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Mild Stroke

Consequences in Everyday Life, Coping and Life Satisfaction

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"If you want to understand how people
understand their world and their life, why not
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Mild stroke - consequences in everyday life, coping, and life satisfaction

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Abstract

Aim: The aim of this thesis was to explore the life situation one year after an apparently mild stroke, and to compare life satisfaction between patients and their spouses.

Method: Seventy-five patients with mild stroke participated. Neurological and cognitive impairment was assessed. Depression, post-stroke fatigue, concentration and memory problems, difficulties tolerating sounds and lights, stress sensitivity, irritability and other emotional changes, as well as problem solving abilities in everyday life were delineated. An interview was conducted that treated experiences of stroke onset, health care and rehabilitation, perceived cognitive end emotional impairments and view of life and the future. Questions were posed about the consequences in everyday life and coping. The patients and their spouses estimated their life satisfaction. In the comparison of life satisfaction 56 couples participated.

Result: After one year 25 % experienced no changes in everyday life. Eighty % were independent in basic activities of daily living. The most common symptom was fatigability reported by 72 %. More than 50 % experienced decreased stress tolerance and memory problems. Between 40 % and 50 % reported irritability, emotionalism, lack of initiative and concentration difficulties. Fatigability was associated with low satifaction with life as a whole, leisure, daily occupation, sex life and social life.

The participants experienced that the stroke had changed them cognitively and emotionally so that they in part experienced themselves as another person. They felt uncertainty about the risk for a new stroke and their prognosis concerning recovery. Their symptoms were to some degree "hidden" and difficult to comprehend and communicate, they were interpreted by others as being just psychological, and the border with normal function was unclear. Although they did not need physical assistance, the participants needed help and support, such as remindings, and help with planning and organising everyday life. In trying to cope with these difficulties the central experience was a feeling of uncertainty and of struggleing. The coping efforts comprised individual, relational and environmental concerns. Life satisfaction was affected for both partners in the couple, although in somewhat different areas of life. Satisfaction with life as a whole, leisure and sex life were affected most, where 70%, 80% and 75% respectively, of both partners agreed in being dissatisfied.

Conclusion: This study stresses the importance of focusing on the life situation in a long term perspective of individuals after a stroke that in the acute phase was apparently mild. The study shows that the problems experienced by these persons are often "hidden" and difficult to comprehend and communicate with others. This apparently mild stroke still had an affect on life satisfaction in both the patients and their spouses after one year.

Key words: Stroke, mild stroke, cognition, post-stroke fatigue, qualitative method, coping, life satisfaction

List of papers

Paper I

Carlsson GE, Möller A, Blomstrand C. Consequences of mild stroke in persons < 75 years - a 1-year follow up. *Cerebrovasc Dis 2003;16:383-388.*

Paper II

Carlsson GE, Möller A, Blomstrand C. A qualitative study of the consequences of "hidden dysfunctions" one year after a mild stroke in persons <75 years. *Disabil Rehabil 2004;26:1373-1380.*

Paper III

Carlsson GE, Möller A, Blomstrand C. Managing an everyday life of uncertainty - a qualitative study of coping in persons with mild stroke. *Submitted.*

Paper IV

Carlsson GE, Forsberg-Wärleby G, Möller A, Blomstrand C. Comparison of life satisfaction in couples one year after a partner's stroke.
In press. J Rehabil Med.

Contents

Abbreviations

AE	Astheno Emotional
BI	Barthel Index
CI	Confidence Interval
CPRS	Comprehensive Psychopathological Rating Scale
DSM	Diagnosis and Statistical Manual of Mental Disorders
I-ADL	Instrumental Activities of Daily Living
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairment, Disability and Handicap
LACI	Lacunar infarct
LiSat-9	Life Satisfaction Checklist 9-item version
LiSat-11	Life Satisfaction Checklist 11-item version
LM	Lindqvist & Malmgren
MMSE	Mini Mental State Exam
NIHSS	National Institute of Health Stroke Scale
OHS	Oxford Handicap Scale
OT	Occupational Therapist
PACI	Partial Anterior Cerebral Infarction
P-ADL	Personal Activities of Daily Living
POCI	Posterior Cerebral Infarction
QoL	Quality of life
SD	Standard Deviation
SSS	Scandinavian Stroke Scale
TACI	Total Anterior Cerebral Infarction
TIA	Transient Ischemic Attack
WHO	World Health Organisation
WHOQoL	World Health Organisation Quality of Life

General introduction

Stroke is a serious condition with respect to its medical features, its multitude of functional symptoms and their impact on everyday life. In the past decades, we have seen a changing face of stroke, with decreased severity, both in terms of lower mortality rates (Sarti 2000) and severity of symptoms at stroke onset (Stegmayr 1994; Numminen 2000) as well as an increase of milder strokes (Terent 2003). Stroke is often considered a disease that primarily affects the elderly, although 20 % of the persons who suffer a first-ever stroke are below the age of 65 years (Stegmayr 2003). Recent studies have also found stroke incidence to increase in people of younger ages (Johansson 2000; Medin 2004).

Stroke is a heterogeneous condition with respect to the multitude of symptoms that can affect patients in different ways. It incorporates all degrees of onset severity and recovery, from complete recovery to devastating impairments on the sensory-motor, cognitive and emotional levels. During their life span people engage in different patterns of activities and participation. Accordingly the impact of the stroke on everyday life will be different depending on age at stroke onset, and the severity of symptoms caused by the stroke.

It is well known that when a person has suffered a stroke, it has an impact on the life situation of their families (Palmer 2003). The stroke and its aftermath can result in chronic stress among spouses as well as patients. Like the person affected by the stroke, spouses also need a long time to adjust to the changes that the illness has made in their lives. The National Guidelines for Stroke Care stipulate involvement of next-of-kin to the stroke patient from the very beginning, in the acute stroke unit. Further, the guidelines state the importance of co-operation with families throughout the rehabilitation process and the importance of support to families after discharge from hospital (*Socialstyrelsen* 2005).

Most stroke studies include all severity levels of stroke, which undermine the opportunity to generate a differentiated picture of the condition. This thesis emphasises the life situation of middle-aged individuals one year after an apparently mild stroke and focuses also on the life situation of individuals with stroke and their spouses.

Stroke and its epidemiology

The World Health Organization (WHO) defines stroke as rapidly developing clinical signs of focal disturbance of cerebral function, with symptoms lasting more than 24 hours with no apparent nonvascular cause (WHO 1989). The two broad categories of the cerebral lesions are infarcts (85%) and haemorrhages (15%) (*Socialstyrelsen* 2005). Cerebral infarctions can be classified according to the artery affected and, in connection with this, the brain area that is damaged. Stroke is the second leading cause of death worldwide and the third cause of death in developed countries (Murray 1997; Sarti 2000). However, stroke is more disabling than lethal, and it is the second cause of long-term disability worldwide in individuals over 60 years of age (WHO 2004). Being the leading cause of lost years and disability, stroke has a very high economic cost, although costs may vary according to subtype (Taylor 1996; Payne 2002) and severity of stroke (Caro 2000). The proportion of informal care provided by relatives has been found to be greater than the proportion of formal care (Claesson 2000).

Studies of stroke incidence during recent decades have shown a less clear picture. Most studies show a decline in incidence during the 1970s and 1980s, but this decline slowed, reached a plateau or even increased between the 1980s and 1990s (Bonita 1993; Feigin 1995; Numminen 1996; Morikawa 2000; Pessah-Rasmussen 2003). Some studies have found the incidence to increase most in younger people (Johansson 2000; Medin 2004). The incidence rate in Sweden is at least 300 cases per 100 000 inhabitants a year (Appelros 2002; Stegmayr 2003) of whom 200 per 100 000 suffer a first-ever stroke. The prevalence of stroke in Sweden is estimated at more than 100 000 persons. Among those suffering a stroke it is almost an equal proportion men (51%) and women (49%). Below 65 years of age there are twice as many men than women but in the age group over 85 years there are twice as many women than men. The mean age at stroke onset is 75 years, 73.3 years for men, and 77.9 years for women (Riks-Stroke 2006).

Consequences of stroke

The impairments that follow stroke are various, such as different degrees of hemiparesis and sensory deficits, hemianopia, impairment of bowel and bladder control, dysarthria, and dysphagia. Attention and abilities necessary for information processing can be impaired, as well as perception, visuo-spatial deficits and hemispatial neglect. Different cognitive and executive abilities, memory, planning, structuring and organising information can be affected. Problems with initiative, motivation, affects and emotions are also symptoms after stroke. With left hemisphere lesions different kinds of aphasia can occur and right hemisphere lesions can result in pragmatic language disturbances (Kolb 2003). A stroke may also lead to symptoms of unilateral disturbance of autonomic function, such as coldness, dryness, and sweating (Naver 1995).

Cognitive impairment is a major sequel of stroke. Studies that have made assessments by brief cognitive screening, have shown significant cognitive deficits in 30 % of persons with stroke two years post stroke (Kase 1998; Patel 2003). A study of individuals with mild stroke with a mean age of 60 years based on more extensive neuropsychological testing showed that patients with impairments in executive functions in the acute phase had nearly sevenfold greater odds of being cognitively impaired six months later as compared to patients without executive disorders (Nys 2005; Nys 2005). This study further showed that impairment of more complex cognitive functioning, i.e., reasoning and executive functioning, were independent predictors of cognitive impairment in the long term, while perceptual and attentional dysfunctions were independent predictors of functional impairment at follow-up. A further study with a more extensive neuropsychological investigation of persons with stroke showed that after an average of 70 days post-stroke, 70 % of the respondents had a marked slowness in information processing, whereas at least 40 % of all participants had difficulty with memory, visuospatial and constructive tasks, language skills and arithmetic (Hochstenbach 1998).

In recent years fatigue after stroke has been recognised as a common complaint of individuals with stroke, but has as yet primarily been interpreted as a somatic symptom of depression (Staub 2001; Staub 2001; Bogousslavsky 2003). The prevalence of fatigue has been found to be between 39% and 72% (Colle 2006), to increase during the first year (Schepers 2006) and to be independently associated with instrumental activities of daily living and health related quality of life, although not with P-ADL (van de Port 2007). While it is well known that there is an overlap between fatigue and depression, it has been stated that post-stroke fatigue exists independent of depression (Staub 2001; Staub 2001; Rödholm 2003). It has also been proposed that neuropsychological deficits, in particular executive dysfunction and aphasia (Staub 2001), but also attentional deficits (Lindqvist 1993; Van Zandvoort 1998) play a role as a cause of mental fatigue.

The system for diagnosing post-stroke fatigue and related cognitive and emotional problems used in this study was the Lindqvist & Malmgren (Lindqvist 1993) system for organic mental disorders. This system is based on a psychophysiological theory postulating that the brain is a complex adaptive system, that tends to behave convergently that is to react in a limited number of ways to different noxae. They suggested six different organic mental disorders, astheno emotional syndrome being the most common after stroke. AE syndrome in it's mild and moderate forms is characterised by mental fatigability, impaired ability to concentrate, memory difficulties, sensitivity to bright lights or loud sounds, irritability and emotional lability with hypersensibility to emotional stress. In more severe forms there is also a general impoverishment of and sluggishness in associational processes, a lack of overview and a reduced capacity for abstraction. It is aetiologically neutral, often with a mixture of organic and psychogenic aetiologies. The condition is sensitive to environmental conditions. The differentiation between mild and moderate forms depends on the degree of these symptoms (Lindqvist 1993).

Emotional disorders after stroke can be divided in mood disorders, emotional dyscontrol and alteration of emotional reactions (Annoni 2006). Post-stroke depression, being the most common mood disorder after stroke, has been reported in both less than 25 % and more than 75 % of individuals with stroke (Provinciali 2002). However, major methodological differences between studies make interpretation of the results difficult. Over the past ten years, a large number of studies have been published concerning post-stroke depression (Gordon 1997). Post-stroke depression was found to be common after stroke both in the short-term (Burvill 1995; Eriksson 2004), and the long-term perspective (Astrom 1993; Kauhanen 1999; Dam 2001; Berg 2003). The prevalence of major depression in the general population has been estimated at

4% to 10% (Åsberg 2004). Anxiety disorders have also been found to be common after stroke (Astrom 1996; Sembi 1998).

Consequences of stroke in every day life

An extensive number of follow-up studies of individuals with stroke have been done with both short-term and long-term perspectives, and have focused on impairment, activity, participation and quality of life. With respect to personal activities of daily living, studies have shown 40 % to 50 % of individuals with stroke to be independent six months after stroke (Langton Hewer 1990; Jorgensen 1995), while other studies have found 70% to 80% to be independent (Schulz 1988; Mayo 1999). Persisting disability and difficulties with I-ADL activities (Thorngren 1990; Taub 1994; Mayo 2002) have been reported in several studies as have participation restrictions (D'Alisa 2005; Desrosiers 2005; Desrosiers 2006). One population-based study showed that 56 % of the respondents reported themselves to be in need of help from another person to manage everyday life. Further, 65 % considered themselves to have made an incomplete recovery (O'Mahony 1999). In a Swedish study based on data from the Swedish national quality register for stroke care 77 % expressed themselves to be fully or partially dependent on support from relatives (Glader 2001), and 30 % could stay alone less than half a day (Hulter-Asberg 2005).

Studies of the consequences of mild stroke are rare. One study of persons with mild stroke (Barthel Index score of ≥ 95), three months post stroke) showed that they had a lower health status as compared to asymptomatic individuals and individuals with TIA in all health dimensions except pain (Duncan 1997). In another study of persons with mild stroke (Barthel Index score of ≥ 95), three months post stroke) the participants showed significant residual disability in hand function, IADL, participation and overall functioning (Lai 2002). Van Zandvoort et al conducted a study with extensive neuropsychological testing of individuals with stroke who were independent in personal activities of daily living. These showed normal performance in 11 of the 17 tested areas. The tests most strenuous for the participants were attention under time pressure, executive functioning, abstract reasoning and the ability to effectively use several cognitive capacities simultaneously (Van Zandvoort 1998).

Stroke in younger ages often impacts the ability to return to work, although studies show different results, from 21 % to 73 % being able to return to work (Ferro 1994). Methodological differences (Wozniak 1999) and different ways to define and operationalize the concept of work (Vestling 2003) have been suggested as reasons for these diverse results, as have different patient mixes in different studies.

Qualitative studies of the life situation after a stroke

There is a growing body of evidence from qualitative studies with different foci on the life situation after the acute phase of a stroke. Studies concerning the ways in which individuals with stroke responded to the changes caused by the stroke showed that they found it important to follow professionals' advice, but also that they make own decisions about their care and rehabilitation, and to maintain a positive attitude and be motivated for change (Cox 1998). Further, individuals with stroke found it important to develop their own strategies for coping with the life situation and to engage in learning and exercise (Pound 1999).

The stroke was described to have disrupted the lives of the individuals affected, and they reported the need of re-establishing a sense of continuity (Kaufman 1988; Becker 1993) and hope (Burton 2000) in life. Qualitative studies have also shown that individuals with stroke define recovery in relation to their social context (Bays 2001) with a wish to return to pre-stroke life, while professionals put greater emphasis on functional recovery (Folden 1994). No qualitative study was found that focuses on the experiences of individuals with an apparently mild stroke.

Stroke and family

It has been written that "stroke is actually a family illness" (Bishop 1980). The impact of social support on the outcome of the stroke has been the focus of several studies, that point out the benefits of social support and social network ties during recovery from stroke. In a review of 78 studies of predictors of disability after stroke (Kwakkel 1996), social support was among the most robust and consistent predictor of post-stroke functional ability. Various other dimensions of family function also seem to influence both physical and psychosocial outcome after stroke, such as communication patterns, coping styles, empathy, conflict resolution, care giving patterns and problem solving abilities (Palmer 2003). Although the positive dimensions of social support dominated the picture, it has also been found that undermining the autonomy of the stroke survivor by overprotection from caregivers can lead to increased risk of post-stroke depression (Thompson 1989).

The impact of stroke and care-giving on family function has also been thoroughly investigated. Stroke has a significant emotional, social and economic impact on families (Payne 2002). Besides the effects of the stroke per se, feelings of sadness, grief, exhaustion, fear and anger were found to be common reactions in individuals with stroke, which increased dependence and vulnerability (Palmer 2003). Family caregivers have an elevated risk for depression, caregiver burn out, social isolation and increased physical symptoms (Han 1999), and decreased participation in social and leisure activities (Pound 1998). Depression is common among caregivers of stroke survivors (Dennis 1998; Nieboer 1998). Two factors have been put forth as being strongly related to care-givers depression: the severity of the stroke survivor's disability and the presence of emotional or behavioural problems that alter the relationship between the stroke survivor and the caregiver (Dennis 1998; Nieboer 1998). A passive coping strategy of caregivers has also been found to be an important predictor of decreased quality of life among spouses (Visser-Meily 2006).

The family situation of younger individuals with stroke is associated with a variety of issues such as childcare responsibilities, return to employment, the family economy and even marital break-up. One study of younger individuals with stroke showed that 14.5 % separated within three months of hospital discharge (Teasell 2000). The life situation of children of stroke survivors has also recently been highlighted. Findings in these studies show that childrens' adjustment was related to the strain perceived by the healthy parent (Visser-Meily 2005; Visser-Meily 2005). The children's functioning at one year post-stroke could best be predicted by their functioning at the start of their parents' rehabilitation process, but spouses' depression and perception of the parents' marital relationship were also significant predictors of the children's functioning (Visser-Meily 2005).

The studies done on the life situation of stroke survivors and their spouses have chiefly addressed the partners separately. However, one study compared the partners in a couple and showed that spouses generally had better health related quality of life than the stroke patients except concerning emotional and mental health domains (Jonsson 2005). Couples' functioning in everyday life and participation in leisure and social activities was found in another study to be related to the joint satisfaction with life as a whole for both partners in couples in whom one had suffered a brain lesion (Eriksson 2005).

One focus of this study was to address the satisfaction with life as a whole and satisfaction with different domains of life as compared between the partners in couples in whom one had suffered a stroke. The life situation of the spouses of the patients in the present study has been studied concerning, psychological well-being (Forsberg-Warleby 2001) , view of the future (Forsberg-Warleby 2002) and sense of coherence (Forsberg-Warleby 2002) in the first phase after the stroke and with respect to psychological well-being (Forsberg-Warleby 2004) and life satisfaction during the first year after their partners stroke (Forsberg-Warleby 2004).

Theoretical and methodological framework

This study has its ground in a combined neurological, psychological, and occupational therapy perspective.

Occupational Therapy and Rehabilitation perspective

A great proportion of individuals with stroke need rehabilitation in the acute and in the long-term perspectives (Lundgren-Nilsson 2000; O'Connell 2001; Bendz 2003; Roding 2003). Stroke as a complex medical condition that with its heterogeneity in symptoms provides a challenge to rehabilitation staff, as it demands knowledge of several areas of human behaviour and functioning.

Research has shown that an early start of rehabilitation after stroke is essential and that stroke care and rehabilitation programs should be conducted in stroke unit care, by a stroke rehabilitation team (Stroke Unit Trialist's Collaboration 2002).

The role of the occupational therapist is to evaluate and treat problems in occupational performance (Law M 1994; Nelson 1994; Kielhofner 1997). In this context the concept of occupation is used in a broad sense comprising all the ordinary and familiar things people do every day (Clark 1991; Christiansen 1995). Engagement in occupations is important for taking control over daily life and enables people to reach competence (Christiansen 1995). Achieving a sense of efficacy, feeling confident and mastering daily tasks have always been central concepts in occupational therapy (Clark 1993), and the relationship between occupation and health is often discussed in the occupational therapy literature (Yerxa 1998; Wilcock 19998). It has been found that relearning based on a task oriented approach, with activities chosen by the patient and performed in a familiar environment, increased activity performance and participation among patients (Ma 2002; Trombly 2002).

A model of human occupation is based on a systems theory view of occupation where occupation is seen as a constant dynamic interaction between the individual, the task and the environment. This model could provide a frame of reference for understanding and treating problems in daily occupations, well suited to stroke with its diverse consequences. The human has three different subsystems, volition habituation and the mind-brain-body system. Volition is defined as dispositions and self-knowledge that dispose and enable persons to anticipate, choose, experience and interpret their occupational behaviour, while habituation consists of habits and roles and the mind-brain-body system is the performance system (Kielhofner 2002). A stroke can affect all three systems.

ICF

The International Classification of Functioning, Disability and Health (ICF) (WHO 2001) is a conceptual framework that classifies consequences of illness and disease, well suited to describe stroke with its heterogeneous impairments and consequences in everyday life. It has two parts: 1. functioning and disability, including the components body function and structures, activity and participation; 2. contextual factors, including the components environmental and personal factors. Impairment is defined as a problem with body function or structure, such as a significant deviation or loss. Difficulties a person may have in performing activities or tasks are defined as activity limitation, and problems an individual has in involvement in life situations are labelled participation restrictions. The dynamic interaction between the levels in the model is shown in Figure 1.

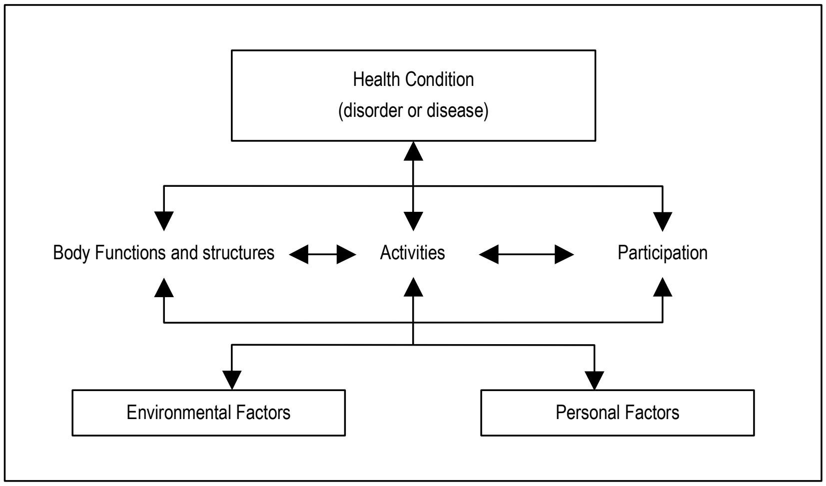

Fig. 1. Interactions between the components of ICF

During the time of this study the ICF has been revised from the earlier ICIDH (WHO 1980), where the central concepts were impairment, disability and handicap. Wherever possible the nomenclature of the ICF is preferred in this thesis.

Stress and coping

Stress and stressful life events and their damaging effects on people's life situation have been extensively studied, and there is rapidly growing knowledge about the ways people cope with stressful life events and their adaptation to a new life situation.

Adaptation as a concept has been defined, as routine modes of getting along with life; and is a broader concept than coping and includes habits.

Coping on the other hand refers to non-routine actions, and involves stress in some form (White 1985). Coping can be seen as adaptation under relatively difficult conditions. A distinction has been made between coping as a trait, treating coping as a personality characteristic, and coping as a process, including environmental influences (Lazarus 1993).

Coping has been defined as: "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resource of the person" (Lazaarus 1984). The person evaluates the potential threat, loss or challenge of the stressor on the basis of what it means to his or her well being, which is the primary appraisal. When the person experiences stress, secondary appraisal occurs. This means that the person considers his or her ability to manage the stressful event. The primary and secondary appraisals are integrated and should not be seen as existing in a cause and effect relation. Coping requires cognitive and behavioural efforts, which excludes automatised behaviours. Coping efforts are independent of outcome, and the term coping is used regardless of whether the process is successful or not (Lazarus 1993).

Stress, emotion and coping should be seen as a unity, existing in a part-whole relationship. As Lazarus points out (Lazarus 1999), there is an interrelationship between the concepts of stress, thinking, emotion and coping. Studying the coping process requires that we describe what the person is thinking, feeling and doing at each stage, and the context in which it occurs. In this thesis we focused on the individual experiences of, and coping with the consequences in, everyday life after a mild stroke. Stroke is an individual experience, and life after a stroke is more concerned with coping and adaptation to a new life situation, rather than being an issue of physical ability (Burton 2000).

Life satisfaction

It has been suggested that research concerning outcome should not only focus on disability and activity performance but also consider satisfaction with everyday life (Johnston 2002). The World Health Organization Quality of Life (WHOQoL) group defines QoL as an individual's perception of his or her position in life in the context of the culture and value system in which he or she lives and in relation to his or her goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's health, psychological state, level of independence, social relationships, and his or her relationships to salient features of his or her environment (WHO 1993).

No consensus concerning the definition of QoL exists, and some authors argue that it should not be used synonymously with happiness, life satisfaction and well-being (Lau 2001), while others use these concepts interchangeable and inconsistently (Frisch 2000. p 207-41). QoL is said to have both objective and subjective aspects while life satisfaction is purely subjective and refers to a person's feelings of happiness with his/her life (Meeberg 1993).

Concerning life satisfaction Campbell (Campbell 1976) stated that satisfaction is based on a cognitive evaluation of one's actual situation placed against external standards of comparison, thus is based on aspiration. It is related to the individual's preferences and wishes and Campbell defines a person's satisfaction within any domain of life as the gap between the aspiration level and perceived circumstances.

It has been discussed whether satisfaction with life as a whole is built up of satisfaction with different important domains of life (the bottom-up model) or whether people are predisposed to experience and react to events in a positive or negative way (the top-down model) (Veenhoven 1998). It has also been stated that life satisfaction consists of both stable individual personal characteristics and of more momentary satisfaction with different life domains of importance and current mood (Heady 1991; Schimmack 2002).

Methodological framework

A combined qualitative and quantitative research approach was chosen to be able to capture the diversity of individual experiences of, and coping with the multitude of symptoms after stroke and their consequences in everyday life. Combining research methods gives the opportunity to use the strengths of different methods and thereby gain a deeper knowledge and understanding of the phenomenon under study (Morgan 1998; Taylor 2000). The nature of the research problem has to guide the choice of research approach (Strauss 1998).

Qualitative analysis has the purpose of identifying and determining phenomena, characteristics and meanings, that are as yet unknown or insufficiently known with respect to variability, structures and processes. The aim of quantitative analysis, on the other hand, is to investigate how previously defined phenomena and their characteristics are distributed in a population or a sample. A further aim of quantitative analysis is to investigate associations and causality between phenomena (Starrin 1994. p 21).

Another difference between quantitative and qualitative research is how the context is taken into account. In qualitative research reality is understood in its context and presumed to be holistic, which means that the context is necessary for the understanding of the phenomenon (Denzin 1994; Patton 2002). In contrast, quantitative research presumes that phenomena can be studied objectively, independent of their context (Nilstun 1996; Hartman 1998).

Grounded theory, the qualitative method used in this thesis, has its roots in symbolic interactionism (Blumer 1969). This theoretical perspective assumes that the human self emerges through the interaction with other people and the environment, and that it develops and changes throughout the life span. Human beings are proposed to act on the basis of the meaning things have for them. Meaning arises from the interaction with others and through the interpretive process people use in dealing with the environment and its manifestations (Glaser 1967; Glaser 1978). Grounded theory is a method for deriving theory by empirically studying the phenomenon it represents; the theory is grounded in data or develops concepts from empirical data (Glaser 1967; Glaser 1978; Strauss 1998).

Ethical considerations

The Ethics Committee of the Faculty of Medicine, Göteborg University, Sweden, granted approval of the study. Oral and written information was given to all participants. Informed consent was obtained from all participants. If the stroke patients in the acute phase were too cognitively disabled to give informed consent, the patient and the spouse were informed together and the spouse gave consent. If a need was found in medical, psychological or practical issues, information was given as to where or to whom the spouses could apply to obtain help.

AIMS

The general aim of this thesis was to investigate the long-term consequences in everyday life of a first-ever stroke in persons < 75 years of age, with a special focus on the stroke patients' experiences of, and coping with, "hidden dysfunctions". Another aim was to investigate the impact of the stroke on the stroke patients' and their spouses' common life situation.

The specific aims were:

* to investigate the consequences of mild stroke in terms of impairment, activity limitations, and participation one year after a first-ever stroke in persons <75 years and its relation to life satisfaction. A particular aim was to investigate what symptoms the patients experienced with a special focus on "hidden dysfunctions" such as mental fatigability, lack of ability to concentrate, memory disturbances, changes in emotional stability, stress resistance, anxiety and uneasiness, together comprising the AE syndrome. (Study I)

* to explore from an actor's perspective how stroke patients with AE syndrome, one year after a first-ever mild stroke, experienced the changes in everyday life caused by the syndrome. (Study II)

* to explore from an actor's perspective how and why stroke patients with AE syndrome coped with their new life situation the way they did, during the first year after the stroke. (Study III)

* to make within couple comparisons of life satisfaction and agreement in life satisfaction among stroke patients and their spouses one year after stroke. A further aim was to compare the patients' and spouses' life satisfaction with norm values and in relation to social factors. (Study IV)

Method

Study group

Inclusion of participants in this study was based on the inclusion in the longitudinal study of spouses of stroke patients conducted in our research group (Forsberg-Warleby 2001; Forsberg-Warleby 2002; Forsberg-Warleby 2002; Forsberg-Warleby 2004; Forsberg-Warleby 2004). Patients were consecutively selected at admission to the Neurological Unit at Sahlgrenska University Hospital. Inclusion criteria were: 1) a manifest first-ever stroke, including minor stroke excluding subarachnoid hemorrhage, 2) age < 75 years, 3) living in Göteborg or surrounding communities, 4) living together in a steady relationship, 5) both stroke patient and spouse able to speak and understand Swedish, 6) no other rapidly progressing/malignant disease and 7) the spouse not having had a stroke or cognitive decline.

Inclusion ran between 1995 and September 1997. The participants were identified by daily contact with the staff in charge at the neurological ward. The stroke patients were contacted at the ward within five days after the stroke for their informed consent for their own participation and their approval to contact the spouses. The patients were contacted again for informed consent to participate in this one-year, cross-sectional, follow-up study.

During the inclusion period 342 stroke patients were identified, of whom 236 did not fit the inclusion criteria. One hundred and thirty were single, 33 were over 75 years, 44 had a recurrent stroke, 16 did not live in the geographic area, three did not speak Swedish and four had co-existing malignant diseases. Two patients were personal friends of one of the researchers and were excluded. Three spouses experienced stroke or suffered dementia themselves and one spouse did not speak Swedish.

As a part of the aim of the study was to make comparisons between patients and spouses, inclusion was based on the possibility of both partners' participation. One hundred and six stroke patients fulfilled the criteria and were contacted three to five days after their stroke. They were informed about the study and invited to participate. A flow-chart showing the participation and dropouts in the one-year follow up is shown in Figure 2.

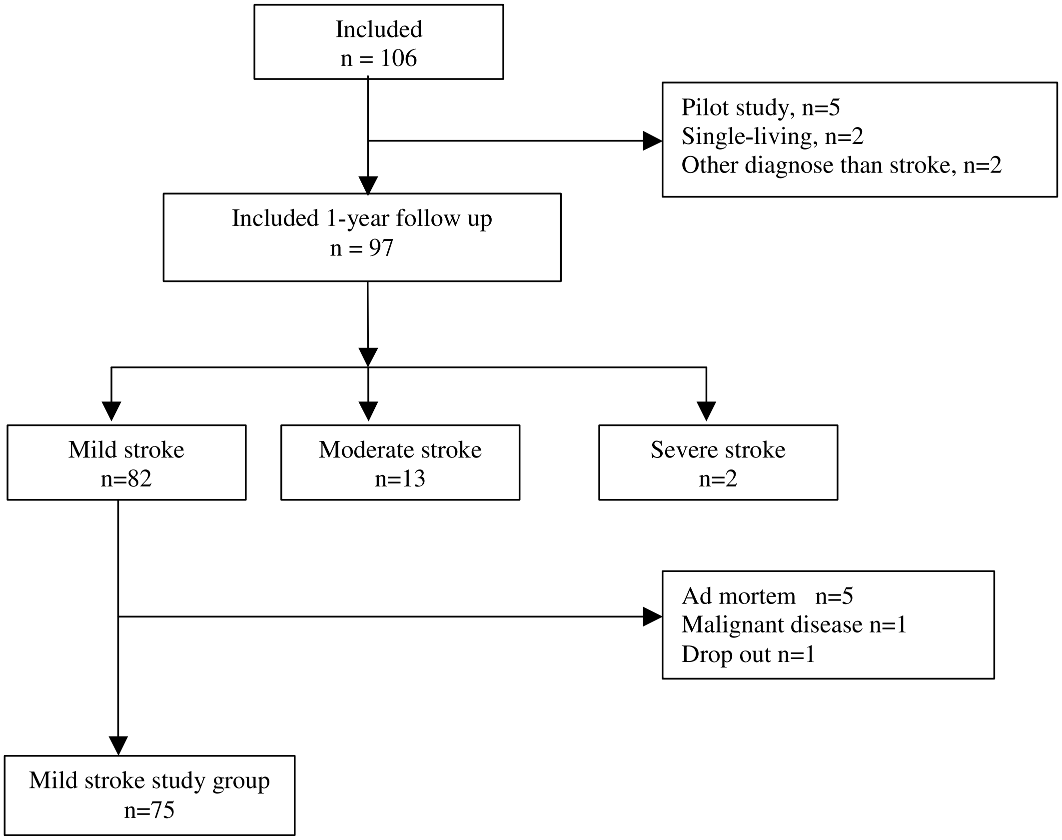

Figure 2. Flowchart describing the inclusion process of the study.

A total study group of 97 stroke patients was included, of which five died between the acute inclusion and the one-year follow up. Of the 92 patients available, the neurologist saw 90. One patient was not able to participate due to a fatal disease, and one patient had developed severe post-stroke dementia. Of the 90 participants 62 (69 %) were male, which could be seen as a normal proportion with respect to sex in these age groups. The mean age was 59 (SD 11.3) years, and the median age was 60 (25th - 75th percentiles 51-68) years. Stroke subtypes according to Bamford criteria were LACI 17, PACI 36, POCI 19, TACI 3 and 15 hemorrhagia cerebri.

The categorization according to stroke severity of the 97 participants included in the acute phase yielded 82 patients with mild stroke. Five died before the one-year follow up, one developed a fatal malignant disease and one developed severe dementia. Accordingly, these 75 patients with mild stroke constituted the study group of **paper 1**. Fifty-two (69%) were male. The mean age was 59.6 (SD 11.3) years and the median age 62 (25th - 75th percentiles 54-68). Stroke subtype according to Bamford criteria was LACI 17, PACI 32, POCI 15 and 11 hemorrhagia cerebri. There were 32 left hemisphere, 27 right hemisphere, 14 infratentorial, and 2 bilateral lesions.

For the qualitative studies in **papers II** and **III** the respondents were recruited from the 75 patients with mild stroke. Fifty-three of these patients were diagnosed with an AE syndrome, which formed the bases for the selection of patients for the qualitative studies. Selection criteria were: a diagnosis of AE syndrome, no or as small other stroke related impairments as possible, a diversity in age although < 75 years, diversity in vocational/occupational situations, and good informants. Patients with aphasia and cognitive impairment on a level where interpretation of the interview data was not considered valid were excluded.

In **paper IV** whose aim was to make a within couple comparison of life satisfaction, the study group consisted of couples where both patients and spouses agreed to participate and both had filled in an estimation of their life satisfaction according to LiSat-9. This study included patients with all degrees of stroke severity at stroke onset, which yielded 47 with mild stroke, seven with moderate, and two with severe stroke.

Withdrawals

In **paper I** there were internal withdrawals from parts of the study. Within the study group of 75 patients, ten did not give approval for a home visit and interview, and two persons were not capable at the home visit of participating in all parts of the study owing to aphasia or severe cognitive impairment; however, these respondents did participate in the other parts of the follow-up. Compared to the group of 63 respondents participating in the total study, there were no significant differences with respect to sex, age, neurological impairment, ability in self-care or level of handicap. There were significantly more hemorrhagic strokes than cerebral infarctions among the withdrawals (Chi2 = 8.32, p = 0.04). Seven had returned to at least half-time work, and their reason for declining participation were that they did not have the time to participate or felt good and wished not to dwell upon what had happened. Three were retired before the stroke and considered themselves to be living the same life as before the stroke. Further one patient declined to fulfil the MMSE and Star Cancellation Test, which means that 62 patients fulfilled these assessments. One patient, whose wife was severely ill from a malignant disease, felt that he was not able to have an opinion about life satisfaction. Further, one patient with dysphasia did not manage to complete the LiSat-9, while he was able to participate in the MMSE and Star Cancellation Test. In conclusion 61 persons filled in the LiSat-9.

There were no persons who withdraw from the patient population in **papers II and III** as the study group were selected from those patients who gave their approval to a home visit including an interview.

The withdrawals in **paper IV** pose special problems. As the aim was to make within couple comparisons, if one partner withdraws, the other also is lost. The inclusion and non-respondents in this study are shown in Figure 3.

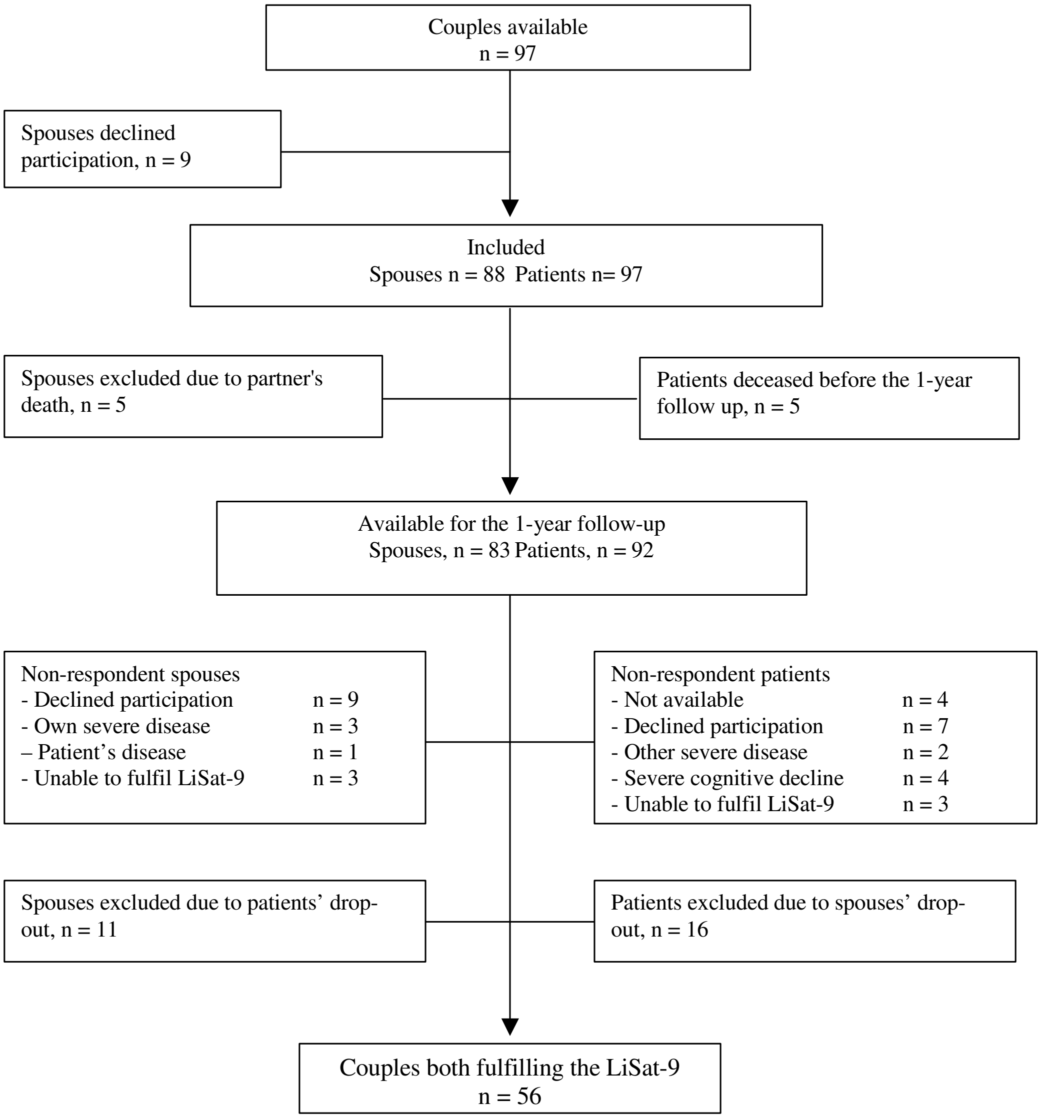

Figure 3. Flowchart of the inclusion and non-respondents in paper IV.

To investigate whether the non-respondents affected the results (Paper IV), a series of worst case/best case scenario analyses were created (Altman 1997). The best case scenarios, which hypothesised that all non-responding couples agreed in their estimations, did not affect the results. The worst case scenario, disagreement between the partners, would, in the case of all non-responding patients being satisfied, have changed the differences between the partners concerning satisfaction with life as a whole. The worst case scenario was that all non-responding patients that were dissatisfied would have changed the differences concerning satisfaction with the partner relationship.

Data collection

The study is based on a combination of quantitative and qualitative research methods.

Data in this one-year follow up were collected at a home visit made by an occupational therapist (GC) and at a visit to a neurologist (CB) at Sahlgrenska University Hospital. In paper IV the data from the spouses were collected from an occupational therapist (G F-W), where the interviews were conducted at the Occupational Therapy Department at Sahlgrenska University Hospital or at some other convenient place chosen by the spouse.

Demographic data concerning age and sex were collected. Subtype of stroke was classified according to localisation using Bamford criteria (Bamford 1991); lesion side was also registered. The following assessments were done in the acute phase and at the one-year follow up.

Body function and structure

Neurological impairment was assessed with the Scandinavian Stroke Scale (SSS) (Scandinavian Stroke Study Group 1985), a prognostic and long-term functional score developed by the Scandinavian Stroke Study Group. The instrument includes measurements of orientation, eye movements, motor power of arm, hand and leg, speech, facial palsy and gait. The maximum score is 48 and the higher the score, the better the functional level. The SSS has been shown to be a valid and reliable instrument for stratification of stroke patients and has good inter-observer agreement (Lindenstrom 1991; Barber 2004).

Cognitive screening was done with the Mini Mental State Exam (MMSE) (Folstein 1975). The MMSE is a well established, brief cognitive screening instrument that is easy to administer. It has a maximum score of 30, and a cut-off equal to or below 24 for a cognitive decline at a level for dementia. Validity and reliability are studied (O'Connor 1989; Mitrushina 1991; Fabrigoule 2003). Age-specific norms are available (Bleecker 1988).

Hemi-inattention was assessed with the Star Cancellation Test (Friedman 1992), which consists of a sheet with 56 target stars of different sizes arranged pseudorandomly throughout the test sheet, and the patient is to identify all stars of a specific size. The number of stars detected at the contralesional side is divided by the total number of detected targets and represented by a percentage measure. It was classified as contralateral asymmetry if a laterality score below

44% and above 56% was found (Samuelsson 1995). Depression was diagnosed according to DSM IV criteria (American Psychiatric Association 1999) by the neurologist. The neurologist also diagnosed the AE syndrome. This diagnosis was based on an overall assessment made in a patient interview with questions on performance in everyday life, especially concerning activities such as reading, watching TV, participating in conversations etc (Lindqvist 1993; Rödholm 2003). Ratings from the Comprehensive Psychopathological Rating Scale (CPRS) (Asberg 1979) are also used as a complement in identifying and grading the severity of the syndrome.

Activity and Participation

Level of independence in basic activities of daily living was assessed with the Barthel ADL Index (Mahoney 1965). The Barthel Index includes ten weighted items: feeding, personal hygiene, bathing, dressing, toilet, bladder/bowel control, chair/bed transfer, ambulation/wheelchair and stair climbing. The maximum score is 100, which implies independence in self-care and indoor ambulation. The guidelines suggested by Wade were used and these state that the index should be used as a record of what the patient does, not as a record of what a patient could do; any kind and degree of help, physical or verbal, as well as supervision renders the patient not independent (Wade 1992. pp. 176-178.). The validity, reliability and responsiveness of the Barthel index have been demonstrated (Collin 1988; Wade 1988).

Further assessments were added at the one-year follow up. Level of handicap was assessed by the Oxford Handicap Scale (OHS) (Bamford 1989). This measure focuses on changes in lifestyle and social roles, capacity to look after oneself, and level of independent existence. It is a single item measure with scores divided into six different degrees (range from 0, no handicap/restriction in lifestyle, to 5, severe handicap/restriction in lifestyle). OHS is a further development of Rankin (Rankin 1957) and the Modified Rankin Scale (van Swieten 1988), which focus on global functioning with a strong emphasis on physical disability (de Haan 1995). (For a detailed description see Appendix 1)

Respondents rated their life satisfaction with the Life Satisfaction Checklist 9 (LiSat9) (Fugl-Meyer 1991). The checklist contains: satisfaction with *life as a whole*, one *health item*; ability to manage self-care, *two provision items*; vocational and financial situation, *three closeness items*; sex life, partner relationship 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. It has been shown to have intra-individual stability and sensitivity to changes (Fugl-Meyer 1991). Norm values from a Swedish population are available (Fugl-Meyer 2000;17.p. 217-234; Fugl-Meyer 2002; Melin 2003). The checklist is often used in a dichotomised version where degrees 5-6 constitute satisfied and 1-4 not satisfied. The arguments for dichotomising the scale were to separate those who were satisfied from those not satisfied. The wording "rather satisfied" was interpreted as the subject not being truly satisfied (Fugl-Meyer 1991). The validity of this dichotomisation has been demonstrated (Fugl-Meyer 2002). In this study we used the dichotomised version of the checklist to be able to make comparisons with the norm values, which are given dichotomised.

Interview data

The one-year follow up also included an interview, comprising all levels of ICF, body function, activity, participation, and personal and environmental factors. In the interview, the areas of the questions concerned the respondents' experience of stroke onset, symptoms and dysfunctions at stroke onset and remaining symptoms after one year, with a special focus on cognitive and emotional dysfunctions. Questions were posed about consequences in everyday life and how and why the respondents tried to handle their difficulties the way they did. A further focus was the patients' experience of their spouses' role in the recovery process.

There were two core concepts in these interviews, experience and coping. To focus on the subjects' experiences, we needed to ask them to tell us about their perceptions, thinking and feelings. By focusing on coping we wanted the subjects to tell us what they did to manage their new life situation with its problems and difficulties, what they were thinking, feeling and doing in specific activities and the situation they described, and the context in which it occurred. Interviews were tape recorded and transcribed verbatim.

Data analysis

Qualitative method

Paper I.

The respondents were interviewed about their perception of symptoms that remained one year after stroke onset with a special focus on cognitive and emotional dysfunctions and symptoms comprising the AE syndrome. These interview data were analysed by content, counting the number of respondents who perceived the symptoms targeted in this study.

Papers II and **III**.

An analysis method inspired by grounded theory was used in the qualitative studies. The transcribed manuscripts and written memos from the home visits and interviews were the sources of data in these analysis. Analysis started on a concrete level with open coding. Transcripts were analysed line by line, broken down into discrete parts, closely examined and compared for similarities and differences. Events, happenings, objects and actions/interactions that were found to be similar in nature or related in meaning were grouped together.

The analysis process continued, to cluster codes with similar content together in categories. In the phase of axial coding which is coding around the axis of one category, the categories were linked with their dimensions and properties. The analysis continued to more abstract levels, linking categories together to main categories, which were further integrated and refined, ending up with a core category, that emerged from the data and covered the phenomenon under study. In this phase the creation of a theory or model becomes an important part of the analysis. This is done by memo writing, linking the different levels of analysis together.

Throughout the whole process of analysis a constant comparison of data, codes and categories was made, assuring that codes and categories were in fact grounded in the data. Analysis was continued until saturation was reached, that is the point in category development at which no new properties, dimensions or relationships emerged during analysis.

The open coding process in Paper II yielded 31 subcategories describing the different experiences of the respondents' everyday life with the AE syndrome on a more concrete level. Further analysis yielded a grouping of these categories into four categories covering different dimensions of what it meant to the respondents to live with this condition. A core category emerged covering the data and summing up the experiences described by the respondents. The respondents reported the mutual influences of experiences and how they affected one another, which is shown in the model as a dynamic pattern between the core category and the four categories.

They also described how the symptoms fluctuated and were more or less apparent in different contexts, which were addressed in the analyses by seeing the four categories as continua between two endpoints.

The open coding process led to 12 subcategories in Paper III. These subcategories were further analysed according to their focus on how and why the respondents chose to cope with their condition as they did, yielding three categories that describe how and why the respondents tried to cope with their condition as they did. Further analysis yielded a core category grounded in data covering the content of the analysis.

Statistical analyses

Paper I and **IV**

The data levels in this thesis, except as concerns the age variable, were on an ordinal and nominal level. Neither did the data show normal distribution. The analyses were therefore based on non-parametrical methods. As it is common, to present ordinal data with means and standard deviations, this was done in some cases to facilitate comparisons with other studies (Altman 1997). Descriptions of basic data are presented with median and 25th - 75th percentiles as well as with frequencies and proportions. The LiSat-9 was dichotomised into “not satisfied” (categories 1-4) and “satisfied” (categories 5 – 6). A comparison was made with norm values in a comparable age group living in a steady partner relationship (unpublished data, personal communication Fugl-Meyer K, 2004) extracted from a Swedish population study (Fugl-Meyer 2000;17.p. 217-234; Fugl-Meyer 2002; Melin 2003).

Paper I

The dichotomised version of the LiSat-9 was used in the comparison between the patients and the norm group. The statistical calculation was made using the Chi^2 test for unpaired data. Correlations between AE syndrome and the ordinal variables Barthel Index, Mini Mental State Exam, Scandinavian Stroke Scale, Oxford Handicap Scale and Life Satisfaction Checklist, depression and age were made with a nonparametric method using Spearman's rank correlation coefficient. The nominal variables of sex, Bamford criteria and stroke location and its relation to the AE syndrome were calculated with the Chi square test. Confidence interval (95%) for proportions and differences between proportions were calculated.

Paper IV

Confidence intervals (95 %) were calculated for the differences in the proportion of satisfied patients and spouses, respectively, as compared to the norm group, and for the difference between paired proportions within the couples. Within couple differences in life satisfaction were calculated with McNemar's test for paired data. Differences between patients/spouses and norm values were calculated with the Chi square test. The relationship between patients and spouses who were satisfied/not satisfied and the dichotomous variables of sex, work situation and responsibility for children was analysed with the Chi square test or Fischer's exact test. A p-value of 0.05 was chosen for the level of significance.

General results

The total study group of 90 patients showed progress in their recovery process during the first year. In the first week after stroke onset, 52 % of the respondents were independent in P-ADL; this was the case among 84 % after one year. In the neurological impairment assessment, 22 % scored maximum in the acute phase and 71 % at the one-year follow-up. Of the 90 patients, 76 % were diagnosed with AE syndrome and 36 % were depressed. Among the female participants 39 % were depressed and among the males 34 % were depressed, which was not a statistically significant difference ($Chi^2=0.197$, $p=0.657$). Neurological impairment, ability in self care in the acute phase and at the 1-year follow up and level of handicap at one year in the 90 stroke patients that participated in the one-year follow up are shown in Table 1.

Table 1. Neurological impairment, ability in self care in the acute phase and at the 1-year follow-up. Level of handicap at the 1-year follow up.

		Mean	*SD*	*Median*	*25th-75th percentiles*	*Range*
Scandinavian Stroke Scale						
	Acute	37.5	12.0	42	33-47	6-48
	1-year follow up	45.1	6.8	48	46-48	12-48
Barthel Index						
	Acute	80.0	27.2	100	60-100	0-100
	1-year follow up	96.7	9.7	100	100-100	45-100
Oxford Handicap Scale						
	1-year follow up			2	2-3	0-5

n=90

After discharge from the acute ward, 44 of the 90 patients received some kind of training, ranging from inpatient rehabilitation to training sessions with most often a physiotherapist. After one year, all patients except one lived in their own homes. One woman lived in a care exchange with two weeks in a nursing home and two weeks in her own home.

Consequences of a mild stroke

This first study (Paper I) explored the patients' experiences of remaining symptoms after one year and focused particularly on AE syndrome, and its consequences in everyday life with respect to activity limitations, participation restrictions and perceived life satisfaction. This study investigated patients with mild stroke (n=75).

Neurological scoring based on the SSS showed that 81 % of the patients rated the maximum score. Among the 14 patients that did not have maximum scores, aphasia was the most common finding. The results of the MMSE were equal to norm values in matched age groups. Five patients scored below the cut-off for dementia, all exhibiting aphasia. In P-ADL as assessed with the Barthel Index 80 % were independent, and the six patients who were dependent needed only minimal assistance. Neurological impairment, cognitive screening, Barthel Index score in the acute phase and at the one-year follow up and level of handicap at the one-year follow up are shown in Table 2.

Table 2. Neurological impairment, cognitive screening, Barthel Index score in the acute phase and at the 1-year follow up and level of handicap at the 1-year follow up.

		Mean	**SD**	**Median**	**25th-75th percentiles**	**Range**
Scandinavian Stroke Scale	**Acute**	42	7.3	43	38-48	8-48
	1-year follow up	47.2	1.9	48	48-48	38-48
Mini Mental State Exam	**Acute n=61**	25	8.3	28	25-29	0-30
	1-year follow up n=62	27.8	3.7	29	28-30	13-30
Barthel ADL Index	**Acute**	90.0	3.2	100	80-100	55-100
	1-year follow up	99.5	0.5	100	100-100	85-100
Oxford Handicap Scale	**1-year follow up**			2	1-3	0-4

n=75

The self-reported symptoms at the one-year follow up showed that mental fatigability was the most common symptom, with 72 % of the respondents reporting this problem. The most common symptoms experienced by the respondents are shown in Table 3.

Table 3. Symptoms perceived by the respondents based on interview data at the 1-year follow- up.

Symptoms	n	%
Increased mental fatigability	54	72
Memory dysfunction	41	55
Concentration difficulties	36	48
Irritability	31	42
Emotional lability	29	38
Anxiety, uneasiness	19	25
Stressfulness	41	55
Lack of initiative or motivation	32	41

n=75

AE syndrome was diagnosed in 53 (71%) of the respondents, which could be seen as giving good agreement with the self-reported symptoms. Depression was diagnosed in 39% of the patients, with no significant difference between male and female participants ($Chi^2=0.793$, $p=0.373$). Concerning the co-occurrence of depression and AE syndrome, 49% of the patients with AE syndrome were not depressed.

The assessment of participation (OHS) showed that 19 (25%) of respondents had recovered (score 0-1 on the OHS). The stroke led to different degrees of handicap in 75% of the patients (OHS scores from 2-4), from a minor handicap leading to some restriction in life style, but not interfering with the capacity to look after oneself, to a moderately severe handicap that clearly prevented independent existence, though not needing constant attention.

The patients had significantly lower satisfaction as compared to the norm group as concerned life as a whole ($p<0.001$), sex life ($p<0.001$), and P-ADL ($p<0.001$). However, they were significantly more satisfied with their financial situation ($p<0.05$). The patients were also less satisfied with their leisure situation although this difference was not statistically significant. Concerning the other domains the patients and the norm group were equally or almost equally satisfied. The differences in proportion satisfied patients' and the norm group's with CI 95 % are given in Table 4.

Table 4. Proportion of satisfied persons in the study group as compared to norm value with CI 95 %.

	Studygroup Proportion satisfied	*Normvalue Proportion satisfied*	*Difference in proportion satisfied patients and norms*
	(%)	(%)	% (CI 95 %)
Life as a whole	48	75	27 (14;40)
Ability in selfcare	82	96	14 (4;24)
Partner relationship	86	83	3 (-9;9)
Family life	85	85	0 (-9;9)
Sex life	40	64	24 (11;37)
Leisure	49	60	11 (-2;24)
Social contacts	67	67	0 (-12;12)
Vocation/Occupation	53	57	4 (-9;17)
Finances	58	43	15 (2;28)

n=75

AE syndrome was diagnosed in 71 % of the patients. The association between AE syndrome and demographical data, neurological and cognitive impairment, depression, ability in self care and life satisfaction is shown in Table 5.

Table 5. Correlation between AE syndrome and age, neurological impairment, cognitive screening, performance in personal activities of daily living, handicap, depression and life satisfaction.

	r_s	*CI 95 %*	*p-value*
Age at stroke onset	-0.18	-0.39; 0.05	0.126
SSS	0.16	-0.07; 0.37	0.177
MMSE	-0.17	-0.38; 0.06	0.187
Barthel Index	-0.17	-0.39; 0.06	0.140
OHS	0.65	0.55; 1.00	0.000
Depression	0.48	0.28; 0.64	0.000
LiSat-9			
Life as a whole	0.41	0.18; 0.60	0.001
Ability in self care	0.12	-0.14; 0.36	0.371
Partner relationship	0.25	0.00; 0.48	0.054
Family life	0.07	-0.19; 0.31	0.611
Sex life	0.31	0.04; 0.54	0.025
Vocation/Occupation	0.26	0.00; 0.48	0.046
Finances	0.25	-0.01; 0.48	0.053
Leisure time	0.37	0.13; 0.57	0.003
Social contacts	0.30	0.05; 0.51	0.019

n=75 Statistics: Spearman rho

The patient's experiences of every day life with AE syndrome

The aim of this study (Paper II) was to gather the experiences of everyday life with AE syndrome as told by the patients themselves. The experiences of the respondents could be grouped into the core category ***harmed/threatened self.***. The respondents told of impaired cognitive abilities and emotions, affecting important dimensions of self, and giving a feeling of being in many ways a different person. They described that their new life situation included feelings of loss of control, of chaos and of life being turned upside down.

They found the condition difficult to comprehend; it was unknown to them, no person in their environment had any earlier experience of it and they tried hard to make sense of it. The reason for naming the core concept the harmed/threatened self was that harm as a concept deals with something that has already taken place, while the concept of threat has to do with harm that has not yet occurred but can or is likely to happen in the future. Both these dimensions were found in the data

Four categories were grounded in the data as dimensions of: **hidden-apparent dysfunction, predictability-unpredictability, independence-dependence and active life - passive life.** The experiences in everyday life that the respondents told of yielded interpretation of the categories as processes with interaction on both an intra- and interindividual level, as well as in relation to environmental factors. To be able to capture the processes and dynamics of the condition and its consequences, the four categories were described as continuas. The model was constructed from a dynamic interactional perspective, with interaction between the core category and the four main categories. The model is shown in Figure 4.

Hidden-apparent dysfunction incorporates the feeling that the symptoms are sometimes invisible or difficult to detect and may all of a sudden become apparent depending on the situation and environmental conditions. It also includes efforts by respondents to sometimes purposely hide their condition. Further, the meaning of the dysfunctions on a more symbolic level both to themselves and significant others was expressed in different ways by the respondents.

The category of *predictability-unpredictability* was grounded in statements about the symptoms per se as unpredictable and of experiences of insecurity about one's capacity and the ability to control one's behaviour in different ways.

Independence-dependence included feelings of in one way or another no longer being independent. Although not needing physical help with everyday life activities, the respondents told of being dependent on support and help with planning, organising and structuring everyday life, and of a disruption of the balance

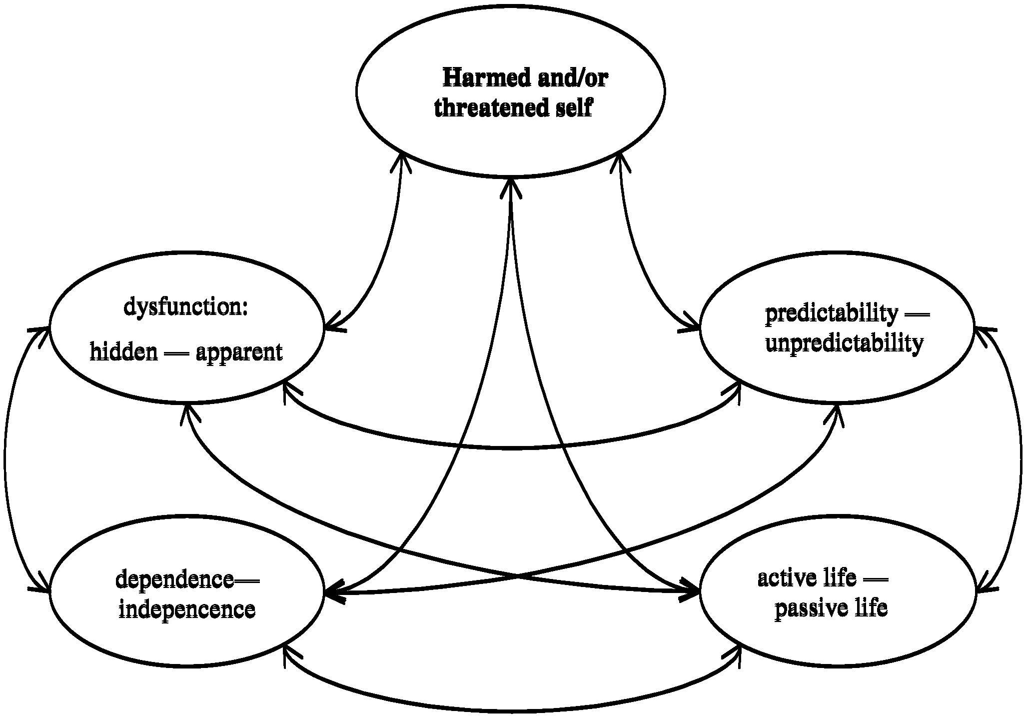

***Figure 4. The model, grounded in data, illustrating the dynamic interaction between the core category and the four main categories*.**

between the spouses concerning the overall responsibility for the family and household. This category also included feelings of the respondents of not being able to respond to their families' need of them in different ways.

The category of *active life-passive life* was built up from statements about how different activity areas of life were affected by the AE syndrome, activity changes and emotions that occurred that were related to activity performance. The four main categories with examples of codes are shown in Table 6.

Table 6. The four categories and the subcategories describing the experiences of living with AE syndrome.

Categories	Subcategories
Hidden - Apparent Dysfunction	- Invisible to other people - Hard to put words into - Incomprehensible behaviour - Almost like normal behaviour - Symptoms are interpreted as psychological reactions - Feeling watched and evaluated - Intentionally hiding the condition - Unrealistic expectances from people in the environment - Comparing with physical disability
Predictability-Unpredictability	- No longer knowing your capacity - Insecurity - Trial and Error, Trial and Success, - Problems with self-control - Environmental influence on the disorder - No longer doing thing spontaneously - The symptoms per se are unpredictable
Independence-Dependence	- Mastering one's everyday life - The respondents´ dependence on the family members - Family members´ dependence on the respondent - Responsibility - Level of dependence - Changes in roles - Dependent on patience from other persons - Conflicts
Active life - Passive life	- Loss of activities - Limitations in activities - Emotions concerning changes in activity - Environmental effects on activity - Imbalance between activity areas - Changed participation pattern - Organization of everyday life

Coping with the consequences of AE syndrome.

The aim of this study (Paper III) was to investigate how and why the respondents tried to cope with their difficulties as they did. The participants all spoke about a complex coping situation. First they had to cope with the experience of having had a serious, life-threatening medical condition, secondly with risk factors for a new stroke, and thirdly with activity limitations and a lack of ability to participate.

The participants described mixed feelings about the stroke event, from gratitude over having such a good outcome to experiencing that the stroke had changed their lives so thoroughly. All the participants had returned to an active life to some extent, which led to facing a diversity of situations where they had to cope with the condition and its consequences. The respondents spoke of co-occurrence of positive emotions such as confidence, joy and eagerness and negative emotions such as watchfulness, uncertainty, worrying and distress during their coping process. They used confrontative as well as avoidant coping strategies and problem-focused as well as emotion-focused coping.

The core category **"striving to manage an everyday life of uncertainty"** emerged, which connected the codes and categories and covered the contents of the experiences as described by the respondents. Three categories were built up from the codes, which captured the thoughts and feelings the respondents had about how and why they tried to cope with their condition as they did. The three main categories were **1) individual concerns, 2) relational concerns and 3) environmental conditions.** Figure 5 shows the interaction between the core and the categories comprising the model.

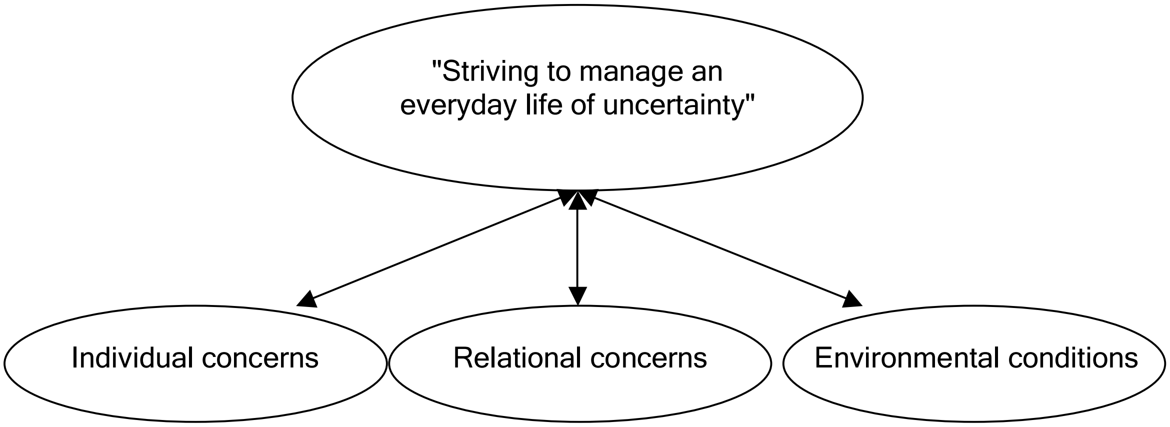

Figure 5. The model grounded in data illustrating how the respondents strived to manage their everyday life the first year after stroke.

Individual concerns comprised steps made to regain and improve health, psychological factors, personality, as well as values and goals, and view of life and the future. The relational concerns consisted of family relations, relations with professionals during the recovery process and, for those who returned to work, their relationships in that context. The environment constituted a challenge to the respondents from the perspectives of complexity, intensity and disturbing factors.

Comparison of life satisfaction between patients and spouses

Fifty-six couples participated in this within couple comparison of life satisfaction one year after their partner's stroke (PaperIV). The median age of the patients was 60 years (range 38 to 74 years) (IQ Range 50 to 67 years) and of the spouses 59 years (range 34 to 79 years) (IQ Range 50 to 66 years). Thirty-nine (70 %) of the 56 patients were male. The median length of the relationships was 32 years (range two to 54 years). Twenty percent of the couples had responsibility for children. The number of patients working full-time fell from 26 before stroke to six after one year, and another six patients worked part-time. Twenty-one spouses worked full-time and 13 part-time both before and after their partners' stroke, although some had changed their time schedules after their partner's stroke. Forty-seven patients had suffered a mild stroke, seven a moderate stroke and two a severe stroke.

Life satisfaction as compared to the norm group

As compared to the norm group the trend was that the patients and spouses were more often less satisfied. These differences were significant for both partners in the couples as concerned their satisfaction with life as a whole: leisure [patients ($p = 0.001$), spouses ($p = 0.01$)] and sex life [(patients ($p = 0.01$), spouses ($p = 0.025$)] and for the patients as concerned satisfaction with ability in self care ($p = 0.001$), family life ($p = 0.05$) and daily occupation ($p = 0.001$). The spouses were significantly less satisfied with the partner relationship ($p = 0.001$), while the patients were almost equally satisfied as norms. The proportions of patients, spouses and persons in the norm group that were satisfied with different life domains and 95 % confidence intervals for differences in life satisfaction between the patients, spouses, and norms are shown in Table 7.

Table 7. Proportion of patients and spouses satisfied according to LiSat-9 and comparison with a Swedish norm population, as well as confidence intervals for the differences between the proportions.

		Patients satisfied %	*Spouses satisfied* %	*Norm group satisfied Age 50-74 years* %	*Differences in proportion satisfied patients and the norm population % CI 95%*	*Differences in proportion satisfied spouses and the norm population % CI 95%*
LIFE AS A WHOLE		39	64	77	38 (25 to 51)	13 (0 to 26)
HEALTH	Ability in self-care	71	93	93	22 (10 to 34)	0 (-7 to 7)
CLOSENESS	Partner relationship	83	67	86	3 (-7 to 13)	19 (6 to 32)
	Family	79	82	89	10 (3 to 19)	7 (-3 to 17)
	Sex life	34	41	58	24 (10 to 38)	17 (3 to 31)
SPARE TIME	Leisure	38	52	71	33 (20 to 46)	19 (6 to 32)
	Contacts	64	73	75	11 (-2 to 24)	2 (-10 to 14)
PROVISION	Vocation /Occupation	45	61	67	22 (8 to 36)	6 (-7 to 19)
	Finances	58	70	65	7 (-7 to 21)	5 (-8 to 18)

n=56. † Fugl-Meyer K. unpublished data 2004,
LiSat-9= Life Satisfaction Checklist 9 item version

Within couple comparisons of life satisfaction

Concerning life as a whole the patients were significantly less satisfied as compared to their spouses (*p = 0.007*), with a difference in the proportion of satisfied patients and spouses of 25% (CI 95 % 9 to 41). The spouses were also significantly more satisfied with their ability in self care (*p = 0.008*), with a difference in proportion of satisfied patients and spouses of 21 % (CI 95 % 16 to 26). In contrast, spouses were significantly less satisfied with their partner relationship than the patients (*p = 0.035*), with a difference in proportion of satisfied patients and spouses of 17 % (CI 95 % 4 to 30). Even though there was a trend that the patients were less satisfied with their family life, sex life, leisure, social contacts, vocation/daily occupation and finances than their spouses, there were no significant differences concerning these items within in the couples.

The proportion of couples in which both partners were satisfied varied between the life domains. The highest proportion of couples where both partners were satisfied was found for family life (66%) and partner relationship (60%). In addition, in 66 % of the couples, both partners were satisfied with their own ability in self care**.** In 48% of the couples both partners were satisfied with their social contacts and 47% with their finances. However, in only 29% of the couples were both partners satisfied with their vocation/daily occupations, 25 % with their sex life and 20 % with leisure time. Both partners were satisfied with their life as a whole in 30% of the couples. The levels of agreement within the couples in their estimation of life satisfaction are given in Table 8.

Table 8. Agreement within the couples in estimation of life satisfaction according to the LiSat-9 (given in .frequencies and proportions).

		Agreement satisfied	Agreement not satisfied	Patient satisfied and spouse not satisfied	Patient not satisfied and spouse satisfied
LIFE AS A WHOLE		17 (30)	15 (27)	5 (9)	19 (34)
HEALTH	Ability in self care	37 (66)	1 (2)	3 (5)	15 (27)
CLOSENESS	Partner relationship	33 (61)	6 (11)	12 (22)	3 (6)
	Family life	37 (66)	3 (5)	7 (13)	9 (16)
	Sex life	11 (25)	22 (50)	4 (9)	7 (16)
SPARE TIME	Leisure time	11 (20)	17 (30)	10 (18)	18 (32)
	Contacts	27 (48)	6 (11)	9 (16)	14 (25)
PROVISION	Vocation/Occupation	16 (29)	13 (23)	9 (16)	18 (32)
	Finances	25 (47)	10 (19)	6 (11)	12 (23)

LiSat 9= Life Satisfaction Checklist 9 item version n=56

Life satisfaction and demographic and social variables

There were no significant differences between men and women with respect to any of the domains of life satisfaction. Among the spouses, responsibility for children was related to lower satisfaction with finances ($p = 0.027$). For patients, responsibility for children was related to lower satisfaction with family life ($p = 0.008$). Spouses who worked as compared to spouses not working were significantly more satisfied with their ability in self care ($p = 0.020$) and vocational/occupational situation ($p = 0.015$). Both patients ($p = 0.018$) and spouses ($p = 0.016$) who worked were significantly more satisfied with their social contacts as compared to those not working.

Discussion

This thesis is focused mainly on the consequences of an apparently mild stroke. It is based on the actor's perspective in terms of self-reported symptoms and the impact of these symptoms on everyday life, life satisfaction and coping, as well on assessment of body functions and structure, activity and participation. It also includes the perspective of the individual with stroke and his or her spouse in a within couple comparison of life satisfaction

Mild strokes – Are they really mild?

The participants had suffered a mild stroke with respect to ability in self care as tested by the Barthel Index the first week after stroke onset (Papers I, II and III). Making this classification in the acute phase was the purpose of the study (Paper I) carried out to highlight problems as perceived by the participants one year after a stroke that in the initial phase was considered mild. However, a patient can be independent in P-ADL and still have far-reaching difficulties in everyday life. In a Swedish two-year follow-up of stroke patients 76 % were independent concerning P-ADL while 59 % considered themselves to be in need of help/support from another person to manage everyday life. The amount of patients dependent on another person to manage every day life had also increased during the most recent years (Hulter-Asberg 2005).

Ability in self-care as tested with the Barthel Index is still also used as a measure of recovery after stroke, where a Barthel Index Score of > 90 is considered the limit for recovery (Lai 2002). If recovery is defined in that way, the majority of the stroke patients will be considered to have recovered. If recovery instead is defined by comparison of prior and post stroke function in higher physical activity, less than 25 % of stroke survivors will be considered recovered. The authors further suggests that the benchmarks for recovery in mild stroke must include measures of higher functioning with respect to sensory-motor function, cognition, language and quality of life (Duncan 2000).

In our study 25 % were considered to have recovered in that the participant experienced no or minimal symptoms, where these had not led to any changes in life style as evaluated by the OHS (Paper I).

Post stroke fatigue, AE syndrome and depression

The most common symptom perceived by the patients in our study was increased mental fatigability, experienced by 72 % in the mild stroke group and in 77 % in the total study group. A complete AE syndrome was diagnosed in 71 % and 78 % respectively. In a study by Leegard (Leegaard 1983) similar constellations of symptoms were reported in 93 % of stroke patients, with fatigability as the most common symptom.

Post-stroke fatigue has been highlighted in recent years as perhaps one of the most common persisting sequelae after stroke (Colle 2006; Schepers 2006; van de Port 2007) (Ingles 1999; van der Werf 2001; Glader 2002) and may be the only persisting symptom in some patients, which may severely limit their return to previous activities (Staub 2001). However, post-stroke fatigue has previously most often been interpreted as a symptom of depression (Staub 2001).

Fatigue as concept is vague. There is no single definition of fatigue (Staub 2005. p. 556-579). It may develop in connection with activity requiring a sustained effort (fatigability), and it can be a primary state that is closer to a lack of initiative owing to an imbalance between motivation and effectiveness. There is physical and mental fatigue; it can be expressed at a behavioural level (objective) or as a state of feeling (subjective). There is no sharp border between normal and pathological fatigue and it can be age-related. The vagueness of the concept makes it difficult to raise and use any operational definition. Neuropsychological deficits can generate mental fatigue, owing to the increase in cognitive demands that must be fulfilled to match pre-stroke performance. Sleep disturbances can also contribute to the development of post-stroke fatigue.

There is an overlap between post-stroke fatigue and depression, and fatigue is a domain in most depression scales (Staub 2005. p. 556-579). Of the 72 % in the mild stroke study group who had the AE syndrome 51 % were diagnosed as depressed. In the study group in Paper IV, which also included moderate and severe stroke, 77% had the AE syndrome, which co-occurred with depression in 78 % of the patients. Some studies have found fatigue to be related to depression (Glader 2002) (Schepers 2006), while other studies have found no association between fatigue and depression (Ingles 1999; van der Werf 2001) (Van Zandvoort 1998). In our study group (n=90) 36 %, and in the mild stroke group (n=75) 39 %, had been diagnosed as depressed, with no significant difference between the male and female participants. The incidence of post-stroke depression has been found to vary slightly with age and sex (Neau 1998). The prevalence of depression in the general population of Sweden has been estimated to be between 4% and 10% (Åsberg 2004).

The system for diagnosing post-stroke fatigue and related cognitive and emotional problems used in this study was the Lindqvist & Malmgren (LM) system for organic mental disorders (Lindqvist 1993; Rödholm 2003). They postulate a dynamic interactional view of the syndrome in which its basic manifestations interact with spared psychical functions and with environmental factors. This makes its consequences differentiated and changeable although the underlying constituents are the same. This view of the syndrome agrees with the experiences of the respondents in our study of their symptoms as unpredictable, fluctuating, and sensitive to environmental conditions (Paper II).

The syndrome is also stated to be aetiologically neutral with a mixed organic and psychological causality, with difficulties in knowing what causes what (Lindqvist 1993). The experiences of the patients in our study were that their problems were often taken as being "just psychological", that if they just pulled themselves together there would be no problem (Paper II). For those who had received the information that their problems *could* be caused by the brain lesion, this helped them to cope with the condition.

Another issue concerning the AE syndrome is that of cause and effect. Having problems with memory, concentration, stressfulness and so forth might lead to fatigability, and having problems with fatigability lead to problems with memory, concentration, irritability and so forth. This has been taken into account in the Lindqvist-Malmgren diagnostic system (Lindqvist 1993). This issue is also important with respect to rehabilitation and strategies taught to individuals with stroke to cope with the condition.

The consequences of the AE syndrome

AE syndrome was not associated with, age, sex, stroke subtype or location, neurological impairment, ability in self care, or cognitive dysfunction (MMSE), but was associated with handicap and changes in life style, which is in line with results of studies of post-stroke fatigue (Leegaard 1983; Ingles 1999). One study of post-stroke fatigue two years after stroke showed that there was a statistically significant increase in both primary and secondary ADL dependency with more severe feelings of fatigue, and fatigue was also an independent factor for having to move into an institutional setting after stroke (Glader 2002). This study included all degrees of stroke severity.

Among the patients AE syndrome was associated with lower satisfaction with life as a whole, and all domains of life except ability in self care and family life (Paper I) while, for their spouses (Forsberg-Warleby 2004), the patient's AE syndrome was associated with lower satisfaction with life as a whole, sex life and partner relationship. This indicates that it affects satisfaction among the patients with most dimensions of life as well as with life in general, while for the spouses it affects the couple's close relationships and life as a whole.

The presence of emotional or behavioural problems in the individual with stroke has been found to be associated with caregiver distress and depression (Dennis 1998; Nieboer 1998; Cameron 2006). Risk factors for negative caregiver outcomes have been thoroughly studied, while little attention has been paid to how caregiver health influences the quality of care given. One study found that significant risk factors for potentially harmful caregiver behaviour was a higher level of help needed, the caregiver being a spouse, cognitive impairment in the caregiver, and caregivers at risk for clinical depression. Nearly 26 % of the care recipients reported at least sometimes being subjected to potentially harmful behaviour from the caregiver (Beach 2005).

Experiences of and coping with the AE syndrome in everyday life

Concerning the experiences in everyday life of AE syndrome one main finding was that the disabilities were perceived as hidden (Paper II), comprising the feeling not only that they were invisible, but also involving a symbolic level. Experiences of the same kind have been observed in other qualitative studies of stroke patients with hidden dysfunctions, giving the patients a sense of not being understood, an experience of uncertainty, and a feeling that they must continually explain themselves to others (Stone 2005).

Another aspect of living with an invisible handicap has been put forth by younger stroke survivors, that stroke is considered to be an illness in the elderly population and that they feel overlooked in their needs and their possibilities for receiving rehabilitation suited for younger people (Roding 2003; Banks 2004; Stone 2005). The patients in this study, who were in need of further rehabilitation after the acute care, in cases of an age below 65 years, were admitted to a rehabilitation unit for younger people, while people over the age of 65 were admitted to geriatric rehabilitation.

A part of the process of adapting to a permanent disability is presenting oneself to others in a way that is psychologically comfortable for oneself (Stone 2005). This is special when disabilities are hidden, as the culturally accepted markers for disability are missing, leading to, one of the problems with invisible disabilities being a problem of presentation. Thus the stroke survivor must repeatedly weigh the advantages against the disadvantages of telling others about their problems, with the risk of not being believed or being misunderstood (Stone 2005). The issue of whether or not to tell others that they had a brain lesion and the problems it caused, and the uncertainty of what reactions this would provoke in the recipients of the information, preoccupied the respondents in our study. This finding was also supported in a qualitative study by Röding et al. (Roding 2003).

The unpredictability of the condition was one major concern of the respondents in our study, both with respect to their own insecurity about their abilities and how other people would respond to them. The salutogenetic model of health created by Antonovsky (Antonovsky 1987) has put a focus on what makes people remain healthy despite having gone through serious life events. Sense of coherence is the central concept and is based on the standpoint that what happens to you in life must be comprehensible, meaningful and manageable. Living with hidden, unpredictable difficulties, that are difficult to comprehend and put into words poses a great challenge to the persons sense of coherence. Addressing these problems should thus be a central aim in the interventions offered to these patients and their next-of-kin.

The respondents also said that the stroke had affected the balance between being dependent on others, and others being dependent upon them. The stroke patients' feelings of not being able to respond to their families' dependence upon them is a finding worth taking into account. A special concern to the patients with respect to their families was their emotional instability and irritability, which could be difficult to control. This same concern was put forth by stroke patients in an interview study where the patients spoke openly about their unease at partners and children assuming a caring role and the impact of their mood changes on their relationships (Banks 2004). Rehabilitation services to stroke patients focus primarily on the patients' dependence-independence. The picture of the stroke patient as the care recipient, a burden of care and a stroke victim (Pound 1999) puts the person in a position of not being an acting subject and could be stigmatising. Individuals with stroke have stated that although they perceived differences among themselves in terms of type of stroke and its impact, they felt that they were all treated on the basis of a collective formula (O'Connell 2001).

The fourth main category (Paper II) was the patients' feelings of oscillating between activity and passivity in life. Some activities were definitely lost, while they could perform other activities under special circumstances. Sometimes they felt like doing things and were fulfilled with energy and sometimes they felt exhausted and could not do anything. An important focus of the occupational therapy intervention for these patients should be to support them in finding a balance between activities, time use, and strategies for learning to know one's ability, and limitations and in making priorities. This is also an important issue with respect to the role of the spouses.

The core category harmed/threatened self comprised these four main categories with their codes (Paper II). According to Mead (Mead 1967) a persons self is a social construct, that develops and changes throughout the lifetime. It is built up of a dynamic system of learned beliefs, attitudes and opinions that a person believes to be true about him or herself. The respondents spoke of how their cognitive and emotional symptoms had changed their way of being, and that they were treated by others as if they were changed, to such a high extent that it seemed adequate to speak of a harmed self picture. On the basis of their statements of the condition as unpredictable, and the insecurity they felt about their abilities it can be sad that they lived with constant threats against the self.

In coping with these difficulties (Paper III) a main finding was that the process was not completed, the respondents had not regained a normal life with its daily routines and habits. The core category ***"striving to manage an everyday life of uncertainty",*** was grounded in that, still after one year, it was a "struggle" and that life was filled with "uncertainty". Similar findings were reported in a study by Eaves where the stroke patients told of their lives as a lifelong adjustment and living with uncertainty (Eaves 2000).

In this study we posed the simple questions *how* and *why* the respondents coped the way they did. Questions concerning *how* contain the aspects of structure, meaning, process, interaction, intention, experiences etc., and the question of *why* deals with causality (Moller 2005), all of these being concepts with important content with respect to coping.

The term coping is used regardless of whether the process is successful (Lazarus 1993). The respondents in our study described their everyday life as unpredictable and insecure concerning whether their coping efforts would succeed or not. Coping with a chronic condition also means that, no matter how well you cope, the problems still remain to some extent. Solving the problem may take greater resources than the person has, and the resources might become depleted as they were used. In the long term this could lead to increased vulnerability and exhaustion (Baumeister 1999. p. 50-69.). Occupational therapy aims at enabling people to develop healthy activity patterns and to prevent occupational dysfunction caused by illness, in order to improve health (Dahlin-Ivanoff 1995). A balance between different daily occupations and a balance between occupation and rest, duty and pleasure are seen as essential (Meyer 1977; Mosey 1986), as well as making the client aware of use of time (Christiansen 1997). This makes occupational therapy a useful tool in the coping process in chronic conditions.

The model proposed in paper III aims to be a description of how the respondents' intra- and interpersonal concerns and the environmental conditions are connected in processes having to do both with resources and obstacles in the coping process. Within the intrapersonal area self reliance was identified as one category. Similar findings were made in a phenomenological study of stroke survivors, where the respondents experienced themselves as having disrupted embodiment and loss of self, with a low confidence in their capabilities. The authors stated that this estrangement that the respondents felt to themselves was an area in need of further research (Murray 2004). Perceived control has also been found to predict outcome of disability after stroke (Johnston 1999).

Leisure activities were used to a great extent in the coping process both as a way of training and for relaxation, but it was also an area affected, where several respondents had to make re-evaluations and new priorities. Research on the role of leisure in coping with stress states two reasons for why people use leisure for coping, active challenging reasons (competing, taking risks, exercise) and recuperative reasons (relaxing, doing something different from work) (Trenberth 2005). The notion that leisure may act as a way to cope with stress and maintain good health is not new. Leisure has been suggested to reduce negative effects of stress (Caldwell 1988), and motives such as relaxation, compensation, escapism and independence have stress-reducing properties (Driver 1991. p. 263-86.).

The respondents spoke of co-occurring positive and negative feelings during their coping process. According to Folkman/Moskowitz, the positive affect side of coping has been neglected and the focus on negative outcome has dominated. They state that positive affect co-occurs with distress during the coping process, that positive affect related to stress has important adaptation value and that coping processes that generate and sustain positive affect in the context of stress involve meaning (Folkman 2000). One qualitative study focuses on positive consequences of surviving a stroke, in which the respondents concluded their positive experiences of surviving a stroke in the following themes: increased social relationships, increased health awareness, changed religious life, personal growth and altruism (Gillen 2005).

Patient-Spouse Perspective

This thesis also included a patient-spouse perspective. The couples' adaptation to the new life situation showed that life satisfaction was affected in both partners of the couple in this study group dominated by patients with mild stroke (Paper IV). Research on close relationships has recently started to emphasise how strongly dependent on one another partners in a couple are, and the concept of dyadic coping has been highlighted (Revenson 2005). Partners share each other's stresses and satisfactions and the difficulties faced by one partner can have profound implications for the well-being of the other (Parris Stephens 1997. p. 221-42.). When couples have lived a long time together, they often have to cope with the same or related stressful events at the same time. When stressors affect both partners, they often feel a need to relate to one another for emotional support while at the same time feeling less able to help one another. When one partner has suffered a stroke, the functional limitations of the affected partner often restrict the social involvements of both, with a risk of both partners being more dependent on one another for support (Parris Stephens 1997. p. 221-42.).

The concept of relational coping has been proposed and is divided into two types: intrapersonal coping that is individual or solitary coping and interpersonal coping that is communication between partners, including strategies for active engagement, approach coping, and seeking social support. Interpersonal coping was found to be significantly positively associated and intrapersonal coping was significantly negatively associated with marital satisfaction for both husbands and wives (Acitelli 2005. p. 121-36.). Despite this, there is a lack of knowledge about what happens within couples when one partner has an illness or has to live with chronic disability, as the majority of all studies address patients and spouses separately.

Intimacy has been found to have a direct relationship to marital satisfaction (Tolstedt 1983). Most definitions of intimacy include behavioural interdependency, fulfilment of needs, and emotional attachment (Brehm 1992), all being dimensions of life described by the respondents in this study as being disrupted after their stroke. Satisfaction with the partner relationship is of central concern. This exploratory study shows a differentiated result in this matter. As compared to the norm group, the individuals with stroke were almost equally satisfied with partner relationship, while the spouses were significantly less satisfied ($p=0.001$), which was also the case in the within couple comparison ($p=0.035$). At the same time, satisfaction with the partner relationship was one of the dimensions with the highest agreement (60%) of both partners being satisfied. This finding suggests the need for individually designed intervention and of creating tools to identify couples in need of support and counselling.

A central experience of the individuals with stroke as pronounced in the interview data (Paper II), concerned the problems of disrupted interdependency within the family. AE syndrome, with its consequences for emotional functions, could have affected the emotional attachment within the couples in our study. AE syndrome was also significantly negatively associated with the spouses satisfaction with the partner relationship (Forsberg-Warleby 2004). One study of the effect of talking about the nature and state of one's relationship, showed that the association between relationship talk and dyadic adjustment was stronger in couples in which one spouse was ill than in couples where both partners were healthy (Badr 2005).

Among the patients on the other hand, 83% were satisfied with the partner relationship (Paper IV). Questions can be raised about this difference between the spouses. A response style has been found in persons with failing health, in spouses giving care to individuals with dementia, and in elderly persons grief when a spouse has died, by which individuals convey an inordinately positive appraisal of their spouse and marriage (O'Rourke 1998; O'Rourke 2001). In the interview data, patients spoke of their uneasiness about their fatigue and their emotional dysfunctions and how it could affect the family, when they failed to cope with it.

The couples also had low agreement in being satisfied with their sex life, and this was an item with a high number of spouses that agreed in being dissatisfied. In a study of moderately-severely disabled stroke patients and spouses, more than 50% reported a marked decline in sexual activity (Korpelainen 1999). In this study of individuals with mild stroke, 50 % of the couples agreed in being dissatisfied with their sex life. Satisfaction with sexlife has been found to be significantly related to the level of family functioning (Greeff 2001).

Engagement in leisure activities is an important predictor of satisfaction with life as a whole in individuals with stroke and their partners (Eriksson 2005) as well as in the general population (Fugl-Meyer 2002), and it has been found to be a powerful resource for coping (Caldwell 1988; Driver 1991. p. 263-86.; Trenberth 2005). Leisure activities was furthermore an area with low agreement with only 20 % of the partners both being satisfied and 30 % both being dissatisfied. Leisure activities was also an area of life in which 32 % of the individuals with stroke were dissatisfied while their spouses were satisfied, indicating that this is an important area in rehabilitation and support for both individuals with stroke and their spouses.

Concerning satisfaction with life as a whole, 70 % of either one or both of the partners in the couples studied here were dissatisfied, while 23 % in the norm group were dissatisfied, indicating the impact that even a mild stroke can have on the life situation of couples.

Family function is an important issue as it has been found to affect outcome after stroke as concerns discharge disposition, treatment adherence, functional recovery and depressive symptoms. Among the many factors that must have to be taken into account in family intervention and counselling is the pre-stroke life situation. Low pre-stroke family functioning has been found to contribute to poor treatment adherence and further interference in family functioning (Evans 1987; Evans 1987). On the other hand, one study of stroke families found that there was little difference in terms of morale, couple functioning, and health status between stroke families and normal healthy families (Bishop 1986), indicating the importance of reliable reference values with which to compare.

Our results indicate the importance of individuality in meeting the couples and seeing their mutual needs. A review study of support to stroke families showed the importance of focusing on the needs of both patients and spouses. Information provision and counselling should be grounded on patients' and spouses' individual needs rather than be based on pre-structured programs and should focus on active problem solving strategies and support seeking behaviour in the couples (Visser-Meily 2005).

Methodological Considerations

Stroke severity

In this thesis we used the method of grading stroke severity, as were used by the Stroke Unit Trialists' Collaboration (StrokeUnitTrialist'sCollaboration 2002), in which a score between 50 and 100 on the Barthel Index the first week after stroke onset was considered to indicate a mild stroke. The different items in the Barthel Index are weighted according to the aim to assess degree of dependence. The values assigned to each item are based on the time and amount of actual physical assistance required if a patient is unable to perform the activity (Mahoney 1965). Accordingly, items such as bladder/bowel control, toilet use, basic transfer and mobility are heavily weighted. Patients independent in these basic functions and activities are considered to have had a mild stroke.

There is no uniform way to classify the severity of a stroke. Neurological impairment as assessed with the Scandinavian Stroke Scale (SSS) or the National Institute of Health Stroke Scale (NIHSS) is often used as an indicator of stroke severity (Appelros 2002. p. 21). The NIHSS has been recommended to assess stroke severity (Socialstyrelsen 2005; Richardson 2006), as it gives a standardised documentation of the most common neurological impairments after stroke and includes a manual for assessment. It has established reliability and validity for use in prospective clinical research and predictive validity for long-term stroke outcome. There is also a standard videotaped programme for training of raters (Kasner 2006).

Sample selection

One methodological issue of concern in this study has to do with the sample selection and its representativity for the stroke population. The sample was consecutively selected at admission to the Neurological Department at Sahlgrenska University Hospital. According to the Swedish National Quality Register of Stroke, 97 % of all stroke patients in Sweden are admitted to hospital with a CTscan verification of the stroke, and in persons < 75 years this number is estimated to be 99 % (Riks-Stroke 2006), which increases the possibility to compare our sample with population-based samples.

In one respect our sample was strictly selected due to the primary aim to study couples. Accordingly, the respondents in our study group were < 75 years and all lived together with a steady partner. The reason for choosing this age level was to explore the life situation of couples in ages before general diseases in the elderly other than stroke dominate too strongly. At higher ages larger proportions would have been widowed and risk of age related comorbidity would also have been increased in the spouses. People with difficult problems such as homelessness, serious alcohol and drug abuse and criminality are less likely to live in stable partner relationships and are therefore underrepresented in this study group as compared to the general stroke population. Being divorced or widowed has been found to increase the risk of stroke as compared to married controls (Engstrom 2004), and it has also been found that people living alone have a higher risk of a delayed arrival to hospital at stroke onset

(Fagerberg 2000; Rossnagel 2004). Studies of life satisfaction in Sweden have shown that single persons are less satisfied than people living in steady relationships (Fugl-Meyer 2000;17.p.217-234; Fugl-Meyer 2002). Married people are significantly happier than singles (Diener 1998), and it has also been found that satisfaction with life as a whole depends largely on marital quality (Veenhooven 1984).

Persons with mild stroke dominated our study group. One reason for this could be the high number of patients that are admitted to hospital for stroke, which means that even mild stroke cases are hospitalised (Riks-Stroke 2006). People who live together with a partner have shorter out-of hospital-delay at stroke onset as compared to singles (Fagerberg 2000; Rossnagel 2004), which could also have biased our sample towards milder stroke. Other studies, however, have reported comparable Barthel Index scores in the acute and sub-acute phases after stroke (Schulz 1988) (Mayo 1999). Although both the median and mean values in our study were high at stroke onset, the distribution was from 0 to a maximum score on the scale.

The purpose of our study was however to study the life situation of couples in which one partner had suffered a stroke, with a focus on apparently mild stroke. Accordingly, the conclusions cannot be generalised to the stroke population in general.

Assessments

Concerning the assessments of neurological impairment (SSS), cognitive screening (MMSE) and ability in self care (Barthel Index), ceiling effects occurred. Scandinavian Stroke Scale as an assessment of basic motor function does not capture more complex motor control. The integration of motor and cognitive function in motor control is essential, especially in more advanced mobility and fine motor functioning (Hochstenbach 1999). The respondents in our study experienced activity limitations in more complex activities. During the home visit such difficulties in activity performance were also observed by the researcher (GC) (*unpublished data*).

MMSE as a brief cognitive screening has been found to be insensitive to amnesia (Benedict 1992), mild cognitive impairment (Schwamm 1995), focal brain lesions and especially right hemisphere lesions (Kupke 1993), and to impairments in abstract reasoning, executive functioning and visual perception/construction (Nys 2005). Despite a high score on the MMSE, more than 50 % of our study group reported difficulties in everyday life with memory and concentration and experienced decreased cognitive ability. The Barthel Index is known to have ceiling effects as it measures limited dimensions of ADL (Duncan 2000).

No single outcome measure can describe all dimensions of recovery and disability after stroke (Kasner 2006), and there is a need of broader assessments concerning stroke outcome, including cognition, depression, language disturbances and disability, participation and quality of life (Kelly-Hayes 1998). It is important that these assessments not only capture a wider range of abilities;

they must also be sensitive to subtle difficulties. The method used in this thesis to gain a deeper knowledge and understanding was based on the patient's perspective by asking the stroke patients themselves which symptoms they perceived after one year (Paper I) and what impact this might have had on their activity performance and participation in life situations (Papers I, II, III) and life satisfaction (Papers I, IV).

It has been found in studies of traumatic life events that persons who are severely disabled by the trauma and people who consider themselves to have no problems are those who most often withdraw from participation in studies (Weisaeth 1989). Concerning the withdrawals in Paper 1 consisting of patients with mild stroke, 12 of 75 participants declined a home visit with an interview, of which ten had made a good recovery and two patients were severely disabled and therefore not able to participate. In paper IV, the withdrawals among the couples showed equal distribution in the mild and moderate stroke groups for both patients and spouses. In the two individuals with severe stroke, both partners in the couples participated in the study.

Multiple variables were included in the statistical analyses. The aim of the study was explorative and the interest was in looking for possible patterns of results in the data. Studying the life situation of people includes the possibility that several factors affect the life situation. Choosing to focus on one or two variables to test a hypothesis, it would raise problems concerning possible confounders (Katz 1999). Combining qualitative and quantitative analyses made it possible not only to investigate how common symptoms were, and to make assessments of different variables, but also to explore in depth and describe the everyday life situation of individuals with mild stroke, which has not previously been sufficiently investigated.

Quality issues in qualitative research

Quality control should be an important part of all phases of the process of qualitative research (Kvale 1997). In this study we used a combination of qualitative and quantitative approaches, which raises some issues concerning sampling. While quantitative studies often use a random sampling according to some basic criteria in the population, qualitative research sampling is strategic or theoretical according to preferred criteria in the respondents, including the possibility to choose good informants (Coyne 1997).

The sampling method suggested in grounded theory is theoretical sampling, that is, a stepwise sampling where one (Glaser 1978) simultaneously collects, codes and analyses the data in order to decide what data to collect next and where to do it (Glaser 1978; Coyne 1997). Owing to the combined qualitative and quantitative design of this study it was not possible to achieve a truly theoretical sampling. The participants in this study were included consecutively at admission to the neurological ward for the combined study of patients and spouses. The participants in the qualitative studies (Papers II, III) were selected from the study group of patients with mild stroke and a diagnosed AE syndrome. Selection criteria were described in the method section. During data collection, the interviews were transcribed and a first analysis was made to be able to broaden the area of questioning and to verify the emerging codes and categories. All patients with mild stroke that agreed to a tape-recorded interview were possible participants in the qualitative studies, and, when all interviews had been conducted, the participants were chosen from the selection criteria and on the grounds of being good-informants.

The qualitative data in this study were collected through interviews (Papers I, II, III). One challenge in interviewing is the researcher being "the measurement instrument" (Robson 1993). A risk is that the first impression in analysing data or preconceptions of the research field in experienced researchers may dominate, making it difficult to change views later. On the other hand, interviewing is flexible. Unexpected answers can yield further questions and there is also an opportunity to clear up misunderstandings and deepen the conversation (Robson 1993). Another advantage of a qualitative approach is the insider perspective, giving the participants opportunities to reflect on complex experiences from their daily lives, which is of great importance in searching for new knowledge about a phenomenon (Glaser 1967).

Both in qualitative and quantitative research approaches the preconceptions in the research field of the researchers should be considered (Malterud 2001). Within the grounded theory paradigm it has been argued that the researcher should be “free from theory” to minimise the intrusion of subjectivity into analysis, and to avoid the theoretical perspective affecting the basic assumptions to discover an empirically grounded theory (Glaser 1967). However, it has also been argued that knowledge and experience in the research area can be a guide in that they initially sensitize the researcher to the research field and that they could enrich the process of analysis (Strauss 1987). It has also been stated that the initial literature review assists the researcher in identifying the current gaps in knowledge (Dellve 2002).

There are two types of grounded theory, substantial and formal. Substantive theory is developed for a substantive or empirical area, while formal theory is developed for a formal or conceptual area (Glaser 1967). The models suggested in this study (Papers II and III) are on a substantive level.

Trustworthiness is the alternative term to validity in qualitative research (Kvale 1997). Kvale proposed validity as craftsmanship where the trustworthiness is emphasised through control, questioning, and theorising. To be able to consider whether a method investigates what it aims to, a theoretical representation of what is investigated is needed. He further suggests communicative validity, that is, the communication of the research and its results with the respondents, the public and the research community. Finally he states the pragmatic criteria for validity, which concern the consequences of the results that have been achieved in a qualitative study, among other things the issues of values and ethics and the power relationships in relation the participants (Kvale 1997).

In this study we addressed the issue of quality throughout the research process. The research group consisted of individuals with different professional and scientific knowledge and experience. The group cooperated through the whole research process from study design to writing reports. With the above mentioned quality criteria in mind the research group continually held discussions about study design, ethical considerations, the process of interviewing, and the interviewer's behaviour towards the respondents, as well as issues of verbatim transcriptions and trustworthiness. The running discussion continued throughout the process of analysis of the emerging categories and the models but also through the process of writing the publications (Glaser 1967; Strauss 1998; Eaves 2001). The first author also attended supervised seminars and workshops with qualitative researchers in the Nordic countries with running discussions concerning the process of qualitative research where the present study was also discussed.

No study, irrespective of the method used, can provide findings that are universally generalisable (Malterud 2001). Qualitative research does not aim to be generalisable in the same sense as quantitative research, which operates on the concept of statistical generalisation. In qualitative methods one speaks of analytic generalisation, which means making a well-grounded estimation of the possibility that the results found in one study or in one case may be able to give guidance as to what will happen in another situation (Kvale 1997). The findings in qualitative studies are not applicable to the population at large, but rather aim to be descriptions applicable within a specific setting (Malterud 2001), which was the case in the study presented in this thesis (Paper II and III).

Conclusions

Mild stroke are not in all respects mild. Just measuring neurological impairment and/or independence in P-ADL as indicators of stroke severity can underestimate cognitive and emotional dysfunction and fatigue in individuals without motor impairment and independent in P-ADL. Such symptoms can severely impact their life situation.

Individuals with mild stroke were often discharged directly to their own home, after a short period of acute care with insufficient follow up beside risk factor control.

In this study of individuals with mild stroke who more or less had returned to an active life, post stroke fatigue was the most commonly experienced symptom.

More than 50 % of the individuals in this study experienced a decreased ability to handle stress, and about 40% experienced problems with emotionalism and irritability, which puts forth the need to emphasize these problems.

The combination of qualitative and quantitative method gave us knowledge concerning how common the problems were, and a deeper understanding of how it can be to live with "hidden dysfunctions".

To live with "hidden dysfunctions" most often makes everyday life uncertain and unpredictable.

One year after an apparently mild stroke, coping was still a struggle to manage everyday life, a struggle one sometimes succeeded or sometimes failed with.

Life satisfaction was affected for the stroke patients, most pronounced concerning life as a whole, sexlife and leisure activities. However, the stroke patients satisfaction with partner relationship and family life was comparable to a Swedish normgroup of persons living in steady relationships.

When making comparison within the couples, satisfaction with life was affected for both partners but in somewhat different areas of life.

Clinical implications and Future Research

To detect activity limitations and participation restrictions caused by subtle cognitive difficulties, executive dysfunction, emotional changes, and fatigue, assessments of broader aspects of life and participation ought to be used.

The "hidden dysfunctions" as described in this thesis have most impact on more complex activities, social relationships and participation. These areas should accordingly be addressed in rehabilitation and support for these patients and their families.

The knowledge gained through the interviews concerning life experiences of "hidden dysfunctions" could add new properties in the interventions and support offered to these persons with stroke and their families.

Coping with a chronic condition is sometimes a life long issue which takes its toll. Long-term support for these individuals and their families is essential, and should be given by persons with knowledge and understanding of the area of "hidden dysfunctions".

To cope with the fear of a new stroke was spoken of by all participants, and risks for a new stroke an area important to take into concern in the follow-up of stroke survivors in the long term.

The life satisfaction of the couples in this study showed a diversified picture, pointing at the importance to find couples in need of support. To be able to understand the problems these couples face, further qualitative studies of couples preferably from a within couple perspective could give us a deeper understanding of the relational, and interactional problems in everyday life they face.

Although there were patterns and trends seen in the result, the results also points at individual differences which supports earlier research indicating that support to families should be based on their individual needs rather than just on prestructured programs.

Populärvetenskaplig sammanfattning

Stroke är en av våra folksjukdomar. I Sverige insjuknar årligen 25 000-30 000 personer och uppskattningsvis lever 100 000 svenskar med sviter efter stroke. Stroke är ett sammanfattande begrepp för blodpropp eller blödning i hjärnan. I 85 % av fallen är stroke orsakat av en blodpropp och i 15 % av en blödning i hjärnan. Medelålder för insjuknande är 75 år och män insjuknar genomsnittligen i 4-5 år yngre ålder än kvinnor. Risken att insjukna ökar med stigande ålder, men 20 % av de personer som drabbas är yngre än 65 år.

Nedsatt kraft, och kontroll över rörelseförmågan i ena sidan av kroppen tillhör de mer kända symtomen efter stroke. Efter en stroke kan man drabbas av en mängd mer svårgripbara och mindre kända symtom som påverkar individens förmåga att leva ett självständigt liv, ofta benämnt "dolda funktionshinder". Sådana symtom kan exempelvis vara mental uttröttbarhet, depression, minnesproblem, koncentrationssvårigheter, oro, irritabilitet, nedsatt förmåga att klara stress, och en ökad emotionalitet och nedsatt informationsbearbetnings- och problemlösningsförmåga.

Syftet med den aktuella avhandlingen var att ett år efter insjuknandet undersöka konsekvenser i vardagslivet av en stroke som i akutskedet bedömts som lätt hos personer yngre än 75 år. Speciellt fokuserades deltagarnas egna upplevelser av "dolda funktionshinder" och deras sätt att hantera dessa i vardagslivet. Ett ytterligare syfte var att undersöka effekten av insjuknandet i stroke på livssituationen för personerna som drabbats och deras makar.

Patienternas neurologiska symtom, kognitiva och emotionella funktionsbegränsningar, depression och upplevelse av "dolda funktionshinder" kartlades. Respondenternas aktivitetsförmåga samt begränsningar i delaktighet skattades. Deltagarna intervjuades angående sina upplevelser av kvarvarande symtom, strokeinsjuknandet, vård och rehabilitering, sin nya livssituation samt förmåga att hantera denna. Respondenterna och deras makar skattade sin livstillfredsställelse.

I studien deltog 75 personer med lätt stroke i åldern 30-75 år. Strokens svårighetsgrad graderades utifrån förmåga att klara de basala aktiviteterna att äta, personlig hygien och påklädning första veckan efter insjuknandet. Efter ett år rapporterade 25 % inga förändringar i livsstil jämfört med innan insjuknandet. Åttio procent klarade självständigt att sköta personlig hygien, och hade inga eller lätta fysiska symtom. För 75 % hade strokeinsjuknandet lett till olika grad av funktionshinder och förändrad livsstil.

Mental uttröttbarhet upplevdes av 72 % av respondenterna. Mer än 50 % av deltagarna upplevde nedsatt förmåga att hantera stress, och nedsatt minnesförmåga. Mellan 40 % och 50 % av deltagarna upplevde irritabilitet, emotionalism, brist på initiativ och nedsatt koncentrationsförmåga. Omkring 25 % upplevde lättutlöst oro. Livstillfredsställelsen var lägre än hos en jämförbar svensk normgrupp framför allt tillfredsställelsen med livet generellt, fritid och sexliv. Mental uttröttbarhet var associerat med lägre tillfredsställelse med livet generellt, fritid, sysselsättning, sexliv, och socialt liv.

Arton respondenter med en genomsnittlig ålder på 50 år djupintervjuades. Dessa personer upplevde att strokeinsjuknadet delvis förändrat dem som personer med nedsatt kognitiv förmåga och emotionella förändringar svåra att förstå och få grepp om. De flesta hade ingen erfarenhet av något liknande tidigare.

”Det här syns inte utanpå”, var ett vanligt uttryck för att beskriva funktionshindret. Att funktionshindret var dolt beskrevs också i termer av att det var svårt att förstå och få grepp om och därmed svårt att förklara för andra och få dem att förstå. Gränsen mot ”det normala” var också oklar. Trötthet, och problem med att få gjort allt man vill har väl alla idag, var kommentarer respondenterna fick när de påtalade sina problem.

Livet upplevdes oförutsägbart. Respondenterna var osäkra på sin kapacitet. Symtomen var svåra att kontrollera och gardera sig mot och känsliga för omgivningens inverkan.

Funktionshindrets ”dolda” karaktär gjorde det svårt för närstående att bedöma grad av hjälpbehov och stöd. Interaktionen inom familjen hade förändrats och respondenterna upplevde begränsningar i att kunna bidra med sin del. Aktiviteter med krav på flexibel kognitiv kapacitet, hade för en del blivit svåra. Att läsa en bok kunde vara helt omöjligt, på grund av att man tappade tråden, inte orkade koncentrera sig, glömde vad man hade läst, liksom att se på TV och få ihop bild, text och ljud till en helhet. Att gå på idrotts- och nöjesevenemang, köra bil, resa på semester, delta i barnens fritidsysslor var problematiskt, liksom övergripande planering och framförhållning som krävs för att få struktur på sin vardag.

Ett strokeinsjuknande innebär att man råkat ut för ett allvarligt sjukdomstillstånd, ofta med riskfaktorer för ny stroke. Det leder också till funktionshinder av varierande grad och art. Vardagen ett år efter insjuknandet var fortfarande präglat av osäkerhet om hur det skulle gå. Upplevelse av vård och rehabilitering var viktiga. För personer som upplevt otillräcklig vård/rehabilitering/stöd kunde detta leda till grubblande som påverkade förmågan att hantera den nya livssituationen.

I parstudien deltog 56 par. Jämfört med den svenska normgruppen var båda makarna mindre nöjda såväl med livet generellt som med sexliv och fritid. De friska makarna var mindre nöjda med partnerrelationen både i jämförelse med patienterna och normgruppen. Trots denna skillnad var ändå 61 % av paren nöjda med sin partnerrelation. Strokedrabbade med ansvar för barn var mindre nöjda med familjesituationen än de som inte hade ansvar för barn. Endast 30 % av paren var nöjda med sitt sexliv. Det var stor spridning, från 20% till 66 %, inom olika livsdomäner vad det gäller makarnas enighet i att vara nöjda.

Konklusion

Konsekvenser av stroke är mycket varierande för den som drabbas. För många leder det till omfattande komplexa funktionshinder medan andra kan bli återställda. Denna studie visar på vikten av att i ett längre perspektiv också uppmärksamma personer med stroke som i akutskedet bedömts som lätt. Den visar att trots att de strokedrabbade till viss del återvänt till ett aktivt liv, upplevde de fortfarande efter ett år problem att hantera sin vardag. Studien visar på betydelsen att öka kunskapen om "dolda funktionshinder" efter stroke inom vård, rehabilitering och till närstående. Livstillfredsställelsen var påverkad för både de drabbade och deras makar, fast på lite olika sätt. Vid rehabilitering och stöd är det viktigt att se familjen som helhet och även inkludera barnen, samt att möta varje individs speciella behov av stöd.

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Appendix 1

Oxford Handicap Scale

Grade	Description
0	No symptoms
1	Minor symptoms that do not interfere with lifestyle
2	Minor handicap, symptoms that lead to some restrictions in lifestyle, but do not interfere with the patient's capacity to look after oneself.
3	Moderate handicap, symptoms that significantly restrict lifestyle and prevent totally independent existence.
4	Moderately severe handicap, symptoms that clearly prevent independent existence, though not needing constant attention.
5	Severe handicap, totally dependent patient requiring constant attention night and day.

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