers and facilitators that affect people with previous stroke's functioning in daily activities. However as the validated additional 2nd level ICF categories in studies I and II and the results in study III showed the validation of the Comprehensive ICF Core Set for stroke from the perspective of persons with previous stroke is still incomplete. 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 previous stroke concerning, problems in functioning in everyday life is important for developing person centred care. The use of the Comprehensive ICF Core Set for stroke can provide a wider perspective of, and a systematic coding system for, understanding the needs of persons with previous stroke that is understood across related professional fields and disciplines and even by the people with previous stroke, ultimately leading to better person centred care and outcomes. The Comprehensive ICF Core Set for stroke also has the potential to be used in development of measures used in the assessment of stroke related functioning problems.

8 FURTHER RESEARCH

The validation of the Comprehensive ICF Core Set for stroke from the perspective of immediate family is an important, unexplored aspect. It is important that immediate family are not only considered as a source of information but also as legitimate clients and as such, formally assess their needs and to accept a change in practice towards a family-centred "rehabilitation" after stroke.

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APPENDIX 1.

Comprehensive ICF Core Set for stroke (Categories in bold belong to the second version of the

Comprehensive ICF Core Set for stroke)

Categories of the component ‘body functions’:

Chapter 1 Mental functions

Categories of the component ‘body functions’:

ICF Code ICF, Category Title 2nd Level

b110 Consciousness functions

b114 Orientation functions

b117 Intellectual functions

b126 Temperament and personality functions

b130 Energy and drive functions

b134 Sleep functions

b140 Attention functions

b144 Memory functions

b147 Psychomotor functions

b152 Emotional functions

b156 Perceptual functions

b164 Higher-level cognitive functions

b167 Mental functions of language

b172 Calculation functions

b176 Mental function of sequencing complex movements

b180 Experience of self and time functions

Chapter 2 Sensory functions and pain

b210 Seeing functions

b215 Functions of structures adjoining the eye

b230 Hearing functions

b235 Vestibular functions

b240 Sensations associated with the eye and adjoining structures

b260 Proprioceptive function

b265 Touch function

b270 Sensory functions related to temperature and other stimuli

b280 Sensation of pain

Chapter 3 Voice and speech functions

b310 Voice functions

b320 Articulation functions

b330 Fluency and rhythm of speech functions

b340 Alternative vocalization functions

Chapter 4 Function of the cardiovascular; haematological, immunological and respiratory systems

b410 Heart functions

b415 Blood vessel functions

b420 Blood pressure functions

b430 Haematological system functions

b435 Immunological system functions

b440 Respiration functions

b450 Additional respiratory functions

b455 Exercise tolerance functions

Chapter 5 Functions of the digestive, metabolic and endocrine systems

b510 Ingestion functions

b515 Digestive functions

b525 Defecation functions

b530 Weight maintenance functions

b535 Sensations associated with the digestive system

b540 General metabolic functions

b545 Water, mineral and electrolyte balance functions

b550 Thermoregulatory functions

Chapter 6 Genitourinary and reproductive functions

b620 Urination functions

b630 Sensations associated with urinary functions

b640 Sexual functions

Chapter 7 Neuromusculoskeletal and movement-related functions

b710 Mobility of joint functions

b715 Stability of joint functions

b730 Muscle power functions

b735 Muscle tone functions

b740 Muscle endurance functions

b750 Motor reflex functions

b755 Involuntary movement reaction functions

b760 Control of voluntary movement functions

b770 Gait pattern functions

Chapter 8 Functions of skin and related structures

b810 Protective functions of the skin

Categories of the component 'body structures':

Chapter 1 Structures of the nervous system

s110 Structure of brain

s120 Spinal cord and related structures

s130 Structure of meninges

Chapter 4 Structures of the cardiovascular, immunological and respiratory systems

s410 Structure of cardiovascular system

s430 Structure of respiratory system

Chapter 5 Structures related to the digestive, metabolic and endocrine systems

S530 Structure of stomach

Chapter 7 Structures related to movement

s710 Structure of head and neck region

s720 Structure of shoulder region

s730 Structure of upper extremity

s750 Structure of lower extremity

Chapter 8 Skin and related structures

s810 Structure of areas of skin

Categories of the component 'activities and participation':

Chapter 1 Learning and applying knowledge

d110 Watching

d115 Listening

d120 Other purposeful sensing

d130 Copying

d135 Rehearsing

d155 Acquiring skills

d160 Focusing attention

d166 Reading

d170 Writing

d172 Calculating

d175 Solving problems

d177 Making decisions

Chapter 2 General tasks and demands

d210 Undertaking a single task

d220 Undertaking multiple tasks

d230 Carrying out daily routine

d240 Handling stress and other psychological demands

Chapter 3 Communication

d310 Communicating with - receiving - spoken messages

d315 Communicating with - receiving - nonverbal messages

d325 Communicating with - receiving - written messages

d330 Speaking

d335 Producing nonverbal messages

d345 Writing messages

d350 Conversation

d360 Using communication devices and techniques

Chapter 4 Mobility

d410 Changing basic body position

d415 Maintaining a body position

d420 Transferring oneself

d430 Lifting and carrying objects

d440 Fine hand use

d445 Hand and arm use

d450 Walking

d455 Moving around

d460 Moving around in different locations

d465 Moving around using equipment

d470 Using transportation

d475 Driving

Chapter 5 Self-care

d510 Washing oneself

d520 Caring for body parts

d530 Toileting

d540 Dressing

d550 Eating

d560 Drinking

d570 Looking after one's health

Chapter 6 Domestic life

d620 Acquisition of goods and services

d630 Preparing meals

d640 Doing housework

Chapter 7 Interpersonal interactions and relationships

d710 Basic interpersonal interactions

d750 Informal social relationships

d760 Family relationships

d770 Intimate relationships

Chapter 8 Major life areas

d845 Acquiring, keeping and terminating a job

d850 Remunerative employment

d855 Non-remunerative employment

d860 Basic economic transactions

d870 Economic self-sufficiency

Chapter 9 Community, social and civic life

d910 Community life

d920 Recreation and leisure

d930 Religion and spirituality

d940 Human rights

Categories of the component 'environmental factors':

Chapter 1 Products and technology

e110 Products or substances for personal consumption

e115 Products and technology for personal use in daily living

e120 Products and technology for personal indoor and outdoor mobility and transportation

e125 Products and technology for communication

e135 Products and technology for employment

e150 Design, construction and building products and technology of buildings for public use

e155 Design, construction and building products and technology of buildings for private use

e165 Assets

Chapter 2 Natural environment and human-made changes to environment

e210 Physical geography

e240 Light

e250 Sound

Chapter 3 Support and relationships

e310 Immediate family

e315 Extended family

e320 Friends

e325 Acquaintances, peers, colleagues, neighbours and community members

e340 Personal care providers and personal assistants

e355 Health professionals

e360 Health-related professionals

Chapter 4 Attitudes

e410 Individual attitudes of immediate family members

e415 Individuals attitudes of extended family members

e420 Individual attitudes of friends

e425 Individual attitudes of acquaintances, peers, colleagues, neighbours and community members

e440 Individual attitudes of personal care providers and personal

assistants

e450 Individual attitudes of health professionals

e455 Individual attitudes of health-related professionals

e460 Societal attitudes

e465 Social norms, practices and ideologies

Chapter 5 Services, systems and policies

e515 Architecture and construction services, systems and policies

e525 Housing services, systems and policies

e535 Communication services, systems and policies

e540 Transportation services, systems and policies

e550 Legal services, systems and policies

e555 Associations and organizational services, systems and policies

e570 Social security services, systems and policies

e575 General social support services, systems and policies

e580 Health services, systems and policies

e590 Labour and employment services, systems and policies

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