Stroke in the younger

Self-reported impact on work situation, cognitive function, physical function and life satisfaction

A national survey

Jenny Röding

Umeå 2009
The most important thing in my life, the only thing that really matters, is trying to be a mom.
This thesis is dedicated to all women who have suffered a stroke and are mothers at the same time.

Und für mein Pappi;
Jetzt hamma!
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ABSTRACT

The majority of people affected by stroke are older however one fifth of all persons with stroke are younger than 65 years. In Sweden the mean age at the time of stroke is 75 years and about 5% of the stroke population are 55 years or younger.

The aim of this thesis was to describe and analyse the consequences of stroke in the younger population in terms of experiences of the rehabilitation process, return to work, self-reported physical and cognitive function and life satisfaction. Sex differences, as well as gender specific associations regarding factors of importance for a return to work, deteriorated physical ability and satisfaction with life as a whole, were also studied.

This thesis was based on an in-depth interview study and self-reported data collected from a questionnaire answered by 1068 individuals, between the ages of 18-55 years with a first ever stroke registered in Riks-Stroke, the Swedish national quality register for stroke care. The questionnaire concerned aspects of current health condition, living and social arrangements, physical and cognitive functions, activities in daily life, relationships, social life, leisure pursuits, self-perception, participation, work and life satisfaction. Most of the questions aimed to investigate differences between the present time and before stroke onset.

In-depth interviews with two men and three women aged 37-54, living at home after their stroke generated the hypotheses that younger persons with stroke are frustrated and feel invisible and outside. Rehabilitation for the younger was perceived as inadequate due to the fact that the rehabilitation setting does not acknowledge the specific needs that younger persons with stroke have.

Prior to the stroke 855 of 1068 (80%) of the participants, had been in paid employment. After the stroke 65% of the men and 66% of the women returned to work. Factors of importance for returning to work were associated with the self-reported data: the feeling that it was important to work (OR 5.1), not perceiving oneself as a burden to others (OR 3.3), not having a deteriorated ability to run a shorter distance (OR 2.8) and having support for return to work (OR 3.7).

Changes in self-reported physical and cognitive functions as compared with pre-stroke condition was explored in 867 (513 men and 354 women) P-ADL independent persons with stroke. Deteriorated physical abilities were reported in 56-79% and deteriorated cognitive abilities in 48-68% of the participants. Women were significantly more affected in terms of both physical and cognitive deterioration than the men. Seventy-two percent of the participants did not know how much they could physically exert themselves after their stroke, women significantly more than men. In addition, significant associations were found between deteriorated physical function and deteriorated cognitive function as well as fear of physical exertion. The strongest association for
deteriorated ability to move in crowded environments was the risk factors deteriorated cognitive ability (OR of 5.4) and being afraid of physical exertion (OR of 3.1).

Life Satisfaction and factors associated with not being satisfied with life as a whole in 1068 (631 men and 437 women) persons with stroke was assessed with the LiSat 9, baseline data from Riks-Stroke and self-reported answers from the questionnaire. Fifty-three percent of the participants were not satisfied with life as a whole. Men and women were analyzed separately in terms of associations with not being satisfied with life as a whole. Women who had a haemorrhage (OR 3.9) and a deteriorated ability to concentrate (OR 2.1) had a higher risk of not being satisfied. For men the risk was associated with living without a significant other (OR 3.2), not working (OR 2.3) and a deteriorated ability to concentrate (OR 2.0).

In conclusion, younger persons who have experienced a stroke feel frustrated and invisible due to the fact that their needs are not acknowledged. Age and gender have an impact on the outcome of present rehabilitation programs and the problems of younger persons with stroke can be detected at an earlier stage by developing appropriate instrument and delivering information directly aimed at physical functioning. Further studies on gender specific differences in stroke outcome concerning physical and cognitive functions as well as the life situation after stroke is needed. In order to optimize rehabilitation in terms of a return to work, external support and motivation seem to be important factors to consider.

Key words: adult, cognition disorders, gender differences, middle aged, motor activity, quality of life, questionnaires, stroke, work
SVENSK SAMMANFATTNING

De flesta som insjuknar i stroke är äldre, i Sverige är medelåldern 75 år men en femte del av alla personer med stroke är yngre än 65 år och 5 % är yngre än 55 år.

Målet med den här avhandlingen var att beskriva och analysera konsekvenserna av stroke i den yngre populationen i hänseende på rehabilitering, återgång i arbete, självskattad fysisk och kognitive funktion och livstillfredsställelse. Köns skillnader likväl som gender specifika associationer gällande återgång i arbete, försämrad fysisk och kognitive funktion och livstillfredsställelse var också studerat.

Dessa undersökningar är baserade på material från en djup intervju studie och självskattat data hämtat från en enkät som besvarats av 1068 individer i åldern 18-55 år med en första gångs stroke registrerade i det nationella kvalitets registret Riks-Stroke (RS). Enkäten innehöll frågor rörande personliga förhållanden som aktuellt hälsostatus och levnadsförhållanden, fysisk och kognitiv förmåga, relationer, socialt liv, fritidsintressen, välbefinnande, medbestämmande och delaktighet, arbete och livstillfredsställelse. De flesta frågorna syftade till att spegla skillnaden mellan nu och före insjuknandet i stroke.

Djupintervjuer med 2 män och 3 kvinnor i åldern 37-54 år (alla hemma boende) resulterade i hypotesen att yngre personer med stroke är frustrerade och känner sig osynliga och utanför. Rehabiliteringen för de yngre uppfattades inte som tillräcklig på grund av att den inte tillräckligt hög utsträckning tillstod de specifika behov som yngre personer med stroke har.

Innan insjuknandet i stroke var 855 av 1068 personer i betalt arbete (80 %). Efter stroke återvände 65 % av männen i arbete och 66 % av kvinnorna. Faktorer som var av vikt för återgång i arbete var huruvida persons upplevde det som viktigt att arbeta efter sin stroke, att inte känna sig som en belastning för andra efter stroke, att ha en oförändrad förmåga att springa en kortare sträcka efter sin stroke samt att ha haft stöd när det gäller arbetssituation efter stroke.

Försämringar i självskattad fysisk och kognitiv förmåga jämfört med innan stroke undersöktes i 867 personer med stroke, oberoende i att klara sina personliga dagliga aktiviteter. Nedsatt fysisk förmåga rapporterades med 56-79 % och nedsatt kognitive förmåga med 48-68%. Kvinnorna var signifikant mer påverkade både gällande fysisk och kognitiv försämring jämfört med männen. 72 % visste inte hur mycket de fick anstränga sig fysiskt efter sin stroke, kvinnorna i en högre utsträckning än männen. Signifikanta samband hittades mellan försämrad fysisk förmåga och försämrad kognitiv förmåga likväl som rädda för att anstränga sig fysiskt.

Livstillfredsställelse och faktorer associerade med att inte vara tillfredsstilld med livet som helhet undersökt hos 1068 individer med stroke med hjälp utav LiSat9, bakgrunds data från RS och självskattade svar från enkäten. Femtiotre procent av deltagarna var inte nöjda med
livet som helhet. Män och kvinnor analyserades separat vad gällande faktorer som var associerade med att inte vara nöjd med livet som helhet. För kvinnor var dessa; att ha haft en blödning samt en nedsatt förmåga att koncentrera sig jämfört med innan stroke. För männens del var det; att inte leva med en partner, inte jobba samt ha en nedsatt förmåga att koncentrera sig jämfört med innan stroke.

Sammanfattningsvis så visade studierna att yngre personer med stroke känner sig frustrerade och osynliga på grund av att deras behov inte är tillgodosedda. Ålder och kön har en påverkan på resultatet av nuvarande rehabiliterings program och problemen som de yngre individerna med stroke har kan upptäckas på ett tidigare stadium med utvecklandet av rätt instrument och genom att ge dem information direkt riktad mot fysisk aktivitet. Fortsatta studier gällande gender specifika skillnader i utfallet efter stroke i hänseende på fysisk och kognitiv förmåga samt livstillförsättningsbehandling är nödvändigt. För att optimera rehabiliteringen gällande återgång i arbete verkar yttre stöd och motivation vara viktiga faktorer att beakta.
### ABBREVIATIONS

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<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
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<tr>
<td>BI</td>
<td>Barthel Index</td>
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<tr>
<td>CI</td>
<td>Confidence Interval</td>
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<tr>
<td>HRQOL</td>
<td>Health Related Quality of Life</td>
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<td>ICD</td>
<td>International Classification of Diseases</td>
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<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
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<td>LiSat9</td>
<td>Life Satisfaction scale</td>
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<td>P-ADL</td>
<td>Personal Activities of Daily Living</td>
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<td>OR</td>
<td>Odds Ratio</td>
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<td>QOL</td>
<td>Quality of Life</td>
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<td>RS</td>
<td>Riks-Stroke, The National Quality Register for Stroke Care</td>
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<td>WHO</td>
<td>World Health Organisation</td>
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This thesis is based on the following papers:


II  Lindström B, Röding J, Sundelin G. Positive attitudes to work and preserved high level of motor performance are important factors for return to work in younger persons with stroke- A national survey. In manuscript


IV  Röding J, Glader E-L, Malm J, Lindström B. Only half of the younger stroke population is satisfied with their life after stroke – different predisposing factors among men and women. Submitted

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INTRODUCTION

The consequences of a stroke range from complete recovery to severe motor and cognitive impairment. The patterns of life, the demands raised, and the needs and goals that a person has changes over a life span. The impact of a stroke will therefore depend not only on the severity of the symptoms but also upon the age of the individual at the time of stroke onset.

Stroke is generally regarded as a condition of the elderly (1) since it predominantly occurs in mid-age and older adults (2). Nevertheless one-fifth of all individuals with stroke world-wide are younger then 65 years of age (3, 4) and across Europe more than 10 % are 55 years or younger (5). Each year about 30 000 Swedes suffer a stroke (6), 23 000 of these are first-ever events (7) and 20 % are younger then 65 (8). About 5 % are under the age of 55 years.

Stroke and its epidemiology

A stroke is caused by the interruption of the blood supply to the brain, generally because a blood vessel bursts or is blocked by a clot. This cuts off the supply of oxygen and nutrients, causing damage to the brain tissue (9). Stroke is defined as rapidly developing signs of focal (or) global disturbance of cerebral function lasting more than 24 hours (unless interrupted by surgery or death) with no apparent nonvascular cause (10). The definition excludes transient ischemic attack (TIA) and stroke events due to blood disease or brain tumours (11). Subdural haemorrhage and traumas are also excluded. About 85 % of all cerebral lesions in Sweden are ischemic (infarcts) and 15 % are bleedings (haemorrhages) (12).

In 2001 more then five million individuals worldwide died of a stroke, this is equal to 1/10 of all deaths (13). Globally, stroke is the second leading cause of death (2) and also the second most common cause for disability (13). Approximately there are 62 million stroke survivors world wide (14).

Consequences of stroke in younger ages

Defining young

When using MeSH terms (the U.S. National Library of Medicine's controlled vocabulary used for indexing articles for MEDLINE/PubMed) age group are categorized into adult (19-44 years), middle age (45-64 years), aged (65-79 years) and aged, 80 and over (15).
In the late 90-ies Kristensen et al studied stroke in young adults (18-44 years) in northern Sweden (16-18). In many ways their work laid the foundation for this thesis. One question that was raised from their research and that we wanted to explore further was why so few of these young persons returned to work. In this thesis we chose to include person aged 18-55 years and defined them as young. This was a pragmatic attempt to argue that 55 years is still fairly young from a medical and social point of view. Statistics from Statistic Sweden (19) show that of those who were working in Sweden 2003 80% were up to 54 years old and only 19% between 55-64 years. This indicates that the cut off at 55 might be more interesting to study than 65 in terms of work. The fact that persons under or equal to 55 years are also likely to have children living at home, was also a reason for choosing this cut off age.

Stroke outcome

The impairments that follow stroke are various (9) and have implications for both the person affected as well as his or her family (20). The disability a person might experience after a stroke, besides reduced survival, concerns both physical and cognitive functions but also the quality of life. In this thesis the focus is on self-reported return to work, function and life satisfaction.

The situation for younger persons with stroke is not well documented (21) however there are some studies and these indicates unmet needs among younger stroke patients (1, 22-26). The main finding here is that rehabilitation of younger stroke patients is associated with a variety of problems not seen in the rehabilitation of the elderly since the life situation is completely different. Issues that needs to be addressed with the young are for example return to work, family support, information, physical function and life satisfaction.

A selection of recent studies on outcome in persons with stroke, suitable for this thesis is presented in Table 1. Due to the fact that there are few studies on persons younger than 55 years studies with older persons are included.
Sex differences and gender based approach in stroke

The intention with this thesis was not to have a gender perspective; however the question of differences between men and women cannot be ignored when studying the consequences of stroke in younger persons.

Disability and quality of life outcomes after a stroke are consistently poorer in women than men, although the reason for this are however not well known and further studies are warranted (27). Some of the differences may be due to the onset of stroke at older ages in women (28); however even after adjusting for age several studies show that stroke outcomes are worse in women (6, 29, 30). Men and women may also have different needs regarding help and support after a stroke depending on differences in social factors and functional ability (6).

In accordance with the WHO definition, this thesis use the concepts sex, men and women for defining the biological characteristics of different species (31). According to this definition gender refers to the socially constructed roles, behaviour, activities and attributes that a particular society considers appropriate for men and women (32). Working with a gender-based approach begins with the recognition of the differences between women and men and it enables identification of the ways in which the health risks, experiences, and outcomes are different for women and men and to act accordingly from that information (32).

Stroke care in Sweden

Organized stroke unit care has been shown to improve survival rates, reduce dependency and need for institutional care (33-36). In 2007 82.4% of all stroke patients in Sweden were treated in stroke units. Men are more likely than women (83.0 respectively 80.2 percent) to receive treatment at stroke units (37).

Riks-Stroke (38) has, based on the National Board of Health Guidelines for Stroke treatment (12), defined a stroke unit by:

- Established program for study and treatment of stroke patients
- Early active rehabilitation
- Specially trained staff working in teams consisting of physician, nurse, nurses' aide, physical therapist, and occupational therapist, and when needed, social worker, speech therapist, psychiatrist/psychologist and dietician
- Physician specialising in cerebrovascular diseases
- Specially trained stroke care nurse works as central coordinator for the stroke team
- Regular registration of functional level
- Continuing education on stroke care for staff
- Detailed information/education for patient and relatives
Close collaboration with rehabilitation and geriatric departments
"Discharge conference" for planning continued care and transfer of information to continued care provider

Stroke and rehabilitation

Research has shown that an early start of rehabilitation after a stroke is essential and that stroke care and rehabilitation programs should be conducted in stroke unit care by a stroke rehabilitation team (39).

Dewey et al. have in their research identified three principals to achieve effective stroke rehabilitation; (1) a functional approach targeted at specific activities e.g. walking, activities of daily living, (2) frequent and intense practice, and (3) commencement in the first days or weeks after stroke (14).

Riks-Stroke uses dependence in personal activities of daily life (P-ADL) as one of the most important outcome measurements, as it reflects the quality of the rehabilitation in a broad meaning. In 2007 78.6% of all stroke patients registered in the national quality register Riks-Stroke were independent in their P-ADL (37).

The International Classification of Functioning, Disability and Health - ICF

The International Classification of Functioning, Disability and Health (ICF) is a classification of health and health-related domains. These domains are classified from body, individual and societal perspectives by means of two lists: a list of body functions and structure, and a list of domains of activity and participation. Since an individual functioning and disability occurs in a context, ICF also includes a list of environmental factors. The ICF defines participation as involvement in a life situation and environmental factors as the physical, social, and attitudinal environment in which people live and conduct their lives. By shifting the focus from cause to impact it places all health conditions on an equal footing, allowing them to be compared using a common metric – the ruler of health and disability. Furthermore, ICF takes into account the social aspects of disability and does not see disability only as a 'medical' or 'biological' dysfunction (40), i.e. requires the health and medical services to take a broader view than the traditional one (12). This thesis tries to share this view.
Introduction

The consequences of a stroke regarding return to work

Today, the rehabilitation of stroke patients is mainly focused on the group of elderly, which might indicate that the needs of the younger are not focused on enough (41, 42). The prognostic factors for return to work can be demographic factors, stroke type and disability, and social factors.

Return to work is highly contextual and comparisons between different countries with differing social security systems are therefore difficult. In a Swedish study of rehabilitated persons with stroke the return to work was as low as 20% (43) and international figures show a return to work up to 73% (44). White collar workers have higher return rates than blue collar workers (44), which is also the case for higher education compared to lower education (45).

The consequences of a stroke regarding physical and cognitive function

Functional outcome has been considered more favourable in younger than older individuals (46). However, a severe stroke may occur at any age and has not been systematically analyzed in previous studies (47). Both physical and cognitive functions are important determinants regarding the possibility of young persons who have suffered a stroke to participate in daily activities, regain independent living and social life as well as return to work (26, 48).

A UK national survey of younger persons with stroke, 18-65 years, reported that those who experienced poor mobility had more unmet needs (24). Unspecific symptoms such as headaches, tiredness and irritation, anxiety and memory problems are reasons cited for why stroke patients have not returned to work (16). It has also been found that the relationship between impairment and motor disabilities is stronger than the relationship between impairment and cognitive disabilities (49).

The consequences of a stroke regarding life satisfaction

Quality of life (QOL) is a broad concept covering several aspects such as health, social life and well-being (50). Life satisfaction on the other hand is seen as a purely subjective aspect of how people perceive their lives (51). With an enhanced stroke survival rate more interest is being directed to quality of life and life satisfaction related research (52, 53). Despite this, there are few studies on QOL or life satisfaction after stroke among younger persons (53-56). QOL outcomes for the young are of special interest since stroke effects many domains of the young stroke survivals lives (26, 53, 57) and because these individuals are at their peak of their professional and family years and may face a lifetime of disability.
Introduction

The few studies that have been made show a 20-30% decrease in QOL (55, 56). A Swedish study on life satisfaction in persons who had suffered a stroke younger than 75 years showed that 39% were satisfied with life as a whole. This can be compared to a normative group of Swedes aged 50-74 years who showed a 77% satisfaction rate with life as a whole (20).

Rationale for the thesis

As the majority of those affected by a stroke are older it is likely to draw the assumption that the rehabilitation is dominated by the older stroke patients’ problems and needs. Those affected by stroke in a younger age are fewer; however this is a significant group since they have to live with the consequences of stroke for the rest of their lives, which for some can be the larger part of their existence. Their current life situation also differs from the elderly since they are at their peak of family and productive years.

The impairments that follow a stroke are various and the impact it has on the every day life of the individual depends on the context the person is living in. There is a need for more detailed measurements of both acute and rehabilitation care to require the information of which component needs to be improved in order to optimize the quality of the outcome for the younger. The scope of this thesis is to investigate the consequences of being young and having a stroke.
AIMS OF THE THESIS

The overall objective of this thesis was to describe and analyse the consequences of stroke in a large nation wide cohort of younger persons, 18-55 years of age, with a first ever stroke, treated in hospital and registered in the Swedish national quality register for stroke care, Riks-Stroke, 8 months to 2.5 years since stroke onset in terms of their experiences of the rehabilitation process, return to work, self-reported physical and cognitive functions and life satisfaction. Sex differences, as well as gender specific associations regarding factors of importance for return to work, deteriorated physical ability and satisfaction with life as a whole, were also studied.

The specific aims of each paper were:

- to describe and analyze the how younger stroke patients had experienced rehabilitation and the time after stroke and to develop a hypothesis about their life situation
- to investigate factors that are associated with return to work among young persons after stroke
- to describe the perceived consequences for physical and cognitive functions after stroke in younger persons independent in P-ADL. In addition, the aim was to investigate whether differences exist between men and women and to find factors that were associated with deteriorated physical function
- to describe self-reported life satisfaction after a stroke in younger persons. In addition, the aim was to investigate whether differences between men and women existed and explore medical or social factors associated with life satisfaction
Methods

The Riks-Stroke register

Riks-Stroke, the national quality register for stroke care in Sweden was established in 1994. Since 1998, the register covers all hospitals admitting acute stroke patients. The register covers acute stroke patients of all ages. It includes key patient characteristics, various aspects of acute stroke management and a follow-up at 3 months after the stroke. Basic patient characteristics, including living conditions and function before a stroke are also recorded (58).

The proportion of acute stroke patients treated in hospital in Sweden is estimated to lie between 84 % (59) and 92 % (60). Between 21000-25000 stroke events have been recorded in the register annually. Based on epidemiological calculations Riks-Stroke has an approximate coverage of 90 % of all ischemic and intracerebral haemorrhages in all ages (61). However, from 2007 Riks-Stroke has decided to change the foundation for estimating coverage which in the latest analyze report from Riks-Stroke leads to a total cover of 82,4% of all stroke events in the country (37). Three-months after stroke the patients are contacted for a follow-up by questionnaire or telephone interviews. The participation rate in follow-up was 89,9% in 2007 (37, 62).

Patients diagnosed with ischemic stroke (ICD-10 I63), intracerebral haemorrhage (ICD-10 I61) or unspecified acute cerebrovascular event (ICD-10 I64) are eligible for registration. Individual hospitals can choose to register additional stroke diagnoses (ICD-10 I69) and transitory ischemic attacks (ICD-10 G45) without being included in the yearly feedback from RS to the hospitals or in this thesis.

All included patients have been informed about the registration in Riks-Stroke. Participation is voluntary and data can be withdrawn at any time (61).

Ethical considerations

The studies in this thesis have been approved by The committee of research ethics at Umeå University (Dnr 99-169) and The Ethics Committee of the Medical Faculty of Umeå University (Dnr 03-165). The informants, who all had been patients at Neurocentrum Umeå, were contacted with a letter informing them on the interview study. Those who were interested in taking part of the study signed an interest form and were later contacted by the interviewer in order to recheck the interest and find a time for the interview. Before the interview took place the informants were once again informed that participation were voluntary and that they at anytime could end the interview. When regarding the questionnaire study a letter of invitation was sent out together with the
questionnaire which informed the patients that participation was voluntary.

All included have been informed about the registration in Riks-Stroke. Participation in Riks-Stroke is voluntary and patients can deny participation or ask that data be withdrawn at any time. Riks-Stroke has been approved by the Regional Ethical Review Board at Umeå University, and the corresponding data handling procedures have been approved by the National Computer Data Inspection Board.

The Grounded Theory approach

The method of Grounded Theory was developed in the 1960s by Glaser and Strauss. It is a qualitative method for deriving theory by empirically studying the phenomenon it represents; the theory is grounded in data or develops concepts from empirical data (63-65).

The purpose of using Grounded Theory is threefold. It is used to find categories about social phenomenon and to relate the categories to each other. It can construct models and hypotheses or even new theories. When there is little or no knowledge in a field Grounded Theory can be a suitable way of obtaining new knowledge. The method can not only be used in qualitative research but also in quantitative since it is a method for discovering and it is not restricted to one specific method (66).

Grounded Theory includes all stages, from formulating research questions through sampling procedures, data collection, analysis and the development of concepts, hypothesis or theories (67). The open and selective coding procedures as well as the categorising of the findings are essential components in the different stages of the analyses.

Questionnaire

A questionnaire was constructed based on the results of the primary qualitative interview study. Items regarding the patient’s current health condition, living and social arrangements, physical and cognitive function, activities in daily life, relationships, social life, leisure pursuits, self-perception, participation and work were included in the questionnaire. In total the questionnaire contained 97 questions to be answered. Incorporated amongst these questions were also the Life Satisfaction instrument LiSat9 (68) parts of the quality of life instrument by Hamedani et al. (69) for young hemorrhagic stroke patients and questions from Bartel Index concerning P-ADL (70). We also included some of the questions from Statistics Sweden yearly Living Conditions Survey (ULF) (71). Hamedani et al. (69) has stressed that since status instruments cannot always assess the extent of a deficit experienced by an individual, the ‘change’ in function or well-being should be evaluated instead. Most of the questions were therefore designed to describe how the current situation differed from the situation before the stroke.
Life satisfaction was rated with the Life satisfaction Checklist 9 (LiSat9). LiSat9 includes satisfaction with life as a whole (global item) and eight domain specific life satisfaction items: One health item; ability to manage self-care, two provision items; vocational and financial situation, three closeness items; sex life, partner relation and family life, two spare time items; leisure and social contacts. The scale has six degrees, from 6 for very satisfied to 1 for very dissatisfied. The checklist is often used in a dichotomized version where degrees 5-6 constitute satisfied and 1-4 not satisfied. The dichotomisation has been made in order to separate those who were satisfied from those not satisfied. The wording rather satisfied is here interpreted as not being satisfied (68). In this thesis we used the dichotomized version.

The checklist has been shown to have intraindividual stability and sensitivity to change (68). The validity of the dichotomisation used has been demonstrated (72).

The questionnaire was primarily intended to be answered by the patients themselves. Help from others was noted in the questionnaire. Prior to the study start; the questionnaire was tested on 6 younger stroke patients and also on four professionals who were all experienced in rehabilitation of stroke patients. They all found the questionnaire easy to comprehend and the questions appropriate for the purpose of the investigation.

In the work of this thesis ICF was not consequently used but there was an attempt to have the classification and nomenclature in mind, specifically when working with the construction of the questionnaire.

Participants

The informants for the interview study (paper 1) were chosen from the following criteria:

- Being able to communicate
- Age 18-55 years
- At least one year since stroke onset
- Living in northern Sweden (convenience)

Inclusion of participants for the population-based cross-sectional study (paper 2-4) were based on:

- Participants in Riks-Stroke (RS)
- 8 months since stroke onset (convenience due to the cohorts of RS)
- Age 18-55 years
- First ever stroke

For specific inclusions criteria of each paper see individual methods paper 2-4.
RS had the courtesy to grant us data from the last six months of 2001 and the whole year of 2002. The initial study population was based on 1631 persons. 186 of these had a recurrent stroke and 20 had no record on recurrent stroke and were therefore excluded. In January 2004, 3 months after the questionnaires and two remainders had been sent out, 1068 out of 1425 (75%) had returned the questionnaire. Figure 1 shows the flowchart of the whole study population.

**Figure 1.** The total study population of persons aged 18-55 years who had suffered a stroke. Participants granted from the Swedish National Quality Register for Stroke, Riks-Stroke, July December of 2001 and January-December of 2002
Methods

**Statistical methods**

The statistical analyses regard papers 2-4. Details of the specific analysis for each paper are presented in their individual section. The general structure of the statistical analysis has been:

1. Descriptive statistics (e.g. mean values and proportions)
2. Univariate analysis (e.g. Pearson χ² test, simple regression (not published) and Spearman rank correlation)
3. Methods to examine association between binary outcome variables and explanatory factors (e.g. variable cluster analysis, multiple logistic regression)

Results from the statistical analyses have been presented with mean values, proportions, p-values, correlations and odds ratios with corresponding 95% confidence intervals. Two-sided tests have been used and the level of significance has been set to < 0.05. Testing several factors increases the risk of a type II error. However, the p-values, in this study, were small and the risk of our findings being spurious is low. Variable clustering was performed with SAS version 9.1. All other statistical analyses were performed using SPSS version 15.0.

**Variable assessment**

In order to define independence (paper 2-4) we used the same definition as prior RS studies have done (6, 34, 61, 73-75) i.e. being able to manage going to the toilet, dressing and walking inside and outside without assistance. This measure of personal activities in daily living (P-ADL) is strongly correlated with the Barthel index (74).

**Dichotomization**

Since we wanted to explore the consequences of a stroke in younger persons we chose a rather strict line in terms of dichotomizing the multiple choice variables. Our principle was that you either could perform a task or you could not. The same reasoning was applied for questions concerning if a situation had become better or worse. For example was somewhat worse dichotomized into worse.

When analysing the data in paper 2-4 only ischemic stroke (ICD-10 I63) and intracerebral haemorrhage (ICD-10 I61) were included. The unspecified acute cerebrovascular event (ICD-10 I64), approximately 4%, of the total study population was therefore excluded in the dichotomization.
Methods for the specific papers

Paper 1

Informants and analysis

An interview guide covering the themes hospital stay, rehabilitation period, and current situation was used when performing in-depth interviews with 5 persons (37-54 years of age) who had had a stroke. According to the informant’s wishes they were interviewed in their homes, except for one who wanted to be interviewed at the Department of Physiotherapy at Umeå University. The interviews were performed by the principal investigator who had not taken part in their rehabilitation. Each interview lasted about one hour. All interviews were tape-recorded and transcribed verbatim.

The analyses used were inspired by the Grounded Theory method of constant comparison. To increase trustworthiness of the results, two different qualitative techniques were used: triangulation of researchers and member checking. The analyses were initiated by an open coding procedure. Three of the authors performed a separate open coding of the interviews. In the following step of analyses, central themes and categories began to emerge. The authors met several times for comparisons and a final negotiated outcome. Member checking was conducted, meaning that a summary of each interview was sent back to the informants for confirmation of the interpretation and conclusions drawn from the interviews.

Paper 2

Participants

Factors that are associated with return to work were investigated in 855 younger (18-55 years) persons with stroke, who prior to the stroke had been in paid employment.

The variables investigated were; Background variables from RS (sex, age, stroke diagnosis, diabetes, treatment ward at hospital, time since stroke onset). Importance to work present time compared to prior to the stroke, type of branch of work prior to the stroke, support to return to work, level of education, socioeconomic belonging, treated at ward aimed at younger, ability to concentrate and run a shorter distance present time compared to prior to the stroke, informed about the stroke disease and its consequences, experience of being a burden to others present time compared to prior to the stroke, experience of being as respected present time as compared to prior to the stroke and side of stroke.
Methods

**Statistical analysis**

Dichotomization; variables were either dichotomized or trichotomized in the analyses.

In order to describe the participants', descriptive analysis were used. Differences between groups were studied with the χ²-tests.

To find factors associated with return to work multiple logistic regression analyses were used. Return to work was used as the dependent variable. The independent variables were; stroke diagnosis, times since stroke onset, treated at ward aimed at younger, ability to concentrate and run a shorter distance present time compared to prior to the stroke, support to return to work, experience of being a burden to others present time compared to prior to the stroke and socioeconomic codes. The variables which showed significant differences with the p-value < 0.05 in the simple analyses were included in the multiple regressions. Significant correlations between the variables used in the univariate tests existed. Thus, only one of the variables was included in the multiple logistic regression analysis. The analysis was adjusted for sex and age although no differences existed in the univariate analysis.

**Paper 3**

**Participants**

Self-reported consequences for physical and cognitive functions, its gender differences, and factors associated with deteriorated physical function in younger stroke patients, independent in their personal activities of daily life (P-ADL), were investigated in 867 younger (18-55 years) individuals.

Variables that were investigated were: the present ability compared with prior to the stroke to run a shorter distance, go up and down stairs, take a walk and move in crowded environments, memory, simultaneously capability, concentration, to engage in discussions, complete a task, stay in crowded environments. The variable frequency of fatigue present time compared to prior to stroke was also used. The self-perceived remaining symptoms speech deficits, headache, pain, vision impairment, balance problems, numbness, other or none were also noted. Five questions regarding the patient’s current perception and attitudes towards physical ability and how much information they had received regarding physical exertion were also included in the analyses. The questions were; Are you afraid of physical exertion after your stroke, How important is it for you to be able perform physical exertion after your stroke, Do you know how much you can exert yourself after your stroke, Has anybody informed you about how much you can exert yourself.
Methods

Statistical analysis

The multiple-choice answers were dichotomized into unchanged-deterioration, important - not important or yes - no. The proportions of men and women with remaining symptoms or deteriorated functions were compared using the $\chi^2$-test.

A variable cluster analysis confirmed that the questions concerning changes in cognitive functions (deteriorated memory, simultaneously capability, ability to concentrate, ability to engage in discussions, ability to complete a task, ability to stay in crowded environments and more frequent fatigue) were highly correlated. Concentration was the single variable which correlated best with that cluster and was therefore chosen to represent cognitive functions in the multiple logistic regression.

Four multivariate analyses were performed with move in crowded environments, run a shorter distance and go up and down stairs, and take a walk as dependent variables. For each of the dependent variables the independent variables deteriorated cognitive function (deteriorated ability to concentrate), afraid of physical exertion, have not received information about physical exertion were used. The independent variables were chosen from the initial $\chi^2$-tests of differences between men and women with a significant p-value < 0.05. The non-significant variable ‘afraid of physical exertion’ was chosen from a clinical and rehabilitation point of view. In addition, sex and age were included in the analysis.

Paper 4

Participants

Self-reported life satisfaction in 1068 younger (18-55 years) persons with stroke was investigated, as well as possible differences between men and women in terms of life satisfaction. We also explored medical or social factors associated with life satisfaction.

The variables investigated were; Life satisfaction values from LiSat 9 (e.g. life as a whole, ADL, leisure, vocational situation, financial situation, sexual life, partnership relation, family life and contact friends/acquaintances). Background variables from RS were used. These were; age, atrial fibrillation at onset of stroke, level of consciousness at onset of stroke, hypertension therapy, previously known diabetes, smoker, and treatment ward at hospital, diagnosis and time passed since stroke onset. Self-reported data from the questionnaire was also used, these were; P-ADL status, living conditions at time of the questionnaire, admitted to clinic specially aimed at younger, marital status at the time of questionnaire, living with children at the time of questionnaire, working situation at the time of questionnaire, ability to concentrate compared to
prior to the stroke and ability to run a shorter distance compared to prior to the stroke.

*Statistical analysis*

The scores from LiSat9 were dichotomized in order to separate those who were satisfied (grades 5-6) and not satisfied (grades 1-4) (68). Multiple choice answers as well as background factors from RS were also dichotomized. The aim here was to separate those who were as well as before from those who had deteriorated.

Differences between men and women as well as those satisfied and not satisfied with life as a whole were calculated by using the $\chi^2$ test.

Multiple logistic regression was used to analyse several factors simultaneously. The multiple logistic regression model was based on significance values (p-value $\leq 0.05$) from the $\chi^2$ test of those satisfied and not satisfied with life as a whole. Men and women were analyzed separately. Not satisfied with life as a whole was the dependent factor. For the men the independent factors were; P-ADL, living condition, marital status, living with children, working situation, and a deteriorated ability to concentrate and run. Independent factors for the women were; diagnosis, P-ADL, treatment ward at hospital, working situation, and deteriorated ability to concentrate and run. The independent variables were chosen from the $\chi^2$ tests of differences between those satisfied and not satisfied.
RESULTS

Frustrated and invisible – younger stroke patients experiences (Paper 1)

Considerable consensus regarding several aspects about how stroke had affected the informant’s lives were found. However, some variations were found which were connected to different gender roles. The conclusion that can be drawn from the strong consensus among the informants is that the attitudes described are commonly shared in the group, although some informants may be more representative than others in each category. Table 2 shows the characteristics of the informants.

Table 2. Characteristics of the informants in paper 1

<table>
<thead>
<tr>
<th>Sex</th>
<th>Age at time of interview</th>
<th>Numbers of years after stroke</th>
<th>Social economic status</th>
<th>Civil status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>37</td>
<td>1</td>
<td>White collar</td>
<td>Married</td>
</tr>
<tr>
<td>Male</td>
<td>54</td>
<td>1.5</td>
<td>Blue collar</td>
<td>Common law husband</td>
</tr>
<tr>
<td>Male</td>
<td>46</td>
<td>1</td>
<td>White collar</td>
<td>Married</td>
</tr>
<tr>
<td>Female</td>
<td>39</td>
<td>1.5</td>
<td>Blue collar</td>
<td>Married</td>
</tr>
<tr>
<td>Female</td>
<td>40</td>
<td>1</td>
<td>Blue collar</td>
<td>Married</td>
</tr>
</tbody>
</table>

There were some feelings that were shared and common for all informants. These were:

- Being ill was equal to being old
- The common stress that is obvious in the society at large but also in the care and rehabilitation setting
- Fatigue, deteriorated ability to concentrate and sensitive to sound

All women expressed an attitude of trying to be

- “Good girls”. They uttered a sense of being ambitious and responsible

All men expressed the

- Importance of being able to support their family
- Need for more exercise and training (provided by the health care)

The analyses resulted in the core category ‘Frustration’ which was derived from the categories labelled ‘The paralysed everyday’ and
‘Outside and invisible’. ‘The paralysed everyday’ category is related to the informants’ everyday life and how the stroke has affected them. The category ‘Outside and invisible’ is derived from attitudes about the rehabilitation setting and how the system of health care affected the informants (Figure 2).

<table>
<thead>
<tr>
<th>Negotiated outcome of Open Coding</th>
<th>Categories</th>
<th>Core Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New orientation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender related expectations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of participation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Invisibility</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of age-adapted rehabilitation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insufficient rehabilitation</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Figure 2.** Summary of the open codes, sub-categories and core category that emerged in the qualitative analysis of the in-depth interviews of younger informants with stroke

**The National Survey (Paper 2-4)**

In total 1199 of 1631 younger persons who had suffered a stroke answered the questionnaire. This is equal to a responds rate of 74%. In the work of this thesis only the answers from persons with a first ever stroke were analyzed. They were 1068 out of 1425, i.e. a responds rate of 75%. Of those who did not respond the questionnaire, relatively more were men, diabetics, not fully conscious on admission and more often diagnosed with hemorrhagic strokes. In addition, non-responders had been less frequently treated in a stroke unit. Table 3 and Figure 3 shows the background data and basic characteristics of the 1068 younger persons with stroke investigated in paper 2-4 in this thesis.
### Table 3. Characteristics of the total sample of the 1068 younger persons with a first ever stroke who answered the questionnaire

<table>
<thead>
<tr>
<th>Category</th>
<th>Persons answering specific question n/N</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sociodemographic data</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age, mean and SD 48.7 ± 6.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-24 years</td>
<td>12/1068</td>
<td>1</td>
</tr>
<tr>
<td>25-34 years</td>
<td>49/1068</td>
<td>5</td>
</tr>
<tr>
<td>35-44 years</td>
<td>158/1068</td>
<td>15</td>
</tr>
<tr>
<td>45-55 years</td>
<td>849/1068</td>
<td>79</td>
</tr>
<tr>
<td>Men</td>
<td>631/1068</td>
<td>59</td>
</tr>
<tr>
<td>Women</td>
<td>437/1068</td>
<td>41</td>
</tr>
<tr>
<td><strong>Prior to the stroke</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living with significant other</td>
<td>743/1056</td>
<td>70</td>
</tr>
<tr>
<td>Living with children</td>
<td>317/1056</td>
<td>30</td>
</tr>
<tr>
<td><strong>At time of the questionnaire</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living in ordinary housing</td>
<td>954/1052</td>
<td>90</td>
</tr>
<tr>
<td>Living with significant other</td>
<td>717/1056</td>
<td>68</td>
</tr>
<tr>
<td>Living with children</td>
<td>294/1056</td>
<td>28</td>
</tr>
<tr>
<td><strong>Treatment wards</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stroke unit</td>
<td>813/990</td>
<td>82</td>
</tr>
<tr>
<td>Clinic specially aimed at younger after initial treatment ward</td>
<td>80/1053</td>
<td>8</td>
</tr>
<tr>
<td><strong>Diagnosis and Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Haemorrhage</td>
<td>160/1068</td>
<td>15</td>
</tr>
<tr>
<td>Infarct</td>
<td>872/1068</td>
<td>82</td>
</tr>
<tr>
<td>Unspecified</td>
<td>36/1068</td>
<td>3</td>
</tr>
<tr>
<td>Independent self rated P-ADL</td>
<td>867/1039</td>
<td>83</td>
</tr>
<tr>
<td>More often fatigued compared to prior to the stroke</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sense of well being</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling older then persons of same age</td>
<td>254/1053</td>
<td>24</td>
</tr>
<tr>
<td>Feeling completely restored after the stroke</td>
<td>204/1054</td>
<td>19</td>
</tr>
<tr>
<td>Have received needed information on stroke and its consequences</td>
<td>479/1040</td>
<td>46</td>
</tr>
<tr>
<td>Perceived that family have received needed information on stroke and its consequences</td>
<td>375/1043</td>
<td>36</td>
</tr>
<tr>
<td>Have regular contact with healthcare today (in terms of the stroke)</td>
<td>535/1051</td>
<td>51</td>
</tr>
<tr>
<td><strong>Participation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has self being able to decide over their own future after stroke</td>
<td>433/1034</td>
<td>42</td>
</tr>
<tr>
<td>Felt that the health care has taken their needs in consideration in terms of actions taken after the stroke</td>
<td>211/1087</td>
<td>21</td>
</tr>
<tr>
<td>Feel that the health care has taken their family situation into consideration after stroke</td>
<td>164/1001</td>
<td>16</td>
</tr>
<tr>
<td>Feel that the health-care has taken special consideration to the fact that they are young for having a stroke</td>
<td>218/1021</td>
<td>21</td>
</tr>
<tr>
<td><strong>General</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.5 years – more than 2 years between stroke and questionnaire</td>
<td>681/1068</td>
<td>64</td>
</tr>
<tr>
<td>Answered the questionnaire themselves</td>
<td>887/1068</td>
<td>87</td>
</tr>
</tbody>
</table>
Factors that are associated with a return to work were studied in 855 younger, 18-55 years, persons with a first ever stroke who had been in employed work before their stroke.

Sixty five percent returned to work after the stroke and there were no significant differences between men and women and return to work. Those with a higher level of education and higher social economic status were more likely to return to work. Being self-employed was also more favourable for return to work. Figure 5 shows the percentage in each employment group in terms of return to work.
From the univariate analysis it was found that a significantly less proportion of participants with a deteriorated ability to concentrate returned to work as well as those who have not kept the ability to run a shorter distance. P-ADL level was not associated with return to work.

The multiple logistic regression analysis showed that the most important factor associated with return to work was to feel that it was important to work. Being able to run a shorter distance was still an associated factor Table 4 shows significant factors associated with return to work.

### Table 4. Multiple logistic regression. Factors associated with return to work for younger persons with stroke

<table>
<thead>
<tr>
<th>Dependent variable</th>
<th>Independent variable</th>
<th>OR</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Return to work</td>
<td>Feeling it is important to work</td>
<td>5.10</td>
<td>3.35-7.74</td>
</tr>
<tr>
<td></td>
<td>Support in return to work</td>
<td>3.66</td>
<td>2.27-5.90</td>
</tr>
<tr>
<td></td>
<td>Not perceiving themselves as a burden</td>
<td>3.33</td>
<td>1.94-5.71</td>
</tr>
<tr>
<td></td>
<td>Run a shorter distance</td>
<td>2.77</td>
<td>1.50-5.12</td>
</tr>
</tbody>
</table>
Results

Perceived impaired physical and cognitive function (Paper 3)

Self-reported answers on physical and cognitive function in 867 P-ADL independent persons, 18-55 years, with a first ever stroke were analyzed. In 85% of the cases, the questionnaires were completed by the participants themselves.

More than half of the participants felt a deteriorated ability both in terms of physical and cognitive function. Women were more affected by their stroke than men.

There was an awareness regarding the positive effects of being physically active; however only a few, 28%, knew to which extent they were allowed to physically strain themselves after their stroke. The women were more likely to lack this information than the men (Figure 5).

![Figure 5. Perception of and information on physical exertion](image)

<table>
<thead>
<tr>
<th>Perception or Information</th>
<th>Women (%)</th>
<th>Men (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did not know how much they could physically exert themselves</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Important to be able to physically exert oneself</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Afraid of physical exertion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deteriorated ability for physical exertion</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Most participants had one or more remaining symptom after their stroke. There were no differences between men and women (Figure 6).

![Bar chart showing symptoms post-stroke]

**Figure 6. Symptoms post stroke**

The multiple logistic regression showed an association with deteriorated physical ability and cognitive functions as well as being afraid of physical exertion. Sex was not associated with deteriorated function (Table 5).

<table>
<thead>
<tr>
<th>Dependent variable</th>
<th>Independent variable</th>
<th>OR</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Move in crowded environments</td>
<td>Deteriorated cognitive function</td>
<td>5.41</td>
<td>3.96-7.94</td>
</tr>
<tr>
<td></td>
<td>Afraid of physical exertion</td>
<td>3.05</td>
<td>1.33-2.57</td>
</tr>
<tr>
<td></td>
<td>45-55 years of age</td>
<td>2.12</td>
<td>1.38-3.25</td>
</tr>
</tbody>
</table>

### Perceived life satisfaction (Paper 4)

1068 younger persons, 18-55 years, with a first ever stroke completed the questionnaire including the LisSat 9. Eighty-seven percent completed the questionnaire themselves.

Fifty-three percent were satisfied with life as a whole. Women were significantly less satisfied with their vocational and financial situation than the men (Figure 7).
Baseline data from RS and self-reported data on living and social conditions as well as physical and cognitive function was analyzed and compared with not being or being satisfied with life as a whole. The women and men were analyzed separately.

The strongest association of not being satisfied with life as a whole in the multiple logistic regression, when also analyzing men and women separately, was having a haemorrhage (OR 3.99) for women and living without significant other (OR 3.17) for men (Table 6).

### Table 6. Multiple logistic regression. Association between not being happy with life as a whole and significant background factors. Men and women were analyzed separately

<table>
<thead>
<tr>
<th>Dependent</th>
<th>Independent</th>
<th>OR</th>
<th>95 % CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not satisfied with life as a whole</td>
<td>Living without husband/wife/partner</td>
<td>3.17</td>
<td>2.05-4.92</td>
</tr>
<tr>
<td></td>
<td>Not working</td>
<td>2.26</td>
<td>1.46-3.48</td>
</tr>
<tr>
<td></td>
<td>Deteriorated ability to concentrate</td>
<td>2.04</td>
<td>1.33-3.12</td>
</tr>
<tr>
<td>Women</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not satisfied with life as a whole</td>
<td>Haemorrhage</td>
<td>3.99</td>
<td>1.68-9.52</td>
</tr>
<tr>
<td></td>
<td>Deteriorated ability to concentrate</td>
<td>2.11</td>
<td>1.20-3.71</td>
</tr>
</tbody>
</table>
DISCUSSION

This thesis investigated the consequences on several aspects and outcomes in younger (18-55 years) individuals with a stroke. Differences between men and women were also studied and associations and explanatory factors were investigated.

There were several results that were shared in the different studies. These were:

- The impact of deteriorated cognitive function (paper 1-4)
- The impact of deteriorated physical ability (paper 1-4)
- The need for information on physical strain (paper 1 and 3)
- Gender differences (paper 1, 3 and 4)

Frustrated and invisible

The general hypothesis generated in paper 1 is that younger stroke patients are frustrated and feel invisible and outside. The rehabilitation for the younger stroke patient is not adequate due to the fact that the rehabilitation setting does not acknowledge that younger stroke patients have different needs.

The sources of frustration were fatigue, lack of participation, lack of information, lack of age-adapted rehabilitation and gender related expectations.

Fatigue was the main source for frustration and it played a significant part in the informants’ lives were it affected them negatively both in terms of family and social commitments as well as return to work. Abnormal fatigue is a major disabling symptom in many chronic neurological diseases and a common complaint among stroke survivors (76-85). There is however, not much known about the severity and etiology of post stroke fatigue (86) and no reliable associations have been found between post-stroke fatigue and contributing factors such as age, gender, lesion location, severity, depression or disability (77-82). Post stroke fatigue is regarded as a multifaceted phenomenon interfering with many aspects of the stroke survivals lives (87-94). However, most studies have relied on one-dimensional fatigue scales and the need for a multidimensional approach is therefore necessary and required (86).

A disease or impairment impact on an individual is related to his/her sex, age, socioeconomic status and overall life situation. In this study men and women expressed different needs and also felt different obligations in terms of what was expected of them. The sample in this study is too small to state that our findings were gendered, but one cannot ignore the need for a gender perspective when studying the consequences of a stroke. It has been shown that social arrangements and expectations significantly influence impairment and disability (95, 96). Social context, gendered role expectations, and impairment seem to be interrelated.
Further analyses that combine and compare these factors among young stroke patients are therefore needed.

There was a lack of both information and participation amongst the informants. This was evident during all phases of the rehabilitation process, i.e. in the acute ward, in the rehabilitation ward and when integrating the family in the rehabilitation process. They were left with unanswered questions although they all claimed that they had received information and that they had understood the information that had been given. Results from other studies indicate that differences between the goals of involved healthcare professionals and the subjective needs and desires of patients, particularly in areas such as interpersonal relationships, roles, mobility and leisure, may result in isolation and development of secondary handicaps (97, 98). Salter et al (25) stress that if rehabilitation professionals actively promote an awareness of patient experiences, priorities and goals, effective strategies leading to care focused on what is most relevant to the individual can be achieved.

Return to work

A positive attitude to work and support from others was significant factors for return to work, as well as sustained ability to run a shorter distance. Surprisingly, the cognitive function and independence in P-ADL did not have the same considerable influence on return to work.

Several studies confirm the result on the importance of a positive attitude in order to return to work (41, 43, 99). An implication of this can be that the nature of the impairment does not need to be the most important determinant for return to work. The need for support from others to return to work has also been found by others (41, 99).

Surprisingly, P-ADL independence did not have the same impact on return to work as did ability to run a shorter distance. Apparently, although the participants were P-ADL independent, they could still have significant motor deficits and cognitive limitations. Similar results have been found by Vestling et al. (45) where the ability to walk was a contributing factor for return to work in an older age group than in the current study. Possibly, the conclusion that can be drawn from this is that in a young population, such as studied here, independence in P-ADL was an insensitive measure to detect significant remaining motor problems. Thus, asking for higher level of physical function, such as running, made it possible to detect those who were most prone for return to work.

Persons with minimal remaining symptoms can still perceive limitations after a brain injury (100). Surprisingly no significant association between cognitive function and return to work was found in this study. Since this was a questionnaire study the dimensions on cognitive function were not captured in the same way as physical aspects. The findings of limitations in higher level of physical function in this study could also indicate existing subtle impaired cognitive function, although not detected as a contributing factor for return to work. Thus, to
understand the physical and cognitive deficits sensitive tests are needed to detect remaining symptoms in order to optimise rehabilitation and return to work.

Although the result showed high percentage of return to work there are still 35 %, of those aged 18-55, who did not get back to working life. This might be due to insufficient rehabilitation strategies for promoting return to work and the possibility that these strategies are not adapted to the needs of the younger age group (41).

Cognitive and physical function

Despite an 83% (867 of 1068) independence in P-ADL, a large number of the respondents reported limitations in their physical and cognitive functions. These results confirm our hypothesis (22, 101, 102) that P-ADL is not sufficient in terms of measuring physical and cognitive abilities in the younger stroke population. Barthel index (70) and the modified Rankin Scale (MRS) (103) are commonly used to access outcome (104) although both have shortcomings (105) in terms of ceiling effects and limitations (103). In order to address these problems we asked questions which enlighten more challenging physical functions such as running a short distance. We also asked about more complex tasks such as moving in crowded environments, engaging in discussions, and concentrating and completing a task. It was here, on the subject of more demanding tasks, that the deteriorated ability was shown. These findings were supported by Sturm et al. (106) who found that in spite of a good recovery in terms of P-ADL, stroke survivors experience limitations in a range of domains.

The majority of the younger P-ADL independent stroke patients had a self-reported deteriorated ability to physically exert themselves and were afraid of physical exertion. As many as 72% stated that they did not know how much they were allowed to exert themselves physically after the stroke. This might be a negative factor in terms of rehabilitation and secondary prevention of the younger individuals with stroke since physical activity can improve well-being and functioning after a stroke (104, 107).

The P-ADL-independent women perceived themselves as being more disabled than the men concerning both physical and cognitive functions. Stroke-related outcomes, including disability, are consistently poorer in women than in men, yet the reasons for this are not well understood (6, 27, 29, 30, 108). There were also more women than men who did not know how much they were allowed to physically exert themselves after their stroke. This lack of information, among women, combined with the assumption that they have a lower physical function than men prior to the stroke (107) should be a target for intervention in stroke rehabilitation.

A strong association between cognition and physical abilities, regardless of sex, was found. This is an important finding for understanding the everyday life situation for the younger stroke
population. We have in a prior study found that women experience more demands on their cognitive abilities than men (102). This is another issue that needs to be taken into consideration when rehabilitating younger individuals with stroke.

**Life Satisfaction**

More than half of the 1068 younger individuals who had suffered a stroke were not satisfied with life as a whole. This could be compared to a normative group of healthy Swedes (25-55 years) (68) who in 30% were not satisfied with life as a whole.

Since results from our prior studies (102, 109) have shown differences between men and women in terms of both needs as well as deteriorated physical and cognitive functions, we decided to analyze men and women separately. However, both men and women who were P-ADL dependent, did not work, had a deteriorated ability to concentrate and to run, were more likely to be less satisfied with life as whole.

Dependency in P-ADL and its association with a lower level of life satisfaction/health related quality of life (HRQOL) and quality of life (QOL) is well documented (22, 110-114). However, to our knowledge no studies have investigated the consequences on life satisfaction of higher levels of physical functioning such as for example; the ability to run in relatively restored persons who have had a stroke. Adequate capturing of both physical and psychosocial well-being of those affected by stroke is critical in assessing effectiveness of therapeutic programs after a stroke (104). Since we believe, and also have shown in our research (102, 109), that higher level of physical function and life satisfaction are interlinked we suggest the need for more accurate measures. In the quest of finding factors associated with not being satisfied with life as a whole the independent factor haemorrhage stood out for women and not living with a significant other for men.

The risk of not being satisfied after a haemorrhagic stroke amongst women is hard to explain but can be due to the facts that absence from obvious neurological deficits does not guarantee that the patient has made a complete recovery from the hemorrhagic (27). Favourable outcomes for hemorrhagic stroke patients have been questioned though they in spite of good motor recovery still exhibit cognitive and emotional disturbances (69, 115, 116). It is common that survivors of hemorrhagic stroke are left with subtle and invisible disabilities such as fatigue, cognitive difficulties, and/ or one sided weakness (116). These disabilities can in some ways be more problematic then the visible ones (117) and have an impact on life satisfaction (22, 116). We have in our prior study found that since the handicap was invisible and therefore not as legitimate as other handicaps the participants felt a sense of not being understood and a fear of what other people would think (102). A previous study of young female haemorrhagic stroke survivors has shown that disability must be visible for the women to feel that it is worth to be taking seriously. They also hide their disabilities in order to be socially
accepted and by doing so allow others to continue believing that disability must be visible (117).

The need for men to have a significant other in their life in order to be satisfied with life as a whole has been seen in another study by Nagayoshi et al (118) who found that male Japanese stroke outpatients who were living alone were less likely to be satisfied than their female counterparts.

For both men and women, deteriorated ability to concentrate was a risk factor for not being satisfied with life as a whole. This is interesting since we in a prior study have shown that there is an association between not being able to concentrate and several physical limitations (109). Since cognitive deficits have also been shown to be a reason for not returning to work (16, 45) and a negative factor for being able to manage daily life (102) we strongly suggest that cognitive abilities need to be more carefully considered when rehabilitating the younger stroke population.

Methodological issues

A major strength with these studies, as all other registered-based studies, is the large size of the study population. The questionnaire was based on the results of an interview study which highlighted the specific needs and demands that were raised by younger individuals with stroke. Therefore, we claim that the questions in the survey are valid for the purpose of the study. The fact that the questionnaire was based not only on these findings but also included parts of established and tested instruments can also be seen as strength. The proportion of missing values were generally low and therefore unlikely to have had affected the results substantially.

The value of a self-reported test compared over a measurable one can be discussed. However; this thesis is based on the framework that all needs, limitations and disabilities expressed by this younger stroke population are just as they describe. It is their truth and experiences and how they, by answering the questions asked express the consequences of a stroke. An opinion that also should count for in research.

This is a national cross-sectional study given at a certain point of time. The aim of the questionnaire was therefore not to be tested on another population or in another period of time. However, as Riks-Stroke has a great coverage throughout Sweden and with a relatively small drop-out rate in this survey, the results may be representative for the younger stroke population in the whole country at the time for the study.

There were more men and disabled persons amongst the non responders than those who responded. This is an important fact that has been controlled for and considered throughout the work of this thesis. This may have influenced the results to some extent.

The association between depression after stroke and well-being is a well known fact. Since depression was not able to be measured in these studies there is awareness that this can have had an impact on the results.
Discussion

Ethical considerations

Although this project has been approved by a research ethics committee, several ethical issues have arisen during the work of this thesis. Some of these concern reactions from participants and some have appeared during the planning of the different studies. The questions that were discussed during the interviews were somewhat private. The informants were allowed to stop or to change the subject at anytime. We therefore hope and believe that no one was offended or felt exploited. Although all persons registered in RS have given their permission some felt upset about being registered. Perhaps this is a matter that needs to be considered when using large register data. As the population in Sweden has become more ethnically diverse, it is also important to consider how being part of another culture might influence the opinion on being part of a register.

Implications for stroke rehabilitation

- The strong association between deteriorated cognitive ability and deteriorated physical ability needs to be further explored
- In order to test physical ability in the younger stroke population more sensitive and demanding test needs to be developed
- The importance of high physical function and performance should be emphasized
- The need for younger persons who had suffer a stroke to receive information on physical strain must be fulfilled
- Motivation and support for return to work needs to be addressed as important factors for younger persons with stroke
- Gender differences must be considered in the care and rehabilitation of the younger individuals with stroke
CONCLUSIONS

Younger persons who have experienced a stroke feel frustrated due to the fact that their needs are not acknowledged. They express a sense of being outside and invisible. Men and women expressed different needs and dealt with the consequences of stroke differently.

External support, motivation and high physical function seem to be important factors for a successful return to work.

There is an association between deteriorated ability in cognitive functions and deterioration in physical functions after a stroke in the younger population.

Minimal symptoms and hidden dysfunction can have a major impact on the lives of younger individuals with stroke.

There is a need to optimize the rehabilitation for young persons with stroke as only 50% were satisfied with life as a whole. Factors that are associated with not being satisfied with life differ between men and women. However, both men and women who have a deteriorated ability to concentrate have a higher risk of not being satisfied with life as a whole.
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