From THE DEPARTMENT OF NEUROBIOLOGY, CARE
SCIENCES AND SOCIETY
Karolinska Institutet, Stockholm, Sweden

Needs for, use of and satisfaction with health care services in the course of the first year after stroke

-the perspective of people with stroke

Malin Tistad

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När du stängde av teven
på kvällen den 13 april
lyckades nå sängen
nu dör jag hade du tänkt
sen blev det svart

ett hårt slag säger du
en oväntad kospark under ditt grålockiga hår
allt började med hjärtat som tappade fart
blodet som samlades i klumpar

kramp
när syret tog slut
centrifugalkraften
och hur du höll dig i möblerna
svärtan och färgblixtarna
och röda trådars som skrumpnar vita på sekunder

en spark av döden men du höll dig kvar
vaknade på örngottet med mormors initialer
precis som vanligt
men något var fel

väldigt fel
det är så konstigt allting
sa du när du ringde
morgonen den 14 april
klockan var tio över nio
jag kan inte koka kaffe sa du

ur *Ansiktet i händerna, en berättelse om stroke* av Jane Morén

ABSTRACT

Background Many people who have had a stroke report unmet needs for rehabilitation. There is, however, a lack of knowledge about what issues underlie the many unmet needs. Assessment tools are used in the health care services to identify the presence of disabilities, but it is not known to what extent patient expressed disabilities are identified in the assessment tools. There is also a lack of knowledge regarding changes over time in length of stay (LOS) at stroke units and subsequent rehabilitation after stroke.

The general aim of this thesis was to generate new knowledge about needs for rehabilitation, use of and satisfaction with health care services in the course of the first year after stroke from the perspective of people with stroke.

Method Data was derived from an observational prospective longitudinal study of people diagnosed with a stroke who received care at the stroke units of Karolinska University Hospital 2006/2007 (n=349). Data was also taken from the control-group in a randomized controlled trial of people who received care at the same stroke unit during 1993/1996 (n=40). Data collection comprised baseline assessment and follow-ups at 3, 6 and 12 months. Data was collected using an open question, established assessment tools, medical records and the Stockholm County Council's computerized registers for use of health care services. Analyses applied in the thesis were: in paper I a comparison of the perspective of people who have had a stroke (categories of self-reported problems in daily life) and the health care services' perspective (results from three established assessment tools); in paper II and III multivariate logistic regression analyses, and in paper IV comparisons regarding LOS, recovery in activities of daily living (ADL) and patient satisfaction.

Results Fatigue was the most common self-reported problem that people experienced in daily life after stroke. Items/domains in three standardized assessment tools corresponded to only 15 of 24 categories of self-reported problems. Furthermore, the assessment tools failed to identify 0-57% of the self-reported problems in the 15 categories that had corresponding items/domains (paper I). Unmet needs for rehabilitation at 12 months were predicted by high impact on strength (on the affected side) at 3 months, and associated with high impact on hand function (on the affected side) and poor self-rated recovery at 12 months (paper II). Among participants with moderate/severe stroke, met needs for rehabilitation was associated with having seen a physiotherapist at least once during each of the 1st, 2nd and 3rd-4th quarters of the first year (paper III). Dissatisfaction with care at 12 months was predicted by poor coping capacity and restrictions in participation at three months, and associated with poor coping capacity and strength (on the affected side) at 12 months (paper II). The LOS at the stroke unit was shorter for patients who received care during 2006/2007 compared to 1993/1996 (median 8 versus 13 days), but no difference in LOS was found regarding the total LOS (stroke unit and subsequent in-patient rehabilitation). The participants from 2006/07 were to larger extent independent in ADL at 3 months after stroke, but no difference at 12 months was revealed and both groups were equally satisfied with health care services received (paper IV).

Conclusion There is poor concurrence between the perspective of the people who have had a stroke and the perspective of the health care services regarding problems experienced in daily life after a stroke. If health care services are to be based on problems experienced by the people who have had a stroke, the use of assessment tools should be complemented by a dialogue. Extra attention should be paid to the rehabilitation needs of people with high impact on strength and hand function and poor recovery since these are more likely to experience unmet needs for rehabilitation. For people with moderate/severe stroke, continuity in rehabilitation and particularly physiotherapy during the first year after stroke seems to contribute to meeting their needs for rehabilitation. It seems possible to reduce the number of days a patient spends in the stroke unit after mild to moderate stroke and for them to spend these days in a rehabilitation unit instead, and yet achieve a faster recovery in ADL.

Key words: activities of daily living, assessment tools, disability, health care services, long-term, length of stay, mixed methods, needs, need assessment, patient satisfaction, rehabilitation, stroke, stroke unit

SAMMANFATTNING (SUMMARY IN SWEDISH)

Bakgrund Många männsikor som haft en stroke upplever att deras behov av rehabilitering inte tillgodoses. Det saknas dock kunskap om vad som bidrar till att så många upplever att rehabiliteringsbehoven inte tillgodoses. I hälso- och sjukvården används mätinstrument för att identifiera förekomsten av funktionshinder men i vilken utsträckning patienternas självrapporterade problem fångas upp av mätinstrumenten har inte studerats. Vidare saknas det kunskap om förändringar över tid avseende vårdtider på strokeenhet och efterföljande rehabilitering.

Det övergripande syftet med denna avhandling var att bidra med ny kunskap om behovet av rehabilitering, nyttjande av hälso- och sjukvård samt tillfredsställelse med hälso- och sjukvården under det första året efter en stroke utifrån perspektivet hos människor som har haft en stroke.

Metod Data samlades in från personer som vårdades för stroke på strokeenheterna på Karolinska Universitetssjukhuset i Huddinge och i Solna 2006/2007 (349 deltagare) samt från kontrollgruppen i en randomiserad kontrollerad studie där personerna rekryterats från samma strokeenhet 1993/1996 (40 deltagare). Datainsamlingen skedde i samband med insjuknandet samt 3, 6 och 12 månader efter stroken. Datainsamlingen omfattade en öppen fråga, standardiserade mätinstrument, data från journaler samt från Stockholms läns landstings datoriserade register för vårdkontakter. Avhandlingens analyser inkluderar i delarbete I en jämförelse av två perspektiv på problem i det dagliga livet efter en stroke, dels hos personer som haft en stroke (kategoriserade självrapporterade problem), dels hos hälso- och sjukvården i form av resultat från tre standardiserade mätinstrument, i delarbete II och III multivariata logistiska regressioner samt i delarbete IV jämförelser av vårdtid, återhämtning i aktiviteter i dagliga livet (ADL) och tillfredsställelse med vården.

Resultat Trötthet var det vanligaste självrapporterade problemet i deltagarnas dagliga liv. De områden som de standardiserade mätinstrumenten täcker överensstämde endast med 15 av de 24 kategorierna av självrapporterade problem. I de kategorier där överensstämmelse med områden i mätinstrument fanns identifierades inte heller 0-57% av de självrapporterade problemen av mätinstrumenten (delarbete I). Att ha rehabiliteringsbehov som inte tillgodosetts 12 månader efter stroken predikterades av nedsatt styrka (på den påverkade sidan) 3 månader efter stroken, samt var associerat med nedsatt handfunktion (på den påverkade sidan) och dålig självskattad återhämtning vid 12 månader efter stroken (delarbete II). För personer med måttlig och svår stroke visade resultatet ett samband mellan tillgodosedda behov av rehabilitering 12 månader efter en stroke och att ha haft kontakt med en sjukgymnast minst en gång under det 1:a, det 2:a samt 3:e/4:e kvartalet under det första året efter stroken (delarbete III). Att inte vara nöjd med hälso- och sjukvården 12 månader efter stroken predikterades av låg copingförmåga och av inskränkt delaktighet 3 månader efter stroken samt var associerat med låg copingförmåga och nedsatt styrka (på den påverkade sidan) 12 månader efter stroken (delarbete II). Vårdtiden på strokeenhet har förkortats mellan 1993/1996 och 2006/2007 (median 13 respektive 8 dagar) men det var ingen skillnad avseende den totala vårdtiden (strokeenhet och inneliggande rehabilitering). Deltagarna från 2006/2007 var i högre utsträckning självständiga i ADL 3 månader efter stroken men vid 12 månader sågs ingen skillnad mellan grupperna och inte heller påvisades någon skillnad avseende tillfredsställelse med vården (delarbete IV).

Slutsatser Det råder brist på överensstämmelse mellan perspektivet hos människor som haft en stroke och perspektivet hos hälso- och sjukvården avseende problem i det dagliga livet efter en stroke. Om hälso- och sjukvårdens insatser ska utgå från de problem som patienterna upplever i sitt dagliga liv bör användning av standardiserade mätinstrument kompletteras med en dialog mellan hälso- och sjukvårdspersonal och patienter. Behovet av rehabilitering hos personer som efter en stroke har nedsatt styrka och handfunktion och lågt självskattad återhämtning, bör uppmärksammas extra noga eftersom det är större risk att dessa personer upplever att deras rehabiliteringsbehov ej har tillgodosetts. För personer med måttlig och svår stroke verkar kontinuerlig kontakt med rehabilitering och framförallt sjukgymnast under det första året efter en stroke bidra till att rehabiliteringsbehoven tillgodoses. Det är möjligt att minska antalet dagar som personer vårdas på strokeenhet och ersätta dem med vård på en rehabiliteringsavdelning och ändå uppnå snabbare återhämtning i ADL efter en stroke.

LIST OF PUBLICATIONS

The thesis is based on the following publications, referred to in the text by their Roman numerals:

I. Tistad M, Ytterberg C, Tham K, von Koch L. Poor concurrence between disabilities as described by patients and established assessment tools three months after stroke: A mixed methods approach. *J Neurol Sci*. 2012;313:160-166.

II. Tistad M, Tham K, von Koch L, Ytterberg C. Unfulfilled rehabilitation needs and dissatisfaction with care 12 months after a stroke: An explorative observational study. *BMC Neurology* 2012;12:40.

III. Tistad M, von Koch L, Sjöstrand S, Tham K, Ytterberg C. What aspects of rehabilitation provision contribute to self-reported met needs for rehabilitation one year after stroke - amount, place, operator or timing? *Submitted*

IV. Tistad M, Ytterberg C, Sjöstrand C, Holmqvist LW, von Koch L. Shorter length of stay in the stroke unit: Comparison between the 1990s and 2000s. *Top Stroke Rehabil*. 2012;19:172-181.

ADDITIONAL ANALYSES/RESULTS

The thesis is also based on analyses and results that were initially planned as a part of paper II but not included in the final version. The analysis and results are referred to as ”additional analyses/results”. The thesis also includes cognitive interviews that not are included in any of the papers. These are referred to as “cognitive interviews”.

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CONTENTS

LIST OF ABBREVIATIONS

ADL	activities of daily living
BI	Barthel Index
CI	confidence interval
ESD	early supported discharge
GEE	generalized estimating equation
I-ADL	instrumental activities of daily living
ICF	World Health Organization’s International Classification of Functioning, Disability and Health
KI	Katz Index of ADL Extended
LAS 1	Life After Stroke 1
LOS	Length of stay
LOS SU	Length of stay at the stroke unit
LOS IRU	Length of stay at subsequent in-patient rehabilitation unit
LOS TOTAL	Length of stay at the stroke unit and at subsequent in-patient rehabilitation unit
MMSE	Mini Mental State Examination
NIHSS	National Institutes of Health Stroke Scale
NRP	National Patient Register
NSQ	Need and satisfaction questionnaire
OR	odds ratio
OT	occupational therapist
P-ADL	personal activities of daily living
PT	physiotherapist
RCT	randomized controlled trial
SIS	Stroke Impact Scale
SOC	Sense of coherence
SSS	Scandinavian Stroke Scale
ST	speech and language therapist
WHO	World Health Organization

1 INTRODUCTION

1.1 STROKE AND CONSEQUENCES OF STROKE

Stroke is one of the leading causes of adult disability worldwide, and the World Health Organization (WHO) estimates it to be one of the four main causes of death globally 2030 [1-2]. In Sweden, stroke is the third most common cause of death, the most common reason for neurological disability and the disease that causes the highest number of days spent in hospital [3]. Approximately 30 000 people suffer from a stroke each year in Sweden [4].

The WHO defines a stroke as "rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin" [5]. The WHO definition includes cerebral ischemia, cerebral hemorrhage and subarachnoid hemorrhage [6]. The symptoms of a stroke depend on localization, etiology and severity but usual symptoms are a sudden onset of paresis, dysphasia, dizziness and perceptual dysfunction.

A stroke causes a sudden change in a person's life and the consequences may affect the individual's whole being, and many describe the impact as devastating [7-9]. More specifically, people who have had a stroke often report impairments related to body functions such as neuromusculoskeletal and movement related function [10-12], memory and higher-level cognitive function [10-11] and energy and drive function [10, 13-15] within the first weeks and months. Activities and participation are also commonly affected; i.e. patients frequently report limitations or restrictions related to oral and written communication, arm and hand use, walking, self-care, aspects of domestic life such as doing house work and preparing meals as well as leisure and recreation [10-11].

Some people will recover completely after their stroke, but many are left with varying degrees of disability; in a qualitative study the long-term nature of stroke was expressed as : *"You can't get away from it. If you've had a stroke, then you've had a stroke. It's always with you."* [16]. Consequences that have been described as due to these impaired body functions and limitations in activity and restriction in participation during the first year after stroke are: deterioration in social life [8-9, 16-18], challenged self-concept or change in roles [8-9, 12, 15-16, 19-20], anger and frustration [8, 16, 20] and problems with relationship with spouses, other family members and friends [9, 12, 21]. Furthermore, several studies record a new dimension of uncertainty about the future and a fear of a relapse [15-18, 22-23]. A review of long-term problems after stroke reveals poorer quality of life, emotional impact such as depression, incontinence, loss of a purposeful role, and problems with falls and fatigue up to ten years after the stroke [24]. People who have had a stroke may consequently be in need of life-long interventions or support from the health care services.

1.2 USE OF HEALTH CARE SERVICES

1.2.1 Stroke units

Today there is conclusive evidence and international consensus regarding how to organise acute care after stroke. Care in stroke units leads to an increase in survival and in independence in activities of daily living (ADL) as well as a decrease in the need for care in nursing homes. The benefit of receiving care in a stroke unit has been shown to be equal for older and younger patients, for men and women, and for all severity grades of stroke [25]. A stroke unit is defined as an organized unit, staffed with a multidisciplinary team who have expert knowledge of stroke and that cares exclusively or almost exclusively for stroke patients. Care in a stroke unit can be considered as a complex organisational intervention [25-26]. In a stroke unit, core components include: systematic assessments of disabilities; active physiological management; early mobilization; early setting of rehabilitation plans; early rehabilitation by the multidisciplinary team, and early assessment of discharge needs and discharge planning that involves both the patient and significant others. The work of the multidisciplinary team is coordinated through meetings at least once a week, and the team consists of physician, nurse, assistant nurse, physiotherapist (PT), occupational therapist (OT), speech and language therapist (ST), and social worker. The team should also have access to a dietician and a psychologist [26-27].

1.2.1.1 Length of stay

Although care in a stroke unit has proven to be beneficial, there is a lack of knowledge about the significance of length of stay (LOS) in stroke units. With regard to the acute phase of stroke, an association has been reported between high-quality care, i.e. care consistent with internationally recommended guidelines, and a shorter LOS in the stroke units [28-29]. However, the process ruling LOS in acute care and subsequent rehabilitation is complex and affected by the processes and organization of care, stroke severity, medical complications and economic factors [28-38]. This is illustrated by the fact that in studies included in the meta-analysis, where the beneficial effect of stroke units has been established, the LOS in these units ranges from a mean/median of eight to 162 days [25].

1.2.1.2 Changes over time in stroke units

Earlier the care given people with stroke was influenced by a feeling that “nothing could be done”' – as reported in a study from the 70s [39] – and also by limited interest in caring for these patients [40]. Despite a lack of effective medical treatments for routine use for ischemic stroke, even in the early 90s [41], the quality of care was improved through the organization of stroke units. This was based on evidence for beneficial outcomes [42] in Sweden, mainly during the early 90s.

During the 1990s and up into the 2000s, major developments and restructuring of the Swedish health care system in general were carried out. This was made possible by rapid medical progress during the 1990s, and restructuring meant a reduced number of beds and more care offered as out-patient care. Parallel to the reduction in the number of beds, elderly people received increased access to advanced and active health care interventions, also for stroke [30]. During this period of time, the days spent at the acute stroke unit decreased from a median of 13 days (1996) to eight days (2007), while the proportion of patients with stroke reported to have received care in stroke units increased from 54% (1995) to 82% (2007) [43-44]. Some specific changes regarding stroke care during this period of time are the approval of thrombolysis in 2003 and the first National Guidelines for Stroke Care in 2000 [45] which was followed in 2005 by the second version that also included priority settings for different interventions [46]. Moreover, the Swedish quality register Riks-Stroke was founded in 1994; it aims to support improvement in the quality of care for patients with stroke, and has since then reported on quality indicators yearly [47].

1.2.2 Rehabilitation

A broad definition of rehabilitation is interventions that are selected after a problem-solving process and that aim to reduce the disability caused by the stroke [48]. Many of those who have had a stroke will need rehabilitation [49], and rehabilitation is a major part of care after stroke.

A common way of organizing rehabilitation after stroke is to provide initial rehabilitation at an acute stroke unit while patients in need of further rehabilitation will be referred either to in-patient rehabilitation in a neurological/general rehabilitation unit, or to out-patient rehabilitation. Alternatively, since rehabilitation by a multidisciplinary team in a stroke unit is a complex rehabilitation intervention that has proven to be beneficial [25, 48, 50], both initial and subsequent rehabilitation may be provided at a comprehensive unit [25]. As an alternative, patients with mild to moderate stroke may be discharged early from stroke units and receive early supported discharge (ESD) service by a skilled multidisciplinary team in their homes. People who receive ESD service are less likely to be in need of institutional care and more likely to become independent in ADL [48, 51-52]. Out-patient rehabilitation can be provided by primary care at home, or at a clinic, and also as specialized day care rehabilitation or vocational rehabilitation. However, there is a lack of knowledge regarding the most favorable way to provide rehabilitation for people living in the community after a stroke [49, 53]. A meta analysis has suggested favorable effects of home based rehabilitation with regard to ADL compared to center based rehabilitation within eight weeks after the intervention, but effects at six months were less clear [54]. In a systematic review of elderly people, many with stroke, no differences between rehabilitation at day hospital care and alternative care (domiciliary/comprehensive care) were however found [55]. Meta-analysis of services with stroke liaison workers have not shown any substantial effects in recovery in ADL [56] and neither have primary care based follow-ups [57] or follow-ups from a hospital located multidisciplinary stroke team or a secondary care based team [58].

1.3 NEEDS FOR REHABILITATION

1.3.1 Identification of needs in the health care services

Disabilities are phenomena that underlie peoples' needs for health care services [59]. Assessment tools are used in rehabilitation services to identify the presence and severity of patient disabilities such as impairments, activity limitations and restrictions in participation. Problems after stroke are complex and attempts have been made both to combine different measures and to develop multidimensional measures that cover different domains [60]. Some of the suggested limitations with the outcome measures used in rehabilitation are that they are too narrow in scope, are imprecise and limited in ability to detect clinically relevant outcome changes [61]. However, although we know of the lack of standardized assessment tools to cover the complex situation after a stroke, it is not known to what extent patient expressed disabilities are identified by standardized assessment tools. If peoples' needs for health care services are to be met, health care professionals need to identify, attend to and monitor the disabilities that are perceived as important. More knowledge about the ability of assessment tools to identify patient expressed disabilities is thus crucial.

1.3.2 Unmet needs among people who have had a stroke

There are reports from people about unmet needs up to 16 years after their stroke; these are related to different aspects of their disability as well as to different health care services. In follow-ups carried out by Riks-Stroke, a Swedish quality register for stroke, about 42% of those who reported needs for rehabilitation reported that their needs were not met one year after the stroke [62-63]. In a follow-up carried out two years after the stroke by the National Board of Health and Welfare, corresponding numbers were 37% [64]. International research has also shown unmet needs for rehabilitation between six months and eleven years after stroke [65-72] as well as also unmet needs for other health care services [18, 24, 68, 70-71]. There are also reports of unmet needs up to 16 years after stroke in relation to: psychological/emotional problems [18, 67-68, 70, 73]; lack of information [18, 65, 68-70, 73]; restrictions in personal ADL (P-ADL) and instrumental ADL (I-ADL) [65, 70]; problems with fatigue [70, 73]; impaired mobility [67-68, 70, 73]; impaired communication [70, 73]; impaired cognition [67, 73]; restrictions in participation in social activities [65, 68-70, 74]; maintenance of mobility aids and barriers related to physical accessibility [65, 68-69]; restrictions in getting paid work [75]; financial problems [65, 69-70], and problems with intimate relations [67-68, 73].

There is a lack of knowledge about what issues underlie the many unmet needs, but some studies have identified different consequences of stroke that are related to unmet needs. In one study, depression, fatigue, impaired motor function and younger age were associated with at least one unmet need related to either mobility, self-care, family role, control of finances, leisure time, relationships, paid work or education [75]. Furthermore, people with greater disability to a larger extent reported unmet needs for e.g. adaptations, physiotherapy, and social life [69], therapy [66, 76] and assistance with I-ADL [66]. Self-reported communication problems have further been associated with more unmet needs for information in relation to driving and to employment [73]. There is evidently a considerable variety both in the type of unmet needs reported in studies, but also in how the impairments/disabilities after stroke are assessed and reported. Only one study has been found that explores the association between aspects of rehabilitation provision and the meeting of needs for rehabilitation. That study did not find any association between ESD service or conventional care, and the meeting of needs among people with stroke, but an association between met needs for rehabilitation and the amount of therapy received was suggested. Those who had received 15-28 units of therapy (PT; OT, ST) during the first four months after stroke were more likely to report that they had received enough therapy compared to those who had received either more or less [76].

1.4 SATISFACTION WITH CARE AMONG PEOPLE WITH STROKE

It is important to measure patient satisfaction because unique information that enables quality improvement can thus be obtained [77-78]. It has, however, been pointed out that such ratings are problematic because the concept of patient satisfaction has not been thoroughly defined and there is a lack of a theory that explains the meaning of satisfaction [77, 79-80]; moreover high satisfaction ratings may not necessarily reflect solely positive experiences [77, 81-82].

Swedish regulations for quality management require that prerequisites for patient satisfaction are created [83]. Since it has been suggested that patients who are satisfied with the health care services are more positive about their situation, take a more active part in their recommended treatment [77, 80, 84] and have a better health outcome [77, 85], it is important to achieve patient satisfaction. It is thus imperative that we acquire more knowledge about factors associated with patient satisfaction after stroke.

Studies that have examined the satisfaction with care after a stroke have mainly focused on the initial phase after stroke. In the yearly follow-up from Riks-Stroke between 2001 and 2007, 88-95% of the people with stroke have reported that they were satisfied with the care in the stroke units [3, 43, 86]. People who are dependent in ADL, feel depressed, have poor self-rated health, and are dissatisfied with rehabilitation and communication with staff, have been more likely to report dissatisfaction with care at the stroke unit at three months after stroke [87]. Dissatisfaction with care at six months after stroke has also been associated with emotional stress and unmet needs for care [88]. Satisfaction with care at the same point in time has been associated with the care providers' adherence to post-stroke guidelines [72]. One study showed that people with more severe disabilities after stroke were less likely to receive a follow-up visit by a specialist or physician in primary care within three months after the stroke [89]; this may affect level of satisfaction when considering care in general and not only care at the stroke unit. Care and rehabilitation are often integrated in services provided after stroke and it is difficult to distinguish between them, but it has been suggested that when the question explicitly relates to rehabilitation, people with less motor impairment or disability are more likely to be satisfied three to six months after stroke [76, 90-91]. Satisfaction has also been rated by patients in relation to specific services. In meta-analysis, people who have received ESD services after stroke have reported higher levels of satisfaction compared to those who received conventional care [38, 51]. In contrast, structured re-assessments evaluated in a randomized controlled trial (RCT) six months after stroke, did not show to any difference regarding satisfaction with care [58]. A finding that is consistent between different settings and different diagnoses is that one of the most important factors for high ratings of satisfaction is the interpersonal aspects of care i.e. the relation between the patient and health care professional including communication and the giving of information [77, 84, 92-93].

1.5 CONCEPTUAL FRAMEWORK

1.5.1 The perspective of people with stroke

One of the overarching aims of this thesis is to apply the perspective of the people who have had a stroke to the three areas: needs for rehabilitation; use of health care services, and satisfaction with health care services. Consequences of a stroke may be chronic disability, and people with chronic conditions become experienced and are often more knowledgeable than the health care professionals about the consequences of their condition in everyday life. When treatment is planned the health care professionals thus have to take their starting point in the needs expressed by the individuals with stroke while still maintaining their role of guide and advisor [94].

To depart from the needs experienced by people with stroke is also in line with aspirations of the National Board of Health and Welfare in Sweden. The National Board of Health and Welfare has adopted a concept of ‘Good care’ which includes patient centered care and five other quality areas (timely care, safe care, evidence based care, equitable care and efficient care). The patient centered approach is defined as care based on respect for the equal value of all human beings, personal dignity, integrity and self-determination. Accordingly, care should be carried out with respect for and sensitivity to the individual’s specific needs, conditions, expectations and values, and with consideration to the individual’s social context [83, 95].

In this thesis, the ratings related to needs for rehabilitation, satisfaction with health care services, functioning and disability originate from people who have had a stroke and who are in their own social context. The use of health care services serves as an additional part of these peoples' environment and aims to increase health and life satisfaction [96]; it is primarily described as a factor that, among other factors, may underlie met or unmet needs for rehabilitation and satisfaction or dissatisfaction with health care.

1.5.2 International Classification of Functioning, Disability and Health

WHO's International Classification of Functioning, Disability and Health (ICF) – a bio-psycho-social model of health [97], is used as a framework to organize data in this thesis. This is also to make use of a commonly accepted language. In the ICF, "functioning" is an umbrella term for body function, body structure, activity and participation and the positive aspects of the interaction of an individual with a health condition and his/her contextual factors. On the other hand, "disability" is the umbrella term for impairments, activity limitations and restrictions in participation, and as such denotes the negative aspects of the interaction of an individual with a health condition and his/her contextual factors.

Contextual factors form the individual's background and include environmental factors and personal factors. Environmental factors are external to individuals and form their physical, societal and attitudinal background. The environmental factors include not only the immediate environment e.g. features of the physical environment like access to mobility devices, residence or workplace but also the societal level e.g. health care services, transportation services, policies and laws. Personal factors are internal background factors in individuals' lives and comprise features such as age, gender, race, coping style and profession. Environmental factors are classified in the ICF (i.e. categories for environmental factors have been developed) whereas the personal factors are not and are left to the user to assess instead.

Environmental factors are to be considered from the perspective of the person whose situation is being described. An environmental factor that increases the level of functioning and decreases the level of disability is described as a facilitator whereas the opposite constitutes a barrier. Furthermore, if an environmental factor is lacking, it can be considered a barrier.

The ICF has been criticized however, because it does not take into consideration peoples' will power [98-100], subjective experiences [101], or the patients' choice [100]. Peoples' will power and subjective experiences are a part of the concepts that are used here: needs for health care services; use of health care services, and satisfaction with health care services. These concepts are not fully covered by the ICF and consequently the concerns of this thesis are on the periphery of the ICF. But in spite of its shortcomings, on a general level the ICF offers a relevant structure for this thesis and needs for rehabilitation, use of and satisfaction with health care services are considered here as aspects of environmental factors.

1.5.3 Needs

There are numerous ways of defining needs from societal, philosophical, pragmatic and financial points of view [102]. In Sweden, one of the ethical principles listed on the platform for the prioritizations of health resources is that of need and solidarity i.e. resources should be used where the needs are considered to be the greatest. According to current directives for priorities in health care in Sweden, a prerequisite for a need is that there are interventions in place that potentially can benefit the patient. If no such interventions exist, there is no need [103-104].

Needs can also be defined in relation to supply and demand. This highlights the fact that needs, i.e. what people can benefit from, are not static but open to interpretation and change, and influenced by research, for example. Demand, which is what people ask for, is considered as even more changeable and influenced by e.g. social and educational background and media. Supply is the services that are provided [105].

1.5.3.1 Bradshaw’s taxonomy of needs

In an attempt to sort out what the word “need” meant, a taxonomy of needs was developed by Bradshaw [106]. This taxonomy distinguishes between different types of need and includes two types of need used in this thesis; normative needs and felt needs. Normative needs are defined by experts, professionals or policy-makers and felt needs are wishes, desires and subjective views of needs.

The taxonomy was used because it makes clear that need is not an objective phenomena but instead is something that may differ if the perspective applied is that of the health care services or of those who perceive the needs.

1.5.3.2 Definition of need

In this thesis, the definition of needs for rehabilitation is in concordance with felt needs in Bradshaw’s taxonomy i.e. as wants and wishes, in other words, a subjective view. Need for rehabilitation is operationalized as peoples’ perception as to whether they have received enough rehabilitation or not after their stroke.

On the assumption that disability is one of the phenomena underlying the needs for health care services [59], Bradshaw's taxonomy is also applied to disability after stroke in this thesis. Patients expressed disabilities are considered as felt disability. Because the items and domains in the assessment tools are likely to address disabilities that are thought by the health care services to be relevant, results from standardized assessment tools are considered as normative disability. These results can consequently be thought to reflect a normative view of disability in relation to a health condition. In order to clarify the source of the normative view of disability, the word "assessed" is used here instead of "normative". Since the point of departure in this study is people who have had a stroke and how they experience their daily life, the word "problem" is used instead of disability. The word problem is also used as a qualifier in the ICF "and having a problem may mean an impairment, limitation, restriction or barrier depending of the construct" [97]. The expressions *felt problems* and *assessed problems* are used here, and felt problems are considered as potential needs for rehabilitation or other health care services in this thesis.

1.5.4 Use of health care services

1.5.4.1 Framework for rehabilitation services

A framework that classifies rehabilitation interventions according to level of complexity has been suggested by Langhorne and Legg [50].

The s*ervice level* is defined as complex packages of care provided by more than one health professional and delivered in a specific context. Examples are rehabilitation provided by a multidisciplinary team at stroke units and ESD-services.

The *operator level* also represents a complex package of care, but is provided by a single therapist and it could include both interaction between the patient and therapist and an intervention. Examples include occupational therapy services for people living at home after a stroke.

The *treatment level* represents specific treatments such as bilateral arm training or the provision of walking aids. The therapist's impact should preferably be removed from consideration, but this if often difficult to achieve.

In this thesis, the use of rehabilitation services is structured into service level and operator level.

1.5.4.2 Definition of use of health care services

In this thesis, the use of health care services is defined as days spent in in-patient health care or as contacts with out-patient health care services.

1.5.5 Patient satisfaction

1.5.5.1 Strasser's comprehensive model of patient satisfaction

A model that explains how patient satisfaction attitudes are formed has been proposed by Strasser et al [107]. This model is founded on six principles. According to the first principle, patient satisfaction is driven by peoples' perception and formed by a cognitive and an affective process. Patient satisfaction is relativistic in the sense that each individual constructs her or his reality and will thereby relate to "their" reality when the perception of patient satisfaction is formed. The second principle suggests that patient satisfaction is both a multidimensional construct, and a single global construct, meaning that people create values concerning single items e.g. satisfaction with information received, as well as a summary judgment about the care received. The third principle describes patient satisfaction as a dynamic process indicating that patient satisfaction may change over time. According to the fourth principle, patient satisfaction is defined as an attitudinal reaction or response to the value judgment formed based on cognitive and affective components (first principle). According to the fifth principle, the patient is seen as an activist and the model thus includes behavioral reaction based on the attitudinal reaction in principle four. The behavioral reaction will strive to maintain or increase satisfying stimuli and/or to stop dissatisfying stimuli. The sixth principle suggests that there can be differences between patients in their formation of patient satisfaction. Even though there may be a general cognitive framework for the process, it is individualized and may be affected by socio-demographic factors, health status, and personality, and furthermore by previous health care experiences.

Strasser's model of satisfaction is used in this thesis because it considers the perspective of people who use the health care services and pays attention to characteristics in individuals that may affect the extent of satisfaction experienced. The model is used to choose variables and to structure the variables according to the characteristics of the individuals included in the model: socio-demographic factors, health status and personality.

1.5.5.2 Ware's taxonomy of patient satisfaction

Whereas Strasser's model is used here with regard to how people form judgments about the health care services, a taxonomy of characteristics of the providers and the health care services created by Ware et al [108] is used to structure the different dimensions of the health care services that are thought to influence patient satisfaction. This taxonomy includes eight dimensions: interpersonal manner; technical quality; accessibility/convenience; finances; efficacy/outcome; continuity; physical environment and availability.

1.5.5.3 Definition of patient satisfaction

In this thesis, in accordance with Strasser, patient satisfaction is, defined as an attitudinal response to the value judgment the patients form about their health care experiences [107] and is operationalized with regard to whether the patient is satisfied or not with the health care services received.

1.6 RATIONALE FOR THE THESIS

A stroke may have severe consequences for the lives of the person who is affected as well as for his or her significant others [109-110]. Life-long contact with health care services, regularly or intermittently, may also be needed. From a societal perspective, stroke is the disease that causes the largest number of days spent in hospital in Sweden and the yearly estimated cost for society is at least 14 billion crowns [3, 111].

Although care in a stroke unit has proved to be beneficial, there is a lack of knowledge about the significance of LOS in the stroke units. There is also a lack of studies linking LOS to level of functioning and patient satisfaction. Such knowledge is needed when deciding how to prioritize, and to achieve equity and an optimal utilization of available health care resources.

There is also a lack of knowledge regarding how long-term health care services best should be organized in order to meet the needs of people who have had a stroke [27, 49, 58, 112] and high frequencies of unmet needs for rehabilitation are reported [62, 64-65, 71-73, 112]. Furthermore, we do not know what issues underlie the many unmet needs. The provision of rehabilitation is complex and several factors may influence whether peoples' needs are met or not. If their needs are to be met, the disabilities people themselves consider as crucial have to be recognized by health professionals and standardized assessment tools can be used to identify patient's disabilities in health care settings [113]. However, it is not known to what extent patient expressed disabilities are identified by standardized assessments tools. We also do not know whether different aspects of disability after stroke, or individual specific characteristics such as socio demographics and personality, or factors related to the provision of rehabilitation affect whether peoples’ need for rehabilitation are met. Furthermore, satisfaction with health care services has so far been primarily studied with regard to initial care and rehabilitation after stroke; there is a lack of knowledge concerning patient satisfaction in a longer time perspective.

Considering not only the impact a stroke has both on the individuals who have had a stroke and their significant others, but also on public spending, it is important that the health care services supplied are effective and meet peoples’ needs even after the initial phase after the stroke. It is hoped that this thesis will contribute to our knowledge of the needs for, use of and satisfaction with health care services in the course of the first year after stroke. As these needs have only been sparsely explored before, this new knowledge may contribute to the development of long-term health care services that meet the needs of people with stroke.

2 RESEARCH AIMS

The overall aim of the thesis was to generate new knowledge about needs for rehabilitation, use of health care services and satisfaction with health care services in the course of first year after stroke from the perspective of people with stroke. More specific research aims are described in relation to each area.

Needs for rehabilitation

- to describe the felt problems and to examine the concurrence between felt problems and assessed problems three months after stroke
- to examine if characteristics found in individuals at three and twelve months after stroke contribute to self-reported unmet needs for rehabilitation at twelve months, and if aspects of the rehabilitation provision contribute to self-reported met needs for rehabilitation twelve months after stroke

Use of health care services

- to examine whether there are differences between two samples with mild to moderate stroke of which one received care in 1993/1996 and one in 2006/2007 with regard to length of stay in the stroke unit and subsequent rehabilitation and recovery in ADLs during the first year after stroke
- to describe the use of rehabilitation services during the first year after stroke with regard to stroke severity

Satisfaction with health care services

- to examine whether there are differences in patient satisfaction over the first three months after stroke between two samples with mild to moderate stroke of which one received care in 1993/1996 and one in 2006/2007
- to examine if characteristics in individuals found at three and twelve months after stroke contribute to dissatisfaction with health care services at twelve months after stroke

3 METHODS

In order to contribute new knowledge about needs for rehabilitation, use of health care services and satisfaction with health care services, different methodological approaches were used. The overall design is longitudinal and the data beyond baseline has been collected in the participants' homes and thus reflects everyday life and changes in everyday life in the course of the first year after stroke. In paper I, the participants' felt problems and the concurrence between felt and assessed problems are explored, and a longitudinal perspective on the felt problems is presented in additional analyses/results. The longitudinal design was utilized when felt problems (additional analyses/results) and other characteristics of the participants (paper II) were examined as predictors and as being associated with unmet needs for rehabilitation and dissatisfaction with care. In order to illuminate further factors that might be associated with met needs for rehabilitation, aspects of the provision of rehabilitation were examined in paper III. The longitudinal design was utilized in paper IV in which a comparison is made between two samples that received care at two different points in time regarding the use of health care services, recovery in ADL and patient satisfaction. An overview of these papers is presented in table 1.

Data for all the papers including additional analyses/results derive from a study named Life After Stroke 1 (LAS 1) described below. In addition, paper IV includes data collected in the context of a RCT. Details about the procedure and data-collection for the RTC are given in the section Participants.

Table 1. Overview of the thesis

Area	**Needs for rehabilitation**	**Needs for rehabilitation** **Satisfaction with health care services**	**Needs for rehabilitation** **Use of health care services**	**Use of health care services** **Satisfaction with health care services**	**Needs for rehabilitation**
	Paper I	Paper II	Paper III	Paper IV	Additional analyses/results
Focus	Felt problems, concurrence between felt and assessed problems	Factors contributing to unfulfilled needs for rehabilitation and dissatisfaction with care	Provision of rehabilitation and its association with fulfilled needs of rehabilitation	Comparison of length of stay at stroke unit /rehabilitation; patient satisfaction; recovery in ADL	Felt problems 3 and 12 months after stroke
Number of participants	203	175	173	40 (1993/1996) + 43(2006/2007)	159
Design and/or research approach	Cross sectional, Explorative, Mixed methods	Prospective longitudinal	Prospective longitudinal/ Cross sectional	Prospective longitudinal	Prospective longitudinal
Method of data-collection	Questionnaires	Questionnaires	Questionnaires, register	Questionnaires, register	Questionnaires
Analysis	Qualitative content analysis, Comparison	Multivariate logistic regression analysis	Multivariate logistic regression analysis	Comparison, Generalized estimating equations	Qualitative content analysis

3.1 LIFE AFTER STROKE

The LAS 1 is a longitudinal observational study of the rehabilitation process after stroke.

3.1.1 Procedure and data-collection

All patients with stroke admitted to the three stroke units at Karolinska University Hospital in Huddinge and Solna, Sweden, between May 15, 2006 and May 14, 2007 were eligible for the LAS 1. Two of the three stroke units can be characterized as acute stroke units that provided acute care and initial rehabilitation. The third stroke unit was a comprehensive geriatric stroke unit that provided acute care and in-patient rehabilitation.

The patients were diagnosed by stroke clinicians on the ward. The regular PT and OT at the stroke units received information from the nurses on the ward about individuals eligible for inclusion. The PT or OT informed these people, or a significant other, about the study and asked the patient whether he or she wanted to participate. If the person's condition was severe, the physician decided if they were to be informed and asked to participate. Following upon informed consent by the person with stroke, or a significant other, the baseline assessment by the OT or PT was carried out at the stroke unit during the first week after arrival. A total number of 373 agreed to participate, but of these 24 people had their diagnosis altered and the final number of individuals included in LAS 1 was 349.

Subsequent data-collections were performed in the patients' home at 3 and 12 months and by telephone at 6 months after stroke. A participant unable to answer the question him- or herself, could receive help in answering the questions from a significant other, or from the staff e.g. at a nursing home; this was then noted. The OTs and PTs who carried out the data-collection were specially trained for the purpose.

The data used in this thesis emanate with a few exceptions from an open question and questionnaires that were filled in during the follow-ups. Exceptions are the Mini Mental State Examination (MMSE) that was used as a clinical test, and also data about health conditions and impairments that was retrieved from medical records. Single missing values on the Barthel Index (BI) and the Katz Index of ADL Extended (KI) at baseline were, when possible, retrieved from the medical records. Furthermore, data on use of in-patient and out-patient health care services were collected from the Stockholm County Council's computerized register.

3.2 QUESTIONS AND INSTRUMENTS

The ICF was used as a framework to collect data. An overview of when the instruments/questionnaire and questions was used is shown in table 2.

Table 2. Data collected at different points in time

Instruments and questions	Points of data collection, months				
	Before stroke[*]	Base-line[†]	3	6	12
Body structure and function					
Stroke diagnosis and localization, comorbidity		■			
Mini Mental State Examination		■			
Speech		■			
Stroke severity (Barthel Index)		■			
Activity and participation					
Open question about changes in everyday activities			■		■
Katz Index of ADL Extended	■	■[‡]	■	■	■
Barthel Index	■	■	■		■
Stroke Impact Scale			■		■
Environmental factors					
Housing situation		■	■	■	■
Need and satisfaction questionnaire			■		■
Use of private health care and health related services from the municipality		■	■	■	■
Use of health care services from the Stockholm County Council's registers		――	――	――	―→
Personal factors					
Civil status, education, personal finances, work situation		■			
Sense of Coherence Scale					■

[*] data about the situation before stroke was collected at baseline

[†] baseline assessment was carried out within one week after arrival at stroke unit

[‡] includs only items considered as p-adl

3.2.1 Body structure and function

Information about the participants' stroke diagnoses, localization and comorbidity at baseline was extracted from their medical records.

3.2.1.1 Mini Mental State Examination

At baseline, participants were assessed using the MMSE [114]. The MMSE is commonly used as a screening tool for cognitive function and has been recommended for initial screening after stroke [115].

3.2.1.2 Speech

The item “speech” from Scandinavian Stroke Scale (SSS) [116] was used to categorize the participants’ speech at baseline according to the following alternatives: no aphasia; limited vocabulary or incoherent speech; more than yes/no but not longer sentences or only yes/no or less.

3.2.1.3 Stroke severity

The BI [117] at baseline was used as a measure of stroke severity but also as an assessment of independence in ADL, which is described below. The BI has been examined in relation to the stroke-severity scales SSS [116] and the National Institutes of Health Stroke Scale (NIHSS) [118], and been found to have excellent agreement when categorized [119]. The SSS [116] was used as a measure of stroke severity in the sample from 1993/1996 in paper IV.

3.2.2 Activity and participation

3.2.2.1 Open questions

The follow-ups started with the standardized open-ended question: “How do you manage your daily activities after stroke, has anything changed?” The answer was written down.

3.2.2.2 Katz Index of ADL Extended

The KI [120-121] is in widespread use in rehabilitation settings in Sweden and assesses whether or not the patient is independent of assistance in six P-ADLs (bathing, dressing, toileting, transfer, continence and feeding) and four I-ADLs (shopping, cleaning, cooking and transportation). Each item was given a score of 1 for independence or else 0.The assessment tool can be used to define the need for assistance among disabled people and to describe and compare disability in an elderly population. Reliability and validity of the KI have been found sufficient [120, 122].

3.2.2.3 The Barthel Index

The BI is used to asses independence in ADL [117]. The BI is a common assessment tool in clinical practice [123] and outcome measure in stroke trials [124-125]. The BI consists of ten essential P-ADLs; feeding, mobility, grooming, toilet use, bathing, transfer, ascending and descending stairs, dressing, bowel and bladder control. Each item on the BI is given a score of 0, 5, 10 or 15 and 100 is the maximum score. There are reports of sufficient reliability and validity for the BI [126-128].

3.2.2.4 The Stroke Impact Scale

The Stroke Impact Scale (SIS) 3.0 is a more recent assessment tool which was developed on the basis of the perspectives of stroke patients, caregivers and health professionals and which aims to detect consequences of stroke [11, 129]. The SIS assesses the perceived impact of stroke within eight domains: strength (on the affected side); memory; emotion; communication; ADL/I-ADL; mobility; hand function (on the affected side) and participation. Each domain contains four to ten items that are rated on a five-graded scale. The score from each domain is transformed to a score between 0-100 for each domain where a score of 100 indicates that there is no impact from the stroke in this domain. Further, the SIS contains a recovery-scale on which the patient is asked to indicate how much he or she has recovered between 0 (not recovered at all) and 100 (completely recovered). The SIS is considered reliable and valid [11, 129], as well as sensitive to change up to six months after stroke [11].

3.2.3 Environmental factors

The follow-ups included questions regarding housing, number of children at home, driving license and use of private health care and health related services provided by the municipality (safety alarm, home-help services and special transport service permit).

3.2.3.1 Questionnaire about needs for and satisfaction with health care services

Data regarding needs for and satisfaction with health care services was collected using a questionnaire, previously used in research, that has explored needs for and satisfaction with health care services among people with neurological disabilities [130-135]. Here the questionnaire is denoted the “need and satisfaction questionnaire” (NSQ). It is based on a taxonomy developed by Ware [108] and covers different dimensions that are thought to influence patients’ satisfaction with care: interpersonal manner; technical quality; accessibility; finances; efficacy/outcome and availability. Levels of agreement concerning 14 statements relating to the different dimensions were rated by the patients on a five-graded, Likert scale with “agree” and “do not agree at all” as the endpoints. In addition, one item was added regarding self-perceived participation in the discharge planning at the follow-up at three months after stroke. The patients were also asked to indicate whether or not they were in need of five different health related services (home-help services, technical aid, home modification, special transport service and workplace adaptation).

3.2.3.2 Use of health care services

Data on use of in-patient and out-patient health care services for the first 12 months after stroke were collected from the Stockholm County Council's computerized register.

3.2.4 Personal factors

The data collection included questions about civil status, education, personal finances and work situation. Data on age was retrieved from the medical record.

3.2.4.1 The Sense of Coherence Scale

Sense of Coherence (SOC) scale is considered to measure an enduring and global attitude to how people view their life and how in stressful situations they use their resources to maintain and develop their health [136-137]. The 13-item version contains statements concerning three dimensions: comprehensibility; manageability, and meaningfulness that are rated on a seven-graded Likert scale. The score range is between 13 (weak SOC) and 91 (strong SOC). The SOC-scale has been used among people who have suffered a stroke [138] and the scale is considered reliable and valid [139-140].

3.3 PARTICIPANTS

Personal factors, health condition, body function and structure for the participants are presented in table 1.

3.3.1 Participants in paper I, II, III and additional analyses/results

Those included in paper I, II, III and additional analyses/results were participants in LAS 1 who lived at home at the time for the follow-ups that were used in the respective papers and who had completed the questions and questionnaires themselves, or with support from significant others (i.e. no proxy-answers).

Table 3. Personal factors, health condition, body function and structure for the participants

	Needs for rehabilitation	**Needs for rehabilitation Satisfaction with health care services**	**Needs for rehabilitation Use of health care services**	**Use of health care services Satisfaction with health care services**		**Needs for rehabilitation**
	Paper I n=203	Paper II n=175	Paper IV n=173	Paper IV		Additional analyses/results n=159
				93/96 group n=40	06/07 group n=43	
Personal factors						
Sex male/female	115/88	102/73	100/73	22/18	28/15	93/66
Age, years mean (SD) range	69(14) 24-93	68 (14) 24-93	68 (14) 24-93	73 (9) 49-89	67 (13) 28-88	68(14) 24-93
Civil status living alone/together	95/108	65/110	65/108	13/27	14/29	68/91
≤9 years/>9 years education	84/96[*]	74/96[†]	73/95[‡]	38/2	21/18[§]	61/82[‖]
Health conditions						
Previous stroke	61	47	47	4	7	25
Previous transient ischemic attack	15	11	11	2	2	11
Body structure and function						
Stroke subtype: Ischemic/ hemorrhagic stroke/subarachnoid	174/28/1	148/26/1	146/26/1	39/1/0	39/4/0	135/23/1
Localization: right/left/bilateral/ brainstem/cerebellum/ unclear	84/89/3/5/16/6	74/77/2/5/13/2	73/77/2/5/12/4	23/14/2/2/0/0	23/20/0/0/0/0	68/71/1/4/12/3
Cognitive function median (interquartile range)	26 (23-29)[#]	27 (24-29)[**]	27 (24-29)[**]	28 (26-28)[††]	27.5 (26-29)[‡‡]	27 (24-29)[§§]
Speech: no aphasia/ limited vocabulary or incoherent speech/ more than yes or no but not longer sentences/ only yes or no or less	148/34/13/5[‖‖]	125/30/10/7[##]	124/30/10/7[***]	5[†††]	39/4/0/0	115/29/8/5[‡‡‡]
Stroke severity mild/moderate/severe	156/22/7[§§§]	144/26/5	142/26/5	37/3/0	36/6/0[‡‡]	135/19/5

[*] n=180, [†] n=170, [‡] n=168, [§] n=39, [‖] n=143, [#] n=165, [**] n=145, [††] n=34, [‡‡] n=42, [§§] n=132, [‖‖] n=200, [##] n=172, [***] n=171, [†††] presence of aphasia, [‡‡‡] n=157, [§§§] n=198

3.3.2 Participants in paper IV

In paper IV, two samples from two different time periods were employed. Regarding the LAS 1, only those who had received care at the stroke unit at Karolinska University Hospital in Huddinge were eligible and the sample is called the 06/07 group here. The other sample was also recruited consecutively at the stroke unit at Karolinska University Hospital in Huddinge but during 1993/1996 and is denoted the 93/96 group.

The 93/96 group was the control group in a RCT, evaluated for ESD service and recruited between March 1993 and September 1996. The inclusion criteria applied in the 1993/1996 RCT were based on two studies: a study that identified a suitable target group for ESD service [141] and a pilot feasibility study [142]. The same inclusion criteria were applied in 2006-2007. Accordingly, people with acute stroke (first or recurrent) were eligible if, five days after stroke onset, they fulfilled the following criteria: independent in feeding and continent according to the KI; received a MMSE score of >23; had remaining needs for rehabilitation, and were residents of the south-west health care district under Stockholm County Council. Patients with subarachnoid hemorrhages were excluded. The 6-months follow-up for the 93/96 group took place in the participants' homes.

3.4 ANALYSIS

Figure 1 presents an overview of the data used in the different papers in this thesis.

3.4.1 Needs for rehabilitation

3.4.1.1 Felt problems and concurrence between felt and assessed problems

On the assumption that disability is one of the phenomenon underlying the needs for health care services [59], Bradshaws' taxonomy of needs [106] was instead applied to problems in paper I. Problems identified and reported by the people with stroke represented felt problems and the results from three established assessment tools (the KI, the BI and the SIS) represented normative problems, here called assessed problems. Even though the KI, the BI and the SIS were self-reported, the items are pre-defined by representatives for the health care system (in the case of SIS, in cooperation with people who have had a stroke and caregivers). These items are considered as normative in the sense that they represent the health care systems' perspective on problems that should be identified and monitored after a stroke.

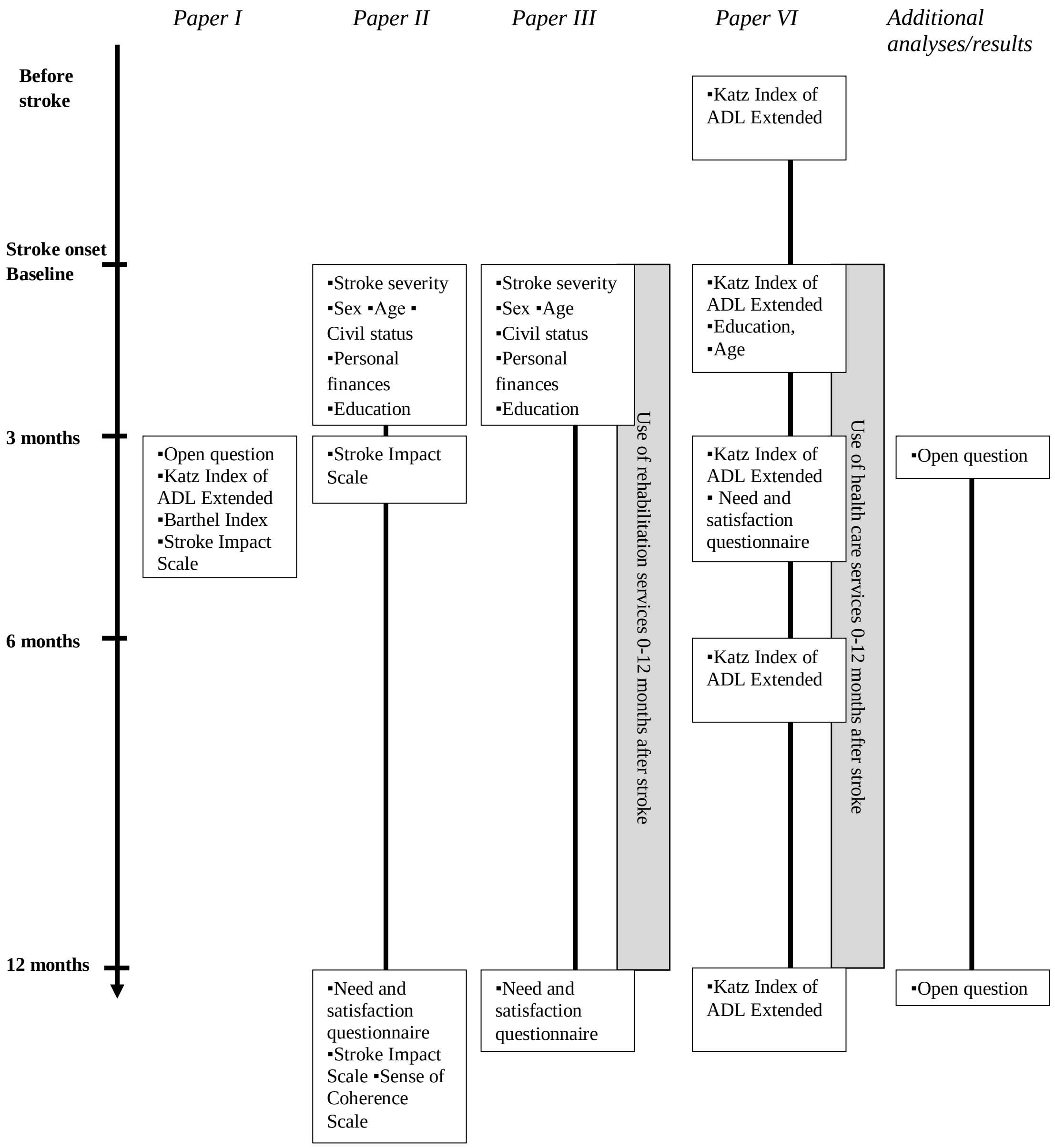


Figure 1. Overview of data and time points for data-collection in the papers

The felt problems reported at 3 months after stroke were described and the concurrence between the patient's felt problem and the assessed problems were examined. In paper I, a mixed-methods approach in three phases was used in the analyses. In additional analyses/results, only the first phase of the analysis was carried out with regard to felt problems reported at 3 and 12 months after stroke.

3.4.1.1.1 Phase 1: felt problems

The manifest content of the answers to the standardized open-ended question was analysed using qualitative content analysis [143]. To begin with, all felt problems were coded based on similarities in the raw data. A common form of answer was "my balance, I notice it for example when I climb stairs". Such sentences were divided into; *balance* and *climb stairs* and each was coded separately. Fifty one codes were identified and these codes were grouped into categories based on similarities in their content. All the coding and categorization was performed by this author (MT). On two occasions, following the initial categorization, the categories were applied by the other authors of paper I to parts of the participants' answers. Each occasion was followed by discussion between the authors and a further development of the categorization and clarification of category definitions. The final discussion agreed on 29 categories including one for "no problem". In order to use a commonly accepted language and to clarify the content of the categories, ICF codes [97] were applied to the categories and a final re-categorization was performed by MT. Furthermore, the categories were labeled according to the ICF with the exception of the categories: *Fatigue, Across activity difficulties, Global, Vertigo, Environment* and *No problem*. The category, *Across activity difficulties*, covers problems that concern several, unspecified activities e.g. that everything takes longer time, whereas the category *Global* contains problems reflecting a global impact on daily life; that everything is more difficult. Problems coded as *Environment* emerge in relation to a specific environment such as a shopping mall (table 6).

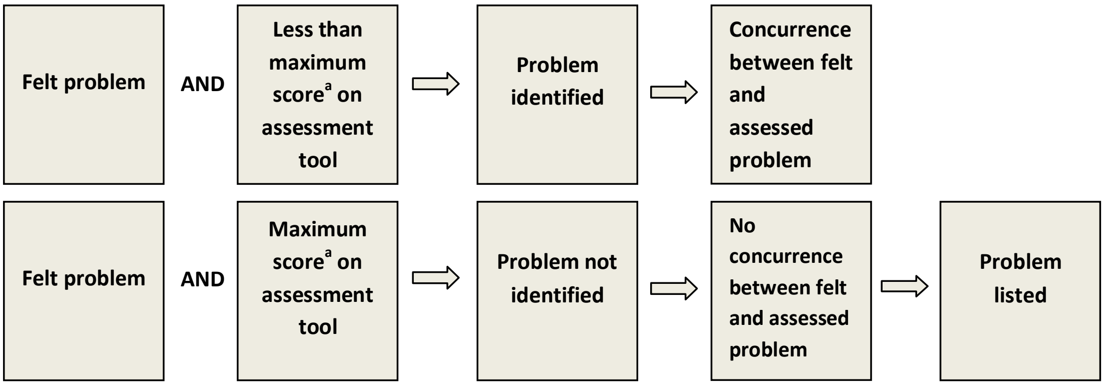
In line with a framework for mixed methods, the categories were quantitized [144], which meant that *for each patient* every category was assigned a "1" when at least one felt problem was present, otherwise the category was assigned a "0". Consequently, a category assigned as "1" might, for one individual, represent more than one felt problem; e.g. problems relating to dressing and to feeding were both categorized as Self-care and reported as the presence of problems in Self-care.

3.4.1.1.2 Phase 2: Assessed problems

In order to examine whether the felt problems concurred with the assessed problems, items/domains in the KI, the BI and the SIS that corresponded to each category were sought.

3.4.1.1.3 Phase 3: Comparison between felt and assessed problems

Comparisons concerning felt and assessed problems in the categories for which corresponding item/domains in KI, BI or SIS were found were carried out as follows (figure 2). The scores on the corresponding item/items or domain/domains in 1) KI and BI jointly, and 2) SIS were examined for each person with one or more felt problems present in a category, i.e. a “1” in a category. Maximum score on an assessment tool was considered to indicate that no impact was identified by the assessment tool. If the person did not obtain maximum scores on corresponding items in 1) either KI or BI or 2) items or domains in the SIS, the felt problem was regarded as identified and a concurrence between felt problems and assessed problems was thought to be present. As the KI and the BI are similar regarding the items P-ADL, the KI and the BI were compared jointly. If a felt problem was not identified by the assessment tools, the original answer to the open-ended question was again reviewed and the unidentified content was listed.



[a] maximum score was considered to indicate that no impact was identified by the assessment tool

Figure 2. Analysis phase 3: comparison between felt problems in categories and corresponding items/domains in three assessment tools

3.4.1.2 Association between characteristics in individuals and unmet needs for rehabilitation

Two multivariate logistic regression analyses were performed in order to explore the predictive capacity of characteristics in individuals at three months and their association at 12 months, with unmet needs for rehabilitation at 12 months after stroke (paper II).

The statement from the NSQ “I have received too little rehabilitation after my stroke” was used as dependent variable. The answer was dichotomized into met needs (4–5 on the Likert scale) or unmet needs (1–3).The choice of independent variables for the logistic regressions was based on Strasser’s theoretical model and on the univariate analyses. The variables were dichotomized as displayed in table 4.

The standard Enter method by SPSS was used to select the most appropriate model.

Table 4. Dependent and independent variables included in the logistic regression analysis regarding unmet needs for rehabilitation and dissatisfaction with care that are based on Strassers' model for patient satisfaction

Concept	Variables	Dichotomization
Dependent variables		
Unmet needs for rehabilitation	I have received too little rehabilitation after my stroke	Met needs, 4-5 /unmet needs, 1-3
Dissatisfaction with care	I am very satisfied with the care I have received	Satisfied, 1-2/not satisfied, 3-5 (denoted dissatisfied)
Independent variables: Strassers' model of patient satisfaction		
Socio-demographic factors	Age	≤65/>65
	Sex	Male/female
	Civil status n=173	Living with a partner/living alone
	Personal finances n=154	Affluent/not affluent
	Education n=170	≤9 years/>9 years
Health status	Severity	Mild (50-100), Moderate (11-49), severe (0-10)
	Stroke Impact Scale (SIS)domains[*] (number of participants at 3 months, number of participants at 12 months)	
	Strength (n=166, n=174)	All domains of the SIS:
	Memory (n=169, n=174)	Low impact (≥median)/high impact (<median)
	Emotion (n=164, n=173)	
	Communication (n=168, n=174)	
	ADL (n=168, n=174)	
	Mobility (n=167, n=174)	
	Hand function (n=163, n=172)	
	Participation (n=n=166, n=174)	
	Recovery (n=167, n=172)	Good recovery (≥ median)/poor recovery (< median)
	Felt problems[†] (n=159)	Felt problem present/felt problem not present
Personality	Sense of Coherence (SOC) (n=158)	Strong or moderate SOC (>lowest quartile)/weak SOC (≤lowest quartile)

[*] SIS at 3 months was used for prediction of and SIS at 12 months for associations with unmet needs for rehabilitation/dissatisfaction with care at 12 months

[†] The felt problems are derived from paper I and additional analyses/results. The felt problems at 3 months were used for prediction of, and the felt problems at 12 months for associations with unmet needs for rehabilitation/dissatisfaction with care at 12 months

3.4.1.3 *Aspects of the rehabilitation service that contribute to met needs for rehabilitation*

In order to explore whether different aspects of the provision of the rehabilitation promoted met needs for rehabilitation at 12 months after stroke, information as to participants' contacts with rehabilitation services was structured into different aspects of services provision (paper III). The statement from the NSQ, "I have received too little rehabilitation after my stroke", was used as dependent variable. The answer was dichotomized into met needs (4–5 on the Likert scale) or unmet needs (1–3).The different aspects of the services provision were structured as follows: level of complexity of the services according to the framework suggested by Langhorne and Legg [50]; amount of rehabilitation received, and time after stroke. In an initial logistic regression analysis that included all the participants, the independent variables represented socio-demographic factors and stroke severity. Stroke severity based on the BI score was dichotomized in accordance with the following: 100 (maximum score) as very mild stroke; 50-99 as mild stroke, and 0-49 as moderate/severe stroke. Multivariate logistic regression analyses with separate models for amount of rehabilitation, service level, operator level and time were performed for each stroke severity-group. The independent variables are illustrated in figure 3 and the categorization and dichotomization are described in table 5.

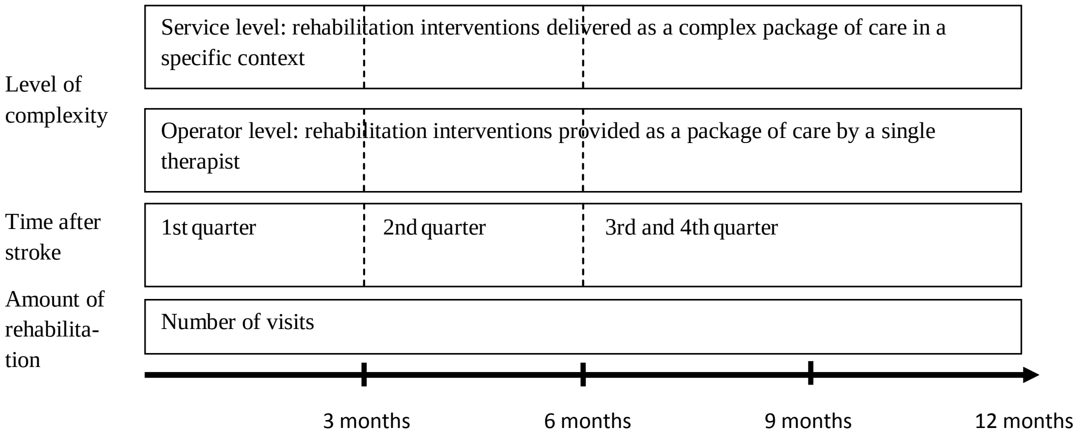


Figure 3. The different aspects of provision of rehabilitation used as independent variables in the logistic regression analyses

Amount of rehabilitation: In the model for the amount of therapy received, the independent variables represented the total number of days spent at in-patient rehabilitation as well as the number of visits to outpatient rehabilitation during the first year after stroke divided into four classes (0-14, 15-28, 29-63 and >63 days and/or visits). The same classes for the amount of rehabilitation have previously been used by Pound et al [76].

Service level: In the model for service level, the independent variables represented rehabilitation services provided from different facilities *(day care rehabilitation during the 1st, 2nd and 3rd-4th quarters, primary care rehabilitation during the 1st, 2nd and 3rd-4th quarters, home based rehabilitation during the 1st, 2nd and 3rd-4th quarters).* In order to mirror all the common service combinations during the first quarter after stroke, in-patient rehabilitation was considered as equivalent to hospital based, home-based or primary care rehabilitation in the analysis.

Operator level: In the model for operator level, the independent variables represented different professionals who had provided rehabilitation *(a PT during the 1st, 2nd and 3rd-4th quarters, an OT during the 1st, 2nd and 3rd-4th quarters, a ST during the 1st, 2nd and 3rd-4th quarters).*

Time: If a model regarding service level or operator level was found to be statistically significant, a model was applied that explored the importance of having used rehabilitation services at that significant operator or service level during three different time periods during the first year after stroke. The time periods used in the analysis were: *during the 1st and 2nd quarters; during the 3rd-4th quarters* and *during the 1st, 2nd and 3rd-4th quarters.*

Table 5. Dependent and independent variables included in logistic regression analyses regarding the association between met needs for rehabilitation and aspects of the provision of rehabilitation

Concept	Variables	Categorization/dichotomization
Dependent variable		
Met needs for rehabilitation	I have received too little rehabilitation after my stroke	Met needs, 4-5 /unmet needs, 1-3
Independent variables		
Socio demographic factors and stroke severity	Age	≤65/>65
	Sex	Male/female
	Civil status n=171	Living with a partner/living alone
	Personal finances n=152	Affluent/not affluent
	Education n=168	≤9 years/>9 years
	Severity	Very mild (100), mild (50-99), moderate/severe (0-49)
Amount of rehabilitation	Class 1	0-14 visits
	Class 2	15-28 visits
	Class 3	29-63 visits
	Class 4	>63 visits
Time periods	1st quarter	≥ 1visit of the specified service within the time period/0 visits
	2nd quarter	
	3rd-4th quarter	
	1st and 2nd quarter	≥ 1visit of the specified service within each time period/< 1 visit in at least one time period
	1st quarter, 2nd quarter and 3rd-4th quarter	
Service level*	In-patient rehabilitation*	≥ 1day/0 days
	Day care rehabilitation*	≥ 1visit/0 visits
	Primary care rehabilitation*	≥ 1visit/0 visits
	Home based rehabilitation*	≥ 1visit/0 visits
Operator level†	Physiotherapist (PT)†	≥ 1visit/0 visits
	Occupational therapist (OT)†	≥ 1visit/0 visits
	Speech and language therapist (ST)†	≥ 1visit/0 visits

*Day-care rehabilitation/ primary care rehabilitation/ home-based rehabilitation are in the analysis combined with the different periods in time

† In the analysis physiotherapist/occupational therapist/speech and language therapist are combined with the different periods in time

3.4.2 Use of and outcome of health care services

3.4.2.1 Changes over time in use of health care services

In paper IV, comparisons between the 93/96 group and the 06/07 group regarding LOS were performed using the Mann-Whitney *U* test. Comparisons of the LOS were performed regarding (1) LOS at the stroke unit (LOS SU); (2) LOS at subsequent in-patient rehabilitation unit (LOS IRU); and (3) LOS at the stroke unit and at subsequent in-patient rehabilitation unit (LOS TOTAL). Additionally, comparisons regarding LOS SU were performed between subgroups: (1) “independent” participants and (2) “dependent” participants regarding P-ADLs, in accordance with the KI at baseline.

3.4.2.2 Changes over time in independence in ADL

Comparisons using chi-squared test were performed in order to investigate whether there were differences in independence in ADL between the 93/96 group and the 06/07 group. The KI was dichotomized into either independent or dependent. Independent meant that the participant was independent in all five P-ADLs for baseline assessment, and in all P-ADLs and I-ADLs for the remaining assessments. Furthermore, generalized estimating equation (GEE) was used to examine plausible factors that would explain differences between the groups regarding their capacity in ADLs at 12 months post stroke. The independent variables included in the model were age, capacity in ADLs before stroke, capacity in ADLs at baseline, group (the 93/96 group or the 06/07 group), access to in-patient rehabilitation (received or not received), length of time since stroke (3, 6 or 12 months) as well as interaction between the time elapsed since stroke and the group.

3.4.2.3 Use of rehabilitation services the first year after stroke

The use of rehabilitation services during the first year after stroke was described with regard to stroke severity in paper III. Use of rehabilitation was described at a service level represented by in-patient rehabilitation, day care rehabilitation, primary care rehabilitation and home based rehabilitation.

3.4.3 Satisfaction with health care services

3.4.3.1 Changes over time in patient satisfaction

Comparisons between the 93/96 group and the 06/07 group regarding differences in the different dimensions of patient satisfaction were performed using chi-squared test or the Fisher exact test (paper IV). The score for each item on the NSQ was dichotomized into *satisfied* (1-2 on the Likert scale) or *not satisfied* (3-5 on the Likert scale).

3.4.3.2 Association between characteristics in individuals and dissatisfaction with care

Two multivariate logistic regression analyses were performed in order to explore the predictive capacity of characteristics in individuals at three months and their association at 12 months, with dissatisfaction with care at 12 months after stroke (paper II).

The statement from the NSQ” I am very satisfied with the care I have received” was used as dependent variable. The choice of independent variables for the logistic regressions was based on Strasser’s theoretical model and on univariate analyses. The variables were dichotomized as displayed in table 4.

The standard Enter method by SPSS was used to select the most appropriate model.

3.4.4 Level of significance and software used in statistical analyses

In all analyses, the significance level was specified at 0.05. The statistical analyses were performed using the SPSS statistical software 17.0 (multivariate logistic regression analysis in paper II), SPSS statistical software 18.0 (GEE regarding recovery in ADL in paper IV) and the Statistica 8-10 software (all descriptive and comparative analyses and logistic regression analyses in paper III).

3.4.5 The need and satisfaction questionnaire

In order to further illuminate the meaning of the answers to the questions in the NSQ regarding needs for rehabilitation and satisfaction with care, comments from the questionnaire and cognitive interviews were used.

3.4.5.1 Comments on the questionnaire

During the follow-up, some participants left comments regarding their answers to the different statements in the NSQ; these were written down. Comments regarding the statement about needs for rehabilitation and satisfaction with care were retrieved and described for each of the two statements.

3.4.5.2 Cognitive interview

Cognitive interviews, can be used to evaluate the process of generating answers to a questionnaire [145-146]. A total of 17 people were interviewed, seven of the interviews were performed face-to face, and ten were carried out over the telephone. The cognitive probes [147] “What were you thinking when you responded to the statement?” were put and if necessary complemented with the probe “What would you like to receive?” All answers but one were tape recorded, then transcribed and have been described in relation to each of the two statements.

The cognitive interviews were partly performed in the context of data-collections that were parts of ongoing studies, and since cognitive interviews may affect how questions are answered, these interviews were performed when the questionnaire was completed i.e. a retrospective interview [146].

4 FINDINGS

4.1 NEEDS FOR REHABILITATION

Aspects of meeting the needs for rehabilitation during the first year after stroke were explored from different perspectives; the felt problems underlying the needs for health care services have been described (paper I, additional analysis/results) and different factors as potential contributors to unmet as well as met needs for rehabilitation have been explored (additional analysis/results, paper II and III).

4.1.1 Felt problems and concurrence between felt and assessed problems

4.1.1.1 Felt problems

Findings in paper I show that there is a great variety of felt problems, which reflects the many aspects of daily life that are affected. Table 6 shows the categories of felt problems, frequencies of felt problems, corresponding ICF-codes and examples of how the participants expressed their felt problems in daily life at three months after stroke. *Fatigue* was the category in which the largest number of participants reported felt problems (n=58, 28%) followed by *Language and communication* (n=51, 25%), *Acquisition meals and housework* (n=41, 20%) and *Recreation and leisure* (n=40, 20%).

4.1.1.2 Assessed problems

There were corresponding items/domains in the KI, the BI or the SIS in 15 out of 24 categories of felt problems (*No problem* was excluded from the subsequent analysis as were the categories *Across activity difficulties, Global* and *Other problems* due to their unspecific and comprehensive nature). Consequently, for more than a third of the categories of felt problems, there were no corresponding items or domains in the assessment tools and it was thus not possible to identify problems in those categories as assessed problems. Five of the categories had corresponding items in the KI/BI, and 14 categories had corresponding items/domains in the SIS. The agreement in content between the category *Language and communication* and the SIS domain communication was not complete, and three domains in the SIS corresponded to more than one category of felt problems. There were no corresponding items/domains in either the KI/BI or the SIS regarding *Fatigue* that is the category with the largest number of reported problems.

Table 6. Categories, corresponding ICF-codes and frequencies of felt problems and quotes

Categories	**ICF-codes**	**participants n=203 (%)**	**Quotes**
Fatigue	b126, b130, b134, b455, b730	58 (28)	“tired”, “mental and physical tiredness”, “have to go and lie down”, “less energy”, “tiredness is limiting, everything takes longer, have to rest in between”
Language, communication	b167, b320, d310, d325, d330, d345, d350, d360	51 (25)	“harder to write by hand”, “reading the paper”, “have double vision when reading”, “it feels as if my tongue does not keep up”, “difficult both to formulate words and to write”, “a bit more difficult to find words”
Acquisition, meals and housework	d620, d630, d640	41 (20)	“changing linen, duvet covers, cleaning windows”, “going shopping and clean not same as before”, “doing housework”, “can not clean up the way I want to”
Recreation and leisure	d910, d920	40 (20)	“cannot play the piano”, “putting on the golf course”, “difficult to take a walk”, “for example to go out to fish”, “difficult to mingle in large groups”
Across activity difficulties	n.d.[a]	40 (20)	“Most seriously: have to turn down certain things”, “everything goes a bit slower”, “have to think more carefully when it comes to carrying out simple everyday tasks”
Cognitive function and memory	b164, b144, b172	32 (16)	“walk to the wrong cupboard”, “less initiative”, “difficulty in thinking and making up my mind”, “ability to concentrate”, “forget sometimes”, “mental arithmetic”
Body position, walking and moving	b770, d410, d450, d455 d460	30 (15)	“stairs”, “still stumbling”, “to go down to the basement is still difficult, the hand-rail does not reach all the way”, “walking on heights, step more carefully”
Movement and muscle functions	b730,b740, b760, d430, d440, d445	28 (14)	“paralyzed in my right hand, it’s more difficult to hold objects”, “left hand does not work, difficulty in braking the walker”
Self care	d510, d520, d530, d540, d550	23 (11)	“can’t wash my hair - go to the hairdresser”, “cutting my nails”, “difficult to go to the toilet”, “getting out clothes”, “more difficult to handle cutlery”
Temperament	b126	21 (10)	“anxiety, a nagging anxiety”, “do not care any longer”, “short tempered, afraid that it will happen again. sad!”, “have lost my spirit”, “restless and nervous”
Seeing function	b210, b215	15 (7)	“field of vision to the left gone”, “poorer eyesight”, “cannot see, cannot read a paper”
Driving a car	d475	16 (8)	“not allowed to drive a car”, “want to be able to drive a car”
Balance	d450, d455, d460, d415	14 (7)	“poor balance”, “no real balance in my left leg”, “balance – pulls to the left “
Emotional function	b152	13 (6)	“afraid to go out by myself”, “annoyed by little things that don't work”, “afraid of falling”
Global	n.d.[a]	12 (6)	“everything has become more difficult”, “everything”, “everything is difficult”
Household	d650	10 (5)	“keeping the flowerbeds weeded and tidy “, “a bit more unsure when changing curtains”, “can not sweep snow”, “don’t do anything with the electricity”
Vertigo	n.d[a].– b.f.[b]	9 (4)	“vertigo in the mornings”, “dizzy”, “vertigo, I am dizzy sometimes”
Environment	n.d.[a] - e.f.[c]	8 (4)	“I get palpitations, especially in Skärholmen centre where everything is very busy because of an ongoing reconstruction”, “still difficult to be among people”
Touch function	b265	8 (4)	“reduced sensation in my feet, sensitive to vibrations”, “left hand swollen and numb”
Other problems	b230, b134, b640, e450, b525, b460	8 (4)	“feels as if I lose touch , started after the operation of the artery in my neck”, “my hearing is worse after the stroke” “difficulty with potency”, “don't sleep”, “attitudes toward neurological diseases takes a lot of my energy”
Employment	d850	7 (3)	“very good except that I don’t work”, “can not work as a taxi-driver”
Transport	d470	6 (3)	“taking the underground”, “difficult to travel”, “do not use public transports”
Pain	b280	6 (3)	“headache sometimes”, “more difficult to use left hand due to pain and reduced flexibility”, “pain in my legs, my osteoarthritis has become worse after the stroke”
Urination function	b620	5 (2)	“wet myself sometimes”, “have to pee more often, have to hurry to the can, leak urine”
Health related services	e120, e540, e850	5 (2)	“social services do not always arrive when they should”, ”I am not satisfied with the rehabilitation service and the municipality”
Ingestion function	b510	3 (1)	“my throat doesn’t function as before, can not swallow when I want to. The saliva is more bubbly, can not spit”, “my throat burns all the time”
Parent-child relation	d7600	3 (1)	“can’t live up to my role as a mother”, “my role as a parent has changed”
No problem	n.d.[a]	23 (11)	”it’s nothing”, “nothing has changed, not anything I have noticed anyway”

[a] not definable [b]body function [c]environmental factor

4.1.1.3 Comparison between felt and assessed problems

Figure 4 shows that even though corresponding items were identified, more than half of the felt problems were not identified by the KI/BI in the categories *Body position, walking and moving* (n=17) and *Self care* (n=13).

Regarding the SIS, 13 felt problems were not identified in *Language and communication*. The SIS identified all felt problems within the categories *Cognitive function and memory, Temperament, Emotional function, Employment, Urination function* and *Parent-child relation (*figure 5).

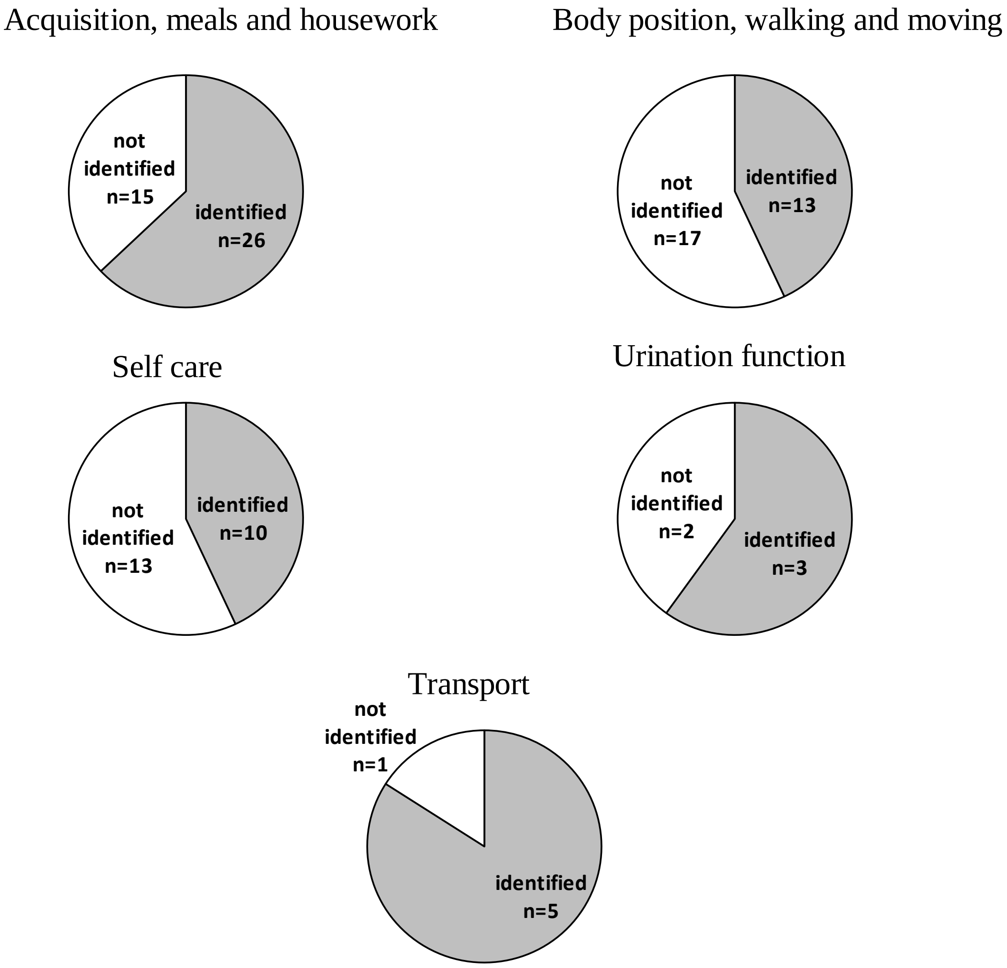


Figure 4. Proportion and number of felt problems identified in the Katz Index of ADL Extended and the Barthel Index within the categories with corresponding items/domains

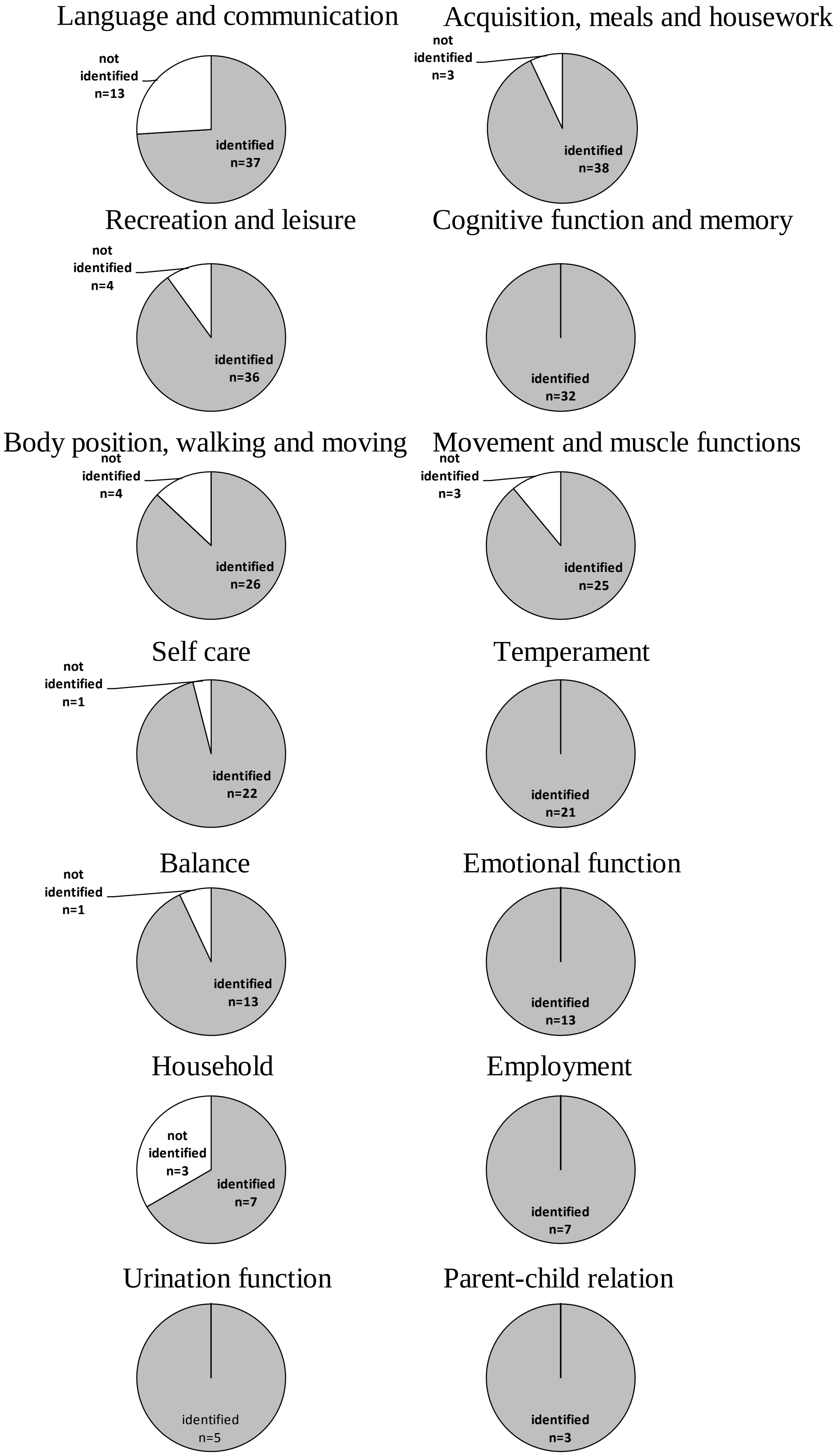


Figure 5. Proportion and number of felt problems identified in the Stroke Impact Scale within the categories with corresponding items/domains

4.1.1.4 Felt problem the first year after stroke

The frequencies of felt problems reported at 3 and 12 months after stroke (additional analyses/results) are shown in table 7. At 12 months after stroke, *Movement and muscle function* was the category in which the largest number of participants reported felt problems (n=32, 22%) followed by *Fatigue* (n=27, 18%) and *Language and communication* (n=27, 18%). An increase in number of problems was also found in the categories *Balance, Pain* and *Other impairments*. One new category, *Personality change*, emerged at 12 months after stroke.

4.1.2 Unmet needs for rehabilitation

4.1.2.1 Felt problems and unmet needs for rehabilitation

Based on knowledge about the poor concurrence between felt and assessed problems at 3 months after stroke, the categories of felt problems were explored as possible predictors or as associated with unmet needs for rehabilitation at 12 months after stroke (additional analyses/results). Univariate analysis showed that felt problems in *Movement and muscle function* at both 3 months (p=0.02) and 12 months (p=0.01) after stroke were associated with unmet needs for rehabilitation at 12 months. However, the category neither predicted nor was associated with unmet needs for rehabilitation in the final model.

4.1.2.2 Factors that predicted or were associated with unmet needs for rehabilitation

In the final models (paper II), none of the variables that represented socio-demographics or personality were associated with unmet needs for rehabilitation. However variables representing health status were. At 3 months after stroke, high impact in the SIS domain strength (OR 7.05, CI 3.38-14.70, p<0.001) predicted unmet needs for rehabilitation at 12 months. At 12 months after stroke, high impact on the SIS domains hand function (OR 4.38, CI 2.03-9.48, p<0.001) and poor self-rated recovery (OR 2.46, CI 1.16-5.19, p=0.018) were associated with unmet needs for rehabilitation at 12 months after stroke.

Table 7. Frequencies of felt problems at 3 and 12 months after stroke

Categories	**3 months** n=159 (%)	**12 months** n=159 (%)
Fatigue	51 (32)	28 (18)
Language, communication	39 (25)	28 (18)
Acuisition, meals and housework	34 (21)	20 (13)
Recreation and leisure	30 (19)	23 (14)
Across activities	36 (23)	18 (11)
Cognitive function and memory	25 (16)	22 (14)
Body position, walking and moving	20 (13)	26 (16)
Movement and muscle functions	22 (14)	35 (22)
Self care	20 (13)	17 (11)
Temperament	14 (9)	13 (8)
Seeing function	9 (6)	9 (6)
Driving a car	14 (9)	7 (4)
Balance	11 (7)	17 (11)
Emotional function	12 (8)	13 (8)
Global	6 (4)	2 (1)
Household	9 (6)	6 (4)
Vertigo	6 (4)	6 (4)
Environment	7 (4)	7 (4)
Touch function	5 (3)	9 (6)
Employment	7 (4)	8 (5)
Transport	4 (3)	4 (3)
Pain	4 (3)	15 (9)
Urination function	5 (3)	2 (1)
Other impairment	4 (3)	14 (9)
Health related services	3 (2)	5 (3)
Ingestion function	3 (2)	4 (3)
Parent-child relation	3 (2)	0 (0)
Other	3 (2)	4 (3)
Personality change	0	4 (3)
Nothing	17 (11)	21 (13)

4.1.3 Met needs for rehabilitation

4.1.3.1 Aspects of the rehabilitation provision that contributed to met needs for rehabilitation

An initial multivariate logistic regression analysis regarding socio-demographic factors and stroke severity showed that participants with mild stroke (OR 0.23, CI 0.09-0.61, $p=0.002$) as well as moderate/severe stroke (OR 0.10, CI 0.03-0.36, $p<0.001$) were less likely to report met needs for rehabilitation compared to those with very mild stroke (paper III).

For participants with moderate/severe stroke, at least one contact with a PT during each of the 1st, 2nd and 3rd-4th quarters during the first year after stroke contributed to met needs for rehabilitation (OR 8.36, CI 1.40-49.88, $p=0.020$). In this group, 13 participants had seen an OT and 15 a PT at least once during the 1st, 2nd and 3rd-4th quarters. The importance of contact with a PT during different time periods in the course of the first year after stroke was further explored. The results of this model indicated a trend towards statistical significance for the interaction between the time variables *1st and 2nd quarters* and *3rd-4th quarters* ($p= 0.101$). Further investigation of the time variables in the model showed that the importance of the variable *1st, 2nd and 3rd-4th quarters* could not be neglected. The final model showed that the interaction variable *1st, 2nd and 3rd-4th quarters* (i.e. at least one contact during each of the time periods) contributed to meeting the needs for rehabilitation amongst participants with moderate/severe stroke (OR 8.36, CI 1.40-49.88 $p=0.020$).

4.2 USE OF AND OUTCOME OF HEALTH CARE SERVICES

Use of, and outcome of health care services were explored both regarding changes over time (paper IV) and also, in more detail, regarding the use of rehabilitation at different service levels (paper III).

4.2.1 Changes over time in use of health care services

A comparison between the 93/96 group and the 06/07 group regarding the LOS at the stroke unit, and subsequent rehabilitation, showed that the LOS-SU was longer for the 93/96 group (median 13 days) compared to the 06/07 group (median 8 days) ($p<0.001$) (figure 6) (paper IV). Moreover, subgroup analysis of the 93/96 group revealed a shorter LOS SU for those independent in P-ADL compared to those dependent in P-ADL at baseline[median (range); 12 (5-24) versus 15.5 (8-44), $p=0.03$]. No corresponding difference was found in the 06/07 group.

No difference in LOS was found regarding LOS IRU or for the LOS TOTAL. The number of patients who received in-patient rehabilitation was 19 in the 93/96 group and 29 in the 06/07 group (p=0.07).

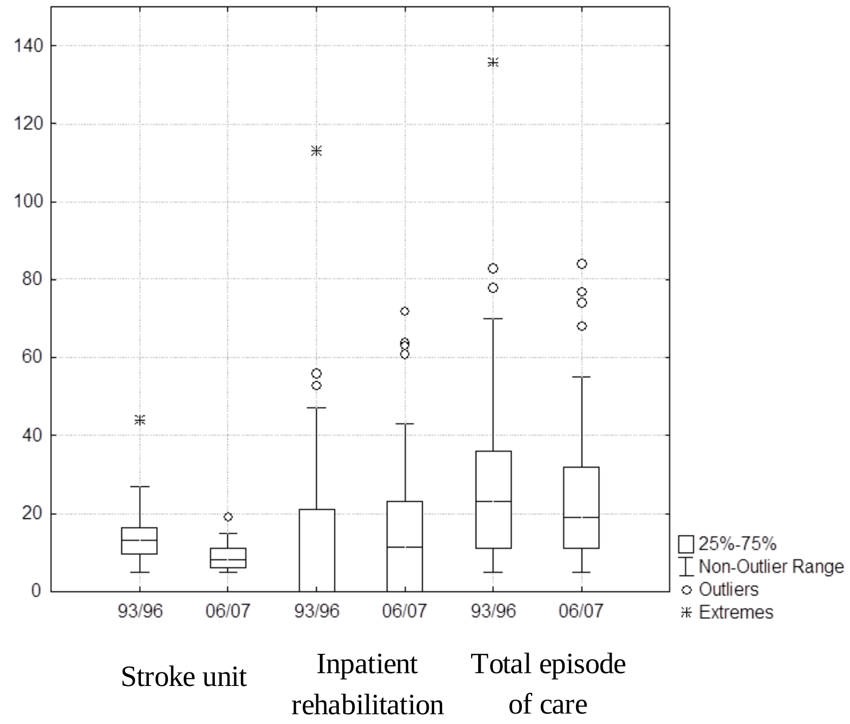


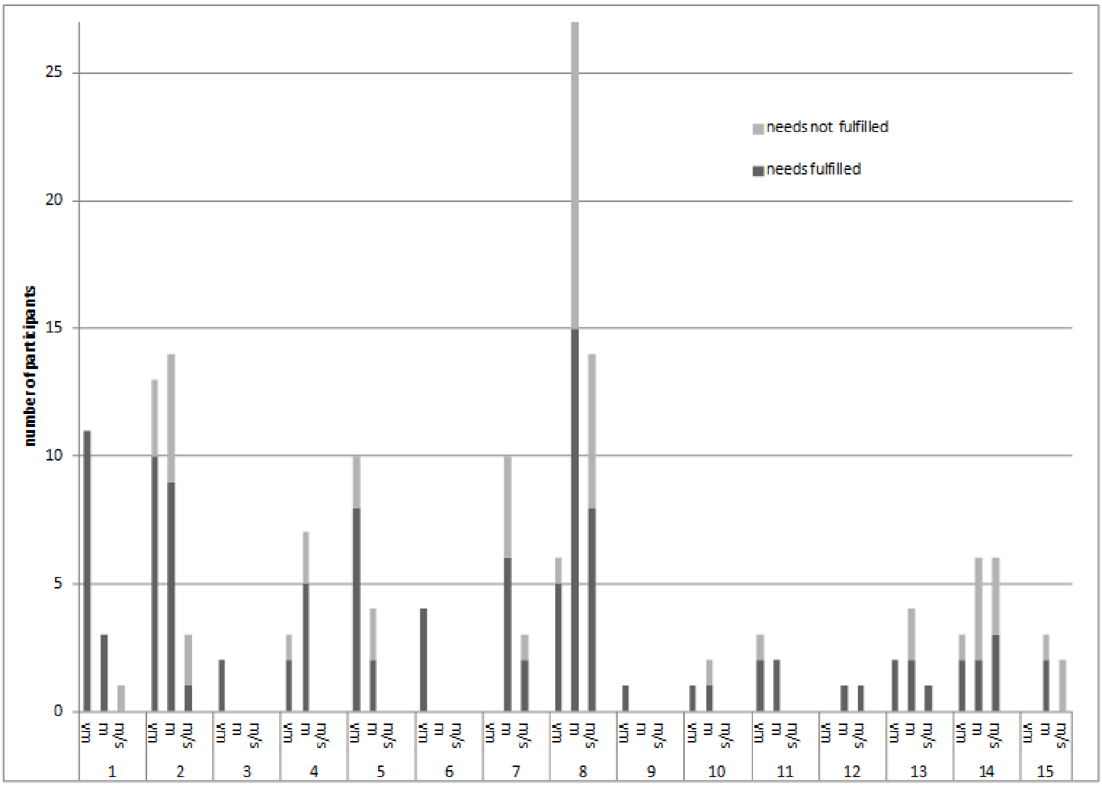
Figure 6. Length of stay (LOS) (days) in the stroke unit, for subsequent in-patient rehabilitation, and for the total episode of care (stroke unit and subsequent in-patient rehabilitation). The LOS in the stroke unit was higher for the 93/96 group compared to the 06/07 group (p<0.001)

4.2.2 Changes over time in recovery in ADL

The number of patients independent in ADL was higher in the 06/07 group compared to the 93/96 group (23 versus 12, p=0.01) at three months after the stroke (paper IV). The difference was not present at 6 or 12 months after stroke. The finding was confirmed in a GEE controlled for age and capacity in ADL before stroke. At 3 months after the stroke, the participants in the 06/07 group had 3.24 times higher odds of becoming independent at 12 months after stroke compared with the 93/96 group; but no difference between the groups was seen at 6 or 12 months.

4.2.3 Use of rehabilitation

A considerable number of combinations of rehabilitation services were provided during the first year after stroke, as displayed in figure 7 (paper III). All participants with very mild stroke, who had been in contact with day care rehabilitation, reported met needs for rehabilitation. Met needs for rehabilitation were furthermore reported by all the participants with very mild and mild stroke who had not received any rehabilitation beyond the stay at the stroke unit.



1 No rehabilitation (after the stroke unit)
2 In-patient rehabilitation
3 Day care rehabilitation
4 Home based rehabilitation
5 Primary care based rehabilitation
6 In-patient + Day care rehabilitation
7 In-patient + Home based rehabilitation
8 In-patient + Primary care based rehabilitation
9 Day care + Home based rehabilitation
10 Day care + Primary care based rehabilitation
11 Home based + Primary care based rehabilitation
12 In-patient + Day care + Home based rehabilitation
13 In-patient + Day care + Primary care based rehabilitation
14 In-patient + Home based + Primary care based rehabilitation
15 In-patient + Day care + Home based + Primary care based rehabilitation

Figure 7**.** Number of participants with very mild stroke (vm), mild stroke (m) and moderate/severe stroke (m/s) and use of rehabilitation services described at a service level the first year after stroke

4.3 PATIENT SATISFACTION

4.3.1 Changes over time in patient satisfaction

Participants in both the sample from 1993/1996 and the sample from 2006/2007 were to a large extent satisfied with the health care services received and no difference between the samples was found (paper IV). With regard to the general statement, “I am very satisfied with the care I have received”, 39 of 40 participants in each sample rated that they were satisfied. Two statement had somewhat lower ratings: costs of care (the 93/96-group satisfied/not satisfied: 21/19; the 06/07-group 26/14) and participation in discharge planning (the 93/96 group 25/15; the 06/07-group 23/17).

4.3.2 Aspects of disability and functioning associated with dissatisfaction with care

Based on knowledge about the poor concurrence between felt and assessed problems at 3 months after stroke, the categories of felt problems reported at 3 and 12 months were explored as possible predictors, or as being associated with dissatisfaction with care at 12 months after stroke (additional analyses/results). None of the categories of felt problems were associated with dissatisfaction with care at 12 months after stroke. The final models (paper II) showed that dissatisfaction with care at 12 months after stroke was predicted by a weak SOC (OR 4.18, CI 1.52-11.53, p=0.006) and high impact on the SIS domain participation (OR 3.78, 1.25-11.39, p=0.018) at 3 months after stroke. Further, at 12 months, a weak SOC (OR 3.63, CI 1.38-9.59, p=0.009) and high impact on the SIS domain strength (OR 3.08, CI 1.66-8.14, p=0.023) were associated with dissatisfaction with care.

4.4 THE NEED AND SATISFACTION QUESTIONNAIRE

4.4.1 Needs for rehabilitation

Comments from the questionnaire related to the statement about met needs for rehabilitation suggest either that more rehabilitation was wanted (n=7) or that follow-up after discharge was lacking (n=2). More specific unmet needs for rehabilitation mentioned were: memory training; speech training; training of hand function; training to write; vocational training; massage and passive movements. One person had remarked that the stroke team did not provide training and instead only checked the wheel chair.

General thoughts from the cognitive interviews were as follows: three persons thought that they had not received any training; three persons expressed overall satisfaction with everything received; three persons thought that the rehabilitation received was good, but two of them thought that it had finished too early and they wanted more whereas one of them thought that he had had to wait too long (several months) before he received the rehabilitation he needed.

More specific thoughts related to unmet needs reflected wishes for physiotherapy (n=2), speech therapy (n=1), vocational training (n=1) and exercises for hand (n=1) and leg (n=1). One person who reported unmet needs had been offered aqua aerobics but did not have energy enough to attend. Moreover, she was also afraid of falling on the slippery floor and wanted balance therapy. Four persons who reported met needs mentioned physiotherapy, one mentioned occupational therapy, one mentioned speech and language therapy and one mentioned interventions related to the body and the brain. Two described how they had received home visits from the physiotherapist, or the stroke team, and been given instructions for exercises and help with walking outdoors. One person also mentioned the follow-ups from the study as very important. One person who reported met needs wondered what and where she would go for training and reported that she took long walks almost every day. One person with met needs answered that it was up to each person to practice. One person who reported unmet needs wanted follow-up after discharge.

4.4.2 Satisfaction with care

Comments related to the statement about satisfaction with health care services after stroke showed that two individuals felt abandoned and that no one cared about them; one mentioned participation in this study as an exception. One person commented on physician continuity, especially at one of the hospitals she visited for further examination. She added that no one knew her there and that it was difficult to find her way around the hospital.

Thoughts recorded at the cognitive interviews related to a large extent to the interviewee’s stay at the stroke unit, but some also related to subsequent care and rehabilitation. With three exceptions, everybody was satisfied with the care he or she had received. One person was very satisfied because he received thrombolysis and recovered completely. Two persons referred to the physician and nurses at the rehabilitation center or at the stroke unit, two to the stroke units and the instructions for exercises received there, two to all the settings they had been at, two to the rehabilitation center in general and one to the stroke team. One person referred to the nice physician who had checked her blood pressure at the primary care center and two to the services from the municipality. One person reported satisfaction, but also lack of information, while one had no ideas about what made her satisfied. The people who were not satisfied with the care, lacked follow-ups and either considered that only controls and no care had been provided, or that no care at all after stay at the stroke unit had been provided.

5 GENERAL DISCUSSION

In conclusion, the most important results regarding needs for rehabilitation showed that there was a substantial lack of concurrence between felt and assessed problems three months after stroke. For example, the BI/KI identified less than half of the felt problems in two of the categories that had corresponding items. Unmet needs for rehabilitation were predicted by high impact on the SIS-domain strength and were associated with high impact on hand function at twelve months after stroke. Findings indicated an association between met needs for rehabilitation twelve months after stroke and having been in contact with a PT at least once during each of the 1st, 2nd and 3rd-4th quarters of the first year after a moderate/severe stroke.

Regarding the use of health care services, there has been a reduction in LOS at the stroke unit for patients with mild to moderate stroke between 1993/1996 and 2006/2007. However, no difference regarding the total LOS, including subsequent in-patient rehabilitation, was found. The recovery in P-ADL and I-ADL was faster in the group from 2006/2007 i.e. a greater proportion of the participants were independent in P-ADL and I-ADL at three months after stroke.

There were no differences in patient satisfaction between the group who received care 1993/1996 and the group who received care 2006/2007. A weak SOC and high impact on participation predicted, and a weak SOC and high impact on strength were associated with dissatisfaction with care at twelve months after stroke.

5.1 NEEDS FOR REHABILITATION

5.1.1 Fatigue, a common felt problem after stroke

Fatigue was the most commonly reported felt problem at three months after stroke (paper I). This is also in line with previous studies in which fatigue has been reported as one of the most disabling symptoms after stroke among 40-50% of the people [148-149]. Other studies have reported the prevalence of fatigue after stroke as being between 38 and 77% [10, 14, 75, 150-151]. Qualitative studies have also shown the pronounced nature of the problem which has been described as overwhelming, for instance, and as something that takes command over peoples' lives and hinders them from planning their days or engaging in daily activities [15, 19, 152-153]. There is no theoretical definition of fatigue after stroke, which is a problem when findings from different studies are compared and interpreted. Furthermore, the similarities between fatigue and depression as well as the difficulty to differentiate between them also has to be taken into consideration [14].

Fatigue was a commonly reported felt problem also at one year after stroke (18%, n=28), but the number of people who reported problems related to fatigue had been reduced (additional analyses/results). Other longitudinal studies have shown quite a stable level of fatigued people between three and six months [149] and up to two years after stroke [154] or a slight reduction in people who report fatigue between six (68%) and 36 months (58%) after stroke [150]. It is difficult to compare the frequencies of felt problems related to fatigue with frequencies in studies in which people have been asked explicitly if they experience fatigue. The findings in additional analyses/results though seem to support the finding about a slight reduction in fatigue at the end of the first year after stroke.

The high frequency of felt problems related to fatigue underlines the need to develop interventions aimed to reduce or handle fatigue. This has also been pointed out in previous studies [149-151, 155]. However, a very limited number of trials have been carried out and current knowledge is not enough to guide interventions directed towards fatigue [155]. A newly published RCT, on the other hand, suggests that cognitive therapy together with physical activity has the potential to reduce fatigue among people who suffered a stroke more than 4 months before [156-157].

5.1.2 Poor concurrence between felt and assessed problems

There was a substantial discrepancy between the felt problems and the assessed problems at three months after stroke. More than a third of the categories of felt problems, including Fatigue, Driving a car, Seeing function and Vertigo did not have corresponding items/domains in the KI/BI or the SIS. Consequently, for these categories there was no concurrence between felt and assessed problems. Even when categories had corresponding items/domains in the established assessment tool, a discrepancy between felt and assessed problems was present. Given the limited range of problems that are assessed by the KI/BI, just above half of the problems were identified. The SIS has a wider scope than the KI/BI and identified a substantial proportion of the felt problems within its domains. Within the categories Cognitive function and memory, Temperament, Emotional function, Employment, Urination function and Parent-child relation, all the felt problems were identified. A review of patient-centered care defines patient-centered outcome measures as outcome measures that should reflect patient priorities and identify outcomes that are desired and valued by the patients. The SIS is believed to meet this definition [158]; this is partly confirmed by these finding. If items regarding fatigue were added, however, the SIS would reflect the patients' experiences to a much larger extent.

What are the consequences of the poor concurrence between the felt and assessed problems? An assessment tool with the potential to identify outcomes that are desired and valued by patients should be able to identify qualitative aspects with regard to *how* tasks are performed. Many of the felt problems in categories that had corresponding items or domains, but were not identified, concerned qualitative aspects. This indicates that the qualitative aspects of performance are of importance at three months after stroke. Corresponding findings about the importance of the quality of the performance regarding e.g. walking have been described [21, 153]. It has also been suggested that the quality of the performance may have direct influence on whether or not an activity is continued [158-159].

The BI was: the most frequently used instrument in clinical practice in the United Kingdom during 2004-2005 [123]; the second most commonly used outcome measure in stroke trials 2001-2006 [125], and, in a recently published review examining prediction of ADL functioning, the most frequently used scale to assess ADL-outcome [124]. The BI was not designed for people with stroke specifically, nor for clinical trials [117], and the outcome measures developed during the 60s and 70s can be considered to reflect the limited expectations of rehabilitation at that time [61]. Consequently, there is a substantial risk that neither relevant problems nor changes are identified when the BI is used in research and clinical practice. The SIS has proven ability to detect persisting consequences of stroke in the domains hand function, ADL/IADL and social participation among people who, according to the BI, have recovered [160]. The present results confirm this higher level of sensitivity. Use of the SIS in combination with discussion [161] may consequently be a good way to identify needs that are important to individuals after stroke. This is crucial if the health care services are to achieve their aspiration for good care.

5.1.3 Hand function and strength

The SIS-domain, strength, consists of items concerning strength in the affected arm, wrist and leg and the capacity to grasp with the affected hand. The SIS domain hand function consists of different activities that involve the hand such as turning a key and tying shoestrings. Unmet need for rehabilitation is consequently associated with, and also partly predicted by impairments in the arm as well as by limitations in activities carried out by the hand.

What role does hand function play? Hand function has been proven to account for 32%, the single most important variable, of global recovery among young people < 65 years at one year after stroke [162]. Upper-limb paresis has also been found to be a strong indicator of performance in ADL [163]. The importance of hand function is confirmed by the felt problems demonstrated by this thesis: in addition to problems such as “my hand is paralyzed” and “difficult to hold things” categorized in *Movement and muscle function*, also a great number of the felt problems categorized in *Recreation and leisure, Self-care* and *Acquisition meals and housework* e.g. “play the piano”, “hold the cards when playing bridge”, “peel potatoes” and “hold a fork” are closely related to impaired hand function. The number of felt problems categorized in *Movement and muscle function* increased between three and 12 months after stroke and 68% of the felt problems in that category at both points in time concerned upper limb function.

People with poor hand function at 12 months after stroke may have received almost no interventions, or no effective interventions for this, which may be reflected in the association between poor hand function and unmet needs for rehabilitation. There is a lack of evidence that can guide interventions concerning arm and hand function; the most robust evidence suggests that Constraint-Induced Movement therapy has the potential to increase arm function, but only for a selected population with less affected hand function [164-165]. A recent review about the type of interventions provided during physiotherapy and occupational therapy showed, furthermore, that upper limb therapy accounted for only a median of 16% of the time for therapy (range 0.9-38.4 %) [166]. People who have had a stroke have also reported that upper-limb recovery is a very important but neglected area [167]. In contrast, a Swedish study listed interventions for motor function in the hand as the most common content in occupational therapy during the first three months after stroke [168]. People with poor hand function may consequently be in need of extra attention and their need for rehabilitation should be carefully assessed and acknowledged.

Is participation in everyday life not more important? The findings about strength and hand function as the domains of importance for unmet needs for rehabilitation was somewhat unexpected. Rehabilitation professionals are criticized for being too focused on physical function whereas the goal for people with stroke is social reintegration and the resumption of previously valued activities [15, 17, 19, 153, 169-171]. In that light, an association between a high impact in the SIS-domain participation and unmet needs for rehabilitation should have been relevant. A reason could be that if the rehabilitation provided so far has not explicitly been directed towards participation, patients may not think of rehabilitation as a mean to this end.

5.1.4 Recovery, rehabilitation and physiotherapy

Poor self-reported recovery at 12 months after stroke was also associated with unmet needs for rehabilitation. Qualitative studies have described recovery as an intensely individual and never ending experience that includes physical, social and emotional aspects such as testing out the body’s capacity in a new environment, social roles, life style choices, hope, anger, uncertainty and frustration [8, 16, 167, 172]. The standard people who have had a stroke seem to apply when measuring recovery is pre-stroke life [8, 16, 173-174]. Their understanding of recovery during the first months after stroke has been described as “full recovery” and as taking up the same activities as before their stroke [174-176].

Since physiotherapy [167, 175, 177-180] or rehabilitation [15, 22, 174, 181-182] has been regarded as a means to general recovery or to physical recovery, poor perceived recovery coupled with the hope or expectation for further recovery may have contributed to reports that not enough rehabilitation had been provided. Physiotherapy, or physical training, has also been described as something that represents faith and hope for further recovery [174, 177]. Many individuals perceive that they are discharged from physiotherapy prematurely [153, 178, 183] and also that the more physiotherapy they receive, the more they will recover [177]. Furthermore, patients might not have been given realistic information about their potential for further recovery at the time of their discharge from rehabilitation [170, 178]. They may thus consider that they have a potential for further recovery if more rehabilitation is provided.

The findings in this thesis indicate that people with moderate/severe stroke might be more likely to report met needs for rehabilitation 12 months after stroke if they had been in contact with a PT during the 1st, 2st and 3rd-4th quarters of the first year. Why does contact with a PT seem to contribute to met needs for rehabilitation but not contact with an OT? This might partly be explained by the fact that OTs and PTs may represent different values for the patients, with PTs being stronger representatives of recovery as described above. This is supported by a study of stroke patients' satisfaction with rehabilitation in which the patients did not consider training sessions during daily activities as training [179]. Such sessions might consequently not be perceived to meet needs for rehabilitation to the same extent as physiotherapy.

5.1.5 Time

The findings suggest that individuals with moderate/severe stroke, who had been in contact with a PT at least once during each of the time periods, the 1st, 2nd and 3rd-4th quarters of the first year after stroke, might be more likely to report met needs for rehabilitation (paper III). Why does it seem to be of importance that physiotherapy is provided throughout the first year after stroke? The first year after stroke has been described as four different phases [184]. The first two phases cover the onset and initial rehabilitation, and are characterized by hard physical training and by beginning to make sense of the stroke. The third phase from eight weeks until approximately six months after stroke consists of psychosocial and practical adjustment, and of testing out the body's capacity in a new environment, while the fourth phase beyond six months post stroke is about getting on with life and resuming previously valued activities. Continuity in rehabilitation during the first year after stroke, in line with the present findings, could, if a more active everyday life gives rise to new rehabilitation needs provide support in the third and fourth phase. Such continuity might also reduce needs that have been reported in other studies such as information, feedback and guidance at a later stage of recovery [167, 177] and patients' sense of abandonment following discharge [22, 171, 185]. Continuity can be defined either as informational continuity, which means the use of information from past events in order to make current care appropriate, or as management continuity i.e. consistency in the approach to the management of a health condition, or to relational continuity i.e. to an ongoing therapeutic relationship [186]. In this study continuity is not defined and the contacts with a PT that seemed to contribute to met needs for rehabilitation may have occurred at different services levels. Thus no conclusions can be drawn as to the influence of different types of continuity.

5.1.6 Severity of stroke

The finding here of an association between met needs and physiotherapy during each of the phases was only valid for people with moderate/severe stroke. Functional recovery after stroke usually takes longer for people with more severe stroke [49, 187]; consequently the time periods used may have been most relevant for this group. There is evidence that rehabilitation has the potential to improve ADL during the first year after stroke [188], and walking ability even beyond that [189-190]. People with more severe stroke are more likely to have more disabilities related to e.g. ADL-function, balance and gait [11]. Those with moderate/severe stroke in this sample might consequently both have been in greater need of rehabilitation and also benefited from physiotherapy/rehabilitation all the periods.

5.1.7 Amount of rehabilitation and service level

The amount of rehabilitation received and service level were not associated with met needs for rehabilitation (paper III). A previous study indicates that a moderate amount of rehabilitation (15-28 units), when compared to less or more rehabilitation, contributes to met needs for rehabilitation over the first four months [76]. No association was found, however, at one year after stroke, which corresponds to the findings in this thesis. One possible explanation might be that the intervals used for categorization of the amount of rehabilitation are inadequate, but it may also be that the contents of the rehabilitation received are of greater importance than the amount. Only one study was found that deals with the association between service level and need for rehabilitation. That study did not reveal any association between ESD-service or conventional care and met needs for rehabilitation [76]. Because studies suggest that patients tend to be more active in problem-solving [191], goal-setting and have greater influence on rehabilitation when it is provided at home [192], home-based rehabilitation could have been expected to meet peoples’ rehabilitation needs better. On the other hand, interventions carried out in the course of daily activities may not be considered as training by the patients [179]; consequently interventions carried out at home might not be considered as rehabilitation or training to the same extent as if they had been carried out at a rehabilitation clinic.

5.2 USE OF HEALTH CARE SERVICES

5.2.1 Shorter length of stay in the stroke unit and faster recovery in ADL

The findings in paper IV show a decreased LOS-SU between 1993/1996 and 2006/2007 for patients with mild to moderate stroke, and further that LOS SU was no longer associated with differences within the group regarding the level of disability (dependent or independent in P-ADL) but is similar for all patients.

Even though several factors may have affected the decrease in LOS SU, a plausible interpretation is that changes in the organization and/or the process of care have had a major effect. Studies have shown that a quality improvement program [34], standard care with the addition of early mobilization [35], or care that was characterized by fulfillment of internationally recommended guidelines for stroke, have been associated with a shorter LOS-SU [28-29]. The two first versions of National Guidelines for Stroke Care in Sweden, published in 2000 and 2005 [27, 45], in interplay with the structural changes overall in the Swedish health care system [30], may also have had a substantial impact on the care given. Thus, the literature supports the view that a number of modifications may have contributed to the reduction in the LOS SU – as shown in this study.

The LOS SU was similar for the patients in the 06/07 group, regardless of whether they were independent in ADL or not, which indicates a change in the pattern of care. In contrast to a previously more individualized LOS SU, the new pattern is characterized by a more standardized LOS SU followed by inpatient rehabilitation. This is supported by the trend (p=0.07) towards a larger number of patients from the 06/07 group being discharged to in-patient rehabilitation units, and also by the fact that the decrease in LOS identified in this study was significant only for the stroke unit and not for the LOS TOTAL.

5.3 PATIENT SATISFACTION

5.3.1 Changes over time in patient satisfaction

No difference in the dimensions of patient satisfaction between the 93/96 group and the 06/07 group was found (paper IV). The proportion of people who were satisfied with health care services at three months after stroke was generally high, which is in line with previous studies about satisfaction with care at stroke units [3, 43, 86-87]. The low ratings for participation in discharge planning is also in line with a previous study in which only 47% of the people with stroke perceived that they had had opportunity to participate in discussions about their needs for care/services after discharge, and only 33% in discussions about their needs for rehabilitation [193]. Even though the ratings for a number of participants may reflect not only the discharge process from the stroke unit but also the discharge process from in-patient rehabilitation, the low rating regarding participation in discharge planning for both samples is notable because involvement in the discharge process is one of the stroke units' core components [27].

5.3.2 Characteristics in individuals associated with dissatisfaction with care

The finding that high impact on the SIS-domain participation predicted dissatisfaction with care at twelve months after stroke is difficult to interpret whereas the association between high impact on the SIS-domain strength is more in agreement with previous findings. Dissatisfaction with acute stroke care has been associated with more disabilities [87-88] whereas people with fewer disabilities have been found to be more likely to be satisfied with rehabilitation [76, 90-91].

How can the finding about the association between a weak SOC and dissatisfaction with care be interpreted? A strong SOC is a resource that makes it easier to cope with stressors whereas a weak SOC is thought to be related to poor ability to mobilize emotional, intra- and interpersonal resources as well as material resources to cope with a problem. SOC also includes the individual’s social network’s ability to act as a potential resource [136]. Previous studies have suggested an association between a weak SOC and dissatisfaction with care [194] and furthermore with low social and emotional support [195]. Emotional, social and practical support from the family has been suggested as being of great importance after a stroke [65, 196] and studies have also recorded unmet needs for psychological support after stroke [17, 67]. In this study, one interpretation of the association between a weak SOC and dissatisfaction with care is that the health care services are preferentially tailored to the demands of people who good coping-ability. This includes a social network that gives emotional and psychological support. People with a weak SOC might thus be in need of extra or different support from the health care services.

5.3.3 Concluding remarks: the importance of the context

The findings in this thesis should be interpreted in relation to the society in which they originate. Which health care services people ask for is changeable and influenced by such factors as new research, social and educational background, the media [102, 105] and knowledge about health [102]. A study from Canada has suggested an increased demand for rehabilitation services during the last decade. Four primary factors that explain the increase are proposed: an aging population; increasing rates of people with chronic and complex conditions coupled to shorter stays in hospital; increasing public expectations regarding quality, amount and type of rehabilitation, and advances in treatment and management of diseases and conditions [197]. Rising expectations of health care due to changing attitudes towards old age, technological developments and the view that good health is something desirable and achievable have also been identified [78]. The factors suggested may vary between different societies and also change over time, which may influence to what extent people are satisfied with the care they receive and experience that their needs for rehabilitation are met.

It has been suggested that people's expectations of the health care services should be examined [77-78]. However, it has also been argued that expectations, even though associated with satisfaction, explain very little of the satisfaction reported [80, 198]. Ware describes how ratings reflect personal preferences, the realities of the care received as well as the patient's expectations [108] and thus does not identify expectations as something that needs to be assessed separately. In Strasser's model, expectations are partly included in the notion of the importance of differences between individuals such as experience of previous use of health care services [107]. Although, information as to expectations regarding care after a stroke might have contributed with relevant knowledge in this thesis, it has, in line with Ware's argument, to be considered as embedded in the ratings.

Even if the possibility to generalize results from one population and one health care service or health care system is limited, such results may still offer valuable suggestions as to how aspects of the care could be improved [78]. It might consequently be possible for stroke care and health care settings to acknowledge aspects of the suggestions resulting from the present thesis's findings

5.4 METHODOLOGICAL DISCUSSION

5.4.1 The sample

5.4.1.1 The LAS 1

All patients diagnosed with stroke were eligible for inclusion in the LAS. Consequently, the data originate from people who may have needs for and use health care services not only because of the current stroke but also due to disabilities from previous stroke or from other health conditions. To that extent, the participants in the LAS may represent the population of people who have had a stroke, which is considered a major strength.

According to statistics from the National Patient Register (NPR), 1231 patients received care for stroke at Karolinska University hospital at Huddinge and Solna during the time for the recruitment to LAS. However, stroke is considered to be somewhat over diagnosed in the NPR [3]. Reasons given as to why individuals had not been asked to participate were e.g. that the patient had been discharged before the question was brought up, or ethical considerations such as that the patient's condition was getting worse, or that the patient was unconscious. The PT and OT did not work at weekends and a number of patients may not have been included as a result.

It is reasonable to believe that people with very mild stroke are under-represented due to shortness of stay. This also applies to people with very severe stroke owing to unconsciousness and ethical considerations. An under-representation of people with very mild stroke may have increased the proportion of people with unmet needs for rehabilitation. Due to the fact that the focus in this thesis is on people who had been discharged home, people with the most severe stroke may not have fulfilled that criteria and this consequently may not have notably affected the results.

One strength, with regard to the two samples in paper I, was the use of the same inclusion and exclusion criteria and also that both samples were recruited from the same health care district, ensuring a similar socio-demographic situation. Some differences between the samples at baseline were however present: the difference in level of education might be explained by the general increase in the level of education in society over the period between the recruitments of the samples [199], while the difference in age probably explains the greater number of patients who were still at work at the time for inclusion in the 06/07 group. Because personal characteristics may be different in those who accept to participate in an RCT, the fact that the 93/96 group was the control group in an RCT might potentially have influenced the sample. The current inclusion criteria, which exclude patients with a shorter LOS SU than five days, place limits on the validity of the findings. Further, the sample size in this study is limited, which makes it difficult to detect differences that are small but meaningful and of clinical and economic importance.

When felt problems and met and unmet needs for rehabilitation and dissatisfaction with care were examined (paper I, II, III and additional analyses/results), people with proxy answers were excluded; this is considered a strength since the purpose was to apply the perspective of the people who have suffered a stroke and not the perspective of significant others. People who had received support from a significant other were, however, included in order to mirror the judgments of people with problems related to communication as well. Proxy answers about satisfaction with care are considered to differ considerably from patients' ratings [84]. This is also in congruence with how, according to Strasser's model, ratings of satisfaction are generated within the patient. It is possible that people with more pronounced communication problems have been excluded from the samples and that they might have contributed with different felt problems. This might also have affected the findings about met and unmet needs for rehabilitation and dissatisfaction with care due to other needs and preferences.

In paper II and III, the participants lost to follow-up tended to have more severe stroke. As the sample may not be quite representative for people with the most severe stroke who were living at home one year after a stroke, this suggests that some caution should be exercised in the interpretation of the findings.

5.4.2 Design and procedure

Major strengths in this thesis are the early recruitment of participants to LAS 1, within the first week after arrival at the stroke unit, and furthermore the prospective, longitudinal design of the study which was utilized in paper II, III and IV and in additional analyses/results.

5.4.2.1 The data-collections

The baseline assessment in the LAS 1was carried out by the PTs or OTs who worked at the stroke units and the subsequent data-collection was carried out by the same PT/OT or another PT/OT who was engaged for collecting data. During this period of time, there was a considerable turnover among the PTs and OTs and altogether 19 persons were involved in collecting the data. A number of participants consequently did not see the same OT or PT for each data-collection, which may have affected the number of participants who chose not to continue their participation in the study (n=75, 21%). The presence of a health professional might have influenced the answers, but since cognitive impairment is common after stroke, it was nonetheless considered superior to a postal questionnaire. In addition to explaining the questions when necessary, reliable information about whether the questions were answered by the person with stroke, or a proxy, was provided. No actual test of inter-rater or test-retest reliability was performed but all the data, with the exception of MMSE and participants' current health condition and impairments, is self-reported and not based on observations or tests. The use of self-reported data is considered a strength since the data thus reflects the participants' perception of their functioning in everyday life. Nonetheless the use of self-reported data also brings with it a risk that disabilities are underreported due to lack of awareness after stroke [200].

In order to identify the felt problems that were most likely to be crucial in daily life, the follow-up started with the open question. It was assumed that this would bring out problems that were of concern and that had been on the patient’s mind. Otherwise the subsequent data-collection might influence the choice of problems presented by the patient. On the other hand, a possible limitation is that, before a relationship between the participant and the data-collector has been established, the participant might be less likely to share problems of a more sensitive nature. Furthermore, the method used, of writing down the answers, might have led to loss of details or to slightly altered answers.

5.4.2.2 The instruments

The BI was used as a measure of stroke severity in all papers. The use of the BI as a measure of stroke severity was due to the fact that a substantial amount of the NIHSS-ratings, that was carried out by the staff at the stroke unit as a part of the routine care, was incomplete. In paper I, the SSS was however used as a measure of stroke severity in the 93/96-group. The use of the same stroke severity scales in both samples would have been preferable, but this was not possible due to changes in clinical practice.

The KI cannot detect improvements among people who are independent in P-ADL and I-ADL. Findings in the comparison between the 93/96-group and the 06/07-group regarding recovery in ADL suggested that there were no changes between three months (the 06/07-group) or six months (the 93/96-group) and twelve months after stroke. This finding might partly be due to a ceiling effect of the instrument and/or to the fact that changes in dependence in single items were not considered, only general dependence/independence in P-ADL and I-ADL. The comparison between felt and assessed problems also suggests that the KI has little ability to identify problems. There might consequently have been changes that are important to the people with stroke in P-ADL and I-ADL that were not identified by the KI.

The BI was used to assess capacity in ADL and the results also represented assessed problems. A ceiling effect has been reported [11, 201] and also a discrepancy between self-reported scores in the BI compared to performance based [202]. Findings about the poor concurrence between felt and assessed problems show that the BI has limited capacity to identify problems after stroke. However the use of BI in this thesis was limited to descriptions of the samples and severity of stroke.

The use of SIS 3.0 is thus considered a major strength of this thesis. The SIS 3.0 was developed from the perspective of, and with input from people with stroke and their caregivers. It aims at detecting not only the physical consequences of stroke but also such aspects as communication, emotion, memory and thought processes as well as participation [11]. The scale has demonstrated reliability, validity and is sensitive to changes up to six months after stroke, even though a potential floor effect in the domain hand function and ceiling effect in the communication domain has been suggested [11, 129]. The scale is considered to measure outcomes that are desired and valued by people who have had a stroke [158] which also is confirmed in paper I.

The SOC-scale was collected only at the follow-up at 12 months after stroke. In theory, the SOC is stable after the ten first years of adult life [136] and this has been confirmed in empirical studies [140, 203]. One study carried out in a general population does, however, suggest a decrease in SOC-score especially among those within the lowest quartile in the course of a 5-year period [204]. Based on an assumption about stability in SOC over time, the SOC score was also used, at three months, to predict unmet needs for rehabilitation and dissatisfaction with care at twelve months. In the multivariate regression analyses, a weak SOC both predicted and was associated with dissatisfaction with care. The association between weak SOC and satisfaction with care at twelve months after stroke may thus be more robust than the prediction.

One weakness in this thesis is the lack of an instrument to assess depression. Depression is a common problem among people who have suffered a stroke [205] and studies have suggested an association between depression and other phenomena examined and discussed here such as fatigue [13-14], unmet needs [75] and satisfaction with care [87, 91]. The SIS-domain emotion may indicate problems within this area, but the use of an instrument that assesses depression would have increased the validity of the findings.

The NSQ has previously been used in studies of people with neurological diseases [131-135, 206]. One of the questionnaire's strengths is that it is based on a taxonomy, Ware's, grounded on empirical studies [108]. Ware's taxonomy has been used as a base for many classifications of patient satisfaction [207]. When examining met and unmet needs for rehabilitation and dissatisfaction with care two statements from the questionnaire were used as outcome variables. In order to clarify what the answers represented and strengthen the validity of the findings, comments left by the participants in the questionnaire were examined and cognitive interviews regarding these statements were carried out. The answers regarding the statement about if *enough rehabilitation has been received* indicate that most people seem to have experienced their rehabilitation as relevant but, in some cases, insufficient. Only a few persons referred to the parts of the body affected or to activities they wished to improve their ability in such as writing or memory training. Instead, many answers related to the access to a service, such as physiotherapy. One interpretation is that wishes for more rehabilitation do not need to be related to a specific ability that the person wants to improve, but might also be related to e.g. a general hope for further improvement. Regarding *satisfaction with care*, most people referred to the stroke unit and in-patient rehabilitation even though one referred to primary care and two to services from the municipality. The general answers reflect the general question and suggest that no conclusion that relates to a specific service can be drawn.

5.4.2.3 Analyses

A major strength in this thesis is the variety of analyses applied; both quantitative, qualitative and mixed analyses have been carried out. Non-parametrical methods were used for comparison regarding LOS, and, due to the small sample size, even for ratio data. A GEE was used to control for differences between the samples. A larger sample would have allowed for adjustments of further variables, which might have affected the result.

Mixed methods were used for the comparison between felt and assessed problems. In mixed-methods research, both qualitative and quantitative data is collected and used in analyses. Quantitative and qualitative methods have different underlying paradigms and, due to that, some researchers have considered mixed methods to be impossible [208]. Other researchers, on the other hand, believe that mixed methods can potentially answer questions that cannot be answered by other methods. Studies where mixed methods are applied may also provide the most comprehensive picture [208-209]. The way mixed methods is applied in this thesis provides the richness of the qualitative data but also offers unique insights into which problems in daily life after stroke that established assessment tools mirror.

Multivariate logistic regression analyses were performed regarding met and unmet needs for rehabilitation and dissatisfaction with care. Logistic regression analysis is used when the outcome variable is categorical. It must be taken into consideration when the findings are interpreted that 17 participants in the analysis of unmet needs for rehabilitation and dissatisfaction with care (paper II) did not have a SOC score and were thus not included in logistic regression analyses in models containing SOC.

This study's analysis of met needs for rehabilitation is a first attempt to explore how different aspects of the provision of rehabilitation contribute to meeting needs for rehabilitation one year after stroke. This raises several methodological considerations. Bearing in mind that the provision of rehabilitation services is complex, the results should be interpreted with care. The structure of factors influencing met needs applied in this paper is necessarily a simplification, and possible interactions between the independent variables need further exploration. A stay at the acute stroke unit that exceeded the median of the group (7 days) was considered as in-patient rehabilitation. The rehabilitation offered there might not correspond to the rehabilitation offered at a dedicated rehabilitation unit, but the presence of a multidisciplinary team, which is one of the core components of a stroke unit, was considered as a guarantee that rehabilitation was provided. In this study however, the treatment level i.e. specific interventions, was not taken into consideration. Since the treatment level i.e. specific treatments, was not considered, the cut-off for what was considered a contact (≥1 visit) was chosen. Even though one visit might not be considered as a treatment/intervention, this choice was based on the assumption that one visit can draw the professionals' attention to rehabilitation needs. Moreover, it was not known whether the disability underlying the contacts with rehabilitation professionals was stroke-related or related to other health conditions. Stroke severity is considered in the analysis, which is considered a strength. At the same time, the limited sample size in each group restricts the number of variables that could be entered into the models and also limits the validity of the findings.

5.4.3 The concepts

5.4.3.1 Needs for rehabilitation

Health care services are classified as environmental factors in the ICF and are as such a part of the physical, social and attitudinal background of individuals. Environmental factors can be a facilitator and improve a person's functioning or reduce disability, but environmental factors can also be barriers that limit functioning or increase the disability [97]. Moreover, the absence of an environmental factor is also considered a barrier and the unmet needs for rehabilitation reported by the participants in this study would, according to the ICF, be considered as barriers from the participants' perspective. However, when the ICF is applied, it is important to clarify whether the perspective is that of the people with a health condition or that of the health professionals'. The ICF has been criticized since it does not include a person's will [98-100] or patients' own choice [100], both of which are highly relevant in relation to needs. A need is not necessarily something that arises as a consequence of disability. This has been shown in studies in which people with disabilities were asked if they wanted rehabilitation. Lilja et al [210] suggested that some people did not want rehabilitation even though OTs had recognized obvious needs. Those who declined rehabilitation were more disabled with regard to mobility, personal hygiene, dressing, cleaning and washing compared to those who accepted rehabilitation. The OTs considered rehabilitation to be a potential facilitator that would improve the capacity or performance of the patients who declined, but it was turned down due to a lack of will. Those who accepted rehabilitation had specific rehabilitation goals, hoped for certain outcomes and wanted greater independence in I-ADL in particular. The fact that people who are not interested in rehabilitation may have poorer ability in ADL compared to those interested has also been reported by de Pedro-Cuesta et al [141]. The need for rehabilitation is thus to a large extent dependent on peoples' will power, choices and goals, whereas the health care services above all may consider if there is an intervention the patient possibly can benefit from [103, 104]. As suggested by Bradshaw, this line of thought supports the relevance of the two perspectives on needs: felt and normative needs. It also emphasizes to the importance of clarifying the perspective applied when needs are reported or discussed.

5.4.3.2 Patient satisfaction

Patient satisfaction was used as an outcome measure both, in accordance with Ware's taxonomy with regard to different dimensions of the care, but also as a single global judgment. The use of a single global judgment has been criticized because it is too general and does not provide any useable information and the concept is multidimensional [79, 81, 211]. But it has also been suggested that summary constructs are of value because patients form both specific and summary judgments [107]. Patients who report a high level of global satisfaction may at the same time report negative experiences related to specific aspects of health care services [81, 212]. This implies both that single negative experiences do not necessarily make for dissatisfaction, and that all negative experiences are not equally important, and that global estimates may be too positive [82]. Those participants in this study who reported satisfaction with the care might consequently have also had negative experiences of single aspects of the care. One way of interpreting this is that those who were dissatisfied have had extensive and/or several negative experiences of the health care services received, and that their judgments thus urge for improvement.

5.4.4 Ethical considerations

All the studies in this thesis were approved by the Regional Ethical Review Board. The participants and/or the participants' significant others received written and verbal information about the study before they agreed to participate. All the participants/significant others consented to participate in writing. The participants/significant others were also given information that they, at any point in time, could withdraw their participation from the study.

This project raises some ethical issues. The follow-ups may have made the participants more aware of their disabilities after stroke, which might have been experienced as discouraging. The questions about needs and satisfaction with care received may also have made participants start to question the care they had received, and led them to wonder if they would have been less disabled if better care had been given. Some questions are of a more sensitive nature and some people might feel uncomfortable about answering questions about e.g. continence. The fact that the follow-ups were carried out by different people meant that some participants had to share sensitive information with more than one person.

On some occasions when there were obvious needs for health care services, the participants either received help to get an appointment with a relevant health care professional or were informed about how to contact the relevant health care professional.

Many people however expressed gratitude and appreciation that someone asked about their situation.

6 CONCLUSIONS

6.1 CLINICAL IMPLICATIONS

It seems possible to reduce the number of days a patient spends in the stroke unit after mild/moderate stroke and instead let them spend days in a rehabilitation unit while achieving similar patient satisfaction and faster recovery in ADL. This knowledge is important when the aim is to achieve an optimal utilization of health-care resources that will enable a larger proportion of the patients with stroke to be cared for in stroke units.

Rehabilitation services, for people with moderate and severe stroke, should offer continuity in rehabilitation and access to physiotherapy during the first year after stroke. If rehabilitation is ended within the first three months after stroke, re-assessment could be offered during the 2nd and the 3rd-4th quarters in the course of the first year after stroke. Such continuity may meet needs for rehabilitation that arise during the first year after stroke – a time when individuals gradually try to resume previously important activities and adapt to a new situation in life. Continuity in rehabilitation may also have the potential to meet needs such as more information and psychological support.

People with poor strength, poor hand function and poor self-rated recovery should have their needs for rehabilitation carefully assessed and attended to. The fact that the felt problems to a considerable extent relate directly, or indirectly, to hand function indicates how valuable hand function is in daily life: this further endorses how important it is to pay attention to the needs among people with poor hand function. If rehabilitation is provided over a longer period, as suggested above, individuals with poor hand function and poor recovery may also be more likely to recognize that they have reached saturation point with regard to rehabilitation. Even if complete recovery is not achieved, they might then be more likely to perceive that met needs for rehabilitation are met. These people might also be in need of interventions that can help to encourage them to have realistic expectations and/or to adapt to a new life-situation

People with a weak SOC may be in need of more support, or other types of support, than what is offered by today’s health care services and scheduled re-assessments by a multidisciplinary team might be one way to provide support. People with a weak SOC have less ability to cope with stressful situations, and since they may get less support from their family or social network, health care services that acknowledge the social situation around the person with stroke too may be of additional value for them.

There is a considerable discrepancy between felt and assessed problems at three months after stroke and if health care services are to be based on problems experienced by the patient, the use of standardized instruments should be complemented by a dialogue. The use of the SIS would identify many of the problems and could serve as a point of departure for a discussion about needs for intervention in care and rehabilitation. However, the SIS should be complemented with questions regarding e.g. fatigue, seeing function, driving and vertigo as well as open questions about problems experienced in everyday life.

The findings about an association between met needs for rehabilitation and physiotherapy in each of the 1st, 2nd and 3rd-4th quarters during the first year after stroke is however statistically weak. Nonetheless, they may serve as a proposal for aspects of rehabilitation services that might be fruitful for further research to examine in relation to met needs for rehabilitation.

6.2 IMPLICATIONS FOR RESEACH

When research is conducted, assessment tools should have the ability to identify problems that are perceived as important to people who have had a stroke. Within its scope, the SIS is well able to identify problems after a stroke. It is, consequently, a good choice when the aim is to evaluate interventions within the SIS’ domains. However, if the impact of stroke in daily life is to be studied, the use of the SIS needs to be complemented with items regarding e.g. fatigue, seeing function and vertigo.

FUTURE RESEACH

Further studies about needs for, use of and satisfaction with health care services after a stroke are needed.

Studies about needs for rehabilitation should explore what needs mean to people who have had a stroke, and if met needs for rehabilitation and health care services are of importance for peoples' ability to adapt to a new life-situation and can facilitate satisfaction with life after stroke. More research is also needed in order to understand what aspects of the provision of rehabilitation contribute to met needs. Such research is especially important for people with moderate and severe stroke who report the lowest frequencies of met needs for rehabilitation. It is also important for those with poor hand function and recovery since they were most likely to report unmet needs. The findings in this study could serve as an indication of aspects that could be further examined in larger samples and/or by qualitative methods. However, other aspects such as treatment level as well as variables related to continuity of care and the health care professionals' expertise could also be explored. Future studies might also explore changes regarding needs for rehabilitation over time.

Studies of satisfaction with health care services could focus on the group studied here that was more likely to report dissatisfaction with care i.e. people with less ability to cope with stressful situations. A qualitative approach might contribute knowledge that could facilitate the development of health care services that are perceived as satisfying by this group as well.

Future studies could also apply a longer-term perspective with regard to both satisfaction with health care services and needs for rehabilitation, and furthermore to changes over time in needs for rehabilitation. There might be a life-long need for recurrent periods of rehabilitation in order to maintain as high a level of functioning as possible. But more knowledge is needed in order to know how such services should best be organized, or what needs can be met outside the health care services. In addition to more research about needs, future studies should also explore what interventions or solutions people who have had a stroke believe could meet their needs.

jag ska ge dig armens styrka tillbaka
fingrarnas finmotorik
jag har redan ställt fram symaskinen åt dig
vi måste tro mamma

ur *Ansiktet i händerna, en berättelse om stroke* av Jane Morén

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