

LONG-TERM EFFECTS OF STROKE SEEN IN YOUNG INDIVIDUALS LIVING IN THE COMMUNITY



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ABSTRACT

Background: Suffering a stroke in the midst of life may lead to half a life-time to be lived with disability. Thus, to meet the needs of long-term measures by health care among young individuals of working age, it is essential that the occurrence of long-term effects of stroke is thoroughly explored and mapped. Although improvements in functioning can be seen over time, the young individuals of working age may still perceive that they are disabled in comparison with their pre-stroke functioning. Therefore, in such an exploration and mapping, focus is needed on self-perceived effects of stroke experienced in an everyday life context.

Aims: To explore self-perceived long-term effects of stroke seen in young individuals of working age, living in the community.

Methods: Among individuals living in the community, differences between younger individuals of working age (<65 years) and older regarding use of health care during the first 12 months after stroke were explored by means of data from the Stockholm County Council. In addition, differences between the same younger and older individuals, regarding self-perceived disability and recovery at 12 months after stroke were explored using the Stroke Impact Scale in structured interviews. Further, to map effects of stroke relevant to individuals of working age, a postal questionnaire (the MYS-questionnaire) was developed and tested by an expert group and the individuals in target. By means of the posted MYS-questionnaire, long-term effects seen up to 6 years after stroke onset were then mapped among young individuals of working age, living in the community in Stockholm. Medical data were retrieved from medical records. Further, the generic EQ-5D questionnaire was used to assess differences in terms of self-rated disability and global health between the same individuals with stroke and a matched general population. In addition, among the individuals with stroke the association between self-rated disability assessed by means of the MYS-questionnaire and the self-rated global health assessed by means of the EQ-5D were explored.

Results: Compared to the older group (n=129), the younger group (n=63) received more care and rehabilitation and at 12 months after stroke the younger group reported less impact on self-perceived disability in terms of strength, mobility, self-care and domestic life. However, ratings of self-perceived global recovery did not differ between the groups. Factors explaining the variance in self-perceived recovery in the younger group were limitations in activities requiring hand function and aspects of self-rated depression. The developed and tested MYS-questionnaire finally consisted of 59

questions and was found to cover relevant aspects of long-term effects of stroke. The posted MYS-questionnaire was responded by 68% (n=158). Of the respondents, 78% had suffered a mild stroke. Irrespective of time elapsed since stroke onset, tiredness was the most commonly reported mental impairment experienced by 44%, and each individual reported a median of 7 concurrent mental impairments. In addition, restrictions in returning to leisure activities and work were reported by 58% and 52% respectively. These factors could not be sufficiently predicted by means of factors known at stroke onset. Further, among the same young individuals with stroke 45% rated a low global health compared to 15% in the matched general population. Among the young individuals with stroke, limitations and restrictions in leisure activities, work, reading as well as low level of physical activity, utilizing personal care provider or personal assistance and tiredness were negatively associated with self-rated global health (R square 0.60).

Conclusion: This thesis presents long-term, multi factorial and substantial effects of stroke seen among young individuals of working age, living in the community. These effects, affected their self-perceived health negatively. A majority had suffered a mild stroke but experienced long-term disability that could not be sufficiently predicted by factors known at stroke onset. Therefore, regular long-term assessments by health care services irrespective of initial stroke severity are warranted in order to improve health states among young individuals with stroke. It is of particular importance to implement regular assessments of mental impairments and future studies are needed to establish evidence-based interventions.

SAMMANFATTNING

Bakgrund: En person som insjuknar i stroke mitt i livet kan komma att leva halva sin livstid med funktionshinder. För att hälso- och sjukvården ska kunna tillmötesgå behovet av insatser hos personer i arbetsför ålder är det därför viktigt att kartlägga effekter av stroke, sett i ett längre perspektiv. Trots att många personers funktionstillstånd förbättras över tid kan yngre personer i arbetsför ålder uppleva att de fortfarande är funktionshindrade i jämförelse med sin tidigare funktionsnivå. Därför är det också viktigt att undersöka och kartlägga effekter av stroke som personen upplever i sin egen vardag.

Syfte: Att undersöka och kartlägga hemmaboende yngre personer i arbetsför ålder gällande deras upplevda långtidseffekter av stroke.

Metod: Skillnader mellan yngre personer i arbetsför ålder (<65 år) och äldre gällande deras förbrukning av vård och rehabilitering under första året efter insjuknandet i stroke undersöktes hos personer som vårdats på Karolinska Universitetssjukhuset i Stockholm och bodde hemma 1 år efter insjuknandet. Information om resursförbrukning hämtades från Stockholms läns landsting. Vid ett hembesök hos dessa personer undersöktes också de yngres och äldres upplevda funktionshinder 1 år efter insjuknandet. Detta gjordes med hjälp av ett frågeformulär (Stroke Impact Scale). För att kunna kartlägga långtidseffekter av stroke som ansågs viktiga för just yngre personer i arbetsför ålder, så utvecklades en enkät (KYS) som testades av en expertgrupp och personer med stroke i arbetsför ålder. KYS-enkäten skickade sedan ut per post till hemmaboende personer i arbetsför ålder och som vårdats för stroke på Södersjukhuset för stroke upp till 6 år tidigare. Vid detta tillfälle undersöktes även personernas upplevda hälsa med hjälp av enkäten EQ-5D. EQ-5D används också för att utvärdera hälsa i normalbefolkningen och därför kunde skattningarna av hälsa jämföras med en matchad grupp ur normalbefolkningen. Slutligen undersöktes om det fanns upplevda effekter av stroke som kunde förklara hur de yngre personerna skattade sin hälsa. Medicinsk information hämtades från datajournalerna på Södersjukhuset.

Resultat: Jämförelsen mellan 63 yngre personer i arbetsför ålder och 129 äldre, visade att de yngre förbrukat mer vård och rehabilitering under första året efter insjuknandet. Vid 12 månader var det ingen skillnad mellan grupperna i hur mycket de tyckte att de hade återhämtat sig efter insjuknandet men olika faktorer påverkade hur de skattade sin återhämtning. Upplevd nedstämdhet och nedsatt förmåga att utföra vardagliga aktiviteter som kräver handfunktion, kunde till viss del förklara hur mycket de yngre tyckte att de hade återhämtat sig efter insjuknandet. Bland de äldre var det istället

förmågan att vara delaktig i meningsfulla vardagliga aktiviteter som hade störst betydelse.

Den utvecklade och testade KYS-enkäten ansågs kunna bedöma långtidseffekter av stroke hos yngre personer i arbetsför ålder. KYS-enkäten skickades sedan ut per post och besvarades av 158 personer (68%). Baserat på den kliniska undersökningen på SÖS vid insjuknandet bedömdes 78% ha drabbats av en lindrig stroke. Resultaten från KYS-enkäten visade att andelen personer med upplevda funktionsnedsättningar inte verkade påverkas av hur lång tid som passerat sedan insjuknandet. Bland de 11 psykiska funktioner som undersöktes var upplevd trötthet vanligast (44%) följt av bl.a. upplevda svårigheter med koncentration, minne och att ta initiativ i vardagliga aktiviteter. I genomsnitt upplevde varje person svårigheter med 7 olika psykiska funktioner. Dessutom hade 58 % inte kunnat återgå till sina tidigare fritidsaktiviteter och bland dem som arbetade innan insjuknandet hade 52 % inte återgått i arbete. Analyser visade att det var svårt att förutse vilka av dessa yngre personer som skulle uppleva funktionshinder en längre tid efter insjuknandet. Det visade sig också att 45 % av de yngre personerna med stroke skattade en sämre hälsa. Orsaker till att de yngre personerna med stroke skattade en sämre hälsa var upplevda begränsningar gällande fritid, arbete, läsning, en låg fysisk aktivitetsnivå och att vara beroende av hjälp i vardagliga aktiviteter och trötthet.

Slutsats: Avhandlingen visar på betydande långtidseffekter av stroke som yngre personer i arbetsför ålder upplever i sin vardag. Dessa långtidseffekter var svåra att förutse och påverkade deras hälsa negativt. Det är därför av stor vikt att dessa personer, uppmärksammas av hälso- och sjukvården åren efter insjuknandet. Särskilt viktigt är att uppmärksamma psykiska funktionsnedsättningar oavsett strokeinsjuknandets svårighetsgrad, men mer forskning behövs för att säkerställa vilken typ av insatser som ger bäst effekt.

LIST OF PUBLICATIONS

- I. Palmcrantz S, Widén Holmqvist L, Sommerfeld DK, Tistad M, Ytterberg C, von Koch L. Differences between younger and older individuals in their use of care and rehabilitation but not in self-perceived global recovery 1 year after stroke. *J Neurol Sci.* 2012 Jul 28. [Epub ahead of print]
- II. Palmcrantz SM, Holmqvist LW, Sommerfeld DK. Development, validity and reliability of a postal questionnaire assessing health states relevant to young persons with stroke in Sweden. *Disabil Rehabil.* 2011;33(13-14):1179-85
- III. Palmcrantz S, Holmqvist LW, Sommerfeld DK. Long-term health states relevant to young persons with stroke living in the community in southern Stockholm - a study of self-rated disability and predicting factors. *Disabil Rehabil.* 2012;34(10):817-23
- IV. Palmcrantz S, Widén Holmqvist L, Sommerfeld DK. Young individuals with stroke: a study of long-term disability associated with self-rated global health. (Submitted)

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LIST OF ABBREVIATIONS

ADL	Activities of daily living
BI	Barthel Index
EQ VAS	Perceived global health rated on a vertical, visual analogue scale
ICC	Intraclass correlation coefficient
ICF	International Classification of Functioning, Disability and Health
IQR	Interquartile range
MMSE	Mini Mental State Examination
MoCa	Montreal Cognitive Assessment
MYS	Mapping Young individuals with Stroke
ROC-curve	Receiver Operating Characteristic curve
SIS	Stroke Impact Scale
SOC	Sense of coherence
SSS	Scandinavian Stroke Scale
TIA	Transient ischemic attack
VAS	Visual analogue scale

1 BACKGROUND

1.1 INTRODUCTION

When I started working as a physiotherapist in primary health care at the turn of the century I soon discovered that individuals of working age (< 65 years) who had suffered a stroke, and especially those who had suffered a mild stroke, were rarely referred to primary health care from the acute wards at the hospitals. The young individuals (< 65 years) that I did meet, were in need of long-term multi professional rehabilitation measures aiming for their life to take a normal course. However, this was something we could not sufficiently provide for at the time. Over the years I have had the opportunity to participate in the development of a stroke team serving the young individuals with stroke living in the catchment area of South Central and South Eastern Stockholm, Sweden. Since 2006 the stroke team includes an occupational therapist, a physiotherapist, a speech and language therapist and a welfare officer who whenever needed collaborate with the general practitioner, district nurses, community based home help services, personal assistance, social services, social insurance agency, and the public employment service. Based on clinical experiences, my colleagues and I find that all individuals with stroke, even those with mild stroke, are in need of follow-ups by primary health care services. Further we find that the rehabilitation planning needs to be strictly individual and that the measures and time needed to fulfil the goals are individual. The site and magnitude of the stroke may be identical for two individuals, but the long-term effects of the stroke may be diverse as the effects are influenced by e.g. contextual factors in terms of personal and environmental factors. Thus contextual factors need to be taken in to consideration in the rehabilitation process. Further, suffering a stroke in the midst of life may lead to half a lifetime to be lived with disability. Consequently, health care and community services need to be armed to meet the needs for long-term measures when needed.

My position as a physiotherapist in primary health care has given me the privilege to follow young individuals with stroke over a longer period of time, sometimes for several years. This thesis is dedicated to the young individuals with stroke who gave me the opportunity to learn about the effects of stroke and thereby encouraged me to scientifically explore whether my local clinical experience also applied to a larger population of young individuals with stroke, living in the community.

I wish to thank all the individuals who participated in the studies for sharing their knowledge of aspects of stroke that are perceived as important in a long-term perspective.

“Ett liv som räddas ska också levas”

(Hjärnskadeförbundet Hjärnkraft, www.hjarnkraft.nu)

1.2 STROKE

The World Health Organisation defines stroke as rapidly clinical signs of focal (or global) disturbances of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin (1, 2).

The most commonly reported cause of stroke is infarction found in approximately 85% of all stroke sufferers (3). The infarction occurs due to an occlusion of an artery or arterioli (a small artery vessel) causing focal cerebral ischemia (local lack of oxygen in the affected part of the brain). Haemorrhage is the other cause of stroke and occurs due to a rupture of an artery or an arteriole, aneurysm (an abnormal artery) or a subarachnoid haemorrhages (a bleeding in the subarachnoid space surrounding the brain) causing damage of the focal tissue and a rise of the intracranial pressure (2, 4).

The clinical signs of stroke are related to the affected arterial area of the brain. The signs are usually one-sided motor and/or sensory impairments that may limit and restrict mobility and the ability to perform activities of daily living (ADL) independently. Impairments related to memory and perceptual functions are common even among individuals with mild stroke. Additional mental impairments in terms of e.g. impaired apprehension of the effects of the stroke and impaired executive function (e.g. limitation in taking the initiative to plan and perform a task) may be limiting and restricting in ADL and in completing the rehabilitation after stroke. Aphasia may occur and may negatively affect the ability to speak and understand speech, as well as the ability to read and produce written messages. (2, 5)

The major risk factors for stroke to be targeted by health care are arterial hypertension, smoking, dyslipidemia, cardiac arrhythmia, diabetes mellitus and physical inactivity (5). Among younger individuals, in addition to the major risk-factors for stroke, a dissection of arteria carotis occurring spontaneously or as a consequence of a light trauma to the neck is the single most common cause of infarction (6). Among younger women migraine, oral contraceptives and pregnancy have been found to be risk factors (7). Nevertheless, in about 35% of the cases the causes remain unclear, a so-called cryptogenic stroke (8, 9). Beside smoking and physical inactivity, other life style factors such as an unhealthy diet, excessive alcohol consumption (7) and psychosocial stress (10) are reported risk factors for stroke. A lower socioeconomic status has also

been found to be associated with stroke incidence. The mechanisms explaining this association are unclear but the prevalence of risk factors for stroke among individuals from different socioeconomic backgrounds may be a contributing factor (11).

In Sweden, approximately 30 000 individuals suffer a first or a recurrent stroke every year and in Stockholm, the capital, the number is approximately 3700. A minority of 20% are < 65 years (12). The 1 year mortality is approximately 30% but a decrease in mortality has been reported in the last decades (13). As the number of individuals living with stroke are estimated to increase there is also an increasing need to study the effects of stroke on disability and how the negative effects can be prevented (13).

In the total stroke population in Sweden, there are no sex differences in stroke incidence but men tend to suffer a stroke earlier in life (approximately 4 years) (14). After stroke older women are more likely to be dependent in ADL than men (14). However, an older age rather than sex has been found to be negatively associated with both initial stroke severity and the effect of stroke in terms of disability (15). Other factors, such as co-morbidities (co-occurrence of diagnoses) and pre-stroke disability that are more commonly reported among older individuals, may also affect stroke outcome (16, 17). Age-related differences in stroke recovery have been reported in terms of greater gains and higher levels of functioning found among younger individuals (18). However, taken together, co-morbidities and pre-stroke functioning and stroke severity may have a larger impact on stroke recovery in terms of dependence in ADL (17-19). Thus, in evaluations of stroke outcome, age, pre-stroke functioning and co-morbidities need to be considered.

1.3 RECOVERY AFTER STROKE

Great gains in recovery are often seen in the first months after stroke and although it is generally considered that a more stable phase of recovery occurs at 6 months, improvements in functioning can be seen long term (20). Three stages of recovery are commonly described. The first phase is the acute phase where the individual may be frightened and shocked by the sudden incidence and might be in need of intense medical assessments, care and mobilization. The second, sub-acute phase, occurs when the individual is assessed and found to be medically stable and focus is shifted to the rehabilitation of lost functioning. It is hard to specify a point in time when the third and long-term phase after stroke occurs as the effects of stroke are diverse in their

manifestations and severity and the perceived impact of the stroke is influenced by both personal and environmental factors. Thus, the long-term effects of stroke will most likely be manifested when the individual has returned to his/her context and has entered a more stable phase of recovery (21).

Recovery has been defined as involving not only a relief from symptoms but also personal and social accomplishments in areas that are defined as important to the individual (22). Notably, although a person may improve in functioning over time (23, 24) they may still perceive that they are disabled compared to, e.g. their pre-stroke condition (25, 26). Thus, we may assume that global ratings of self-perceived recovery after stroke involve a vast number of factors including not merely recovery from impaired body functions, but also aspects of activity and participation defined as important by the individual. Personal factors such as an individual's sense of coherence i.e. a way of regarding your life as comprehensible, manageable and meaningful may also be involved (27). Further, self-perceived recovery may potentially vary according to age (28-31) but we still lack studies exploring differences after stroke between older and younger individuals of working age, in self-perceived recovery.

1.4 EFFECTS OF STROKE IN A LONG-TERM PERSPECTIVE

Individuals of working age (<65 years) are a minority in the total stroke population and may deviate from the majority in expectations on functioning and health that commensurate with age related goals and expectations on recovery. Since the turn of the 21st century more stroke related research, international and national, have focused on young individuals of working age. When I compare results from different qualitative studies of individuals with stroke living in the community, younger individuals express more concerns about returning to work; and older individuals express difficulties more related to physical impairments e.g. walking and difficulties in leaving the house, driving a car and using public transport, but retrieving their social role appear to be a mutual concern (28-30). These results imply that there are self-perceived differences between younger and older individuals that need to be explored further.

In clinical assessments of mental functions such as orientation, memory, attention, arithmetic skills and language, the majority of the assessed individuals have been found not to improve during the first 2 months to 2 years after stroke (23). Among young individuals of working age who had suffered a mild stroke, self-perceived restrictions

in work and social participation were found among 70%, 6 months after stroke. Further, clinically assessed depression and impaired working memory has been found to be associated with these restrictions (32). An international review has found the return to work rate to be 19-73% (33). In Sweden, up to 3 years after stroke, 20% have been found to be dependent in ADL but only 20% have been found to return to work (24). Thus, suffering a mild stroke and long-term effects of stroke in terms of mental impairments may influence activity and participation negatively.

In a qualitative interview study (34), young individuals with stroke living in the community report that mental impairments concerning memory, concentration and fatigability, are invisible and hard for others to appreciate. Moreover, these disabilities negatively influence their interaction with others in everyday life. A population-based survey (25) of young individuals < 55 years has shown that despite independence in ADL, 60% report impairments and limitations, in comparison to their pre-stroke condition up to 3 years after stroke onset. These include experienced impaired ability to concentrate and to complete a task, as well as limitations in taking a short walk and moving around in crowded environments (25). These results imply that when assessing long-term effects of stroke focus is needed on mental impairments, activity limitations and participation restrictions.

There is a need to map aspects of self-rated functioning, disability and health among young individuals living in the community. As the official age of retirement in Sweden is 65 years, individuals < 65 years should be in target. Such a mapping would increase the knowledge of long-term effects of stroke perceived as important to the vast majority in this target group.

1.5 HEALTH

Health has been defined as comprising not only physical and mental aspects but also social aspects (35) as well as demands of life that commensurate with contextual factors such as age, culture and personal responsibility (36). Different aspects of poor health can be defined as: 1) a medically defined disease, 2) an illness as perceived by a lay person and 3) sickness disabling a person's functioning in the social environment (37). Thus, health defined as poor includes changes in body function, the perceived effect of these symptoms and their consequences for activity and participation in a social context (38). Using a global rating of health, a recent Swedish study (39) finds

that among individuals with stroke, disability in terms of mental impairments, limitations in mobility and in domestic life explain approximately half of the variance in self-rated health after stroke. Notably, in the total stroke population, a majority of the individuals are ≥ 65 years and as a result, there is a risk that aspects of self-rated health perceived as important to individuals of working age will not be captured.

Consequently, there is a need to explore aspects of health that are important to young individuals with stroke. A Norwegian study (40) found poorer ratings of health among young individuals with stroke compared to the general population. There is thus a need to explore if this applies to young individuals in Sweden.

1.6 INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH

As the effects of stroke are diverse and often found to be multi factorial the International Classification of Functioning, Disability and Health (ICF) (41) can be a useful tool in mapping the effects that the stroke has on the individual in the context where he/she lives. The ICF presents a standardized framework and terminology for health related states and their consequences from a bodily, individual and societal perspective. The ICF consists of two parts, i.e. functioning with the negative term disability and contextual factors which interact. Functioning and disability comprise: 1) body functions, anatomic structures and their impairments; 2) activities and activity limitations; and 3) participation and participation restrictions. Each component consists of various domains (involving e.g. mental functions and mobility) and the term “health state” is used to describe the level of functioning an individual has within a certain domain. These health states are influenced by the contextual components: 1) personal factors and 2) environmental factors (Figure 1). The ICF is used as, e.g. a clinical tool in rehabilitation, outcome evaluations and as a research tool in assessments of outcome as well as contextual factors (41). The ICF can also be a useful tool in mapping functioning and disability associated with health (42). Thus, in the present thesis the ICF is used as a frame to visualize the areas that are being targeted.

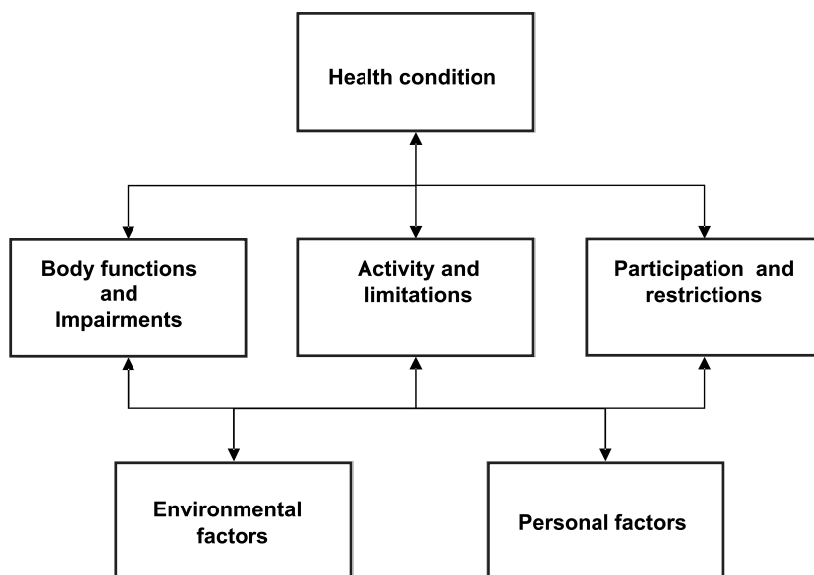


Figure1. The International Classification of Functioning, Disability and Health (ICF) (41)

1.7 STROKE CARE AND REHABILITATION

1.7.1 Stroke care

In Sweden, 86% of all those who suffer a stroke are treated in a stroke unit. A stroke unit can be defined as: “an organized in-hospital facility that entirely (or next to entirely) is devoted to the care of patients with stroke. It is staffed by a multidisciplinary team with special knowledge in stroke care.” (43). A previous retrospective study of medical charts in a hospital in Stockholm has found that among patients who had been admitted to a stroke unit 75% had seen an allied health care professional (occupational therapist, physiotherapist, speech therapists or a welfare officers) during their stay in the stroke-unit (44). However, there are local differences in the organization of the multidisciplinary teams. In personal communication with team members at the large hospitals in Stockholm, I have found that while all patients are assessed by a physician, a nurse, an occupational therapist and a physiotherapist in one stroke unit, in another unit allied health care professionals are only consulted when a need has been identified by the physician or nurse. Furthermore, there are also differences in what and how information is documented in medical records, the type of

routine assessments that are made in the stroke unit before discharge and consequently in the information that can be reported to the next level in the care and rehabilitation trajectory (45). Nevertheless, irrespective of age, individuals who are treated in a stroke unit, have the largest reduction in mortality compared to persons treated in other types of wards. However, younger individuals (<65 years) tend to benefit the most in terms of long-term survival (46). Seen in a national context older individuals are less likely to be treated in a stroke unit compared to younger individuals (14) and the total length of stay in hospital has been found to be predicted by stroke severity and pre- stroke dependency in activity and not by age (47). However, the length of stay in hospital may also reflect local differences in the organization of stroke rehabilitation e.g. a shorter length of stay in the hospital in favor of home based rehabilitation by a stroke team (48). Thus, in evaluations of stroke care and rehabilitation, both in-patient and out-patient care need to be considered.

In Stockholm, Sweden, after the initial stroke-care in hospital and depending on stroke severity, the patient is either discharged home or to a rehabilitation clinic or a nursing home. In addition, individuals <65 years can be referred to work-oriented rehabilitation programs while individuals ≥ 65 years can be referred to geriatric rehabilitation when necessary (49). Furthermore, beside hospital outpatient care and rehabilitation, measures by primary health care can be provided by a home based stroke team or by single professions in the home or in the clinic (49). In Stockholm as well as nationwide approximately 80% of all individuals have returned home 1 year after stroke (12).

1.7.2 Rehabilitation after stroke

Rehabilitation has been described as: “A process of active change by which a person who has become disabled acquires the knowledge and skills needed for optimal physical, psychosocial and social function” (50).

As the effects of stroke are diverse and often found to be multi factorial, multi disciplinary measures are commonly needed. Thus, teamwork is essential to secure that the rehabilitation measures are targeted toward common goals. In a stroke team, each team member contributes on the basis of their specific professional competence to the assessment of the patient’s functioning and disability. When put together, these assessments provide a multi factorial picture of the patient. This is the foundation on which the decisions are made regarding possible health-care interventions that can be

provided based on evidence, clinical experience and health-care finances (51). However, measures should not be taken without a mutual care and rehabilitation planning. All health-care interventions should aim at being patient-centered. If the patient is engaged in the goal setting it enhances their compliance and increases the chances of achieving the goals set up in the rehabilitation planning (21). Further, as evidence-based decisions can be seen as an integration of best evidence with clinical expertise and the patients' values and preferences (52), it is essential that the expectations and wishes that the patient expresses are taken into consideration when goals are formulated in the rehabilitation planning. Possible negative effects of stroke on e.g. mental functions and communication may be factors preventing a patient from participating in the rehabilitation planning. In these cases, knowledge of personal and environmental factors as well as functioning before the stroke can be gained from a significant other. Significant others, personal assistants and home help services are involved in the rehabilitation process and long-term management when needed.

The Swedish ethical principles of equal care, greatest support to those in greatest need and cost effectiveness (53) are the foundation of the priority settings developed by the Swedish National Board of Health and Welfare and presented in the Swedish National guidelines for Stroke Care (54). In Sweden as well as in international research good stroke care is most commonly evaluated by process indicators such as the proportion of patients admitted to a stroke unit as well as indicators of stroke outcome in terms of mortality and dependence in ADL (43, 55-57). According to the Swedish National Board of Health and Welfare stroke care is also evaluated by indicators such as recurrent stroke within the first year, self-rated health, disability and living condition at 3 and 12 months after stroke (58). Although there are differences between younger individuals of working age (<65 years) and older in the provision of stroke care and in expectations of recovery (e.g. in return to work), as a rule, these two age groups are not analyzed separately or compared in evaluations stroke care and rehabilitation.

The continuous work to accomplish equal care for those in greatest need as well as cost effectiveness put high demands on good stroke care. Since age-related differences in the organization of health care exist, there is an evident need for explorations of age-related differences in the distribution of health-care resources not only in the acute phase but long term. However, results from an exploration as such cannot be fully evaluated without knowledge of age-related differences in long-term stroke outcome.

These differences need to be explored not only in terms of dependence in ADL but also in other aspects of recovery and disability that the individual perceives as important.

1.8 RIKS-STROKE, THE SWEDISH STROKE REGISTER

The national quality register for stroke care, Riks-Stroke (59), was started in 1994 on behalf of the Swedish National Board of Health and Welfare. Since 1998 all acute hospitals in Sweden participate. Riks-Stroke evaluates initial stroke care at the hospital, rehabilitation, secondary preventions and measures provided by the county council. Using a questionnaire developed by the board of Riks-Stroke the patients' experiences of measures provided by health care as well as their self-perceived functioning and disability are assessed (58). The clinical data regarding the acute phase at stroke onset, are collected from the hospital. At 3 and 12 months self-reported data are collected by means of a postal questionnaire addressed to the patient. The collected data are used to evaluate the quality of stroke care e.g. compliance with the National Guidelines for Stroke Care (58). In a 1-year follow up (12) performed by Riks-Stroke a cut off at 75 years is chosen to present differences between a younger and older stroke population. The results from the follow up show that individuals < 75 years report less disability and better health but still, 35% experience unmet needs regarding rehabilitation 1 year after stroke. In the older group (≥ 75 years) as many as 50% experience unmet rehabilitation needs of rehabilitation but these older individuals are more satisfied with care. As there are differences between individuals of working age and older in the allocation of rehabilitation measures there is a need for studies that explore the use of care and rehabilitation and perceived long-term effects of stroke among individuals grouped with a cut off set at 65 years (the official retirement age in Sweden).

1.9 ASSESSING SELF-RATED EFFECTS OF STROKE BY MEANS OF A POSTAL QUESTIONNAIRE

One way of performing population based surveys on individuals living in the community is to use a postal questionnaire. However, when assessing self-rated effects of stroke high demands are posed on questionnaires to capture the diversity of effects of stroke. Further, the negative effect of stroke on body functions (2) may be hindering factors that prevent an individual from participating in an assessment.

A base requirement when developing a questionnaire is that experts on the target group are involved in testing the content validity, i.e. that the content in the questionnaire is

sufficient to evaluate what it is intended to evaluate. Furthermore, a representative sample from the target group needs to assess face validity, i.e. that the questionnaire covers relevant areas “on the face of it”. An equally important factor that needs to be tested is the readability, i.e. difficulties and obscurities identified in the group in target with regard to their interpretation of and in filling in the questionnaire. In addition, the questionnaire needs to be tested for reliability, i.e. that the results from an assessment are reproducible under different conditions. A test for reliability in terms of test-retest stability reveals the measurement’s ability not to be influenced by temporary changes. A validated questionnaire enlarges the chance of a result that is more true to answer the research question. The fact that validity is dependent on reliability, in that the higher the reliability the higher the maximum validity, enhances the importance of a reliable questionnaire. (60)

In a postal survey the layout of the questionnaire is particularly important as it is to be filled in independently. By carefully considering the lay-out, problems with readability, e.g. ambiguities and misunderstandings that consequently will decrease the validity of the data collected, can be avoided. Further, not to tire the respondent when filling in the questionnaire, the questionnaire needs to be short but still long enough to capture what it is intended to assess. These factors are particularly important if the respondent is limited in responding to the questionnaire due to e.g. mental impairments following stroke. Some individuals may even need assistance from a significant other when filling in the questionnaires, and a proxy assessment may be needed when the individual with stroke is unable to communicate. Using different methodologies, postal questionnaires have been constructed and used in population-based studies of individuals with stroke. The questions in the postal questionnaires are either formulated by an expert group (61), based on interview studies of individuals with stroke (31) or on interviews with a subgroup of young individuals with stroke (25). Though questionnaires assessing effects of stroke have been constructed and used in population-based studies, we still lacked postal questionnaires tested for content and face validity, readability as well as test-retest stability. A postal questionnaire that could be used for the mapping of young individuals with stroke needed to be developed.

1.10 RATIONALE

Suffering a stroke in the midst of life may lead to half a lifetime to be lived with disability. Thus, to meet the needs for long-term measures by health care there was a need to explore differences between younger individuals of working age and older regarding the use of health care, self-perceived recovery and disability. Further, a mapping of younger individuals of working age was needed with regard to perceived long-term functioning, disability and health. This mapping also enabled an exploration of the ability to predict long-term effects of stroke, aspects of stroke that were associated with health and differences in ratings of health compared to the general population. These studies were needed to gain valuable knowledge that can be used in the organization of health care.

2 AIMS

The overall aim of the thesis was to explore self-perceived long-term effects of stroke seen in young individuals or working age (<65 years), living in the community.

The specific aims were:

I.

to explore:

- differences between younger and older individuals in the use of health care, stroke characteristics, personal factors, dependence in ADL, self-perceived disability and global recovery at 12 months after stroke
- how initial stroke characteristics, personal factors, dependence in ADL and self-perceived disability are associated with self-perceived global recovery in younger and older individuals respectively at 12 months after stroke

II.

to develop and test:

- a postal questionnaire for content and face validity, readability and reliability in terms of test-retest stability, in order to assess effects of stroke relevant to young individuals with stroke

III.

to map:

- long-term functioning and disability among young individuals

to explore:

- whether initial stroke characteristics, personal- and environmental factors can predict self-rated long-term disability

IV.

to explore:

- differences between young individuals with stroke and a matched general population with regard to self-rated global health, functioning and disability
- aspects of long-term functioning and disability associated with self-rated global health in the same young individuals with stroke

3 INDIVIDUALS INCLUDED AND METHODS

3.1 PAPER I

3.1.1 Individuals included

At the Karolinska University Hospital a 1 year prospective longitudinal study (Life After Stroke phase 1) was conducted including individuals diagnosed with stroke according to the ICD-10 classification (62) and who had been admitted to the stroke units from May 2006 to May 2007.

The occupational therapist and physiotherapist working at the stroke units were informed by the nurses regarding patients eligible for inclusion. The physician at the stroke unit was consulted in cases of a severe condition, before approaching the patient or significant other. The occupational therapist or the physiotherapist informed the patient or a significant other about the study and obtained their informed consent.

In total, 349 individuals were included in “Life After Stroke phase 1”. In the study presented in Paper I individuals who had completed the follow-up at 12 months and were living part or full-time in their home at the time of the 12 month follow up were included, which left 192 individuals. In order to address the research questions the study population was divided in two subgroups i.e. a younger (<65 years) and an older (≥65 years) group. To ensure that the individuals in the younger group were of working age during the first year after stroke, the division was based on their age at the 12 month follow up.

3.1.2 Methods

Data was retrieved from the computerized register at the Stockholm County Council regarding use of health care during the first 12 months after stroke, i.e. days in a hospital stroke unit including rehabilitation and other departments, days in daycare rehabilitation and visits to hospital out-patient care and primary health care (allied health care professionals, assistant nurses, nurses and physicians included). Medical data regarding stroke diagnosis, lateralization, diabetes and cardiovascular diagnoses i.e. transient ischemic attack (TIA), previous stroke, ischemic heart disease, peripheral vascular disease, cardiac infarction and hypertension) were retrieved from the medical records. Self-rated data was collected from the patients or proxies in structured interviews by data collectors who were clinically experienced occupational therapists and physiotherapists specially trained for the study. Baseline data were collected in the

hospital regarding: level of education (\leq senior high school or university level), living alone or with a significant other, perceived insufficient or sufficient private financing. Stroke severity at onset was assessed with the Barthel Index (BI) score ranging from 0-100 points (63, 64). Independence in ADL before stroke; and at stroke onset was indicated by ≥ 95 points on the BI. Speech function, based on the speech criteria included in the Scandinavian Stroke Scale (SSS), was assessed by the data collectors during the interview (65). In the present study impaired speech was defined as being present (limited vocabulary or incoherent speech, more than yes/no but no longer sentences, or only yes/no or less, according to the SSS) or not (no aphasia, according to the SSS). At the 12 month follow-up data were collected in the patient's home for: 1) Independence in ADL (BI ≥ 95 points), 2) Sense of coherence (the Sense of Coherence (SOC) Scale (27)), 3) Self-perceived disability and global recovery after stroke (the Stroke Impact Scale (SIS) (66)).

3.1.3 Assessment tools

3.1.3.1 Barthel Index

BI has been used to evaluate the patient's progress during rehabilitation since the 1950s (63). BI assesses independence in 10 tasks and is scored 0-100 points based on the level of assistance needed by the patient (63). The tasks involves: feeding, bathing, grooming, dressing, bowels, bladder, toilet use, transfers (bed to chair and back), mobility (on level surface) and stairs (63, 64). BI is commonly used in clinical practice and stroke trials and independence is commonly reported at ≥ 95 points (64). Notably the BI assesses physical dependence in self-care and in-door mobility and does not assess the patient's independence in e.g. domestic life, communication and social participation. Thus, the BI gives valuable but limited information on stroke- outcome and needs to be accompanied by complementary assessment tools (64, 66). The BI is proposed and used as a standard measure of physical disability in clinical practice and trials (67). Further the BI can be used to assess stroke severity and the cut offs 0-14 for severe, 15-49 for moderate and 50-100 for mild stroke were used for the descriptive presentation of stroke severity in Paper I (68). Using these cut offs, BI has been found to be equivalent to the categorized SSS and Modified Ranking Scale in prediction of death and dependency (68) however a ceiling effect has been found meaning that the BI could not capture the effects of stroke among individuals with a mild stroke (64). The test-retest reliability (stability over time) and inter observer reliability (agreement of scoring made by different observers) have been described as good (67, 69).

3.1.3.2 Sense of coherence scale

Based on the salutogenic theory the SOC scale assesses an individual's way of regarding their life as comprehensible, manageable and meaningful. In the study presented in Paper I the 13-item version of the SOC Scale was used for personal ratings and not by proxy. The statements given in the SOC Scale are responded to on a 7-point scale and the total score ranges from 13-91 where a higher score indicates a higher SOC. The SOC is considered reliable in test-retest among adults when performed within 1.5 years but have been found to increase slightly with age. In terms of validity, a higher SOC has been found to predict a better outcome after illness. (27)

3.1.3.3 Stroke Impact Scale

The SIS assesses the self-perceived disability after stroke through 64 questions grouped in to 8 domains (memory, emotion (changes in mood and ability to control emotions), communication, strength, mobility, hand function (activities requiring hand function), activity in self-care and domestic life, and participation in meaningful activities that give life purpose). The questions are responded to on a 5-point scale. A total score for each domain is calculated using an algorithm with a minimum score of 0 points (maximum disability) and a maximum score of 100 points (no disability). One question regarding the individuals' global perception of their percentage of stroke recovery (abbreviated to self-perceived global recovery, in Paper I) completes the questionnaire. The self-perceived global recovery is rated on a vertical visual analog scale (VAS) ranging from 0 (no recovery) to 100 (maximum recovery). The criterion and construct validity of the SIS 3.0 used in the study presented in Paper I are good and it is reliable in test-retest in studies including individuals with mild to severe stroke and proxy assessments (66, 70). The SIS has been found to detect age related differences in a stroke population (71).

3.2 PAPER II

3.2.1 Individuals included

A professional expert group was recruited. The expert group consisted of an occupational therapist, a physician, a physiotherapist, a psychologist, a speech and language therapist and a welfare officer. All were working in a stroke team attached to primary health care in the south-central and south-east areas of Stockholm.

Young individuals with stroke (<65 years) were identified in the primary health care in the south-central and south-east of Stockholm. They were identified among individuals who were living in their home in the south-central and south-east of Stockholm and who had received or were currently receiving rehabilitation measures following stroke from occupational and/or physiotherapists linked to the primary health care. Among the eligible individuals a representative sample of individuals with stroke, below 65 years was included in the study presented in Paper II. They were selected with regard to age (median 55 years, interquartile range (IQR) 43-60, range 32-64), years since stroke onset (median 2 years, IQR 1-7, range 0-12), site of stroke, impairments, independence in self-care and domestic life, sex, level of education, co-habitation with a partner and children below the age of 18. Data on age, years since stroke onset and further characteristics of the selected sample were extracted from the medical records at the occupational and physiotherapists' clinic. Those who were unable to communicate verbally and/or understand oral instructions and/or unable to read were not included.

3.2.2 Methods

In the construction of the MYS-questionnaire (Mapping Young individuals with Stroke) aspects of functioning and disability as well as contextual factors were considered in order to map different health-related domains (41) potentially affected by stroke. During this construction, questions were derived from several sources. Questions comprising stroke diagnosis and incidence as well as body functions, activities and participation, personal and environmental factors were gathered from a questionnaire that has been constructed and used by The Swedish National Board of Health and Welfare (61). Additional questions comprising body functions, activities, participation and personal factors, were gathered from a questionnaire constructed by the Swedish National Institute of Public Health and used in a public health survey (72). Finally, questions regarding body functions, activities, participation, personal and environmental factors were formulated based on the literature (73, 74) and clinical practice, and these were constructed to fit the template of the other questions included in the MYS- questionnaire. The alternative answers following the questions regarding impaired body functions were mainly formulated as ratings of occurrence (almost never, sometimes, often, or constantly). Questions regarding activity and participation in self-care and domestic life were formulated to assess the need of assistance when executing tasks. The possible alternatives to questions regarding activity limitations, participation restrictions, environmental and personal factors were formulated as a

choice of yes/no or a number of alternative statements. To increase interpretability, the questions were ordered, altered, fused or split up when needed in order to suit the target group of young individuals with stroke (60).

The MYS-questionnaire was thereby ready to be tested for content validity, readability, face validity and reliability in terms of test-retest stability. This process was performed according to the guide presented by Streiner and Norman (60).

Content validity was assessed by the expert group who analysed and commented on the MYS-questionnaire in order to determine whether it included a sufficient number of questions and covered the research area. Moreover based on their professional knowledge and clinical experiences of the group in target, the group of experts assessed readability and commented on the lay-out and wordings to avoid misunderstandings, missing values or tiring the individual when filling in the questionnaire. (60)

The young individuals with stroke filled in and commented on the questions, one at a time, with the researcher present. The term face-validity was used to define the patient-centred method of involving younger individuals with stroke in the construction and testing of the questionnaire. In the role of experts regarding their individual perception of functioning and disability after stroke they were asked to comment on whether they found that the questionnaire “on the face of it” covered relevant aspects of stroke. Moreover aspects of readability were assessed by their comments on ambiguities and other problems related to filling in the questionnaire but also by problems observed by the interviewer during the time the young individual with stroke filled in the questionnaire. These interviews were performed in a so-called ‘sampling to redundancy’ process, where one person after another filled in and commented on the questions in the interview situation until no new problems were revealed. To test the MYS-questionnaire for test-retest stability after the final revision, the questionnaire was administered by post and re-administered within 14 days or was completed twice (14 days apart) in a telephone interview. Twenty young individuals with stroke were included in the test-retest. (60)

3.3 PAPER III AND IV

3.3.1 Individuals included

Young individuals with stroke were identified through the hospital medical records at the Södersjukhuset (Stockholm South General Hospital). All young individuals aged 18-64 were eligible for the study if they: 1) had been admitted to Södersjukhuset when suffering a first or recurrent stroke during the period 2000-2006, 2) after giving their informed consent, had been registered in the Swedish Stroke Register: a Swedish quality register for stroke (Riks-Stroke) (59) which was a way of securing that the individual had been admitted due to stroke, 3) were registered residents in the south of Stockholm; and 4) were living at home at the time of the survey. A time span of 6 years (2000-2006) was chosen as the time that has elapsed since stroke onset may be of relevance for the experience of problems. Of the 238 eligible individuals, 6 were excluded for the following reasons: living in an institution though having an official home address (n=3), no official home address (n=1), homeless and could not be reached at the time of the survey (n=2), which left 232 young individuals with stroke to be included in the survey.

3.3.2 Methods Paper III and IV

Within one week before the dispatch of the MYS-questionnaire individuals who were deceased, institutionalized, living in sheltered accommodation, or had moved outside the geographic area between the first identification and the dispatch of the MYS-questionnaire were identified and excluded. This identification was performed through the hospital's patient administrative system.

The MYS-questionnaire was sent by post in January 2007 together with the EQ-5D questionnaire. A letter containing information about the study, the person's rights, the name, address and phone number to the researcher responsible -in case of queries or comments -and a stamped, addressed envelope were included. Individuals who had not returned the questionnaire within 4 weeks were contacted over the telephone and were given the opportunity to fill in the questionnaire by means of a telephone interview. Individuals who could not be reached over the telephone received a new letter as a reminder (60).

Stroke related medical data in terms of stroke diagnosis according to the ICD-10 classification (62), lateralization, time for stroke onset, sex and stroke severity were

obtained from the medical records at Södersjukhuset (Stockholm South General Hospital). Stroke severity assessed with the SSS was classified as being mild, moderate or severe (65, 68). To determine stroke severity in individuals with incomplete SSS scores (n=47), missing data was obtained from the hospital medical records (75).

3.3.3 Additional method Paper IV

Diagnosed risk-factors for stroke (previous stroke, hypertension, hypercholesterolemia, cardiac arrhythmia, diabetes mellitus) were obtained from the medical records at Södersjukhuset (Stockholm South General Hospital).

Comparative normative EQ-5D data were retrieved from an age (range) and geographically matched reference group in the general population (76) that had filled in the questionnaire in a public health survey in 2006. This was done approximately 6 months before the distribution of the EQ-5D questionnaire to the young individuals with stroke.

3.3.4 Assessment tools in Paper III and IV

3.3.4.1 *Scandinavian Stroke Scale*

The SSS includes assessments of body functions (consciousness, eye movement, arm strength, hand strength, leg strength, orientation, speech and facial palsy) and activity (walking). The items are weighted and the sum score can be divided into mild (43-58 points), moderate (26-42 points) and severe (0-25 points) stroke (68) and is used to determine severity, progress and prognosis after stroke (68, 77). To estimate the SSS score retrospectively from medical records has been found to be a valid and reliable way to evaluate stroke severity (75).

3.3.4.2 *MYS-questionnaire*

The MYS-questionnaire is a study specific postal questionnaire consisting of 59 questions comprising self-rated body functions, activities and participation as well as personal and environmental factors. As presented in Paper II, the MYS-questionnaire was found to be valid in terms of content validity, face validity and readability by an expert group and young individuals with stroke. In addition, the MYS-questionnaire was found to be reliable in test-retest stability with the exception of 2 questions and 1 alternative answer which were not included in Paper III or IV.

3.3.5 Additional assessment tool in Paper IV

3.3.5.1 EQ-5D

EQ-5D is a generic questionnaire used to assess health outcome and contains a quantitative measure that assesses perceived global health rated on a vertical, visual analogue scale (EQ VAS) which is calibrated with the anchors “worst imaginable health-state” (0) and “best imaginable health state” (100) (78). Further, the EQ-5D includes 5 self-classifier health-state dimensions (EQ-5D dimensions): mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each EQ-5D dimension is graded by the alternative statements: no problems, some problems or extreme problems (78). The questionnaire has been used in public postal surveys (78, 79). Reasonable concurrent validity has been reported when EQ-5D ratings were compared to ratings made by using other relevant questionnaires in a stroke-population (80), and the EQ-5D is found to be reliable in test-retest (81). The instrument can be used in postal surveys, interviews and by proxy (78, 81, 82).

3.4 STATISTICS

3.4.1 Analyses and limits for interpretation

Table 1. Analyses used in Paper I-IV

Analyses	Paper I	Paper II	Paper III	Paper IV
Differences between groups	Chi-squared test		Chi-squared test	Chi-squared test
	Fisher ‘s exact test		Fisher ‘s exact test	Student’s t-test
	Student’s t-test		Student’s t-test	
	Mann-Whitney U-test			
Test-retest stability		Kappa Weighted kappa ICC *		
Associations between variables	Linear regression		Binary logistic regression	Linear regression

*Intra-class correlation coefficient

Table 2. Limits of interpretation in Paper I-IV

Paper	Analyses	Limits of interpretation
Paper I-IV	Significance level	$p < 0.05$
Paper I and IV	R square	An adjusted R-square explaining the variance by 0-0.25 was considered little to poor, 0.25-0.50 fair, 0.50-0.75 moderate and ≥ 0.75 very good to excellent (83).
Paper II	Kappa	Values < 0.40 indicated low agreement; 0.40-0.75, fair to good agreement; and values > 0.75 indicated very good agreement (84).
Paper II	ICC	Values < 0.40 indicated poor agreement, 0.40-0.60, fair to moderate agreement, 0.60-0.75 good, and values > 0.75 indicated excellent agreement (85).
Paper III	C statistics	A c statistic of 0.7-0.8 indicated an acceptable, 0.8-0.9 an excellent, 0.9-1.0 an outstanding, and 1.0 indicated a perfect level of predictive accuracy of a model (86).
Paper III	Sensitivity and Specificity	High values for both sensitivity (≥ 0.7) and specificity (> 0.6) were considered to accurately predict, both disability and absence of disability (87).

3.4.2 Paper I

In 3 different models, multiple linear regression was used to explore factors associated with self-perceived global recovery. Factors included as independent variables in the models were: 1) stroke related factors, 2) personal factors and 3) self-perceived disability. The dependent variable was self-perceived global recovery.

One additional 4th model was explored. A univariate linear regression analysis was performed with independence in ADL at 12 months as the independent variable and self-perceived global recovery as the dependent variable. All regression analyses were controlled for sex and performed separately in the younger and the older group. A forward stepwise method was used.

3.4.3 Paper II

The test-retest was analysed using the kappa for nominal data and weighted kappa for ordinal data. For questions with continuous data, the ICC was used.

3.4.4 Paper III

The multiple comparisons performed to assess differences in the occurrence of rated disability, year by year, and by sex, were controlled for by using a Bonferroni correction.

Univariate binary logistic regression analysis was used to analyse the associations between the independent variables: stroke characteristics, personal factors, and the environmental factor, i.e. living alone at time of stroke onset, and the dependent variables: mental impairments, pain, impaired swallowing, and activity limitations/participation restrictions. All dependent variables in the univariate binary logistic regression analyses with a p-value <0.1 was included in multiple binary logistic regression models (86). A forward stepwise method was used.

The Receiver Operating Characteristic curve (ROC-curve) was used to assess the overall predictive accuracy of the model. In a logistic model with a high predictive accuracy, the ROC-curve rises quickly. Thus, the area under the curve (c statistic) is large for a model with high overall predictive accuracy. A c statistic (ranging from 0-1) of 0.5 indicates an equal distribution of individuals being correctly or incorrectly classified as, e.g. disabled. The sensitivity and specificity (ranging from 0-1) indicates how accurately an event and a non event, e.g. disability and absence of disability can be predicted in a model.

3.4.5 Paper IV

To determine the number of younger individuals with stroke who rated a low global health a cut off was set by subtracting 1 SD from the mean ratings of global health in the matched general population.

In 4 different models, multiple linear regression analyses were used to explore factors associated with self-rated global health. Factors included as independent variables in the different models were: 1) impaired body functions, 2) limitations and restrictions in activity and participation, 3) personal factors and 4) environmental factors.

A 5th multiple linear regression analysis was performed by entering all significant independent variables in analyses 1-4 in a final model. In 1 additional model, 1 multiple linear regression analysis was performed using the stroke related medical factors known at stroke onset as independent variables. In each of the analyses the dependent variable was self-rated global health. All analyses were controlled for sex and time since stroke onset and a forward stepwise method were used.

4 RESULTS

4.1 PAPER I

4.1.1 Characteristics of the included younger and older individuals with stroke

Included were 192 individuals. The median age was 71 years (IQR 62-80, range 24-93) at stroke onset. Sixty three individuals were <65 years (the younger group) and 129 were ≥65 years (the older group) at 12 months after stroke. The median age at 12 months was 55 years (IQR 45-63, range 25-64) in the younger group and 78 years (IQR 72-83, range 65-94) in the older group. The proportion of women was 38% in the younger and 43% in the older group. The distribution according to stroke severity at onset in the younger group was 81% with mild, 13% with moderate and 6% with severe stroke. In the older group the distribution was 73%, 19% and 8% respectively. was 30% in the younger and 29% in the older group. Between groups, no significant difference in initial stroke severity or impaired speech function was seen. In the older group, the occurrence of cardiovascular diagnoses and/or diabetes, dependence in ADL pre stroke and at 12 months after stroke were significantly more common.

4.1.2 Differences between the younger and older individuals with stroke in their use of health care

Differences between the younger and older individuals with stroke in the use of health care during the first 12 months after stroke are presented in Table 3. The number of days in the stroke unit care and the rehabilitation unit care as well as visits to hospital out-patient care was higher in the younger group but there was no significant difference between the groups in the number of visits to primary health care.

4.1.3 Differences between the younger and older individuals with stroke in self-perceived disability

Self-perceived disability and recovery at 12 months after stroke in the younger and older group assessed with the SIS are presented in Table 4. The younger group perceived significantly less disability than the older group in terms of strength, self-care and domestic life, as well as mobility at 12 months after stroke. No significant difference in self-perceived global recovery was found between the groups and full self-perceived global recovery was rated by 5% in the younger and 12% in the older group at 12 months.

Table 3. The use of health care 0-12 months after stroke (Reprint from publication I, presented in List of publications)

Use of health care 0-12 months after stroke	Younger group (<65 years) n=63		Older group (>65 years) n=129		number of persons	p	number of days/visits
	n (%)	median (IQR) range	n (%)	median (IQR) range			
Total n of days in hospital	63 (100)	28 (10-77) 2-251	129 (100)	16 (8-37) 2-93	NA*		0.006
Stroke unit and rehabilitation, days	63 (100)	28 (7-71) 1-158	129 (100)	14 (7-30) 2-93	NA*		0.004
Other departments, days	26 (41)	6 (2-13) 1-93	41 (32)	5 (3-24) 1-55	0.195		0.628
Day-care rehabilitation, days	23 (37)	33 (12-44) 1-90	1 (1)	18 (0) 18-18	0.000		NA†
Total n of visits in hospital out-patient care and primary health care	63 (100)	32 (17-45) 1-202	129 (100)	27 (13-49) 1-346	NA*		0.541
Hospital out-patient care, visits	62 (98)	7 (3-14) 1-93	115 (89)	4 (2-7) 1-181	0.018		0.001
Care‡, visits	62 (98)	5 (3-11) 1-57	108 (84)	3 (2-5) 1-64	0.001		0.000
Rehabilitation§, visits	28 (44)	3 (1-5) 1-64	38 (29)	1 (1-3) 1-160	0.040		0.016
Primary health care, visits	62 (98)	23 (7-37) 1-188	124 (96)	24 (10-43) 1-327	0.358		0.259
Care , visits	57 (90)	11 (4-22) 1-159	122 (95)	14 (7-28) 1-285	0.289		0.072
Rehabilitation§, visits	37 (59)	17 (6-28) 1-142	80 (62)	11 (2-25) 1-76	0.661		0.714

* n=63 (100%) in the younger and n=129 (100%) in the older group, †n=1 in the older group, ‡Physician, nurse, §Allied health care professionals, || Physician, nurse, assistant nurse

Table 4. Self-perceived disability and recovery at 12 months after stroke in the younger and older group assessed with the SIS (Reprint from publication I, presented in List of publications)

Stroke Impact Scale		Younger group (<65 years) n=63	Older group (>65 years) n=129	p
Self-perceived disability	Domains	median (IQR) range	median (IQR) range	
Self-perceived disability	Strength	84 (63-100) 13-100*	75 (56-88) 13-100†	0.035
	Memory	89 (79-100) 32-100	89 (75-96) 18-100†	0.381
	Emotion	83 (67-94) 14-100*	83 (64-94) 22-100‡	0.843
	Communication	96 (86-100) 32-100	93 (82-100) 21-100†	0.171
	Self-care and Domestic life	95 (83-100) 10-100	83 (65-96) 0-100§	0.000
	Mobility	94 (78-100) 6-100	86 (66-97) 0-100§	0.001
	Hand function	95 (65-100) 0-100	80 (50-100) 0-100§	0.061
	Participation	86 (54-97) 8-100	75 (61-97) 11-100§	0.672
	VAS-scale	80 (60-90) 21-100	70 (50-90) 0-100#	0.305
	Self-perceived global recovery			

*n=62, †n=127, ‡n=125, §n=126, ||n=60, #n=124

4.1.4 Factors associated with self-perceived global recovery in younger and older individuals with stroke

Among the stroke related factors initial stroke severity alone, explained the variance in self-perceived global recovery by 19% in the younger and 13% in the older group. Among the personal factors SOC alone explained the variance in self-perceived global recovery by 12% of the younger and 8% of the older group. Dependence in ADL at 12 months explained the variance in self-perceived global recovery by 20% of the younger and 6% of the older group. Among the SIS domains hand function and emotions in the younger group were associated with self-perceived global recovery and explained the variance by 39% (of which 32% was explained by hand function). Participation (including restriction in retrieving social roles and social activities), communication and hand function in the older group were associated with self-perceived global recovery and explained the variance by 42% (of which 33% was explained by participation).

4.2 PAPER II

4.2.1 Characteristics of the included young individuals with stroke

Of the selected sample of young individuals with stroke included in the test for validity in terms of readability and face validity (n=15) the median age was 55 years (IQR 43-60, range 32-64). Eight were women. A median of 2 years (IQR 1-7, range 0-12) had passed since stroke onset. Of the young individuals with stroke included in the test of reliability in terms of stability (n=20) the median age was 60 years (IQR 57-62, range 43-64). Nine were women. A median of 1 year (IQR 0-2, range 0-13) had passed since stroke onset. Impairments, activity limitations and participation restriction, and environmental factors presented in the selected sample of individuals with stroke is presented in Table 5.

Table 5. Impairments, activity limitations and participation restriction, and environmental factors presented in the selected sample of individuals with stroke.

Characteristics of the selected sample	Phase I Validity n	Phase II Reliability n
Total n	15	20
<u>Impairments</u>		
Primarily impaired muscle power; tone and/or sensory functions	12	18
Primarily impaired movement functions (coordination and balance)	2	1
Primarily impaired memory function	1	1
Impaired language function	4	4
<u>Activity limitations/Participation restrictions</u>		
Dependent in self-care and domestic life	4	6
Dependent in domestic life only	5	9
Independent in self-care and domestic life	6	5
<u>Environmental factors</u>		
Compulsory school/ Upper secondary/ University level education	7/4/4	8/4/8
Co-habiting with partner	5	12
Living with children below 18 years	3	0

4.2.2 Testing of the MYS-questionnaire

The expert group requested additional alternative answers and clarifications in terms of design to increase readability for individuals with mental impairments after stroke. Ambiguities in wording and referrals in conjunction with attendant questions were identified. The representative sample of young individuals with stroke suggested 1 additional question and additional answering alternatives. In all, 15 individuals were required to assess face validity and readability in the ‘sampling to redundancy’ process. The MYS-questionnaire was revised accordingly. Thereafter, the young individuals considered that the MYS-questionnaire addressed relevant domains in their lives after stroke and the expert group found that the MYS-questionnaire covered all relevant domains.

The origin of the questions and alterations made during the validation process are presented in Table 6.

Overall the test-retest agreement was overall fair to very good. All young individuals with stroke reported that they filled in the MYS-questionnaire twice in the same manner i.e. independently, with assistance or by proxy (kappa 1.0). Two questions and 1 answering alternative showed poor agreement: question 7, 21 and 1 answering alternative in question 9 (“I train on my own”) (kappa <0.40). These questions were not analysed in Paper III or IV.

The final questionnaire is presented in the Appendix.

Table 6. Presentation of the origin of the questions and alterations made during the validation process. The questions are presented in direct translation from Swedish to English.

Questions number 1-34 in the MYS-questionnaire	Origin	Alterations
1. When did you suffer a stroke?	#	
2. What kind of stroke?	#	+
3. Have you suffered a stroke earlier or later?	#	+
4. Do you see a physician for regular check-ups due to your stroke?	□	+
5. Where do you see a physician?	□	+
6. What is your primary reason for not being in contact with a physician about your stroke?	□	
X. Do you have any unanswered questions about stroke? (excluded in the validation process)	#	+
7. Has a plan been instituted for your ongoing rehabilitation/training?	□	
8. Do you receive rehabilitation/training today?	□	+
9. From whom do you receive rehabilitation/training?	□	+
10. How do you rate your current health state?	□	
11. Do you receive assistance with eating and drinking?	□	+
12. Do you experience difficulties when swallowing?	#	
13. Do you receive assistance when using the toilet?	□	+
14 a) How do you handle your movements indoors?	□	+
14 b) How do you handle your movements outdoors? (Divided into two parts during validation)		
15. Do you receive assistance with dressing and undressing?	□	+
16. Do you receive assistance with your everyday personal care?	□	+
17. Do you receive assistance with house cleaning?	□	+
18. Do you receive assistance with shopping for groceries?	□	+
19. Do you receive assistance with cooking?	□	
20. Do you receive assistance dealing with your private finances?	#	+
21. Are your everyday needs met?	□	+
22. Who meets your needs of support/help?	□	+
23. Are you presently dependent on support/help from your next of kin/significant others?	□	+
24. Do you feel tired?	□	
25. Do you feel sad?	□	
26. Do you feel anxiety?	#	+
27. How is your sleep?	#	+
28. How is your appetite?	#	
29. Do you feel pain?	□	
30. Do you find it hard to concentrate?	□	
31. Do you experience difficulties in taking the initiative in everyday life situations and activities?		+
32. Do you easily burst into tears in everyday life situations?	□	
33. Do you feel stressed?		+
34. Do you get annoyed/angry easily? (fused from 2 questions to 1)	□	+

Questions number 35-59 in the MYS-questionnaire	Origin	Alterations
35. Do you experience impaired memory?	#	+
36. Do you experience speech difficulties?	□	+
37. Do you experience reading difficulties?	□	+
38. Do you experience writing difficulties?	□	+
39. Do you experience counting difficulties?		
40. Can you maintain the personal interests you had before stroke?	#	
41. How much time, in an ordinary week, do you devote to moderately strenuous physical activities that raise your body temperature?	*	
42. Is there someone in particular that you feel gives you true support?	□	+
43. Can you use public transport?	□	+
44. Do you use mobility services?	□	+
45. Do you drive?	□	+
46. Who do you live with?	*	+
47. What was your vocation before stroke? (developed from the following question)	*	+
48. What is your current vocation?	*	+
49. What is your highest level of education?	*	
50. Do you suffer from any of the following diseases? (developed from the following question)	#	+
51. Do you take medication for any of the following diseases? (4 questions fused to 1 question with the questions as answer alternatives)	□	+
52. How tall are you?	*	
53. How much do you weigh?	*	
54. Do you smoke daily?	□	
55. Are you a male or a female?	#	
56. What year were you born?	□	
57. Do you participate in a research study where you receive treatment or training?	#	
58. Who replied to this questionnaire?	□	
59. Finally! Is there anything I have forgotten to mention and that you find is of particular importance to add? Or, is there something that you think I need to know more about? Please tell me in your own words.	□	

#Questions based on literature and clinical experience presented as they were formulated after validation

□ Questions gathered from The Board of Health and Welfare presented as they were formulated after the validation

*Questions gathered from The Swedish National Institute of Public Health presented as they were formulated after the validation

+Questions added, removed or altered in the validation process

4.3 PAPER III AND IV

4.3.1 Characteristics of the respondents

The MYS -questionnaire was filled in and returned by 158 individuals (68%) and the EQ-5D by 150 young individuals with stroke (65%). According to data from the medical records linked to Riks-Stroke at Södersjukhuset, no significant differences between respondents and non-respondents were seen in regard to age, sex and years passed since stroke onset. The proportion of respondents who had suffered a stroke in 2000-2006 ranged from 11-20% a year. The median age of the respondents was 59 years (IQR 54-62; range 32-64). The proportion of women was 34%. A median of 3 years (IQR 1-6, range 0-6 years) had passes since stroke onset. The distribution in terms of stroke severity was 78% with mild, 13% with moderate and 9% with severe stroke. No significant differences according to sex, was found in the proportion of individuals that rated impairments and activity limitations/participation restrictions. Nor was a significant increase or decrease over time seen in the proportion of individuals that rated impairments and reported activity limitations/participation restrictions. Consequently the young individuals with stroke were analysed as a group irrespective of sex and time passed since stroke onset.

4.4 PAPER III

4.4.1 Mental impairments and pain in young individual with stroke

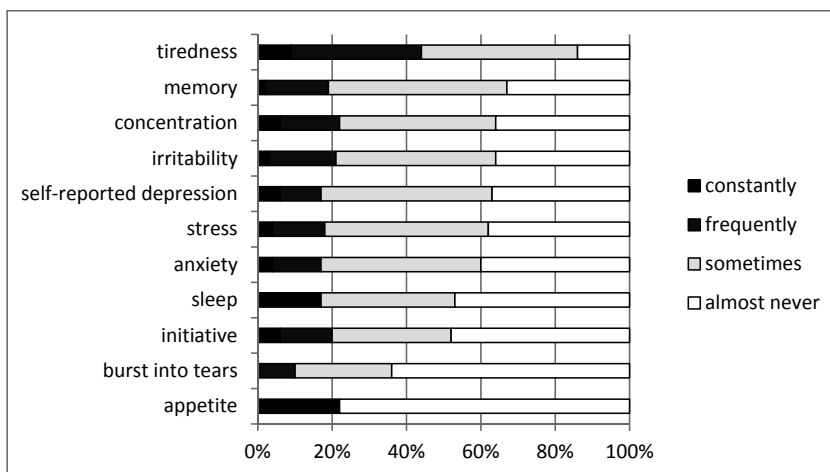
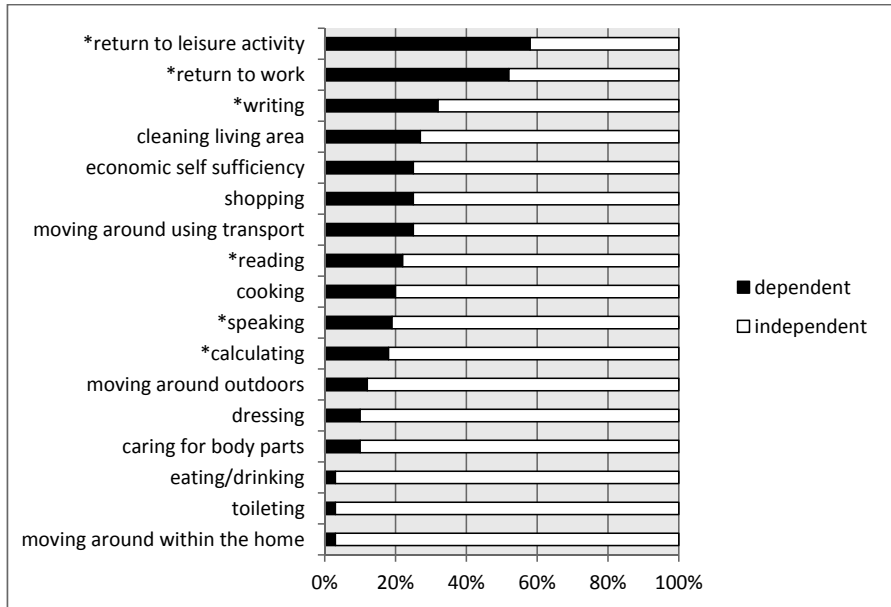


Figure 2. Percentage of young individuals with stroke (n=158) rating their mental functions as impaired constantly, frequently, sometimes and almost never presented in descending order (Reprint from publication III, presented in the List of publications)

Of the young individuals, 68% experienced ≥ 1 mental impairment (often or constantly). A median of 7 (IQR 4-9) concurrent mental impairments (experienced sometimes, frequently or constantly) per person was found. Pain experienced often or constantly was reported by 19%.

4.4.2 Activity limitations and participation restrictions in young individuals with stroke



*Dark bar indicates percentage of individuals limited and restricted

Figure 3. Percentage of young individuals with stroke (n=158) who reported dependence and limitations and restrictions in the assessed activities presented in descending order. (Reprint from publication III, presented in the List of publications)

Of the young individuals, 36% reported dependence in ≥ 1 of the included domains. Fifty-eight percent had not been able to return to their previous leisure activities and, of the 79% who were working before stroke, 52% had not returned to work after stroke.

4.4.3 Predictors of self-rated long-term disability in young individuals with stroke

The predictive accuracy of the multiple regression analyses was acceptable (c statistic ≥ 0.70) for the following 3 models: 1) a moderate/severe and left hemispheric stroke predicted limitations/restrictions in writing and speaking, 2) a moderate/severe stroke predicted limitations/restrictions in mobility, domestic life and economic transactions, and 3) a moderate/severe stroke, a low level of education and living alone at stroke onset predicted limitations/restrictions in returning to work. The predictive accuracy of the models was not acceptable (c statistic < 0.70) for anxiety and ratings of ≥ 7 concurrent impairments; and limitations/restrictions in calculating and ability to return to leisure activities. In the 3 models with an acceptable predictive accuracy (c statistic ≥ 0.7) sensitivity ranged from 0.28 to 0.59 and specificity from 0.70 to 0.92.

4.5 PAPER IV

4.5.1 Differences between young individuals with stroke and a matched general population in regard to self-rated disability and global health

Normative EQ-5D data was retrieved from 2661 geographically and age (range) matched individuals in the general population (median 46 years, inter quartile range 38-55 and 54% women). The young individuals with stroke rated significantly lower global health (mean 63, SD 24) than the matched general population (mean 79, SD 18) ($p < 0.000$). Forty-five percent ($n=67$) of the young individuals with stroke as opposed to 15% ($n=392$) in the general population rated low global health. The proportion of individuals that rated disability according to the EQ-5D self-classifier dimensions is presented in Table 7. When differences between groups were explored significantly more individuals with stroke rated disability according to the EQ-5D dimensions: mobility, self-care, usual activities and anxiety/depression. No significant difference between groups was found in the EQ-5D dimension regarding pain/discomfort.

Table 7. The proportion of individual that rated disability according to the EQ-5D self-classifier dimensions

Dimension	Young individuals with stroke %	Matched general population %
Mobility	40	9
Self-care	17	2
Usual activities	28	10
Pain/discomfort	52	44
Anxiety/depression	53	36

4.5.2 Factors associated with self-rated global health in young individuals with stroke

Sex and time since stroke onset were not associated with self-rated global health in any of the 5 models explored in the linear regression analyses. In the final model, health-states from the MYS-questionnaire explained 60% of the variance in self-rated global health. Self-rated functioning and disability that were associated with self-rated global health are presented in Table 8.

Table 8. Results of the 5 linear multiple regression analyses exploring self-rated functioning and disability (assessed with the MYS-questionnaire) that were associated with self-rated global health (EQ VAS) among the younger individuals with stroke. The independent variables which were the main contributors to explain the variance in self-rated global recovery are presented first and thereafter in descending order for each analysis.

	B*	95% CI†		p	Adjusted R square
1. Impairments					
Tiredness	-12.3	-19.6	-5.0	0.001	
Initiative	-11.5	-20.4	-2.7	0.011	
Depression	-12.2	-21.5	-2.9	0.010	
Pain	-10.2	-19.1	-1.3	0.026	0.32
2. Activity limitations and Participation restrictions					
Leisure activities	-15.6	-21.9	-9.3	0.000	
Work	-11.3	-17.5	-5.1	0.000	
Reading	-14.0	-21.6	-6.4	0.000	
Cleaning	-11.0	-18.1	-3.9	0.003	0.50
3. Personal factors					
Low physical activity	-21.2	-29.6	-12.9	0.000	0.15
4. Environmental factors					
Dependence on significant other	-18.2	-25.6	-10.7	0.000	
Personal assistance ‡	-20.2	-30.1	-10.3	0.000	0.30
5. Final model§					
Leisure activities	-14.3	-20.5	-8.2	0.000	
Work	-11.7	-17.5	-6.0	0.000	
Reading	-10.2	-17.6	-2.7	0.008	
Low physical activity	-10.8	-16.8	-4.9	0.000	
Personal assistance‡	-10.8	-18.8	-2.9	0.008	
Tiredness	-7.6	-13.6	-1.6	0.013	0.60

*Regression coefficient, †Confidence Interval, ‡ Utilizing personal care provider or personal assistance, §Including all significant independent variables in models 1-4

In the multiple linear regression analysis including stroke related medical factors known at stroke onset, only stroke severity was associated with self-rated global health (B -19.254, CI 95% -28.553 to -9.956, $p < 0.000$, Adjusted R square 0.10) rated 3 months to 6 years after stroke onset.

4.6 UNPUBLISHED DATA REGARDING INTERVENTIONS BY HEALTH CARE

Data from the study presented in Paper III and IV show that: 47% did not see a physician for follow ups, 36% of these individuals reported that they had not been summoned or did not know where to turn to and 22% expressed a need of, but did not receive training/rehabilitation.

5 DISCUSSION

5.1 MAIN FINDINGS

Among individuals living at home 12 months after stroke, the occurrence of comorbid conditions and pre-stroke dependence were more common among the older individuals compared to the younger. Furthermore, a larger impact on perceived disability in terms of strength, mobility, self-care and domestic life was found among the older. In the course of the first 12 months after stroke the younger individuals received more care and rehabilitation than the older individuals but nonetheless, at 12 months, no difference in self-perceived global recovery was found. Contributing factors to explain the variance in self-perceived global recovery were the SIS domains: hand function and emotion among the younger individuals, and participation, communication and hand function among the older individuals. These factors explained the variance but only fairly, thus additional factors than those assessed in the SIS appear to be involved. (Paper I).

A study specific questionnaire (the MYS-questionnaire) was developed and tested (Paper II). The MYS-questionnaire aimed to map aspects of body function, activity and participation, contextual factors and health that were relevant to young individuals with stroke. The MYS-questionnaire finally consisted of 59 questions and was found to be valid by an expert group and young individuals with stroke and stable in test-retest with the exception of 2 questions and one answering alternative.

By means of the MYS-questionnaire and the EQ-5D questionnaire incorporating body function, activity and participation, contextual factors and health, the long-term effects of stroke was explored in a population-based sample of young individuals living in the community at 3 months to 6 years after stroke. The response rate to the MYS-questionnaire and the EQ-5D questionnaire was 68% and 65% respectively (Paper III and IV). A majority in this population based sample of young individuals were initially diagnosed with a mild stroke (78%). However, irrespective of sex and the time that had elapsed since stroke onset, 68% experienced long-term mental impairments either often or constantly. In addition, 36% reported dependence in activity and participation, 58% had not been able to return to their previous leisure activities and 52% had not returned to work after their stroke.

By means of initial stroke characteristics and personal or environmental factors known at stroke onset, mental impairments could not be predicted long term among the young individuals. Long-term limitations and restrictions in return to work, economic transaction, domestic life, mobility, speech and writing were predicted, but the results were weak. Thus, these results indicate that although the long-term effects of stroke on functioning and disability were substantial among the young individuals, these effects could not be sufficiently predicted in the acute stage after stroke onset. (Paper III).

In the same population based sample of young individuals with stroke 45% rated low global health as opposed to 15% in the matched general population. Furthermore, compared to the matched general population, a higher proportion of the young individuals with stroke rated problems in mobility, self-care, usual activities and anxiety/depression. Among the young individuals with stroke, irrespective of sex and the time elapsed since stroke onset, limitations and restrictions in leisure activities, work, reading as well as low physical activity, utilizing personal care provider or personal assistance and tiredness were negatively associated with self-rated global health. (Paper IV).

Given these results, the long-term effects of stroke seen in young individuals living in the community in Stockholm appear to be substantial, multi factorial and long-standing.

5.2 DIFFERENCES BETWEEN YOUNGER AND OLDER INDIVIDUALS LIVING IN THE COMMUNITY AFTER STROKE

5.2.1 Use of health care

As younger individuals are often expected to return to a higher level of functioning in the process of recovery, they may have been prioritized in the organization of care and rehabilitation measures by the health-care services (46, 88). This possibly explains the greater use of care and rehabilitation to be found in the younger group presented in Paper I. It is plausible then that the disparity in the distribution of health care between the younger and older group is a sign of an attention to individual health care needs and not an indication of structural inequalities.

A potential explanation for the disparity in days that has been discussed, is that younger individuals more often are in need of extensive assessments after their first stroke event in order to reveal the cause of the stroke incidence (89). In Paper I, in accordance with

previous studies (17, 90), risk factors for stroke in terms of cardiovascular diagnoses and/or diabetes at stroke onset were less common among the young individuals. Further, the higher occurrence cryptogenic strokes found among younger individuals (8) indicates that more extensive assessments are needed among the younger individuals. The latter may also explain the larger number of visits to hospital out-patient care in the younger group, presented in Paper I. Persons with a mild to moderate stroke and with limitations in ADL and mobility have been found to benefit from rehabilitation measures in a home setting; thus home based measures by primary health care may be a suitable intervention (48, 91). The home setting however, may not offer an environment that is sufficiently demanding for persons who are independent in ADL but still in need of rehabilitation measures e.g. to return to work. Interventions in the primary health care clinic may not be sufficient either as they most commonly involve interventions by single professions and not by a joint stroke-team (49). This might be a reason why the younger individuals in Paper I received more day-care rehabilitation in a specialized clinic (only 1 person in the older group received day-care rehabilitation).

In Sweden, there are geographical differences in the organization of stroke care after discharge from hospital. A national survey of Stroke Care in Sweden from 2011 has identified geographical inequalities in access to stroke care (92). One reason may be that a sparse number of inhabitants spread over a vast rural district make it difficult to provide stroke care and rehabilitation in accordance with the national guidelines. Nevertheless, the experienced needs of rehabilitation and stroke outcome rated nationally appear to correspond to ratings made by inhabitants in the Stockholm County. Swedish data from 2008-2009 show that on a national level, at 12 months, 42% of the individuals with stroke experience unmet needs of rehabilitation, 18% are dependent in dressing and toileting, and 15% report self-perceived depression (often or constantly). The corresponding ratings in Stockholm county are 41%, 17% and 14% respectively (92). Thus, although there are geographical differences it appears that the findings in this thesis may be applicable on a national level.

Studies in Europe and in the USA (90, 93-95) show contradictive results regarding equality in the distribution of measures to younger and older individuals. These different findings may be explained by differences in health care systems, differences in study methods and in the time elapsed since stroke onset. They may also reflect the need for more extensive evaluations in order to determine whether the differences in

the distribution of health care are a matter of structural inequalities or a sign of attention to individual health care needs. However, to fully evaluate structural equalities in the distribution of stroke care, focus is needed not only on the amount of care and clinically assessed stroke outcome but also on the content of the interventions given and the patient's self-perceived disability, recovery and health.

5.2.2 Self-perceived disability and global recovery

Among both younger and older individuals in Paper I, stroke characteristics, independence in ADL at 12 months and SOC explained self-perceived global recovery, but only to a poor extent. Instead, among both younger and older individuals, the largest impact on self-perceived global recovery was found in the SIS domains that assess self-perceived disability. The results showed that the domain hand function was a major factor in explaining self-perceived global recovery in the younger group (32%) together with the domain emotion. However, the domain hand function, contributed only to a small degree in explaining self-perceived global recovery in the older group. These results complement previously presented results in a study population ranging from 22-88 years where 12% of the variance in self-perceived recovery using the SIS VAS scale was explained by the ability to use the arm in everyday tasks (96). Notably, in contrast to this general ability to use the hand in everyday tasks, the SIS domain regarding hand function used in Paper I incorporates the use of the hand in defined activities such as carrying heavy objects, turning a door knob, opening a jar, tying a shoe lace and picking up a dime. Thus, the domain deals with the actual use of the hand in specified activities. As good recovery has been defined as incorporating the ability to use the arm in desired activities (97), other specified, more up to date, activities involving fine hand use e.g. using a computer or a smart-phone, may have explained the variance further in both groups. We may also assume that a need to perform activities requiring more demanding bilateral and/or high speed fine-hand use may be found in a work related context. Thus, differences in perceived activity limitation as such may be dependent on whether an individual is planning to, or has returned to work.

In the younger group, the SIS domain participation did not explain the variance in self-perceived global recovery at 12 months (Paper I). However, in the young study population in Paper III, restrictions in participation in terms of work and return to leisure activities were commonly reported, irrespective of the time that had elapsed

since stroke onset. One explanation for this discrepancy may be that the whole domain in the SIS regarding participation was assessed. The domain participation includes questions regarding work, social activities, quiet recreation (crafts, reading), active recreation (sports, outings, travel), role as family member and/or friend, participation in spiritual or religious activities, ability to control your life as you wish and ability to help others. An analysis that includes the separate questions regarding work and recreation may give a different result. Thus, how return to work and recreation is associated with global recovery need to be explored further.

Nevertheless, in the older group, limitations and restrictions in the SIS domain participation was the major factor associated with lower ratings in self-perceived global recovery together with limitations and restrictions in the SIS domains communication and hand function. Notably, a larger proportion in the older group was dependent in ADL compared to the younger group. These results are supported by a qualitative study where older individuals have reported difficulties related to physical impairments that in turn lead to difficulties in leaving the house and retrieving their former social role (29). In the present study the proportion of persons with impaired speech function at onset was similar in both groups, but only in the older group was difficulty in communicating a factor associated with self-perceived recovery at 12 months. We might believe that the younger individuals had made a better recovery with regard to their impaired speech function. However, no significant difference in self-perceived ability to communicate (according to the SIS domain) was seen between the groups at 12 months. Nevertheless, older people, with aphasia in particular, have reported limitations in the activities of everyday life and in participation in social activities (98, 99). Thus, as the result in Paper I points out, limited ability to communicate in combination with limitations in mobility and hand activity (assessed in the SIS domain hand function) appear to be involved in the participation restrictions associated with recovery in the older group.

These results complements the results previously presented by Duncan et al who have found that the domains in the SIS regarding physical function (including the domain hand function) and ADL (fused into 1 domain), emotion and participation explain the variance in self-perceived global recovery at 6 months in a stroke population (66). However, in these analyses, age-related differences were not explored. The explanatory levels reached an acceptable but only fair level in both Paper I and in the study by

Duncan (66). Together, these results indicate that other factors than those assessed in the SIS may be of relevance to the individual long term after stroke.

Thus we may conclude that there are differences between younger and older individuals that need to be considered in the distribution, content of and evaluations of stroke care.

5.3 MYS-QUESTIONNAIRE

5.3.1 Validity, readability and test-retest stability

Of mental functions, only memory and emotion are assessed in the SIS. However, the results from the validation of the MYS-questionnaire showed that additional aspects of mental impairments need to be assessed. This stresses the need to use questionnaires that are sufficiently validated on the target group and where the group itself has been involved in the validation process. This assumption is supported by a recent study that reveals a poor concurrence between disability frequently described by the patient and disability assessed with commonly used measures such as the BI and the SIS. Fatigue was most commonly reported, but not captured in the BI or the SIS (100). Nor were e.g. reported pain and reported limitations in writing and reading.

As a result of the validation of the MYS-questionnaire where young individuals with stroke took part, the MYS-questionnaire focuses on mental impairments with only 2 questions regarding physical impairments (swallowing and pain) and a majority of the questions dealing with activity limitations and participation restrictions.

Although we may assume that impaired neuromusculoskeletal and movement-related function or sensory function such as e.g. impaired strength, tone and impaired touch function persist long term, the effects of stroke that were relevant to the young individuals with stroke were not oriented toward these aspects of effects of stroke. The focus on mental functions, activity and participation, in the MYS-questionnaire, is supported by the fact that assessments of mental impairments in combination with activity limitations and participation restrictions are commonly found in studies using both standardized assessments and in depth interviews long term after stroke (24, 25, 31, 101-104).

Notably, in Paper I, the domain hand function was the main contributing factor to explain the variance in self-perceived recovery in the younger group. However, the items in the SIS domain hand function incorporate the actual use of the hand in specified activities. Thus, the questions, as perceived by the respondent, deals with activity. Specified hand activities are not assessed in the MYS-questionnaire. However, with the exception of mobility and speech, all the questions in the MYS-questionnaire regarding activity, may involve hand activity although this is not explicitly addressed. In addition, it needs to be pointed out that the aim of the MYS-questionnaire was to map functioning and disability among young individuals with stroke and consequently to give an over-all picture of relevant aspects and health-states after stroke in a young stroke population living in the community. In a postal questionnaire, in order not to tire the individual, careful consideration needs to be given to its length before adding more questions. Nevertheless the relevance of hand activities was presented in Paper I and needs to be accounted for in future assessments of long-term effects of stroke seen in young individuals with stroke.

As presented in Table 6 few new questions were added during the validation process of the MYS-questionnaire. This may indicate that the content and number of questions were well targeted from the start. A majority of the questions in the MYS-questionnaire were developed on the basis of pre-existing questionnaires that had been developed and used in surveys. This is a method previously used for further development or construction of new questionnaires (60). However, as the expert group and the individuals with stroke were presented with a ready-made questionnaire, their reflections may have been influenced by the character of the already existing questions. A way of avoiding this potential bias is to start with interviews with a selected sample of the target group and to use these interviews as a base when developing the questionnaire (60). It is plausible that a combination of these 2 methods would be beneficial in the initial stages.

Further, before a questionnaire is validated on the target group we need to consider what we are really aiming to measure and differences between perceived difficulty and perceived dependence need to be discussed. It has been argued that questions regarding perceived problems is an assessment of disability, while dependence in terms of assistance needed in an activity is an assessment of the consequence of disability (105). Nevertheless, a Swedish study (106) finds that these 2 ways of assessing effects of

stroke gave similar results but the importance of including tasks that are relevant to the individuals living in the community was stressed. The questions regarding, e.g. mobility in the MYS-questionnaire assess perceived dependence whereas in the SIS the perceived problems with mobility are assessed. These two ways of posing a question give valuable information and the choice of formulation needs to be based on the aim. The aim of the MYS-questionnaire was not only to map the perceived impairments but also to assess the dependence in activity and participation as well as return to work and leisure activities. Thus the final questionnaire consisted of both self-perceived ratings of impairments and self-assessed dependence in activity.

Several questions were found to be in need of alternations during the validation process including the test of readability. Questions 7 and 21, originally gathered from a questionnaire used by the Swedish National Board of Health, showed low test-retest agreement, as did one alternative answer to question 9 that was suggested during the validation process. These findings stress the importance of testing a questionnaire through several steps of re-modeling and re-testing.

The Swedish MYS-questionnaire, in its present content and lay out, incorporates relevant health-states and can be recommended for use in surveys of young individuals with stroke. Exceptions are questions 7 and 21 and the answering alternative to question 9, all of which need to be tested further before being included in any analysis.

5.4 LONG-TERM EFFECTS OF STROKE SEEN IN YOUNG INDIVIDUALS LIVING IN THE COMMUNITY

5.4.1 Self-perceived mental impairments

In Paper III mental impairments that had been found to be relevant to younger individuals with stroke during the validations process of the MYS-questionnaire were mapped. This was done in order to get a global picture of the occurrence and perceived degree of mental impairments among young individuals living in the community.

Notably, the occurrence of mental impairments was not affected by the time elapsed since stroke onset. These findings are supported by the fact that mental impairments are targeted as major problems for young individuals in research performed at different time points after stroke (32, 34, 103). Paper III adds to this knowledge by presenting

the occurrence and presence of mental impairments among young individuals of working age living in the community.

In Paper I, aspects of self-perceived depression (107) (included in the emotional domain in the SIS) contributed, although only to a small degree, to lower ratings in self-perceived global recovery in the younger group at 12 months. In addition, in Paper III, irrespective of time elapsed since stroke onset, self-reported depression, experienced often or constantly was reported by 17% of the younger individuals. These findings are supported by a Swedish national survey (108), in which 15% of the younger individuals of working age report depression 3 months after stroke, using the same question and cut off. Further, in the same survey, a younger age was found to be associated with self-perceived depression. These percentages may be considered minor, but when the magnitude of perceived problems with anxiety/depression was assessed in Paper IV the results showed that 53% in the younger group experienced moderate to severe problems as opposed to 36% in the matched general population. Thus self-perceived depression is an important aspect of mental impairments following stroke among younger individuals of working age not the least as it has been found to affect the social adjustment, i.e. return to normal life in this age group (32) .

Of the young individuals in Paper III, 44% experienced tiredness often or constantly. Thus, tiredness was the most commonly reported mental impairment irrespective of time elapsed since stroke onset. Tiredness and fatigue after stroke are often used interchangeably and in Swedish, the colloquial word is tiredness in direct translation. We are still lacking a valid definition of post stroke fatigue. Fatigue perceived by individuals with multiple sclerosis has been defined as “a subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual and desired activities” (109). A definition that focuses more on mental aspects of fatigue has been used to describe post stroke fatigue; “a feeling of early exhaustion developing during mental activity, with weariness, lack of energy, and an aversion to effort” (110).

Tiredness expressed as fatigue can be a symptom of depression but even among individuals that do not report depression, post stroke fatigue has been reported by 39%, 2 years after stroke (111). Longitudinal studies have found that fatigue is common and persists during the different phases of recovery after stroke (112, 113). Thus, fatigue

can be described as a common long-term consequence of stroke. Among young individuals fatigue appears to have a negative impact on “normal” life, as post stroke fatigue has been described as overwhelming and uncontrollable and to affect work, family and social life negatively (30).

In Paper III, the most commonly reported mental impairment apart from tiredness was impaired concentration, irritability and memory (experienced often or constantly). These mental impairments have been reported to affect the ability to complete a task in everyday life negatively and lead to dependence (114).

In Paper III, 20% reported impaired ability to initiate and complete a task in everyday situations. This impaired ability may be due to impaired executive function. Different definitions exist, but executive function can be defined as including aspects of motivation, planning, purposive action and performance effectiveness and is said to underlie everyday activity (115). Impaired executive function has been found to be associated with depressive symptoms (116) and to affect the ability to return to work negatively after stroke (117).

In Paper III, the occurrence of single mental impairments (experienced often or constantly) was approximately 20% apart from tiredness that amounted to 44%. Taken together, 68% experienced ≥ 1 mental impairment (often or constantly). In addition, when investigating this co-occurrence further, the young individuals reported a median of 7 concurrent mental impairments (experienced sometimes, often or constantly). This co-occurrence of mental impairments among young individuals with stroke has, to my knowledge, not been reported. It is possible that these concurrent mental impairments when seen from an individual’s perspective may influence their experience of disability and may thereby add to the knowledge of the impact of the mental impairments on the individual. These results imply that a considerable number of young individuals with stroke in the community live with non visual but substantial mental impairments.

In Paper III, mental impairments were not predicted by means of the SSS at stroke onset. Mental impairments are reported as leading to major activity limitations and participation restrictions 1 year after stroke in an interview study of young individuals with near or full recovery according to the standardised assessment tools SSS and Mini

Mental State Exam (MMSE) (34). Thus, the importance of finding ways to identify individuals living with mental impairment is evident.

5.4.2 Pain

In Paper IV, in the pain/discomfort dimension, no difference was found between the young individuals with stroke and the matched general population. This is in accordance with a Norwegian study (40). Furthermore, similar ratings of pain/discomfort (using the same EQ-5D domain) have been reported in a Swedish national survey including young individuals in the general population (79). Notably, in the general population the occurrence of rated pain has only been found to be approximately half of the occurrence of rated pain/discomfort. This result indicates a great difference between rated pain and rated pain/discomfort (118). Thus, future studies need to consider what these ratings of pain/discomfort incorporate as well as how the expression “discomfort” is interpreted by the rater. Nevertheless, in the study population included in Paper III and IV we found that 19% among the young individuals with stroke living in the community reported pain often or constantly irrespective of time elapsed since stroke onset. In accordance with the study findings in the present thesis, a Swedish study shows that the occurrence of post stroke pain is found among approximately 20% initially after stroke onset as well as long term (119). In addition, in a stroke population in Norway, pain in non paretic limbs is reported by 16% and in paretic limbs by 12%, irrespective of time elapsed since stroke onset (120).

In Paper IV, pain contributed to explain the variance in global health in the model including impairments. However, in another stroke population, pain was found to be associated with global health at 3 months after stroke, but not at 12 months (39). Pain after stroke has also been found to be associated with a younger age (120) and to be co-occurring with fatigue and self-reported depression (121). Thus, regardless of being stroke related or not, pain needs to be targeted by health care in the long term.

5.4.3 Self-perceived activity limitations and participation restrictions

In Paper I the older group reported a higher degree of limitations and restrictions in mobility, self-care and domestic life than the younger group and in qualitative research activity limitations and participation restrictions are found to be related to limited mobility and physical performance among older individuals (28, 29). These findings can be interpreted as age-related. Nonetheless, a study (122) including young

individuals with moderate to severe disability after stroke has found that activity limitations and participation restrictions mainly concerned activities involving mobility and physical performance but limitations and restrictions related to work and leisure activities were also reported. These results imply that the crucial factor may not be the biological age as such but rather the level of disability.

If an individual has suffered a moderate to severe stroke the predominant aspects of disability as perceived by the individual, may be limitations and restrictions in mobility and dependence in self-care and domestic life. Among individuals who are independent and perceive limited or no limitations in mobility, self-care and domestic life the predominant aspects of disability may be more related to higher levels of functioning i.e. mental function.

The key issue is: what level of functioning is required in the context where the individual person lives and dwells? Not to forget; the level of functioning that the individual needs to retain in order to be able to return to their “normal” life is related to the perceived distance to the life before stroke (26).

In Paper III and IV a majority had suffered a mild stroke but nevertheless, only a minority had returned to their previous leisure activities and to work. Leisure activities and work were also found to be the most commonly reported activity limitations and participation restrictions in Paper III and have previously been found to be among the most commonly reported aspects of disability in young individuals with stroke (122).

High demands are placed on an individual of working age in terms of mental function. A majority of the work engagements today not only require that you are a well educated and a skilled worker, but also that you are flexible, sociable and capable of working under stress (123, 124). Also, the matter of returning to work after stroke is complex and involves other factors that may need to be considered, such as whether the work is manual or non-manual, the nature of the welfare system and the employment market (125, 126). Personal factors such as flexibility and being realistic have also been identified (127) as well as factors such as the perceived importance of work, external support and the ability to walk (128, 129).

Consistent with the findings in Paper III, studies involving both young and old individuals with stroke find that stroke severity is associated with activity limitations/participations restrictions (68, 77). However, in Paper III, only acceptable levels of predictive accuracy were found in the models that included writing, speaking, mobility, dependence in domestic life, economic transaction and in return to work as outcome variables. Further, low sensitivity and high specificity indicate a tendency for the models to assess absence of disability rather than presence of disability. These results imply that commonly used assessment tools such as the SSS, cannot predict long-term activity limitations and participation restrictions among young individuals where a majority have suffered a mild stroke. Therefore, I argue that, irrespective of initial stroke severity, further assessments are needed at a later stage in recovery.

5.4.4 Self-perceived global health

In Paper IV lower ratings of health among young individuals with stroke compared to a matched general population was found which is in accordance with a previous finding in Norway (40). Further, although 79% of the young individuals in Paper IV had suffered a mild stroke 45% rated a low global health compared to 15% in the general population. These results indicate that among a substantial number of young individuals in the stroke population, the long-term effects of stroke are associated with low ratings of global health.

In Paper IV, notably, none of the diagnosed risk factors for stroke (previous stroke, hypertension, hypercholesterolemia, cardiac arrhythmia and diabetes mellitus) were significantly associated with long-term self-rated global health among the young individuals. In addition, although associated, stroke severity poorly explained the variance in self-rated global health irrespective of the time elapsed since stroke onset. Instead, the main contributing factors that explained the variance in global health were long-term limitations and restrictions in leisure activities, work, reading, low physical activity and utilizing personal care provider or personal assistance as well as tiredness. As long-term effects of stroke relevant to the young individuals appear to be oriented toward mental impairments and activity limitations and participation restrictions we may now also conclude that these factors affect their global health negatively.

5.5 METHODOLOGICAL CONSIDERATIONS

5.5.1 Individuals included

To ensure that the study population was representative to a true stroke population all the individuals in the present thesis were included irrespective of previous stroke occurrence. Due to the focus of the thesis, all the individuals included were living at home at the time of the survey. Yet, the fact that >80% are living at home, 3 months after stroke (130), indicates that the results may be representative to the total stroke population in Sweden at this point in time. However, as a majority in the study populations in this thesis had suffered a mild to moderate stroke, the self-perceived disability and global recovery, as well as the use of health care were perhaps not fully picked up on in individuals with a severe stroke. Although they are not the focus of the present thesis, younger individuals with a severe stroke, who may be living in an institution, is another minority in need of surveying in future studies.

5.5.1.1 Individuals in Paper I

In Paper I only individuals who were treated in a stroke unit were included. This can be seen as a limitation as approximately 60-80% have been reported to be treated in a stroke unit at the Karolinska University Hospital at the time of the survey (131). However, by only including individuals treated in a stroke-unit, the individuals received similar initial access to care and rehabilitation. This fact strengthens the results concerning differences in the use of health care. Another limitation can be that the data collectors may have missed individuals with a mild stroke who did not stay long in the stroke unit. However, these losses were not considered substantial. A strength of the study, presented in Paper I, is the fact that most of the individuals included were actively involved in the structured interviews although individuals in need of proxy assessments were also represented.

5.5.1.2 Individuals in Paper II

The patients that I met in primary health care at the time of the validation of the MYS-questionnaire (Paper II) had been referred to the clinic due to neuromusculoskeletal and movement-related impairments. Still they often reported major disability due to mental impairments that affected their everyday life negatively. This clinical knowledge together with current literature, influenced the initial gathering of questions from existing questionnaires and how we formulated new questions. In Paper II the individuals eligible for the sampling to redundancy process were identified among

individuals who had received or were currently receiving rehabilitation measures following stroke by occupational and/or physiotherapists linked to the primary health care clinic. In the selection of individuals for the validation process, factors including a spread in site of stroke, impairments after stroke, age, sex, years since stroke onset, co-habiting with partner, children below 18 years, level of education, and level of independence in self-care and domestic life were sought. Yet, a limiting factor may be that those who were unable to communicate verbally and/or understand oral instructions were not represented in the selection. Nevertheless, individuals with impaired speech following stroke but who were still able to communicate were included, which is a strength of the study. Another limitation may be the age range of 32-64 years. As there may be age-related life style differences that need to be targeted when the effects of stroke are mapped, comments from individuals younger than 32 years might have increased the validity.

5.5.1.3 *Individuals in Paper III and IV*

The study population in Paper III and IV was a population based sample of young individuals of working age who were living in the community. For inclusion, the turn of the century was chosen as the upper limit for inclusion and 3 months as the lower limit (i.e. 2000-2006). Thereby a spread in time elapsed since stroke onset was accomplished. The lower limit was chosen as a majority of the young individuals with stroke in Sweden have returned home at 3 months after stroke onset. This choice of method enabled the mapping of a true sample of individuals living in the community after stroke. However, due to the limited geographic area, the number of individuals when presented by year may be considered small. Nevertheless, the number of individuals was fairly evenly distributed over the years and no significant differences between the years were seen for the ratings of disability. Consequently, the individuals included could be analyzed as a group and the results were presented as long-term effects of stroke as seen in young individuals living in the community.

5.5.2 Methods for data collection

5.5.2.1 *Data collection in Paper I*

In the study presented in Paper I, data were collected using standardized and tested assessment tools and the questionnaires were filled out in an interview situation led by an occupational therapist and or physiotherapist specially trained for the study. This procedure evidently decreases the risk of missing values or of misinterpretations when

the questionnaires are filled in. Further, more than one questionnaire can be used in a face to face situation where the interviewer can be a guide through the procedure and thus limit the strain on the individual that is being assessed. Moreover, ambiguities and missing values can be avoided. By choosing appropriate questionnaires, a comprehensive picture of the assessed functioning and disability can thereby be given (60). Nevertheless, as the individuals are supervised and/or assisted by a health care professional, deference to the interviewer may lead to individuals refraining from answering or not answering truthfully (60).

5.5.2.2 Data collection Paper II

Data collection through a posted questionnaire gives the respondent the opportunity to fill in the questionnaire without being supervised by a health care professional (60). When using a postal questionnaire in a stroke population, however, a limiting factor is that the respondents may have difficulties responding due to e.g. impaired hand function and/or mental impairments following stroke. Thus, when developing the MYS-questionnaire presented in Paper II, consideration was given to content and layout of the questionnaire, not to tire the respondent. The results of the validation of the MYS-questionnaire in Paper II emphasize the importance of these considerations and the need to test questionnaires on the target group before using them.

5.5.2.3 Data collection in Paper III and IV

The response rate to the MYS-questionnaire (Paper III and IV) was 68%. The lower response rate of 65% to the EQ-5D questionnaire (Paper IV) may be due to fact that the EQ-5D questionnaire was placed at the back of the MYS-questionnaire. It is possible that by placing the shorter EQ-5D questionnaire first, the response rate would have increased without this influencing the response rate to the MYS-questionnaire. As a mean response rate of 62% in postal surveys published in medical journals has been reported (132) the response rate appears to be as can be expected. Nevertheless, the risk of response bias needed to be considered further. According to data from the medical records linked to Riks-Stroke at Södersjukhuset, no significant differences between respondents and non-respondents were seen for age, sex and years passed since stroke onset. These results indicate that the respondents were representative to the eligible study population.

However, this choice of data collection may prevent individuals with severe disability and those who are lacking a significant other, from responding due to their limited ability to fill in the questionnaire. Nevertheless, in the study presented in Paper III and IV, 11% filled in the MYS-questionnaires with assistance and 3% by proxy thus individuals with a disability that prevented them from filling in the questionnaire independently were represented. To increase the number of respondents and decrease the number of missing values further, respondents with missing values were contacted over the telephone and were given the opportunity to complete the questionnaire when needed.

By assessing differences in global health between the young individuals with stroke living in the community and an age and geographically matched general population (Paper IV) the magnitude of the negative long-term effects of the stroke on health was manifested.

5.5.3 Using the International Classification of Functioning, Disability and Health as a frame

In the present thesis the ICF was a valuable tool when developing the methods, and in communicating the results. Nevertheless, the vocabulary used in the thesis is not entirely true to the ICF. In developing the MYS-questionnaire in Paper II, the ICF was merely used as a frame to ensure that main domains affecting an individual's health states were represented. The questions were formulated in colloquial language in order to suit the young individuals with stroke. The ICF domains and terminology have previously been used as the origin and base in the development of a questionnaire but alterations had to be made after the testing on a target group (133). Moreover, the ICF terminology has been found to pose problems when used as a tool for communication with the participants in a study and consequently the authors have suggested a translation of the ICF domains into more colloquial language (134). Further, ICF Core Sets for stroke have been developed (73) but have been found to be too extensive for use in clinical practice and a reduction of items has been suggested after an assessment of individuals with stroke (135). Thus although one aim of the ICF is to establish a common language to describe health and health related states (41), science, health care and the individual living with disability, cannot rely solely on the ICF vocabulary and coding. Nevertheless, my experience tells me that the components of body functions and structures, activities and participation and environmental and

personal factors are useful tools when used as a frame in research, clinical practice and education. The development of a common language for health and health related states is favorable and will hopefully continue. Meanwhile, to ensure that no valuable information is lost, careful consideration should be given to the vocabulary used in research, clinical practice, education and in social policy.

5.6 CLINICAL ISSUES AND IMPLICATIONS – LONG-TERM MEASURES BY HEALTH CARE

Long-term measures by health care need to be discussed. Recovery is dependent on the restoration and reorganization of pathways in the brain, but also on narrowing the gap between the disability and the demands of the environment by performing goal oriented intense task specific training and strategies (136). In clinical practice it is commonly assumed that at 12 months, the individuals with stroke have reached a phase of recovery where health care is more oriented towards preserving regained functioning and preventing relapses. However, it has been argued that the stable phase that usually occurs at 6 months, may be related to less intense rehabilitation, rather than a plateau in recovery without further improvements to be expected (20).

Unpublished data from the study presented in Paper III and IV show that among the young individuals living in the community 3 months to 6 years after stroke, 47% did not see a physician for check-ups. In addition, 36% of these individuals reported that they had not been summoned or did not know where to turn to. Further, in a previous study, young individuals of working age have reported a lack of measures, adjusted to their age-related needs (30).

In addition, unpublished data from the study presented in Paper III and IV also showed that 22% of the young individuals with stroke expressed a need of, but did not receive training/rehabilitation up to 6 years after stroke onset. In the total stroke population in Sweden 33-53 % experienced unmet needs of rehabilitation 12 months after stroke (40% in Stockholm) (92). Thus, unfulfilled needs of measures by health care are expressed long term after stroke.

In Paper I, at 12 months after stroke, the vast majority did not perceive a full recovery and no age related differences between the groups were seen. These results emphasize the need of long-term follow ups by health care irrespective of age. As self-perceived

recovery after stroke involves factors that are important to the individual, it is crucial that factors associated with self-perceived recovery is thoroughly assessed and dealt with in order to offer patient centered interventions. As a person may improve in functioning over time (23, 24) they may still perceive that they are disabled compared to their pre-stroke condition (25, 26). Thus, health care needs to be prepared to support individuals who are motivated and have the capacity to improve further, long term.

How can health care improve and how do we identify young individuals with stroke who are in need of long-term measures by health care? In Paper III, initial stroke-related as well as personal and environmental factors failed to predict any of the self-rated mental impairments and did not sufficiently predict the assessed activity limitations and participation restrictions. These results indicate that by means of the SSS, stroke-related factors determined in the acute stage after stroke onset is not sufficient to predict long-term outcome in terms of mental impairments in young individuals where the majority had suffered a mild stroke. Further, as other commonly used standardized assessment tools, such as the Modified Ranking Scale, the Barthel Index and the modified National Institute of Health Stroke Scale have been found to be equivalent to the SSS, these instruments are probably not sufficient in this respect either (68). It is fair to assume that irrespective of initial stroke severity, there is a need of regular use of standardized assessment tools covering mental impairments e.g. the MMSE and the Montreal Cognitive Assessment (MoCA). It has been argued that the MoCA is more suited to assess individuals with mild stroke. The MoCa includes more tests of executive function that when impaired, is found to affect e.g. leisure activities and work negatively (137). Further, thorough assessments by health-care providers regarding physical and mental impairments as well as a mapping of contextual factors are warranted in the whole care trajectory. Assessments of self-perceived effects of stroke are essential and particularly important when the individual has returned home to his/her everyday life context. Then, if not sooner, will the self-perceived effect of stroke be fully evident.

The chance of providing the right measures at the right point in time may increase by implementing these assessments of self-perceived effects of stroke during regular and long-term follow ups. One question we might ask is: what would the beneficial effects of long-term measures be? Firstly, long-term support from the health care system as such, has been identified as important to enhance long-term recovery (97). The need of

recurring feed-back and further guidance regarding self-administered measures and an annual follow up by a stroke team has been reported (97). Further, the benefit of distributing information over a longer period of time has been stressed as appropriate information can then be given at an appropriate time of recovery (97, 138). Significant others have also stressed the need for information and support long term (138, 139). It is also possible that compliance with the use of prescribed drugs for secondary prevention will increase (140). Secondly, in Sweden, it is estimated that the care, rehabilitation and social services for an estimated yearly number of 19.200 individuals with a first ever stroke carries an estimated excess cost of SEK 9.9 billion (based on prices from 2000). Further, a cost of 2.4 billion due to premature deaths and early retirement has been estimated (141). The health care system may possibly reduce these costs by providing long-term measures aiming at reducing or preserving the level of dependence in ADL as well as reducing the number of individuals in need of assistance in ADL. In addition, costs may be reduced by providing long-term measures aiming for the individual with stroke to return to work.

Long-term gains in recovery are reported as a result of interventions by health care providers. Walking, e.g. is found to improve after training > 6 months after stroke in a meta analysis (20). The main focus on lower extremity function and walking during rehabilitation has been reported as a long-term issue among individuals with stroke. They perceive that their upper extremity function has been neglected (97). Robotics have been used to improve functioning long term but more research is needed to establish its effect (5). However, arm function is improved by constraint induced movement therapy > 1 year after stroke among individuals who are highly motivated and with some preserved hand function (142). In rehabilitation it is crucial to reach a level of recovery where the arm and hand can be used in every-day activities without too much effort. If an individual perceives that the use of the affected hand is beneficial and does not hinder or slow down an activity, everyday life activities will already provide the high intense, high speed and repetitive and task-specific training that we are trying to achieve in rehabilitation (143, 144). In this way, retrieved functioning can be sustained and/or further recovery can be achieved long term. By applying the phrase "use it or lose it" we may assume that this way of thinking applies to other stroke related impairments as well. Impaired physical and mental functions after stroke may lead to a sedentary life that is not sufficiently demanding to sustain or improve physical or mental functions. Physical activity is found to improve health in the general

population as well as in the stroke populations (145). According to the Global Recommendation on Physical Activity for Health presented by the World Health Organization (146), aerobic physical activity and muscle strengthening activity several times a week is needed to achieve a positive impact on health. Thus, when providing rehabilitation measures and in planning for long-term self-management in terms of physical activity, health care providers need to consider intensity in terms of sessions per week and the aerobic aspect of the training. The effects of physical fitness training on fatigue, depression and falls need to be studied further (147).

Interventions by an occupational therapist, a physiotherapist or a stroke team during the 1st year after stroke have been found to reduce the risk of death and deterioration in ADL among individuals living in the community (5). In addition, assistive devices and home modifications reduce the level of dependence in ADL long term (5). Yet, further research is needed to establish the beneficial effect of vocational rehabilitation (148). Furthermore, mental impairments were commonly reported by respondents in Paper III and have been found to affect everyday life negatively (34). Mental impairments have also been found to influence costs for society in terms of use of care and rehabilitation and loss of productivity among young individual of working age (102). Thus, the need of interventions targeting mental impairments is evident. A recent study show promising results in treating long-term fatigue after stroke by means of cognitive and graded physical activity training as well as by teaching compensation strategies (149). In addition, the use of assistive devices for individuals with impaired memory and problem solving strategies for individuals with impaired executive function may improve the ability to performing everyday life activities (150). However, the effect of computerized brain-training programs, used to improve mental functions, have not been found to transfer to untrained tasks (151). Further studies are needed to establish evidence-based interventions for mental impairments seen in individuals with stroke (5).

The multi factorial effects of stroke among young individuals of working age are presented in this thesis. Notably, the young individuals are not a homogenous group. The long-term effects of stroke are diverse and are influenced by individual differences in contextual factors such as pre-stroke lifestyle and current life situation. Knowing this, the focus of all care and rehabilitation planning should be on the individual's expectations of recovery in terms of the level of activity the individual is aiming to

return to. Nevertheless, the goals that are set in care and rehabilitation planning are often the result of a delicate balance between the expectations of the individual, clinical experience, scientific evidence, the financing of health care and the rules and regulations executed, e.g. by the Swedish Social Insurance Agency.

In 2001 the American Institute of Medicine (152) has presented areas of competence that need to be mastered by all health care professionals to meet the needs of future health care. These areas include the ability to deliver patient-centered care, to work in multidisciplinary teams, to practice evidence-based knowledge, to continue to work with improvements /quality assurance and to use informatics.

During professional education at an academic level the health care student is trained to gain knowledge by searching for and analyzing scientific literature and to apply this knowledge in a clinical context (153). Reality hits them when they find that in a clinical setting, time is short, and evidence-based practice is not always on the agenda in times of financial cutbacks (153). As pointed out by the American Institute of Medicine, in a successful clinic the legitimacy of being updated scientifically and working evidence-based need to be emphasized and prioritized by the health care organization. For future development of stroke care, focus is needed on a deepened collaboration between patients and patient organizations, clinicians, the County Council and the Municipality. Such a collaboration, called Stroke Forum, has been developed in Gothenburg, a city situated in the South-West of Sweden (<http://www.sahlgrenska.se/su/strokeforum>).

5.7 CONCLUSION

This thesis presents long-term, multi factorial and substantial effects of stroke seen among young individuals of working age, living in the community. These effects affected their self-perceived health negatively. A majority had suffered a mild stroke but experienced long-term disability that could not be sufficiently predicted by initial stroke-related, personal and environmental factors. Therefore, irrespective of initial stroke severity, regular long-term assessments by health care services are warranted in order to improve health-states among young individuals with stroke. It is of particular importance to implement regular assessments of mental impairments and future studies are needed to establish evidence-based interventions.

This thesis also demonstrates the necessity of involving self-rated assessments of the effects of stroke at different points in time, and among individuals of working age and older individuals, when evaluating differences in the provision of health care and stroke outcome.

Notably, young individuals are not a homogenous group. The long-term effects of stroke are diverse and are influenced by individual differences in contextual factors such as pre-stroke life style and current life situation. Thus, in order to be patient-centered and evidence-based, the take off point for all care and rehabilitation planning after stroke should be an integration of the individual's values, clinical expertise and best evidence.

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8 APPENDIX

Ett frågeformulär till dig som är boende på
Södermalm eller i Östra Söderort och som
insjuknat i stroke under 2000 till 2006



Sätt X för det alternativ som stämmer bäst
Om du har svårt att besvara frågorna be en närstående hjälpa dig

1. När insjuknade du i Stroke? månad _____ år _____

2. Vilken typ av stroke? Sätt kryss i lämplig ruta.

Hjärnblödning ☐ Hjärninfarkt ☐ Vet ej ☐

3. Har du insjuknat i stroke tidigare eller senare? Sätt kryss i lämplig ruta.

- ☐ Ja, vilket år? Skriv året här _____
☐ Nej
☐ Vet ej

4. Går du på kontroll hos läkare för din stroke?

- ☐ Ja
☐ Nej *Gå vidare till fråga 6*
☐ Ej aktuellt *Gå vidare till fråga 7*
☐ Vet ej/minns ej *Gå vidare till fråga 7*

5. Var går du till läkare för din stroke?

- ☐ Till läkare på sjukhus
☐ Till läkare på vårdcentral
☐ Till privatläkare
☐ Till företagsläkaren
☐ Annan, ange vem _____

Gå vidare till fråga 7

6. Vilken är den främsta orsaken till att du inte haft läkarkontakt för stroke?

- ☐ Jag behöver ingen läkarkontakt
- ☐ Jag har inte råd
- ☐ Jag går hos läkare av annan orsak
- ☐ Jag har inte blivit kallad
- ☐ Jag vet inte vem jag skall vända mig till
- ☐ Annan anledning, ange vad? _____

7. Finns det någon plan upprättad för din fortsatta vård och rehabilitering/träning?

- ☐ Ja
- ☐ Nej
- ☐ Ej aktuellt
- ☐ Vet ej/minns ej

8. Får du rehabilitering/träning idag?

- ☐ Ja
- ☐ Ja, men inte tillräckligt
- ☐ Ja, men rehabiliteringen/träningen är inte anpassad till mina behov
- ☐ Nej, men jag behöver rehabilitering/träning *Gå vidare till fråga 10*
- ☐ Nej, jag behöver inte rehabilitering/träning *Gå vidare till fråga 10*
- ☐ Nej, jag har uppehåll efter en period med rehabilitering/träning och en ny rehabiliterings/träningsperiod är planerad *Gå vidare till fråga 10*

9. Av vem eller vilka får du rehabilitering/träning?

Du kan kryssa för fler alternativ på denna fråga.

☐ Arbetsterapeut

☐ Kurator

☐ Logoped

☐ Läkare

☐ Psykolog

☐ Sjukgymnast

☐ Sjuksköterska

☐ Jag tränar själv

☐ Övrig: _____

10. Hur bedömer du ditt allmänna hälsotillstånd?

☐ Mycket bra

☐ Bra

☐ Någorlunda bra/dåligt

☐ Dåligt

☐ Mycket dåligt

11. Får du hjälp av någon med att äta och dricka?

☐ Nej

☐ Ja

12. Har du svårighet att svälja?

☐ Nej

☐ Ja

13. Får du hjälp av någon vid toalettbesök?

☐ Nej

☐ Ja

14 a. Hur klarar du dina förflyttningar inomhus? När du går med eller utan hjälpmedel.

- ☐ Jag förflyttar mig själv inomhus
- ☐ Jag får hjälp av annan person när jag förflyttar mig inomhus

14 b. Hur klarar du dina förflyttningar utomhus? När du går med eller utan hjälpmedel.

- ☐ Jag förflyttat mig själv utomhus
- ☐ Jag får hjälp av annan person vid förflyttning utomhus

15. Får du hjälp med på- och avklädning?

- ☐ Nej
- ☐ Ja

16. Får du hjälp med din dagliga hygien?

- ☐ Nej
- ☐ Ja

17. Får du hjälp med städning?

- ☐ Nej
- ☐ Ja
- ☐ Jag städar inte och har inte städad tidigare heller

18. Får du hjälp med matinköp?

- ☐ Nej
- ☐ Ja
- ☐ Jag gör inte matinköp och gjorde inte matinköp tidigare heller

19. Får du hjälp med matlagning?

- ☐ Nej
- ☐ Ja
- ☐ Jag lagar inte mat och lagade inte mat tidigare heller

20. Får du hjälp med din ekonomi? Att betala räkningar och/eller andra bankärenden.

- ☐ Nej, jag behöver ingen hjälp med min ekonomi
- ☐ Nej, men jag skulle vilja ha hjälp med min ekonomi
- ☐ Ja, jag får hjälp med min ekonomi
- ☐ Jag har inte hand om min ekonomi och hade inte hand om den tidigare heller

21. Är dina behov av stöd/hjälp i din vardag tillgodosedda?

- ☐ Jag behöver inget stöd/hjälp *Gå vidare till fråga 24*
- ☐ Ja, mina behov av stöd/hjälp är tillgodosedda
- ☐ Jag får stöd/hjälp men inte tillräckligt
- ☐ Nej, men jag skulle vilja ha stöd/hjälp *Gå vidare till fråga 23*

22. Vem eller vilka tillgodoser dina behov av stöd/hjälp? Du kan kryssa i fler svarsalternativ.

- ☐ Anhöriga/närstående
- ☐ Kommunal hemtjänst
- ☐ Vårdpersonal inom särskilt boende
- ☐ Personlig assistent
- ☐ Annan _____

23. Är du idag beroende av hjälp/stöd av anhörig/närstående?

- ☐ Jag är inte beroende av hjälp/stöd av anhörig/närstående
- ☐ Jag är delvis beroende av hjälp/stöd av anhörig/närstående
- ☐ Jag är helt beroende av hjälp/stöd av anhörig/närstående
- ☐ Jag har ingen anhörig/närstående eller saknar kontakt med anhörig/närstående
- ☐ Vet ej

24. Känner du dig trött?

- ☐ Nästan aldrig
- ☐ Ibland
- ☐ Ofta
- ☐ Ständigt

25. Känner du dig nedstämd?

- ☐ Nästan aldrig
- ☐ Ibland
- ☐ Ofta
- ☐ Ständigt

26. Känner du oro?

- ☐ Nästan aldrig
- ☐ Ibland
- ☐ Ofta
- ☐ Ständigt

27. Hur är din sömn?

- ☐ Jag sover lugnt och tillräckligt länge för mina behov
- ☐ Jag har vissa sömnsvärigheter
- ☐ Jag sover mycket dåligt
- ☐ Jag sover mer än vanligt

28. Hur är din aptit?

- ☐ Min aptit är som den brukar vara
- ☐ Min aptit är sämre än tidigare
- ☐ Min aptit är nästan helt försvunnen
- ☐ Min aptit är bättre än tidigare
- ☐ Jag äter mer än vanligt

29. Har du smärta?

- ☐ Nästan aldrig
- ☐ Ibland
- ☐ Ofta
- ☐ Ständigt

30. Har du svårt att koncentrera dig?

- ☐ Nästan aldrig
- ☐ Ibland
- ☐ Ofta
- ☐ Ständigt

31. Har du svårt att ta egna initiativ i vardagliga situationer och vardagliga aktiviteter? *Att komma igång och slutföra en eller flera aktiviteter under dagen.*

- ☐ Nästan aldrig
- ☐ Ibland
- ☐ Ofta
- ☐ Ständigt

32. Har du lätt för att falla i gråt i vardagliga situationer?

- ☐ Nästan aldrig
- ☐ Ibland
- ☐ Ofta
- ☐ Ständigt

33. Känner du dig stressad?

- ☐ Nästan aldrig
- ☐ Ibland
- ☐ Ofta
- ☐ Ständigt

34. Har du lätt för att bli irriterad och/eller arg?

- ☐ Nästan aldrig
- ☐ Ibland
- ☐ Ofta
- ☐ Ständigt

35. Har du svårigheter att minnas?

- ☐ Nästan aldrig
- ☐ Ibland
- ☐ Ofta
- ☐ Ständigt

36. Har du svårigheter att tala?

- ☐ Nej
- ☐ Ja

37. Har du svårigheter att läsa? Även med hjälp av glasögon.

- ☐ Nej
- ☐ Ja

38. Har du svårigheter att skriva?

- ☐ Nej
- ☐ Ja

39. Har du svårigheter att räkna?

- ☐ Nej
- ☐ Ja

40. Kan du utöva de intressen du hade innan du fick stroke?

- ☐ Ja, som förut
- ☐ Ja, men inte riktigt som förut
- ☐ Nej, nästan inte alls eller aldrig

41. Hur mycket tid ägnar du en *vanlig* vecka åt måttligt ansträngande fysiska aktiviteter som får dig att bli varm?

- ☐ 5 timmar per vecka eller mer
- ☐ Mellan 3 och 5 timmar per vecka
- ☐ Mellan 1 till 3 timmar per vecka
- ☐ Högst 1 timme per vecka
- ☐ Inte alls
- ☐ Vet inte

42. Finns det *någon* särskild person som du känner att du verkligen får stöd av?

- ☐ Ja
- ☐ Nej

43. Kan du använda allmänna kommunikationsmedel? *Buss, tåg, tunnelbana etc.*

- ☐ Ja
 - ☐ Ja, men jag känner mig osäker
 - ☐ Ja, men jag kan inte använda vissa kommunikationsmedel. Ange vilket/vilka
-

- ☐ Nej, jag kan inte använda allmänna kommunikationsmedel

44. Använder du särskild kollektivtrafik? *Färdtjänst, sjukresor mm.*

- ☐ Nej
- ☐ Ja → välj ett eller flera alternativ
 - ☐ färdtjänst
 - ☐ färdtjänstbuss
 - ☐ sjukresor
- ☐ Annat, ange vad _____

45. Kör du bil? *Du kan kryssa för fler alternativ på denna fråga.*

- ☐ Ja
- ☐ Nej, men jag körde bil före insjuknandet i stroke
- ☐ Nej, och jag körde inte bil före insjuknandet i stroke
- ☐ Nej, men jag åker med anhörig/bekant

46. Vem delar du bostad med?

D.v.s. vem bor du tillsammans med under större delen av veckan. Du kan ange fler svarsalternativ.

- ☐ Ingen
- ☐ Föräldrar/syskon
- ☐ Make/maka/sambo/partner
- ☐ Andra vuxna
- ☐ Barn → Hur gamla är de?
 - ☐ 0-6 år
 - ☐ 7-12år
 - ☐ 13-17 år
 - ☐ 18 år eller äldre
- ☐ Jag har delad vårdnad om barn som vistas i hemmet regelbundet

47. Vilken var din sysselsättning innan du insjuknade i stroke?

- ☐ Yrkesarbetade → Jag arbetade _____% av heltid
- ☐ Arbetstränade
- ☐ Tjänstledig eller föräldraledig
- ☐ Studerade, praktiserade
- ☐ Arbetsmarknadsåtgärd
- ☐ Arbetslös
- ☐ Sjukskriven
- ☐ Förtidspensionerad
- ☐ Långtidssjukskriven med sjukbidrag eller sjukersättning
- ☐ Skötte eget hushåll
- ☐ Annat, vad? _____

48. Vilken är din nuvarande sysselsättning?

- ☐ Yrkesarbetar → Jag arbetar _____% av heltid
- ☐ Arbetstränar
- ☐ Tjänstledig eller föräldraledig
- ☐ Studerar, praktiserar
- ☐ Arbetsmarknadsåtgärd
- ☐ Arbetslös
- ☐ Sjukskriven
- ☐ Långtidssjukskriven med sjukbidrag eller sjukersättning
- ☐ Förtidspensionerad
- ☐ Sköter eget hushåll
- ☐ Annat, vad? _____

49. Vilken är den högsta utbildning som du har?

Om du studerar kryssa i den utbildning du går. Sätt bara ett kryss.

- ☐ Folkskola eller grundskola
- ☐ Realskola eller flickskola
- ☐ 2-årigt gymnasium eller yrkesskola
- ☐ 3-4 årigt gymnasium
- ☐ Universitet eller högskola, 2,5 år eller kortare (mindre än 120p)
- ☐ Universitet eller högskola, 3 år eller längre (120p eller mer)
- ☐ Annan utbildning, vilken? _____

50. Har du någon/några av följande sjukdomar? Sätt ett kryss på varje rad.

	Nej	Ja	Vet ej
Diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Högt blodtryck	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hjärtflimmer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Höga blodfetter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

51. Tar du mediciner mot någon/några av följande sjukdomar? Sätt ett kryss på varje rad.

	Nej	Ja	Vet ej
Diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Högt blodtryck	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hjärtflimmer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Höga blodfetter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

52. Hur lång är du? Svara i centimeter.

____ _ cm

53. Hur mycket väger du? Svara i hela kilo.

____ _ kg

54. Röker du dagligen?

- ☐ Ja
- ☐ Nej

55. Är du kvinna eller man?

- ☐ Kvinna
- ☐ Man

56. Vilket år är du född? Skriv året.

19_____

57. Deltar du i någon forskningsstudie där du får behandling eller träning?

- ☐ Nej
☐ Ja → Beskriv vilken typ av behandling eller träning du får.

58. Vem har besvarat detta formulär?

- ☐ Jag själv
☐ Jag själv, med hjälp av annan
☐ Anhörig/närstående
☐ Vårdpersonal
☐ Annan _____

Till slut! Är det något som jag glömt att ta upp som känns **angeläget att tillägga**? Eller är det något som du tycker att jag borde veta mer om? Berätta gärna med egna ord, fortsatt på baksidan eller på ett separat papper om raderna inte räcker till.

Kontakta mig gärna om du har frågor eller synpunkter.

Susanne Palmcrantz
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Tack för att du ville medverka och tog dig tid att fylla i formulären!

Var vänlig och skicka in de ifyllda formulären i det bifogade svarskuvertet så snart du har möjlighet.



Med vänliga hälsningar

Susanne Palmcrantz
leg sjukgymnast

