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SPOUSES OF STROKE PATIENTS

Psychological Well-Being and Life Satisfaction

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ABSTRACT

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Gunilla Forsberg-Wärleby. Institute of Clinical Neuroscience, Stroke Research Group.
The Sahlgrenska Academy at Göteborg University. Göteborg. Sweden

English text with a summary in Swedish

Aim: The aim of this study was to investigate longitudinal changes in spouses' psychological well-being and life satisfaction between the first weeks, four months and one year after their partners' stroke and to study the associations between spouses' psychological well-being and life satisfaction and characteristics of the spouses and stroke patients at these three points in time.

Method: Eighty-three consecutively recruited spouses of first-ever stroke patients < 75 years participated. The spouses' self-rated psychological general well-being, life satisfaction and sense of coherence were measured in the first week, four months and one year after stroke in a semi-structured interview also including open questions about experiences of their ongoing life situation. The stroke patients' physical and cognitive impairments and level of self-care were documented in the first week and one year after stroke. Depression and astheno-emotional syndrome were documented at one year. The interview data were analysed with qualitative analysis methods. The quantitative data were analysed with non-parametric statistical methods.

Results: In the first weeks, the spouses' psychological well-being was significantly lowered as compared with norm values. Four different categories of the concept of "view of the future" were developed on the basis of the interviews. The spouses' view of the future was strongly associated with their psychological well-being. Their sense of coherence was associated with satisfaction with social relationships and financial situation prior to stroke and with psychological well-being in the present. Four months after the stroke, the spouses' psychological well-being had increased. However, as compared with life prior to stroke, their life satisfaction was lower. There were no statistically significant changes in psychological well-being or life satisfaction between four months and one year. The spouses' sense of anxiety, depressed mood and vitality as well as satisfaction with their daily activities and leisure situation were significantly associated with the stroke patients' physical impairments and ability in self-care. Their sense of positive well-being and their satisfaction with the partner relationship and family life were significantly associated with the presence of cognitive impairments and astheno-emotional syndrome in the stroke patients. The spouses' and stroke patients' emotional health was related. The associations between the spouses' psychological well-being and the stroke patients' impairments were most marked at four months, except for sensorimotor impairment, while the associations between spouses' life satisfaction and the stroke patients' impairments were most marked at one year.

Conclusion: The spouses' individual appraisal of the consequences for their personal lives seems to have a greater impact on their well-being than the patients' objective impairments in the first period after stroke. The visible physical impairments had a great impact on spouses' well-being in the first phase, while the impact of cognitive and emotional impairments became more evident in everyday life. Some months after the initial crisis reaction, the psychological well-being of the spouses increased, while satisfaction with valuable domains of life decreased. Between four months and one year, individual changes were observed in both positive and negative directions. Spouses of stroke patients with persisting dependency often perceived a decline in life satisfaction.

Keywords: Stroke, caregivers, rehabilitation, adaptation, psychological, personal satisfaction, sense of coherence, longitudinal studies

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SPOUSES OF STROKE PATIENTS

Psychological Well-Being and Life Satisfaction

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- II: Forsberg-Wärleby G, Möller A, Blomstrand C. Spouses of first-ever stroke patients: psychological well-being in the first phase after stroke. Stroke 2001;32:1646-1651
- III: Forsberg-Wärleby G, Möller A, Blomstrand C. Spouses of first-ever stroke victims: Sense of coherence in the first phase after stroke. J Rehabil Med 2002; 34:128-133
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- V: Forsberg-Wärleby G, Möller A, Blomstrand C. Life satisfaction of spouses of stroke patients during the first year after stroke. Submitted 2002.

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Gunilla Forsberg-Wärleby



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..... but the greatest of these is charity.

1 Corinthians 13: 13

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LIST OF PAPERS

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ABBREVIATIONS

AE	Astheno-emotional syndrome
BI	The Barthel Index
CI	Confidence interval
CT	Computerised Tomography
GRR	Generalised resistance resources
LACI	Lacunar cerebral infarction
LiSat-9	The Life Satisfaction Checklist, nine items version
LiSat-11	The Life Satisfaction Checklist, eleven items version
PACI	Partial anterior cerebral infarction
PGWB	The Psychological General Well-Being Index
POCI	Posterior cerebral infarction
SOC	The sense of coherence
SOC-29	The Sense of Coherence Questionnaire (The Orientation to Life Questionnaire), 29 items version
TACI	Total anterior cerebral infarctions

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INTRODUCTION

When a family member suffers from disease and impairments, there is an impact on daily activities, roles and emotional health of others in the family members (1). The severity and characteristics of the impairments, such as physical (2), cognitive (3) or emotional (4) impairments, is crucial to what sort of impact on everyday life the family must face. The characteristics of the onset of the disease (sudden or progressive) and the development (recovery, stability or progress) is also important to the experience of stress and the ability to cope with the change in life circumstances (5). Although the impact on children, relatives and friends may be marked, the spouses of persons with disabilities run the highest risk of deterioration in their emotional health, because of the increased burden of care (6).

One large group of spouses at risk of negative effects on their well-being and health is spouses of patients with brain lesions caused by stroke. The brain is the "engine" for perception, interpretation, processing, judgement, planning, performance, interaction and communication. According to the complexity and permanence of impairments and the uncertain nature of the disease, stroke can have a very widespread impact on the family and everyday life.

Spouses play an important role in their support of stroke patients in the course of their rehabilitation. The physical, cognitive and emotional disorders that can ensue stroke have a great impact on the stroke patients' ability to carry out daily activities and on social interaction (7, 8). About 70% of stroke patients are partially dependent on other persons and about 30% are in need of great support in managing activities in personal care and domestic and community activities (9-11). Families, and especially spouses, provide the greatest amount of support, and the estimated cost of informal caregiving is high (10, 12-15). Adequate emotional and practical support is known to affect stroke patients' functional (16) and psychosocial rehabilitation (17-21). The family's knowledge of (22, 23) and attitudes to stroke (24) are of great importance for their ability to manage the consequences of the disease in everyday life.

The WHO's Helsingborg Declaration on Stroke Management in Europe (25) stipulates that:

- the interest and needs of stroke patients and their families should be the principal concern of all professionals.
- the management of all aspects of disability should be planned in close collaboration with patients and their families and be sensitive to their needs.
- rehabilitation should be planned in close collaboration with the patient and family members who are recognised as important contributors to the rehabilitation process
- evaluation of stroke outcomes should include proportions of carers who are satisfied with the information, support and training received and assessments of the emotional effects of providing care.

However, informal caregivers of stroke patients are not always satisfied with the support they receive from the health care system as concerns their own needs for planning for the future and knowledge about stroke and about how to manage the consequences of stroke in everyday life (26-30). To better support the spouses of stroke patients from the time of acute care and during the adaptation process, there is a need of a better understanding of their experiences in

everyday life after stroke and of factors affecting their psychological well-being and life satisfaction.

Few studies have focused on the impact of stroke on the informal caregivers', although the number of studies of this kind has increased greatly in recent years (23, 31). While these studies have made major contributions to the knowledge and understanding of the needs of informal caregivers to stroke patients, important weaknesses have been pointed out (23). Previous studies have often included only a small number of participants. They have often focused on the caregivers of stroke patients with more severe stroke, and thus less is known about caregivers of stroke patients with mild physical impairments. The study groups most commonly consist of informal caregivers with different relationships with the patients, different experiences of previous strokes and different durations of caregiving experience. Data on spouses' life satisfaction are especially scarce (23). It can also be assumed that spouses of stroke patients of different ages face different effects on life and have different resources for managing the consequences of stroke in terms of interpersonal resources such as their own health, and environmental resources, such as social support.

The studies reported here are the first parts of a longitudinal study that uses a combined methods design, focusing on a population of spouses of stroke patients younger than 75 years that was recruited consecutively from an acute neurological ward. The study was conducted according to a theoretical model of the assumed associations between the impact of stroke, coping and outcome with respect to subjective well-being. The model has been developed from clinical experience, previous research and theoretical frames of reference and is presented in Figure 1. The study is interdisciplinary and focuses on the research problem from neurological, psychological and occupational therapy perspectives.

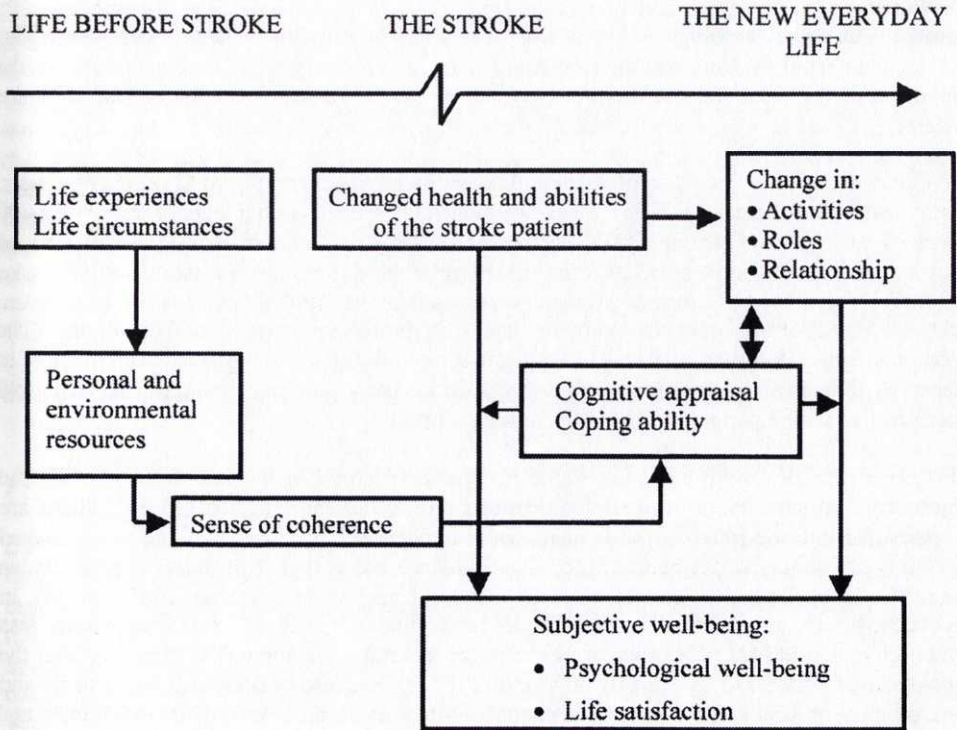


Figure 1. Theoretical assumptions of the study: all spouses have individual experiences and circumstances in their lives before stroke. A stroke is a sudden and unexpected event and results in changes in the health and ability of the stroke patient. The changes in the partners' health and ability are assumed to have an impact on the everyday life of the couple as regards activities, roles and relationships and to have an impact on the spouses' subjective well-being in terms of psychological well-being and life satisfaction. The spouses' life experiences and life circumstances before stroke form the basis of the development of their personal and environmental resources, which are assumed to build up their sense of coherence. Their sense of coherence is assumed to be important for their cognitive appraisal of the situation and their coping ability. The spouses' cognitive appraisal of the situation and their ability to cope with the emotional impact of the stroke event, the changes in their activities and roles and their burden of care are assumed to be mediators between the consequences of stroke and the adaptational outcome in terms of subjective well-being.

STROKE

Stroke is an acute neurological dysfunction of vascular origin with a sudden (within seconds) or at least rapid (within hours) occurrence of symptoms and signs corresponding to the involvement of focal areas in the brain. Symptoms last more than 24 hours or lead to death (32).

Stroke is the third major cause of death and disability after ischemic heart disease and cancer, in industrialised societies (32, 33). Stroke incidence in Sweden is on a level of at least 30 000 persons each year, of whom 20 000 persons suffer their first-ever stroke (9). About 20% of stroke patients who have suffered a first-ever stroke die during the first months after stroke (34). The prevalence of stroke in Sweden is estimated at over 100 000 persons (9). In Sweden, about 55% of stroke patients living in their own home are married or cohabitants (The National Stroke Register in Sweden. Personal communication E.-L. Glader, 2002). Thus, at least 10 000 spouses experience a partner's stroke each year and approximately 50 000 persons live with a partner who has experienced a stroke.

The incidence of stroke has been stable in Western Europe in the last decade, while the mortality and severity of stroke have declined during the same period (35-37). There are reports that indicate trends towards increases in incidence, however, which are most marked in terms of younger stroke patients (38). The incidence rate is higher for men than for women (32, 37), most marked in middle age (39). Stroke incidence rises sharply with age (40). In Sweden, the mean age of stroke onset is 75 years, although 20% of stroke patients are less than 65 years old (41). With increased age in the general population, it is estimated that the incidence of stroke will increase by 30% until 2010 (9). Because of decreases in mortality and the severity of stroke, the numbers of patients with stroke who live in their own homes and are in need of support from professional health care, the community and the family will therefore increase (42).

Stroke is made up of two broad two categories: cerebral infarction (85%) and intracerebral haemorrhage (15%) (9). Cerebral infarctions can be classified into five categories according to etiology, the three main categories being large artery arteriosclerosis (30%), cardioembolism (25%) and small vessel occlusion (20%). The other two categories are stroke of other determined etiology and strokes of undetermined etiology (9, 43). Cerebral infarctions can also be classified according to the artery affected and, in connection with this, the brain area that is damaged. Total anterior circulation infarctions (TACI) affect both cortical and subcortical areas, partial anterior infarction (PACI) predominantly affect cortical areas, posterior circulation infarcts (POCI) involve the vertebrobasilar arterial territory and lacunar infarcts (LACI) involve deep perforation arteries (44).

Different types of cerebral infarcts also have different characteristics of onset and result in different kinds and combinations of impairments (44). The clinical symptoms of stroke are extremely heterogeneous. Impairments include such broad areas as hemiparesis, sensory deficits, disturbed vital functions such as urinary incontinence, dysarthria, dysphagia, impaired perceptual function, cognitive dysfunction such as dysphasia, dyspraxia and memory deficits and social behavioural disturbances (21, 45-47). The severity of impairments can differ from very disabling to no remaining deficit at all.

Emotional disorders such as anxiety and post-stroke depression are common in both the acute phase (48-50) and in the long- term perspective (49-53). The prevalence rate varies between

25% and 79% according to methodological differences and difficulties in the diagnostic procedures in patients suffering from post-stroke depression (54).

Organic mental disorders, such as astheno-emotional (AE) syndrome, are common after stroke (55, 56). In mild or moderate forms the AE syndrome is characterised by an impaired ability to concentrate, memory difficulties, increased mental fatigueability, irritability, stress sensitivity and emotional instability. Bright lights and loud sounds can be unpleasant and disturbing. In the severe forms, emotional instability is more marked. Some patients show emotional flattening, sluggishness in association processes and slowness in thought, a lack of overview and a reduced capacity for abstractions and judgements (55, 56).

The complexity of symptoms means that spouses of stroke patients may experience different types of impact on family life and daily activities and gives spouses different experiences both in the acute phase and during the stroke patients' recovery process.

PREVIOUS RESEARCH AND THEORETICAL FRAMEWORK

LIFE BEFORE STROKE

In their ordinary life prior to stroke, all spouses have individual life experiences and lifestyles that involve daily occupation and personal care, leisure activities, financial situation, family relationships, relationships with friends and so on (57). Daily occupations are dependent on individual values and established patterns of roles and habits that constitute normal daily routines and on the individual's abilities and skills (58). Daily occupations are carried out within a temporal, physical and sociocultural context (58). The family function before stroke and previous satisfaction with the partnership relation has been assumed to have an impact on spouse's emotional health and on family adaptation after the onset of a disease (59, 60).

STROKE IMPACT ON EVERYDAY LIFE

A stroke very frequently results in changes in the family's daily activities, roles and habits in everyday life (19, 61-63). Spouses must take greater responsibility and carry out new activities in the family and domestic settings (57, 61, 64, 65). Impacts of stroke on families have long been noted (20, 66, 67), but it was not before the studies of Brochlehurst *et al.* (68) and Holbrook (69) that the widespread impact on family life was documented. Of spouses who have occupations outside the home, 31% - 83% reported changes in their ability to carry out their occupations (64, 69, 70). Changes in the financial situation are also frequently reported (14, 57, 64, 65, 69-73). However, differences in community support such as the availability of day care for stroke patients and the social security system may have different impacts on spouses' satisfaction with their vocational and financial situation after stroke.

The spouses' leisure situation and social life are also at risk of being affected (57, 61, 65, 70). The same is true in social areas such as partnership and family relations (57, 61, 64, 70-72). Effects have also been reported in sex life, caused by both physical and psychological impairments (64, 69, 74, 75).

Changes in daily activities, roles and relationships are not always negative experiences, however. They may also offer positive experiences, such as greater intimacy and satisfaction with the ability for taking care of a beloved wife or husband (57, 64, 70, 76). There may also be positive experiences in terms of greater self-esteem in handling new challenges and in managing caregiving in an adequate way (77).

Nevertheless, increases in the tasks as caregiver and restrictions of activity have been shown to be associated with changes in spouses' emotional health (78, 79). The balance between work, rest and leisure is important to the individual's perception of health and well-being (80). This is also true for the possibilities for, knowledge of and of ability in performing activities of value for the individual (81).

SUBJECTIVE WELL-BEING

The question of what constitutes a good life has concerned thinkers since the ancient time (82). Concepts such as subjective well-being (83), happiness (84), life satisfaction (85) and quality of life (86) have been developed to define the "good life" and are often used synonymously. These concepts are all concerned with the individual's own perception and evaluation of his life, (82, 84, 85, 87), with the exception of the concept of quality of life which may also include objective measurements of employment, housing, health and so on (84, 85, 88).

Subjective well-being has been considered to consist of three parts: positive affect, negative affect and cognitive judgement of one's own life (85). The concept of psychological well-being represents the intrapersonal affective or emotional state (89). Peoples' emotions are assumed to reflect an immediate reaction to events that happen to them (82). People also make broader judgements about their life as a whole, as well as about domains such as marriage and work (82). Life satisfaction is the individual judgement of the overall quality of his life as a whole (84). Satisfaction with life is assumed to be achieved when a state, a goal or a need is fulfilled (Telic theoris), by social interaction or specific activities (Activity theory) or by comparison with standards and the actual condition (83). Cultural factors are also assumed to have an impact on the perception of satisfaction (82). Satisfaction with life can be affected by changes in an individual's needs, expectations, physical or psychological health, relationship to the social environment and society, and material standards (87). The individual's appraisals of "what he feels" for the most part and of whether life has given him "what he wants" do not necessarily coincide (84). Neither do positive affect and negative affect necessarily correlated (83).

The majority of individuals in western societies rate themselves as being satisfied with life (90, 91). Perceptions of life satisfaction are rather stable over time (90). However, proportions of individual's who are satisfied with different domains of life are different in different ages and between sexes (92, 93). The direction governing causes and consequences of subjective well-being has been debated, however. The "top-down approach" has assumed that personality influences the way a person experiences events, and thus, indication that the individual's overall life satisfaction is the cause of his or her satisfaction with different life domains (94). The "bottom-up approach" assumes that satisfaction with life as a whole is made up of the sum of the satisfaction that is felt in many different domains (83, 95). The picture of the causes and consequences between satisfaction with life as a whole and satisfaction with different domains of life seems indeed to be complex. There is evidence in an integrated top-down and bottom-up model that life satisfaction is caused by both stable individuals' personal characteristics, and their momentary judgement of satisfaction with different life domains important to them and on current mood (96, 97).

SPOUSES' EMOTIONAL HEALTH AND SUBJECTIVE WELL-BEING

The onset of stroke is sudden and unexpected and is most often perceived as a critical life event (98). Spouses of patients that have experienced an unexpected and acute illness feel intensive emotional turmoil that shifts between a fear of deterioration and a sense of happiness when improvements are observed (99). Like spouses of patients with heart disease (100, 101), spouses of stroke patients often feel fear of greater impairment or death in the case of a new stroke and of the future caregiving burden (6).

The spouses' level of stress has been assumed to be associated with the severity of the stroke and the type of impairment. Spouses of stroke patients who suffer depression have been shown to perceive a deterioration in their own emotional health (51, 71, 102). Spouses of patients with severe cognitive impairments and behavioural disturbances (103-105) have also been shown to feel burden and poor emotional health. The relationship between spouses' emotional health and stroke patients' physical impairments and ability in terms of self-care is not well known and different studies show conflicting results (6, 73, 79, 102, 105-107).

The impact of stroke on caregivers' emotional health has been measured in terms of burden (73, 79, 108, 109), stress (65, 110), strain (104, 111, 112), psychological well-being (113), life satisfaction (114), depression (6, 19, 51, 72, 79, 102, 105-107, 115-117) and anxiety (64, 72, 105-107, 117, 118). The concept of burden includes both objective components, such as changes in the patient's personality and behaviour and alterations in financial and social activities, and a subjective component, such as the caregiver's negative reaction to the objective burden (73). Strain is defined in terms of the enduring problems that have a potential to provoke threat (57). Stress is defined as a particular relationship between a person and his or her environment that is judged by that person as being taxing or as exceeding his or her resources and endangering his or her well-being (119). The level of perceived stress and burden correlates significantly with the level of depression (112, 120).

The impact of stroke on the psychological health of caregivers in the first weeks after stroke is poorly investigated (6, 107, 121), while the impact at the time of six to 12 months (6, 18, 51, 102, 103, 106, 107, 111), one to three years (51, 72, 107, 113, 115) and more than three years after stroke (14, 73, 104, 108, 117) has been more frequently investigated. In the different studies that have been done, between 11 and 50% of informal caregivers have been shown to experience an emotional disturbance, especially depression. However, one study showed no differences in emotional health and family function between spouses of stroke patients and spouses of partners without stroke (122). The proportions of spouses with impaired emotional health seem to be stationary after stroke (6, 51, 107), although there are signs of an increased proportion of depression among caregivers over time (115).

Previous studies have chiefly been cross-sectional and less is known about variations in emotional health over time. Longitudinal studies have been requested (23). Most studies have also focused on the emotional health of the spouses with regard to depression. Studies focusing on the spouses' life experiences and judgement of their quality of life are also needed (23). In the present studies, the spouses' subjective well-being are being investigated according to the concepts of psychological well-being and life satisfaction.

COPING

Not all spouses experience poorer emotional health as a result of their partners' stroke. Other factors such as coping resources and coping capacity are known to have a great impact on health and the sense of well-being (119, 123). The spouses' appraisal of their life situation and their coping strategies is shown to be of importance for their perception of their burden (104, 105, 120, 121, 124) .

Coping is defined as a constantly changing cognitive and behavioural effort to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person (119, p.141). Coping is a process concerned with what a person actually thinks and does in a specific context and what changes in thoughts and actions occur as the "situation" proceeds (119). Coping serves to manage or alter a specific problem (problem-focused coping) and to regulate the emotional response to the problem (emotion-focused coping) (119).

The cognitive appraisal of the event is the starting point of the coping process. Cognitive appraisal is defined as an evaluative process that determines why and to what extent a particular transaction or series of transactions between the person and the environment is stressful (119). Appraisal is divided into two main categories. Primary appraisal has to do with what implications the situation has for the person's well-being. Primary appraisal may be irrelevant or benign-positive but may also encompass a stress appraisal that includes harm/loss (damage that has already happened), threat (damage that is anticipated) or challenge. Secondary appraisal is an evaluation process dealing with what coping alternatives exist and what the likelihood is that a given strategy will be successful and can be applied effectively (119). According to Lazarus, a person's coping strategies depend on his or her internal and external coping resources. Internal coping resources can be health, existential values, beliefs, general beliefs about control, problem-solving skills and social skills. External coping resources can be material resources and social support (119).

The individual's coping resources and coping abilities are important factors in his or her adaptation process. To adapt is defined as "to put oneself in harmony with changed circumstances" and "adaptation" is defined as "the act or process of adapting" (125). Adaptation is a dynamic process that occurs over time, during which the individual moves from being preoccupied with a change in life or with the fact that an expected and desired change did not come about, to integrating the change / lack of change into his or her life (5). Adaptation occurs always in an interaction with the social and physical environment. It may result in change in thoughts, values, behaviour, occupations, habits and relationships. The outcome of the adaptation process is the achievement of a state of well-being (58).

THE SENSE OF COHERENCE

Sense of coherence (SOC) is a concept associated with coping ability and adaptation. SOC is defined as "a global orientation that express the extent to which one has a pervasive, enduring though dynamic feeling of confidence that the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable; the resources are available to one to meet the demands posed by these stimuli; and these demands are challenges, worthy of investment and engagement" (123, chap.2). This concept was developed by Aaron Antonovsky and represents the core concept in his salutogenic model of health (126, chap. 7). The SOC is assumed to be a personal disposition, the individual's global orientation to life, including both cognitive and emotional perception. According to the definition, the SOC consists of three dynamic inter-related sub-components:

(a) comprehensibility (the cognitive component): the sense that one's internal and external environment is ordered, consistent, structured and clear. (b) manageability (the instrumental component), the sense that there are resources at one's disposal that are adequate to meet the demands of the stimuli and (c) meaningfulness (the motivational component), events tend to be viewed as challenges worthy of emotional investment and commitment (123, chap 2). Antonovsky assumed the SOC to have its origin in the individual's socio-cultural context in which his or her internal and external generalised resistance resources (GRR) are built up, such as material resources, knowledge, ego identity, flexible coping strategies, preventive health orientation, social support and so on. The individual's GRRs provide him/her with life experiences of consistency, participating in shaping outcomes and of an under-load/over-load balance that in turn create the SOC. A person with a strong SOC is assumed to have a better coping ability than a person with low SOC when he or she is confronted with stressors, and is assumed to be capable of clarifying and structuring the nature of the stressors, to believe that the appropriate resources for coping are available, to have the ability to mobilise his or her GRRs, to be able choose what seems to be the most appropriate strategy to cope and to be motivated to deal with the stressor that he or she regards as a challenge rather than a burden. (123, chap. 6).

The role of SOC as a mediator between stressful life events or conditions and outcome in terms of well-being and mental health has been investigated in several studies that have shown that individuals with a high SOC seem to cope in a more successful way (127-130). The SOC has also been investigated as a mediator between disability and handicap. The studies showed no association between the SOC and the level of impairment (131, 132), while the SOC was associated with variables such as perception of social functioning (131), depression (132-134), family adaptation (133) and perceived well-being (135). The SOC thus may reflect the individual's coping ability (136).

Antonovsky viewed the SOC as a continuum and assumed that the adult individual's position on the SOC continuum is fairly stable (123, chap 5). When a stressor must be faced, the position on the SOC continuum may decline. After a period of time, however, when the individual has mobilised his or her GRRs, he/she returns to his/her original position. If an individual faces a permanent change in his or her life situation, however, with new life experiences of a lack of consistency, of not being able or allowed to participate in shaping outcomes and of a load imbalance, there may be a negative impact on his/her SOC. On the other hand, gaining new positive experience of consistency, participation and load balance may over a long period of time increase an individual's SOC (123, p 123).

Antonovsky also assumed that the SOC is related to health and that a person's position on the SOC continuum is associated with his/her position on the ease-disease continuum (126, chap 6). Some longitudinal studies of the association between the SOC and physical health provide support for this (137, 138) while another cross-sectional study showed only a moderate association between physical symptoms and the SOC (139). The association between individuals' subjective health and SOC is strong, however. (140, 141). Several studies have shown the SOC to be associated with such emotional disorders as depression (142, 143) and anxiety (143, 144).

Disease and disability in a family are great psycho-social stressors (145, 146). The level of SOC in caregivers to patients with physical and cognitive impairments such as dementia, spinal cord injuries and stroke has been shown to be important for their adaptation to their new life situation (147-149).

METHODOLOGICAL FRAME OF REFERENCES

In research projects that focus on complex problems, different research methods afford different perspectives of the research problem. The research question guides the choice of research methods. Methodological pluralism in the same research project makes it possible to bring the strengths of different methods together in order to gain greater knowledge and understanding of the problem (150, 151).

Qualitative and quantitative research methods are taken from different traditions of thoughts in theoretical science (152, 153). The different research methods thus have different demands, possibilities, strengths and limitations. Quantitative research methods are useful in studies of a predefined phenomenon, its distribution within a population, associations between two or more different variables and in detecting any cause and effect relationships (152). In statistical analyses of quantitative data it is important to be aware of the theoretical framework and the operational definitions of the variables measured (154). Qualitative research methods are useful to identify and define phenomena, characteristics and meaning which are as yet unknown or about which little is known with reference to variability, structures and processes (152, p. 23). To gain more knowledge here, it is necessary to explore both the depth and the richness of the individual's experiences of the phenomena. Interviews and/or observations in a natural setting are common means of gathering these data (153). Through systematic analyses of the data, the researcher tries to identify patterns that can describe people's experiences and contribute to an understanding of people's actions and reactions.

Combining the two methods makes it possible to investigate the extent and distribution of results obtained in the qualitative data analysis by statistical analyses. The qualitative data analysis makes it possible to validate the results obtained from the quantitative data analyses. The qualitative data analysis can also contribute to the work of the interpretation and to a deeper understanding of the results obtained in the qualitative data analyses (150).

The impact of stroke on spouses represents a complex research problem with many different facets. Thus, for the purpose of capturing different perspectives on the problem, a combination of qualitative and quantitative research methods was used. One main purpose of the study was to gather knowledge of the distribution, change and associations in predefined concepts such as psychological well-being, life satisfaction and sense of coherence, which are assumed to be associated with life changes and coping. To answer these questions, it was necessary to use a deductive approach and to record data in self-rating scales with predefined questions (151, 152). It was also interest to gain a better understanding of the richness in the spouses' individual experiences and perceptions of their life situation to get an "insider" perspective on the research problem. Doing this required an inductive approach and open questions to obtain data on each individual's personal experiences (151, 152).

AIM

The aim of this study was to investigate longitudinal changes in spouses' psychological well-being and life satisfaction between the first weeks, four months and one year after their partners' stroke and to study the associations between spouses' psychological well-being and life satisfaction and characteristics of the spouses and stroke patients at these three points in time.

The specific aims were:

- to explore the spouses' thoughts about their future daily life in the in the first weeks after the onset of stroke (*Study I*)

- to investigate
 - the spouses' perceived psychological well-being and sense of coherence in the first weeks after stroke (*Studies II, III*).

 - the longitudinal changes in the spouses' psychological well-being between the first weeks and four months and one year after stroke (*Study IV*).

 - the longitudinal changes in the spouses' life satisfaction from the time prior to stroke until four months and one year after stroke (*Study V*).

- to investigate the associations between
 - the spouses' satisfaction with life before stroke, their sense of coherence, thoughts about their future life and psychological well-being in the first weeks after stroke, their age and sex and the neurological characteristics of the stroke patients (*Studies I, II, III*).

 - the spouses' level of psychological well-being and satisfaction with life at four months and one year after stroke, their age and sex and the characteristics of the stroke patients (*Studies IV, V*).

METHODS

INCLUSION PROCEDURE

The study group consisted of spouses of stroke patients hospitalised at the Department of Neurology, Sahlgrenska University Hospital, Göteborg. Sahlgrenska University Hospital is both a secondary care hospital in the city of Göteborg (approximately 470 000 inhabitants) and a regional care hospital for the western part of Sweden (approximately 1.6 million inhabitants). Spouses of stroke patients with a confirmed diagnosis of first-ever stroke (excluding subarachnoid haemorrhage), aged less than 75 years and living in Göteborg or surrounding areas were included in the study. Spouses of stroke patients with evidence of co-existing known malignant or other rapidly progressive medical disease or who did not speak and understand Swedish were excluded. Spouses who had suffered a stroke or had a cognitive impairment themselves were also excluded.

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. The spouse was then contacted at the ward or by letter and telephone and invited to participate. The same person (G.F-W.) made all contacts with the staff in charge, the stroke patients and the spouses. The participants were included consecutively from September, 1994, to October, 1997, except during holidays and during the period from January to March 1997 for practical reasons.

PARTICIPANTS

Of a total of 342 stroke patients consecutively admitted to the Neurological Department, 236 were excluded. One hundred and thirty were single, 33 were over 75 years, 44 had a recurrence of 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 the researchers and were excluded. Three spouses experienced stroke or suffered dementia themselves and one spouse did not speak Swedish.

The available population thus consisted of 106 stroke patients. Of these, two stroke patients did not give permission to contact their spouses and two died. One spouse was not available. Eighty-three spouses agreed to participate in the first interview (*Studies I-III*). Seventy-three spouses participated in the follow-up at four months and 71 spouses at one year. Sixty-seven spouses participated in all of the three interviews and these spouses constitute the study group in the longitudinal studies (*Studies IV-V*). A flowchart describing the spouses' continued participation and dropouts in each step is presented in Figure 2.

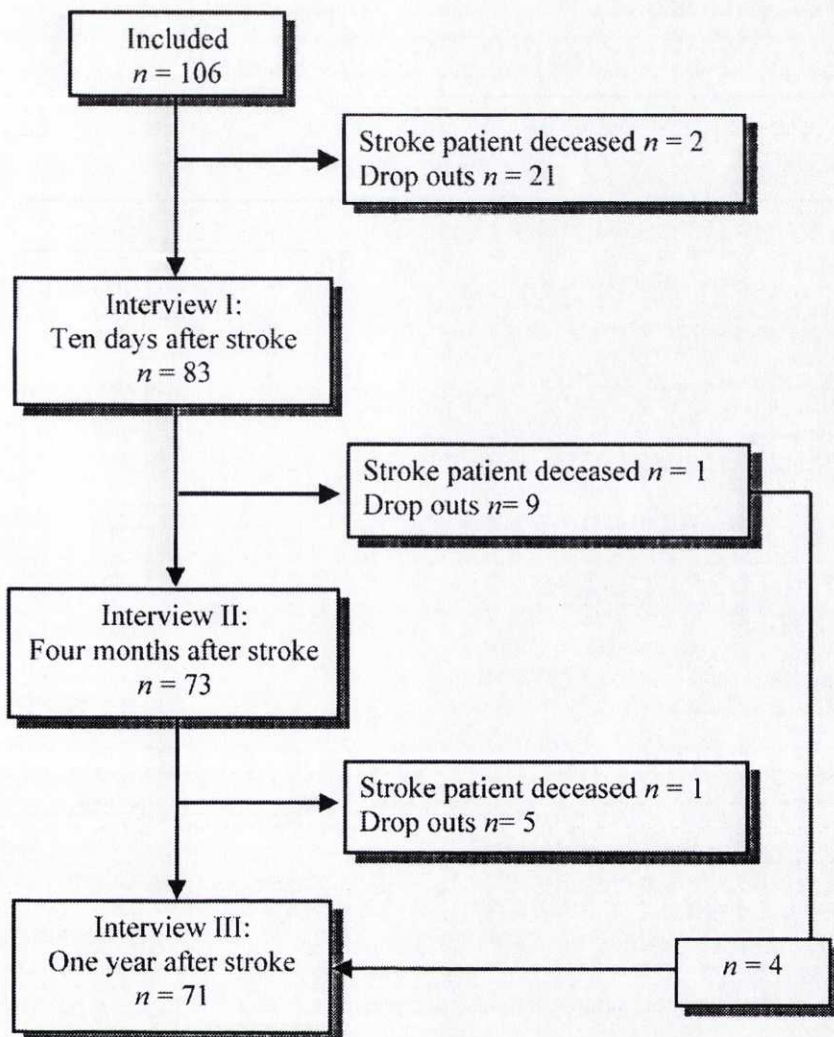


Figure 2. Flowchart describing the spouses' continued participation and dropouts at each step.

THE STROKE PATIENTS

The baseline characteristics of the stroke patients are given in table I.

Table I. Stroke patients

Data shown in <i>n</i> (%)	Studies I-III <i>n</i> = 83	Studies IV-V <i>n</i> = 67
Men / women	62 (75) / 21 (25)	47 (70) / 20 (30)
Age: mean (range)	58 years (23 to 75 years)	58 years (37-75 years)
Cerebral infarction / intracerebral haemorrhagia	69 (83) / 14 (17)	55 (82) / 12 (18)
Location of stroke:		
Right hemisphere lesion	34 (41)	26 (39)
Left hemisphere lesion	35 (42)	30 (45)
Bilateral lesions	2 (2)	2 (3)
Infratentorial lesions	12 (15)	9 (13)
TOAST classification:		
Large-artery atherosclerosis	18 (26)	16 (29)
Cardioembolism	16 (23)	13 (24)
Small-vessel occlusion	17 (25)	14 (25)
Undetermined etiology	18 (26)	12 (22)
Bamford's classification:		
Lacunar infarcts	17 (25)	14 (26)
Partial anterior circulation infarcts	34 (49)	29 (53)
Total anterior circulation infarcts	2 (3)	2 (3)
Posterior circulation infarcts	16 (23)	10 (18)
Pure sensorimotor impairment	36 (43)	31 (46)
Moderate or severe motor impairment	38 (46)	33 (49)
Aphasia	18 (22)	17 (25)
Barthel Index: Median (I-Q range)	100 (60-100)	95 (60-100)

THE SPOUSES

The characteristics of the spouses are presented in table II.

Table II: The characteristics of the spouses

Data shown in <i>n</i> (%)	Studies I-III <i>n</i> = 83	Studies IV-V <i>n</i> = 67
Men / Women	21 (25) / 62 (75)	20 (30) / 47 (70)
Age: Mean (range)	57 years (27- 79 years)	57 years (30 - 79 years)
Employed full or part time	47 (57)	36 (54)
Have/had occupations requiring:		
Compulsory school	53 (64)	41 (61)
Upper secondary or tertiary education	25 (30)	21 (31)
Higher academic degree	5 (6)	5 (8)
Length of relationship: Mean (range)	30 years (2 - 54 years)	30 years (2 - 54 years)
Responsibility for children	16 (19)	13 (19)

THE WITHDRAWALS

Primary withdrawals

Eight men and 15 women did not participate in the first interview. No further demographic data about the spouses are available. Of the 18 spouses declined to participate, three spouses withdrew on the grounds of their own impaired emotional health, five for practical reasons and ten for lack of interest in participating.

There were no statistically significant differences among the stroke patients with respect to age, sex or level of self-care between the spouses who participated and those who withdrew from the study. The baseline characteristics of the stroke patients are given in table III.

Secondary withdrawals

One man and 15 women withdrew from one or both of the follow-ups. Two withdrawals were related to the death of the partner. One spouse withdrew owing to illness and five for personal reasons. Two spouses perceived no changes in their life situation after stroke and therefore decided to withdraw. Six spouses reported that they had decided to withdraw due to their own impaired emotional health. During the first months after the stroke these spouses experienced cognitive and/or behavioural changes in their partners that they reported not having been prepared for and not being able to cope with. Five partners of these six spouses had a lesion in their right hemisphere and five also suffered from no or slight sensorimotor impairment in the first phase of stroke.

There were no statistically significant differences between the spouses who participated and those who withdrew from the follow-ups according to age (56 years vs. 57 years), the PGWB total score in the first phase after stroke (median 92, IQ range 76 to 103 vs. median 88, IQ range 69 to 114) or satisfaction with life as a whole prior to stroke (median 5, IQ range 4 to 6 vs. median 6, IQ range 4 to 6). Neither were there any statistical significant differences in the neurological or emotional characteristics of the stroke patients of the spouses who participated and the withdrawals. The baseline characteristics of the stroke patients are given in table III.

Table III: Stroke patients: the primary and secondary drop outs

	Primary drop outs <i>n</i> = 23	Secondary drop outs <i>n</i> = 16
Men / women: <i>n</i> (%)	15 (65) / 8 (35)	15 (94) / 1 (6)
Age: mean (range)	61 (30-74)	58 (23-74)
Cerebral infarction / intracerebral hemorrhagia: <i>n</i> (%)	20 (87) / 3 (13)	14 (87) / 2 (13)
Barthel Index in the acute phase: median (range)	100 (0-100)	100 (35 - 100)

DATA COLLECTION

DATA ON THE SPOUSES

Data on the spouses were recorded in a semi-structured interview, which included both self-rating questionnaires and open questions. Information on caregiving tasks, domestic activities, leisure activities and social contacts was also recorded in the interview on checklists developed for the study. These data are not presented in the present thesis, however. The first interview was held an average of ten days after the stroke (SD. four days). The follow-ups were carried out at an average four months (SD. five weeks) and at one year (SD. four weeks) after stroke. Seventy-four of the first interviews, 53 of the first follow-up interview and 50 of the second follow-up interviews were carried out in a home-like environment at the Occupational Therapy Department at Sahlgrenska University Hospital. The rest of the interviews were held according to the spouses' own requirements, however, generally in their homes. The interviews lasted an average of one hour and 45 minutes (range: 45 minutes to three hours). All of the spouses who withdrew in the follow-up period participated in a telephone interview that dealt with their experience of the ongoing life situation.

Demographic data

Demographic data such as age and sex of the spouse, family members, occupation and length of relationship were recorded.

Data on experience of the ongoing life situation and coping

A semi-structured interview included open questions on experience concerning the themes: the life before the event; the ongoing life situation; belief in the future and coping strategies and resources used. The majority of the interviews were tape-recorded with the spouses' informed consent and then transcribed. A few interviews were put into writing immediately after the interview.

Psychological well-being

The spouses' sense of psychological well-being during the most recent week was measured by the Psychological General Well-Being (PGWB) Index (89). This index was developed to "measure self-representations of intrapersonal affective or emotional states reflecting a sense of subjective well-being or distress" (89, p. 170). The index includes 22 items that can be summed to form a global overall score or be divided into six dimensions: anxiety (five items), depressed mood (three items), positive well-being (four items), self-control (three items), general health (three items) and vitality (four items). Each item has six response options scored on a scale from 1 (most negative option) to 6 (most positive option). The total score can range between 22 and 136. The index correlates significantly with other scales of emotional health and current mood (89, 155, 156) and has also been shown to be sensitive to an affect balance between subjective states of positive and negative affect (89). It has also been shown to be sensitive to change in subjective well-being in clinical trials (155, 157, 158) and in distinguishing between persons with impaired mental health and community residents (89, 156). The index has high test-retest reliability in a short time perspective of one week but lower in a long-term perspective of six months (89). The items in the PGWB Index have high internal consistency. The alpha coefficient ranges between 0.90 and 0.94 (89). Norm values from a Swedish population are available (159).

Life satisfaction:

Satisfaction with life was rated by the Life Satisfaction Checklist (also called the Life Satisfaction Questionnaire) (160). The Life Satisfaction Checklist is available in a nine-item (LiSat-9) (160) and an 11-item (LiSat-11) version (161). The LiSat-9 was used in the present study. In the first interview, the spouses rated their satisfaction with ordinary life prior to stroke. In the follow-ups, the spouses rated their satisfaction in ongoing life. This checklist consists of the items: Satisfaction with: life as a whole, ability to manage self-care, leisure situation, vocational situation, financial situation, sexual life, partnership relations, family life and contacts with friends and acquaintances. Since the study group involved persons who were employed, were homemakers or were retired, the original item "satisfaction with vocational situation" was extended to read "satisfaction with vocational/occupational situation", which means satisfaction with ordinary daily occupation (personal communication K.S Fugl-Meyer, 1995). There is a six-grade scale for each item ranging from 1 ("very dissatisfied") to 6 ("very satisfied"). The LiSat has shown intra-individual stability and sensitivity to changes (162) and has been shown to be able to describe life satisfaction in persons with and without impairments in pertinent items (163-166). The checklist is used in studies of life satisfaction in Swedish community samples (93) and in persons with impairments and disabilities (161, 163, 167-169).

Sense of Coherence:

The "Sense of Coherence Scale" (SOC) consists of 29 items measuring the three SOC components of comprehensibility (11 items), manageability (ten items) and meaningfulness (eight items) (123). Each item has a seven-point semantic differential scale with two anchor phrases (for example "never - very often"). Although the items in the three dimensions are visually separable, the SOC scale was developed to measure the SOC as a global concept and is used in that way in the present study. Each item is meant to measure the reaction to a specific "dimension" of stressors. The score of each item is added to reach a total score that ranges between 29 and 203 points. The higher the score, the stronger the sense of coherence. The validity of the SOC is investigated by consensual validity by persons familiar with the theory, correlation with other scales meant to measure the same concept and correlation with measurements of phenomena external to the SOC but with which SOC should be correlated according to the theory, such as generalised perception of self and environment, perceived stressors, health and well-being and attitudes and behaviours (170, 171). The internal consistency of SOC-29 is reported to be high where the alpha coefficient ranged between 0.82 and 0.95 (170). The questionnaire has high test-retest reliability in a short time perspective of two weeks but lower in a long-term perspective of two years (170). Values among a Swedish urban population sample aged 26 to 70 years are available (172).

DATA ON THE STROKE PATIENTS

Data on the stroke patients' neurological and cognitive impairments in the first week after stroke were recorded by the neurologist on duty at the ward, by the speech therapist and by the neuro-psychologist. The stroke patients' level of self-care was assessed an average of seven days after stroke (SD. four days) by occupational therapists experienced in neurological rehabilitation. One year after stroke, a neurologist re-assessed the stroke patients. A re-assessment of the stroke patients' ability in self-care was made by a registered occupational therapist. At one year, however, data on the first five patients' clinical situation was drawn from their medical records. The spouses supplied information on their ability in self-care. Three further stroke patients were too ill to participate in the formal interviews and data were recorded by the same procedure.

Neurological deficits

The type and location of the brain lesion were recorded with CT. Subtypes of the cerebral infarctions were categorised regarding etiology to the TOAST classification (43) and regarding location according to the Bamford classification (44). The neurological and cognitive deficits of the stroke patient as recorded by neurologists, the speech therapist and the neuro-psychologist were categorised by a neurologist according to severity. Inability to use the limbs was classified as "severe sensorimotor impairment", ability to use the limbs but with impaired force and/or co-ordination as "moderate impairment" and impaired fine sensorimotor ability as "slight impairment".

Emotional disorder

Depression and astheno-emotional syndrome were rated by a neurologist one year after stroke. Depression was rated according to the DSM-IV™ criteria (173). Astheno-emotional syndrome was rated according to Lindqvist & Malmgren's criteria (55, 56, 174).

Ability of self-care

The level of self-care was assessed by the Barthel Index (BI) (175), which includes ten weighted items concerning personal activities: feeding, dressing, personal toilet, getting on and off toilet, bathing, chair/bed transfer, walking/use of wheelchair, stair climbing, controlling bowel and controlling bladder. The score for each item can be summed to give an overall score ranging from 0 (total dependence) to 100 (independence). The values of each item are based on the time and amount of physical assistance the patient requires (175). The BI has been found to be a valid and reliable instrument in measuring ability in self-care in stroke patients (176-179).

DATA ANALYSIS

ANALYSIS OF THE INTERVIEW DATA

The first ten interviews on the spouses' experiences in each of the three time points after stroke were consecutively transcribed verbatim, analysed line by line, coded by open coding and put into categories covering the themes of the interview (180). The categories were independently verified by a clinical psychologist experienced in qualitative research. The categories developed formed the structure for the analysis of the subsequent interviews, which were closely analysed by listening. Every statement was registered beneath the category to which it belonged in the form of transformations close to the data and quotations.

Of the 83 interviews on the spouses' experiences in the first phase after stroke, one interview did not contain sufficient data and was removed from the material. The 82 transcribed interviews were analysed in terms of content according to what sort of apprehensions or expectations the spouses expressed about their future (180, 181). The statements on perceptions of the future were analysed line by line, coded and categorised by comparison within and between the participants, where similarities and differences were sought (180). This analysis resulted in three main sub-dimensions of the spouses' view of the future: their perception the impact on the stroke patients' future health and abilities; their perception of further impact on their own daily activities and life circumstances; and their perception of their own coping ability. The interviews were then re-analysed, again in this case by comparison within and between the participants' statements seeking similarities and differences in their perceptions of these three sub-dimensions. This analysis resulted in the

development of four categories of the concept of "view of the future" regarding the degree of optimism or pessimism about life in the future (*Study I*).

STATISTICAL DATA ANALYSIS

The quantitative data in the present study consist primarily of dichotomous, nominal and ordinal data. Thus, non-parametric statistical analyses methods were generally used (182). Data are presented in terms of median, interquartile range and frequencies. However, since results of the PGWB, the SOC and the BI are given as means and standard deviations in reference studies, we present these data to facilitate comparison.

Intra-rater and inter-rater assessments were made of the categories that were developed in the qualitative data analysis. Percentage agreement was used to determine the number of exact agreements between the ratings. To measure agreement better than chance, the kappa coefficient was calculated (182). The intra-rater reliability in the categorising procedure was assessed using the same transcribed interview data by a re-assessment after a three-month interval. Inter-rater assessment of 20 transcribed verbatim interviews was done by two independent raters (*Study I*).

Differences between independent groups were analysed with Fisher's exact test, Pitman's test (183) and the Mann-Whitney test (*Study I, IV, V*).

To investigate the distribution of the different variables related to the characteristics of the stroke patient between the four categories in "view of the future", the data were analysed with the Chi squared test, test for trends or test for semi-trends (*Study I*). Associations between variables were analysed with Pitman's test (183) and Spearman's rank correlation test (*Studies I-V*).

To compare the level of PGWB Index in the study group with a normal population, a statistical calculation was made based on normal distribution after a transformation (Odén and Dimenäs. Unpublished data 2000). The transformation was determined by use of the large population sample described by Dimenäs (159) (*Studies II, IV*).

The intra-personal change in well-being and life satisfaction was investigated with the Wilcoxon's signed rank sum test and the McNemar test (*Studies IV, V*).

To investigate the proportion of spouses that showed a change in psychological well-being, a difference of five score units in the PGWB total score was considered a clinically relevant difference (157) (*Study IV*). To investigate the proportion of spouses that showed a change in life satisfaction, a difference of one category in the LiSat-9 checklist was considered a clinically relevant difference (*Study V*).

Since several spouses of the dropouts reported chiefly negative life experiences, the withdrawals can be suspected to have affected the results of the study. To investigate whether the withdrawals had any impact on the results, a "worst case /best case scenario analysis" was made. In the worst case scenario analysis, the missing data in the SOC was replaced with the lowest score in the study group, in the PGWB Index with scores nearest to but below the 25th percentile and in the LiSat-9 with category no 3. In the best case scenario analysis, missing data in the SOC were replaced with the highest score in the study group, in the PGWB Index with scores nearest to but above the 75th percentile of the study group and in LiSat-9 with category no 6. However, statistical analyses of the theoretical model "worst case and best case

scenarios” showed that these withdrawals did not have an impact on the conclusions drawn in the study. (*Study III-V*).

The size of the study group that was required be able to show differences and associations were estimated before the start of the study. Power analyses showed that, in order to be able to detect change in life satisfaction a simple size of 43 persons was needed. A sample size of 67 was determined to have a sufficient power of 80% provided that the correlation coefficient was at least 0.33 (or -0.33), with a the level of significance of 0.05. A sample size of 83 was determined to have a sufficient power of 80% provided that the correlation coefficient was at least 0.36 (or -0.36), with a level of significance of 0.01. Inclusion in the study was completed in consultation with a statistician.

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. Written informed consent was obtained from all the participants. If the stroke patients 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 whom the spouses could apply to obtain help.

RESULTS

THE STROKE PATIENTS ONE YEAR AFTER THE STROKE (Study IV)

A statistically significant improvement was observed between the first week and one year after stroke in the stroke patients' sensorimotor impairments, aphasia and BI scores, see table IV. At one year, 38% of the stroke patients were rated as being depressed. Seventy-seven percent suffered from astheno-emotional syndrome. During the first year, seven stroke patients had suffered a re-infarction. Two persons had died.

After acute care, 42 of the 83 stroke patients received rehabilitation care at a geriatric or neurological rehabilitation ward. Thirteen patients received outpatient rehabilitation. At four months after stroke, four stroke patients' with severe impairments were still hospitalised at a rehabilitation ward. At one year, all patients were living in their own home.

Table IV. The stroke patients' neurological improvement

Statistical test: Wilcoxon signed rank sum test. Data presented *n* (%)

	Studies I-III <i>n</i> = 80			Studies IV-V <i>n</i> = 67		
	The first week	One year	Change <i>p</i> =	The first week	One year	Change <i>p</i> =
Pure sensorimotor impairment	36 (43)	34(42)	0.157	31 (46)	29(43)	0.157
Moderate or severe sensorimotor impairment	38 (46)	15(18)	< 0.001	33 (49)	14(21)	<0.001
Aphasia	18 (22)	6 (7)	< 0.001	17 (25)	5 (8)	<0.001
Barthel Index: median (IQ range)	100 (60-100)	100 (95-100)	< 0.001	95 (60-100)	100 (95-100)	<0.001

THE SPOUSES' "VIEW OF THE FUTURE" (Study I)

The first study explored the spouses' thoughts about their future life in the first weeks after their partners' stroke. The qualitative analysis of the interview data resulted in establishing the concept of "view of the future", which was composed of three related sub-components: 1) perception of the disease and its impact on the future health and ability of the stroke patient, 2) perception of changes in their own daily activities, roles and life circumstances and 3) perception of their own coping capacity.

The spouses' statements were further analysed with regard to how they expressed their thoughts about each of these three sub-components. The analysis resulted in four different categories reflecting the degree of optimism/pessimism about their future life. The definitions of the four groups are given in Appendix I. Quotations that illustrate the different sub-components in each of the categories are given in Appendix II.

All participants were then categorised according to the definitions. Twelve participants were categorised as belonging to category A "very pessimistic", 27 to category B, "pessimistic but

hope for improvement”, 32 to category C “optimistic, but prepared for alterations” and 11 to category D “very optimistic”.

The intra-rater analyses of the categorising of the spouses showed a percentage agreement of 88%, unweighted kappa coefficient: $k = 0.83$. The inter-rater analyses showed a percentage agreement of 85%, unweighted kappa coefficient: $k = 0.79$. In the few cases in which there were not full agreement, a consensus was reached.

There were no statistically significant differences between the sexes or between the ages of the spouses with respect to their view of the future.

THE LEVEL AND CHANGE IN SPOUSES' PSYCHOLOGICAL WELL-BEING, LIFE SATISFACTION AND SENSE OF COHERENCE (Studies II-V)

SPOUSES' PSYCHOLOGICAL WELL-BEING (Studies II, IV)

In the first weeks after their partners' stroke, the mean level of all dimensions of the spouses' PGWB Index was statistically significantly lower than Swedish norm values with respect to age and sex ($p < 0.001$), except for the dimension of “general health”. However, their PGWB Index did not differ from Swedish norm values at four months and at one year. The mean level of the spouses' PGWB dimensions in the first weeks, at four months and at one year after stroke is shown in table V.

Table V: Spouses' Psychological General Well-Being (PGWB) Index.

Data presented: mean (95% CI). $n = 66$

	Norm values *	First weeks	Four months	One year
Total score	102.94	88.89 (84.30; 93.49)	103.73 (99.96; 107.49)	103.14 (98.99; 107.28)
Anxiety	24.06	18.97 (17.57; 20.37)	24.41 (23.37; 25.44)	24.15 (23.03; 25.27)
Depressed mood	15.53	13.27 (12.43; 14.11)	15.79 (15.41; 16.44)	15.65 (15.00; 16.30)
Positive well-being	16.12	12.38 (11.45; 13.31)	15.85 (14.99; 16.71)	16.24 (15.38; 17.11)
Self-control	15.29	14.00 (13.27; 14.73)	15.47 (14.98; 15.96)	15.41 (14.91; 15.90)
General health	14.61	14.95 (14.20; 15.71)	15.08 (14.38; 15.77)	14.59 (13.83; 15.35)
Vitality	17.21	15.32 (14.38; 16.26)	17.14 (16.35; 17.92)	17.09 (16.09; 18.10)

* ref: Dimenäs *et al.* 1996 (159)

There was a statistically significant intra-individual improvement between the first weeks and four months in all of the PGWB dimensions ($p < 0.001$) except for “general health” ($p = 0.889$). No significant changes in any of the PGWB dimensions were found between four months and one year. Changes took place on the individual level, however both in a positive and a negative direction. The proportion of individuals that showed changes in the PGWB dimensions between the first phase and four months after stroke (period 1) and between four months and one year after stroke (period 2) is shown in Figure 3.

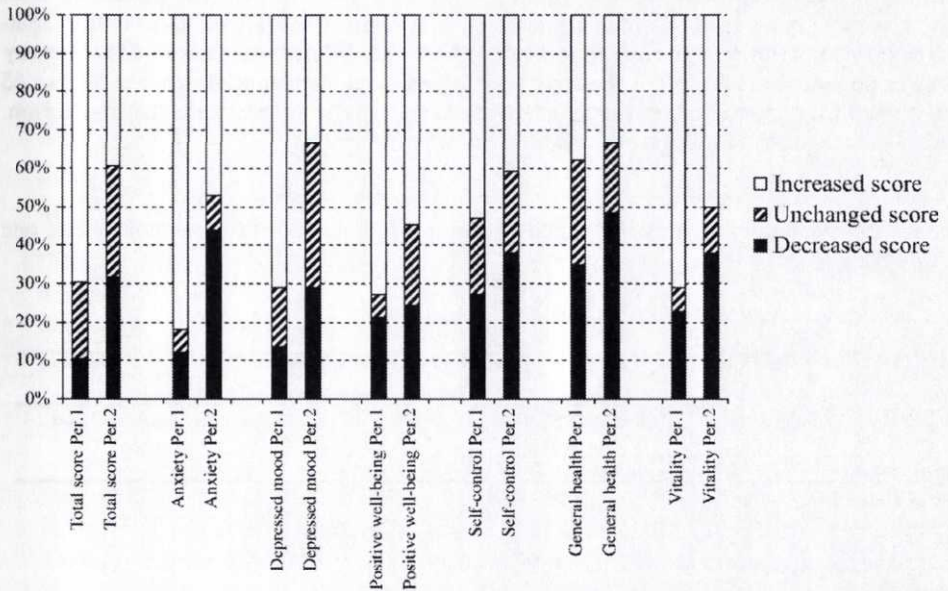


Figure 3: The figure shows the proportions of increased, unchanged or decreased psychological well-being between the first phase and four months after stroke (period 1) and between four months and one year after stroke (period 2). An increase in the score means an increase in the sense of general well-being, positive well-being, self-control, general health and vitality and a decrease in the sense of anxiety and depressed mood.

$n = 66$.

Men scored higher in self-control than the women in the first weeks after their partner's stroke ($p = 0.014$). Otherwise, there were no statistically significant differences between the sexes. There were no statistically significant differences between the sexes at four months or at one year in any of the PGWB dimensions.

At four months, the younger spouses were less depressed than older ones ($p = 0.037$). At one year, however, the younger spouses showed lower mood scores and no significant associations were then found between age and the PBWB Index.

SPOUSES' LIFE SATISFACTION (Studies II, V)

The majority of the spouses were satisfied with their prior life situation. The median score of life satisfaction ranged between five and six (satisfied/very satisfied) in all items in the LiSat-9. The proportions of the spouses who were satisfied with different domains of life (category 5-6) are presented in table VI. The proportions of men and women aged between 50 and 65 years, recorded as being satisfied in a general population study are presented for comparison. Forty-six percent of the study group fall within this age group.

Table VI. Proportions of spouses satisfied with life before stroke, at four months and at one year.

n = 66 except for sexual life (*n* = 62) and family life (*n* = 65)

Satisfied with:	Percent satisfied				
	Swedish populations 50 to 65 year*		Before stroke	At four months	At one year
	Men	Women			
Life as a whole	73	73	74	52	59
Ability to manage self-care	91	95	98	92	91
Leisure situation	67	66	71	43	44
Vocational/Occupational situation	64	61	77	57	53
Financial situation	60	58	64	62	58
Sexual life	58	51	69	39	32
Partnership relations	85	81	82	65	62
Family life	87	85	77	73	77
Contacts with friends and acquaintances	69	75	83	67	68

*ref. K Fugl-Meyer (93)

The spouses' satisfaction with life as a whole ($p = 0.001$), leisure situation ($p < 0.001$), vocational/occupational situation ($p = 0.022$), sexual life ($p < 0.001$), partnership relations ($p = 0.001$) and contacts with friends and acquaintances ($p = 0.001$) decreased statistically significantly between the time before the stroke, as rated in the first week after stroke and four months afterwards. Between four months and one year after stroke, no significant changes occurred in any of the domains of life. However, changes among individuals occurred in both a positive and a negative direction, as shown in Figure 4.

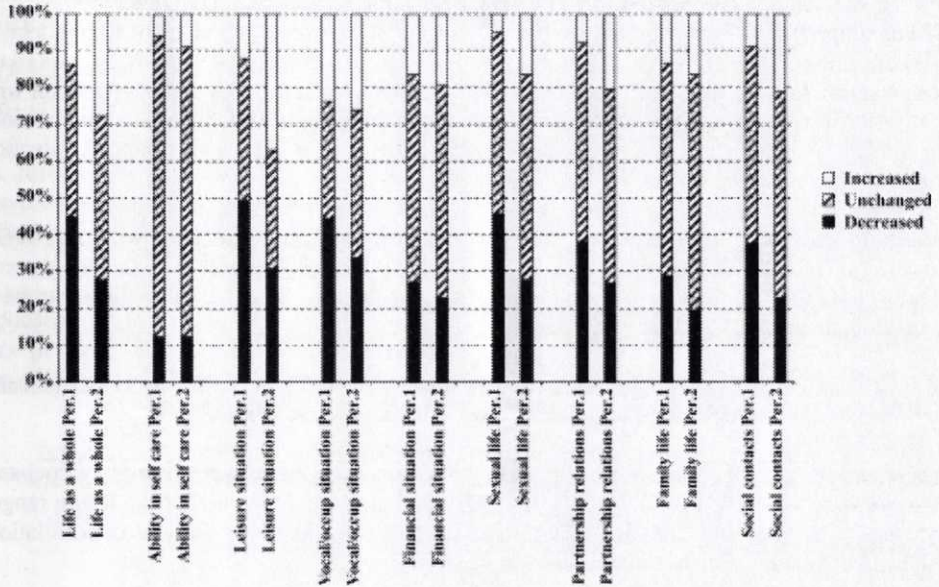


Figure 4. The figure shows the proportions of spouses with greater, unchanged or lower life satisfaction between their lives before their partners' stroke and four months after the stroke (period 1) and between four months and one year (period 2).

The men rated lower satisfaction with their own ability in self-care ($p = 0.011$) and with their sexual life prior to stroke ($p = 0.042$) than the women. The men were also more satisfied with their leisure situation ($p = 0.024$). No significant differences in any of the domains of life were observed between the sexes at four months and one year after the stroke.

The younger spouses were more satisfied with their sexual life than older spouses prior to the stroke ($p = 0.005$) but not at four months or one year. The younger spouses were also significantly less satisfied with their financial situation both at four months ($p = 0.019$) and at one year after stroke ($p = 0.001$). The older spouses were significantly less satisfied with their life as a whole ($p = 0.049$) than younger spouses at four months ones but not at one year. There were otherwise no statistically significant associations between the spouses' age and their life satisfaction.

SPOUSES' SENSE OF COHERENCE (Study III)

The median of the spouses' SOC scores was 148 and the interquartile range was 139 to 159. The mean score was 149.7, the standard deviation was 14.4 and the 95% confidence interval ranged between 146.4 and 153.0. The total range of the score was 115 to 195. The mean level of the study group was within the 95% confidence interval of a Swedish norm group, even when the differences in the range of ages between the two groups were taken into consideration.

ASSOCIATIONS BETWEEN THE SPOUSES' VIEW OF THE FUTURE; PSYCHOLOGICAL WELL-BEING, SENSE OF COHERENCE AND LIFE SATISFACTION AND THE STROKE PATIENTS' ABILITY IN SELF-CARE IN THE FIRST WEEKS AFTER STROKE.

(Studies II, III)

The spouses' level of SOC was statistically significantly associated with their satisfaction with life prior to stroke with respect to life as a whole ($p < 0.001$), partnership relations ($p = 0.002$), sexual life ($p = 0.005$), family life ($p < 0.001$) and financial situation ($p < 0.001$).

The spouses' sense of coherence was also statistically significantly associated with the PWGB total score ($p = 0.003$), positive well-being ($p = 0.007$), self-control ($p = 0.009$), general health ($p = 0.009$) and vitality ($p = 0.002$). Spouses with a low SOC were more likely to have a pessimistic view of the future ($p = 0.006$).

The stroke patients' ability in self-care in the first week after stroke were statistically significantly associated with the spouses' view of the future ($p < 0.001$)

The spouses' psychological well-being and their view of the future were strongly associated. The correlation coefficient between the PGWB dimensions and the view of the future ranged between 0.58 (general health) and 0.79 (total score). The results of the analyses of correlations between the main variables are presented in Figure 5.

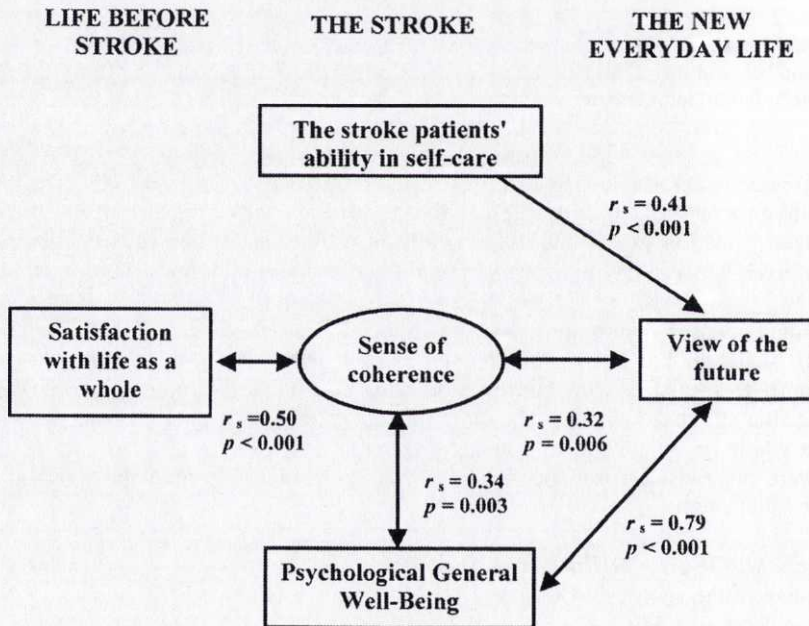


Figure 5. The figure shows the correlation coefficients for the statistically significant associations between the spouses' satisfaction with life as a whole before their partners' stroke, the stroke patients' ability in self-care in the first week after stroke and the spouses' view of the future, psychological general well-being and sense of coherence in the first weeks after their partners' stroke.

ASSOCIATIONS BETWEEN THE SPOUSES' VIEW OF THE FUTURE, PSYCHOLOGICAL WELL-BEING AND LIFE SATISFACTION AND THE NEUROLOGICAL CHARACTERISTICS OF THE STROKE PATIENTS.
(Studies I, II, IV, V)

A further aim was to study the associations between the spouses' view of the future, psychological well-being and life satisfaction and the neurological and emotional characteristics of the stroke patients at the three measurement times.

An overview of the results of the statistical analyses, as regards the associations between the spouses' psychological well-being and the neurological characteristics of the stroke patients are given in table VII a-d. The associations between spouses' life satisfaction and the neurological characteristics of the stroke patients are presented in table VIII a-d.

Table VII. Associations between the spouses' PGWB Index and the neurological characteristics of the patients' impairments.

Table VII a. Pure sensorimotor vs cognitive impairments

PGWB at:	Pure sensorimotor vs Cognitive impairment			
	first week		One year	
	first week	four months	One year	One year
Total score				
Anxiety				
Depressed mood				
Pos.well-being				
Self-control				
General health				
Vitality				

Table VII b. Aphasia

PGWB at:	Aphasia vs. no aphasia			
	first week		One year	
	first week	four months	One year	One year
Total score				
Anxiety				
Depressed mood				
Pos.well-being				
Self-control				
General health				
Vitality				

Table VII c. Sensorimotor impairments

PGWB at:	No/slight vs moderate/severe sensorimotor impairment			
	first week		One year	
	first week	four months	One year	One year
Total score				
Anxiety				
Depressed mood				
Pos.well-being				
Self-control				
General health				
Vitality				

Table VII d. The Barthel Index

PGWB at:	The Barthel Index			
	first week		One year	
	first week	four months	One year	One year
Total score				
Anxiety				
Depressed mood				
Pos.well-being				
Self-control				
General health				
Vitality				

The level of significance:

□ n.s.

▨ $p < 0.05$

▩ $p < 0.01$

■ $p \leq 0.001$

Table VIII. Associations between the spouses' life satisfaction and the neurological characteristics of the stroke patients.

Table VIII a. Pure sensorimotor vs. cognitive impairments

Life satisfaction at:	Pure sensorimotor vs Cognitive impairment		
	first week		One year
	four months	One year	One year
Life as a whole			
Ability in self care			
Voc./occup. situation			
Leisure situation			
Financial situation			
Sexual life			
Partnership relations			
Family life			
Social contacts			

Table VIII b. Aphasia

Life satisfaction at:	Aphasia vs. no aphasia		
	first week		One year
	four months	One year	One year
Life as a whole			
Ability in self care			
Voc./occup. situation			
Leisure situation			
Financial situation			
Sexual life			
Partnership relations			
Family life			
Social contacts			

Table VIII c. Sensorimotor impairments

Life satisfaction at:	No/slight vs moderate/severe sensorimotor impairment		
	first week		One year
	four months	One year	One year
Life as a whole			
Ability in self care			
Voc./occup. situation			
Leisure situation			
Financial situation			
Sexual life			
Partnership relations			
Family life			
Social contacts			

Table VIII d. The Barthel Index

Life satisfaction at:	The Barthel Index		
	first week		One year
	four months	One year	One year
Life as a whole			
Ability in self care			
Voc./occup. situation			
Leisure situation			
Financial situation			
Sexual life			
Partnership relations			
Family life			
Social contacts			

The level of significance:

n.s. $p < 0.05$ $p < 0.01$ $p \leq 0.001$

PURE SENSORIMOTOR VS. SYMPTOMS INCLUDING COGNITIVE IMPAIRMENTS

View of the future

The spouses of stroke patients with pure sensorimotor impairments had a more optimistic view of the future than the spouses of stroke patients who also had cognitive impairments ($p = 0.019$).

Psychological well-being

The spouses of stroke patients with pure sensorimotor impairments and of patients that also suffered cognitive impairments did not differ significantly in the PGWB Index in the first weeks after their partners' stroke. At four months, the spouses of stroke patients with cognitive impairments had statistically significantly lower scores in the total score ($p = 0.011$), and in anxiety ($p = 0.020$), positive well-being ($p = 0.002$) and self-control ($p < 0.001$). At one year, they still scored statistically significantly lower on positive well-being ($p = 0.010$) than the spouses of stroke patients with pure sensorimotor impairments.

Life satisfaction

The spouses of stroke patients with cognitive impairments scored lower than the spouses of stroke patients with purely sensorimotor impairment in satisfaction with their partner relationships at four months ($p = 0.047$) and at one year ($p = 0.012$). At one year, they also scored lower in satisfaction with life as a whole ($p = 0.006$) and family life ($p = 0.004$).

APHASIA

View of the future

In the first weeks, the spouses of stroke patients with aphasia ($p = 0.022$) had a more pessimistic view of the future than the spouses of stroke patients without aphasia.

Psychological well-being

The spouses of stroke patients with and without aphasia did not differ in the PGWB Index in the first weeks after their partners' stroke. At four months, the spouses of stroke patients with aphasia in the first week showed significantly lower scores in positive well-being ($p = 0.001$) and self-control ($p = 0.011$) than the spouses of stroke patients without aphasia and still scored lower in positive well-being at one year ($p = 0.035$). The spouses of stroke patients with persisting aphasia at one year scored significantly lower in positive well-being ($p = 0.033$) than the spouses of stroke patients without aphasia at that time.

Life satisfaction

The spouses of stroke patients with aphasia in the first phase after stroke scored significantly lower than the spouses of stroke patients without aphasia in satisfaction with family life at four months ($p = 0.031$) and at one year ($p = 0.009$). At one year, the spouses of stroke patients with persisting aphasia scored significantly lower in satisfaction with family life ($p = 0.029$).

SENSORIMOTOR IMPAIRMENTS

View of the future

The spouses of stroke patients with moderate/severe sensorimotor impairments in the first week after stroke had a significantly more pessimistic view of future than the spouses of stroke patients with no/slight sensorimotor impairments ($p < 0.001$).

Psychological well-being

These spouses also felt more anxiety ($p = 0.043$) and were more depressed ($p = 0.021$) than the spouses of stroke patients with no/slight sensorimotor impairments in the first weeks after their partners' stroke. At four months and at one year, the two groups of spouses showed no significant differences in any of the dimensions of the PGWB Index. However, the spouses of stroke patients with persisting moderate/severe sensorimotor impairments at one year scored significantly lower in the total score ($p = 0.013$) and in anxiety ($p = 0.027$), depressed mood ($p = 0.008$), positive well-being ($p = 0.013$), self-control ($p = 0.018$) and vitality ($p = 0.007$) than the spouses of stroke patients with no/slight sensorimotor impairments.

Life satisfaction

The spouses of stroke patients with moderate/severe sensorimotor impairment in the first week after stroke scored lower in satisfaction with their vocational/occupational situation ($p = 0.045$) than the spouses of stroke patients with no/slight sensorimotor impairments at four months after stroke. There were no significant differences between the two groups at one year. However, at one year, the spouses of stroke patients with remaining moderate/severe sensorimotor impairments scored lower than the spouses of patients with no/slight sensorimotor impairments in satisfaction with life as a whole ($p < 0.001$), their own ability in self-care ($p = 0.001$), vocational/occupational situation ($p = 0.046$), leisure situation ($p < 0.001$), sexual life ($p = 0.022$) and partner relationship ($p = 0.001$).

ABILITY IN SELF-CARE

View of the future

The spouses of stroke patients with low ability in self-care in the first week after stroke had a significantly more pessimistic view of the future ($p < 0.001$).

Psychological well-being

These spouses were also more depressed in the first weeks after their partners' stroke ($p = 0.013$). At four months, the spouses' total score ($p = 0.002$) and score on anxiety ($p = 0.013$), depressed mood ($p = 0.013$), positive well-being ($p = 0.001$) and vitality ($p = 0.003$) were still associated with the stroke patients' BI in the first phase after stroke. A significant association was still seen at one year between the spouses' positive well-being and the stroke patients' BI in the first phase ($p = 0.043$). There was also a significant association at one year between the spouses' depressed mood and the stroke patients' BI score at that time ($p = 0.019$).

Life satisfaction

The spouses of stroke patients with a low BI score in the first week after stroke were more likely to score low in satisfaction with life as a whole ($p = 0.036$), vocational/occupational situation ($p = 0.004$), leisure situation ($p = 0.018$), sexual life ($p = 0.009$) and social contacts ($p = 0.033$) at four months. At one year, there were still significant positive associations between the spouses' satisfaction with their sexual life ($p = 0.047$), partner relationship ($p = 0.005$) and the stroke patients' BI score in the first phase after stroke. At one year, the spouses of stroke patients with a remaining low BI score scored low in satisfaction with life as a whole ($p = 0.001$), their own ability in self-care ($p = 0.028$), leisure situation ($p < 0.001$), sexual life ($p = 0.003$) and partner relationship ($p = 0.002$).

EMOTIONAL DISORDERS

Psychological well-being

One year after stroke the spouses of stroke patients who suffered depression scored lower in the PGWB total score ($p = 0.003$) and in anxiety ($p = 0.043$), depressed mood ($p = 0.002$), positive well-being ($p = 0.034$), general health ($p = 0.001$) and vitality ($p = 0.021$) than the spouses of stroke patients without depression. Furthermore, spouses of stroke patients who suffered astheno-emotional syndrome showed a lower total score ($p = 0.021$) and scored lower in anxiety ($p = 0.048$), depressed mood ($p = 0.017$) and positive well-being ($p = 0.019$).

Life satisfaction

Spouses of stroke patients who were depressed rated a significantly lower satisfaction with sexual life ($p = 0.003$) than the spouses of stroke patients who were not depressed.

Spouses of stroke patients with astheno-emotional syndrome scored significantly lower in satisfaction with life as a whole ($p = 0.008$), sexual life ($p = 0.048$) and partner relationship ($p = 0.011$) than the spouses of stroke patients without astheno-emotional syndrome

GENERAL DISCUSSION

Stroke is known to have a widespread impact on the family in terms of daily activities, social relationships and emotional health. Less is known, however about spouses' experiences in the first period after their partners' stroke and about the importance of their sense of coherence in this period. Less is also known about longitudinal changes in the spouses' psychological well-being and life satisfaction and about the associations between spouses' psychological well-being and life satisfaction and the stroke patients' impairments at different time points after stroke. These were the major questions of this thesis.

Spouses' thoughts and feelings in the acute period.

Stroke commonly strikes without previous warning and disrupts regular life routines. Although the majority of the stroke patients showed moderate or mild disabilities in the first week according to their BI score (176), the spouses experienced the stroke onset as a stressful, critical life event. In the first weeks, the spouses' psychological well-being was in most cases significantly lower than Swedish norm values and the emotional state of most of the spouses was characterised by anxiety, sadness and tiredness (*Study II*). However, the spouses often perceived a mixture of feelings of anxiety and depression and of hope and joy in seeing improvements in the patients' health and ability. A similar turbulence of negative and positive affects is described in families in acute care (99).

In studies of families in critical care units, it has been noted that what the family believed about the chances for recovery or possible disfigurement had a great impact on their perception of the event (184). Spouses' uncertainty about the nature of the disease, life in the future and how to manage stroke patients' disabilities has been described in previous studies (185, 186). The qualitative analysis of the spouses' description of their thoughts about the future in the first weeks after their partners' stroke resulted in the development of three main related subdimensions of their view of the future: their perception of the impact of the disease on their partner's future health and ability; the impact on their own daily activities, roles and life circumstances; and their own ability to cope. (*Study I*). Although the spouses' cognitive image of their future everyday life varied in the study group, it was possible to categorise the cognitive image of future life into four different categories according to the degree of optimism / pessimism about their life in the future (*Study I*). A similar classification of the appraisal of the significance of stroke was developed by King (186). The findings on the spouses' variation in their perceptions of the disease and of its impact on daily activities, roles and life circumstances agree with Lazarus' theory about primary appraisal, i.e. the individual's cognitive appraisal of the impact of the stressor on his or her own well-being or the well-being of another person with whom there is an emotional relation (119). The spouses also varied concerning the cognitive image of their ability to cope with expected changes and demands in the future. The spouses' perception of the internal and external resources available to them and ideas about how to use these resources were of great importance for the degree of optimism they reported. This finding also agrees with Lazarus' theory about the individual's secondary appraisals, i.e. the cognitive appraisal of the effectiveness of resources and strategies for managing the stressor (119).

The spouses' cognitive image of the impact on their future life and of their own coping ability had a strong association with their PBWB Index (*Study II*). Spouses' uncertainty about the severity and prognosis of the disease and concerns about future care have previously been

found to be predictive variables for depression (6, 116). Pessimism has also been found to be a predictor of depression, both in the acute state and the long-term perspective (6, 79, 116). According to Lazarus, the cognitive activity of appraisal of the situation precedes emotions and is later affected by emotions (187). The associations between the cognitive image of the situation and emotions are probably interrelated in both directions.

Spouses' sense of coherence

Antonovsky makes the assumption that, when a person faces a stressor, the SOC will first decrease and then increase when the GGR is mobilised (123). Although the spouses' level of SOC was measured during a stressful event that entails a great deal of uncertainty, their mean level of SOC did not differ in a statistically significant way from the mean level in a Swedish community group (*Study III*). The spouses' level of SOC before the onset of stroke is not known, however. Their sense of coherence was significantly associated with their view of the future and spouses with a high SOC had a more optimistic image of the future, which agrees with Antonovsky's theory (123). In agreement with previous studies (137, 139), the spouses' level of SOC was significantly associated with their sense of positive well-being, general health and vitality. It seems that, in an unexpected, stressful life situation, the spouse's SOC is of importance for his or her appraisal of the situation and ability to cope with practical and emotional demands. However, it is possible that the feeling of positive well-being, general health and vitality has an impact on the level of SOC that can not be investigated in a cross-sectional study. The associations between the SOC and the PGWB dimensions of depressed mood and anxiety were not as strong as reported in previous studies (142, 143). However, in the present study, depression and anxiety are measured as emotional states in an ongoing critical life event, while previous studies have measured anxiety and depression as a trait (144) or a perception of mood in a stable life situation (143). The lower association rate indicates that the insecurity of the situation makes it difficult for them to recruit and use appropriate GGRs, however. It also seems that the immediate emotional response to the critical event is dominant.

The study also showed that the spouses' SOC was associated with their satisfaction with life as a whole, their close relationships and their financial situation. The results support Antonovsky's assumption of the socio-cultural context as the origin of the SOC and that social support and material resources are significant GRRs for the creation of SOC (126). However, the opposite may also be true: individuals with a high SOC may be more likely to have the ability to create good relationships and manage education and work. It is also possible that the level of both SOC and life satisfaction are affected by factors such as personality (188).

The spouses' level of depression and lack of optimism in the first weeks after their partners' stroke have been shown to be predictive for their depression later on (116). The findings in studies I, II and III underline the importance for all professionals in medical care and rehabilitation to take the spouses' own thoughts about apprehensions and hopes and their attitudes to stroke in consideration in instructing, counselling and planning. This will probably contribute toward giving the spouses a more optimistic, although realistic, view of the future, reducing anxiety and depression and facilitating their coping ability in the new life situation.

Change in spouses' psychological well-being

From the low level of psychological well-being in the first period after the partners' stroke, the spouses' psychological well-being increased between the first weeks and four months after stroke. Especially, their sense of anxiety was lower and their sense of happiness increased (*Study IV*). Decreases in caregivers' depression after the stroke patients' discharge from

hospital have also been shown by King (121). At four months, most of the stroke patients had improved and returned to their homes. It can be assumed that the spouses' worry for a new stroke had eased, even though most still reported worry over their partners' health (*unpublished data*), and they felt hope for further improvement.

Between four months and one year, there were no statistically significant changes in the spouses' psychological well-being, although there were marked individual changes in both a negative and a positive direction (*Study IV*). New life events in the social environment, a partner's further stroke, changes in their own health and differences in coping ability and coping resources are some of the factors of the that may have an impact on changes in emotions. This must be investigated in future studies, preferably using qualitative methods.

In previous studies, between 11 and 55% of informal caregivers reported poorer emotional health, most often measured in terms of depression, more than three months after their partners' stroke (6, 51, 102, 106, 107). In the present study, the mean value of the spouses' PGWB Index did not differ significantly from Swedish norm values at four months or one year (*Study IV*). There may be several reasons for this. One reason could be that the present sample size is rather small, which may have an impact on the chance for detecting significant differences between the two samples. However, in the present study, a majority of the stroke patients did not suffer a severe stroke. Hulter-Åsberg & Johansson showed in a group of spouses of stroke patients aged between 60 and 85 years that 43% of the spouses did not perceive any increased burden owing to their partners' stroke in cases of mild stroke and no negative change in personality and that 57% of the spouses perceived an increased burden, most often because of severe cognitive and behavioural impairments (189). Furthermore, in the present study, the stroke patients were treated at an acute stroke unit with early rehabilitation and following this care, about half were treated at a specialised stroke rehabilitation ward. Information to and involvement of the family in individualised care and a rehabilitation plan are parts of the ordinary routine in these experienced, multidisciplinary units. This may have had an impact on the spouses' ability to cope and, thereby, their psychological well-being. Further, being participants in a longitudinal study that focuses on the spouses' life situation may have affected their perception of their psychological well-being. In previous studies spouses' emotional health has been measured in terms of depression (6, 51, 107). The PGWB Index also contains items on positive well-being. The PBWB Index is not condition specific and is not oriented solely towards discriminating psychiatric cases from healthy individuals (156). It has also been observed in studies on women with Turner syndrome that their PBWG Index did not differ from norm values, but that those women experienced more difficulties in the area of social and partner relations than women without Turner syndrome (190). In the present study, even though the mean level of the spouses' PGWB Index did not differ in a statistically significant way from Swedish norm values at either four months or after one year, the spouses who scored below the median value described a stressful daily life that they experienced as having an impact on their psychological health. Spouses who scored below the 25th percentile reported widespread practical and social consequences of their partners' stroke which they reported perceiving being difficult to cope with (*unpublished data*).

Change in life satisfaction

In Sweden as in most European countries the majority have been shown to be satisfied with life as a whole (91, 93). In our material, the majority of the spouses were satisfied with their lives before their partners' stroke (*Studies II, V*). Even though the majority of the stroke patients suffered moderate to mild stroke, the consequences of the stroke seemed to have an

extended impact on their spouses' life satisfaction. At four months, the spouses' satisfaction with life as whole, with daily activities in terms of daily occupation, leisure situation, partner relationship, sexual life and contacts with friends and acquaintances had decreased (*Study V*). Less satisfaction with life as a whole among spouses of stroke patients than in the general population has been reported previously (114). Although we did not note statistically significant changes in life satisfaction between four months and one year, there were individual changes in both a negative and positive direction. This could reflect a greater burden but may also be a sign of an ongoing adaptation process with a normalisation of daily routines and relationships. There is a need of further qualitative studies to better understand the causes of change in spouses' life satisfaction during the time after stroke.

In agreement with previous studies, many of the spouses perceived a decrease in their satisfaction with their partnership relation (57, 69). Intrapersonal communication between the partners has been found to be of importance for caregiver stress (191). Stroke patients are reported more often to use unsupportive communication than their spouses (191). Factors such as stroke patients' decreased emotional health, organic mental disorders or role expectations are assumed to be reasons for this (191). However, previous studies have reported both deteriorations and improvements in partner relationships and family life after stroke (57, 64), which were also seen in the present study. In our study, the deterioration in relationships was most marked during the first months after stroke while the changes show greater inter-individual variations in a longer perspective. Happiness over the partner's improvement, a change in values and greater mutual emotional involvement may be some factors behind the improvement. Satisfaction with sexual life also declined. Decreases in sexual activity and satisfaction with sexual life after stroke for psychological, social and physical reasons have been reported previously (74). Conflicting results have been published on the impact on social contacts (57, 69, 118). In the present study, the spouses' satisfaction with their social contacts decreased during the first months after stroke and the frequency of spouses who were not satisfied with their social contacts was stable at one year. Factors such as the physical, cognitive and emotional condition of the stroke patients, lack of time owing to having to attend to caregiving tasks, the emotional condition of the spouses and attitudes in the social environment may have impacts on the ability to maintain social contacts after stroke. Satisfaction with life domains that are perceived valuable for the person, such as leisure, partner relationship and social life, has previously been shown to be strongly associated with satisfaction with life as a whole (84). In rehabilitation of the stroke patients, the spouses' ability and opportunity to carry out activities valuable to them must also be given great consideration.

Satisfaction with the financial situation was not found to change in the study group in contrast to previous studies (70). However, younger spouses were less satisfied with their financial situation after stroke than older ones. Despite the Swedish social welfare system, the loss of one income can result in serious financial consequences for the family.

It must be mentioned that the first rating was made in a period during which there was a great deal of anxiety about the future life situation. This fact could have an impact on the spouses' ratings of satisfaction with life before stroke onset, in that they perhaps perceived their lives before stroke as more satisfying than it actually was. However, the proportions of spouses who were satisfied with life as a whole or with their partner relationship before stroke onset were similar to the proportions of those who were satisfied in the community (93).

Associations between the spouses' psychological well-being, life satisfaction and the stroke patients' impairments

While the spouses of stroke patients with cognitive impairments had a more pessimistic view of the future in the first period after stroke onset than the spouses of stroke patients without cognitive impairments, cognitive impairments in the stroke patients were not statistically significantly associated with their spouses' psychological health (*Studies I, II*). In the interviews, the spouses often indicated that they had hope for speedy recovery from these impairments, but sensorimotor impairments were perceived as more disabling (*unpublished data*). The consequences of cognitive impairments including aphasia in terms of partner relationships, social relationships and the ability to carry out daily activities seemed to be more obvious after hospital discharge (*Studies IV, V*). Cognitive impairments including aphasia have been shown to have a strong impact on family role changes and spouses' emotional health (65, 104, 105, 192). It was found in the present study that the spouses of stroke patients with cognitive impairments were less happy than spouses of patients without cognitive impairments. They also reported a lower level of satisfaction with the partner relationship and family life. However, the spouses of patients with aphasia did not differ from the spouses of patients without aphasia in satisfaction with their partner relationship, which was also shown by Williams & Freer (193). These findings point out the importance of preparing the spouses and the patients for the impact of "hidden" cognitive impairments on their everyday life even before hospital discharge. The spouses of patients with cognitive impairments also showed lower satisfaction with life as a whole at one year, but not at four months. Persisting cognitive impairment seemed to have a long-lasting impact on spouses' life satisfaction which underlines the need of long term support for the family.

In the first period after stroke, visible impairments, such as sensorimotor impairments, seemed to have the greatest influence on the spouses' psychological well-being (*Study II*). However, at four months after their partners' stroke, the level of the stroke patients' sensorimotor impairments in the first week after stroke onset was not significantly associated with either the spouses' psychological well-being or satisfaction with life as a whole (*Studies IV, V*). Accordingly, the extent of sensorimotor impairment in the first period is not a good predictor of the spouses' psychological well-being and life satisfaction in a longer time perspective. However, in agreement with previous studies (79, 115, 194), but in contrast to one other study (102), spouses of stroke patients with persisting moderate/severe sensorimotor impairment experienced an impact on their psychological well-being, especially on their sense of depression and vitality. They also felt an impact on satisfaction with life as a whole, leisure situation, partner relationship and sexual life. It must be noted, however, that the widespread impact on these spouses' subjective well-being may also be caused by the fact that brain lesions that result in lasting severe sensorimotor impairments commonly also result in a complexity of cognitive, organic mental and emotional disorders and thus have a complex impact on the lives of the spouses.

Stroke patients' functional ability has been assumed to be associated with spouses' burden and emotional health (6, 107, 114, 195). The stroke patients' ability in self-care as recorded by the BI is strongly associated with their ability in sensorimotor function (176). The stroke patients' ability in self-care as recorded in the first phase after stroke seemed to have the greatest impact on spouses' psychological well-being during the first months after hospital discharge as they face the practical and emotional problems caused by such impairments in everyday life. This finding underlines the importance of counselling after hospital discharge to support spouses' knowledge and confidence in caregiving tasks. However, in agreement with a previous study (107), the association later became weaker, which indicates an improvement in

the stroke patients' ability, adaptation in the spouses and that other life events have also had an effect on the spouses' well-being. The relationship between the PGWB dimension of depressed mood and stroke patients' BI level was nevertheless the same at all three time points after the partners' stroke.

The spouses of stroke patients with a low ability in self-care one at year reported less satisfaction with their leisure situation than spouses of stroke patients who could manage self-care alone, although this was seen more strongly at one year than at four months. It can be assumed that the spouses' concerns during the first few months after discharge focus on the stroke patients' well-being and on managing the change in roles in domestic activities and family life (61, 62). In a long term-perspective, while new daily routines are probably established, it is likely that the more lasting deterioration of the leisure situation is perceived as more distressing. Spouses of stroke patients with a severe decrease in their ability in self-care also reported less satisfaction with their own ability in self-care one year after the stroke. A previous study reported that 30% of the caregivers perceived their own daily personal care as being affected by a lack of time for their own personal concerns (57). It should be mentioned, however, that some of the most physically and cognitively impaired stroke patients were still at the rehabilitation ward at the time of the four month follow-up, and thus their spouses had not yet faced the extensive impact on their daily life. Furthermore, a small number of the patients had a second stroke during the first year. Accordingly, increased impairments in the stroke patients caused by the second stroke may have had a further impact on the spouses' everyday lives at one year. The finding in the present study highlights the long-term impact of stroke impairment on spouses' satisfaction with life. The need of family support over a long period of time is obvious.

In previous studies, emotional changes in the stroke patients have been associated with a risk of burn-out among informal caregivers (104). In the present study, the ratings of spouses of depressed stroke patients showed greater emotional impairments than the spouses of stroke patient without depression. They also scored lower in general health and vitality. The direction of the associations is not clear and indicates an interaction in emotional health between the partners. This finding highlights the importance of taking the emotional health of both partners into consideration in medical treatment and rehabilitation. Spouses of stroke patients with depression and/or with astheno-emotional syndrome also scored lower in satisfaction with sexual life. Again, sexual life is probably affected by emotional and physical factors in both of the spouses (74).

Presence of an astheno-emotional syndrome has been shown to be highly related to decreased social function in patients with subarachnoid haemorrhage (56). This corresponds with the findings in the present study, where the spouses of stroke patients who suffered from astheno-emotional syndrome scored lower in happiness and in satisfaction with the partner relationship than the spouses of stroke patients without the syndrome. Astheno-emotional syndrome was not only frequently found in stroke patients with severe stroke but also in stroke patients with less serious sensorimotor or cognitive impairments. In the interviews, the spouses frequently reported an impact on their daily lives that was related to these kinds of impairments, primarily emotional irritability in the stroke patients, post stroke fatigue and impaired ability to initiate activities (*unpublished data*). The consequences of astheno-emotional syndrome for both partners must be considered in the information provided to patients and their partners and must be taken into account in the planning of daily activities.

METHODOLOGICAL CONSIDERATIONS

Generalisation

Some methodological difficulties should be discussed with respect to this cohort study of stroke patients and their spouses. One question concerns the sample selection and its representativity for the population studied. Previous studies have often focused on the spouses also of older stroke patients (6, 51, 71, 72, 107, 121) and of stroke patients with more severe impairments that have been recruited from rehabilitation wards (102), stroke clubs (104) and community care (115). The present study group consists of spouses of stroke patients consecutively admitted to the Neurological Department at Sahlgrenska University Hospital. The primary catchment is the central and western parts of Göteborg, but young stroke patients from all parts of the city and the surrounding areas are admitted. In Sweden, stroke patients are generally admitted to a hospital for evaluation and treatment (9). This means that this prospective consecutive study also includes stroke patients with less severe impairments, which makes the case mix more representative for younger stroke patients. The study focuses on the spouses of stroke patients less than 75 years old. At the time of the study, stroke patients who were admitted to Sahlgrenska University Hospital with an acute stroke and were younger than 70 years were generally treated at the stroke unit at the Neurological Department. Stroke patients older than 70 years could also be randomly treated at general wards and at the stroke units for older people, however. Although a large part of the patients below 75 years old patients were treated at the time in the neurological stroke unit, some bias has probably occurred among the older patients in the study. Because of the age limit, it is not possible to generalise the results of the study to the whole stroke population. Older patients often show multiple age related co-morbidity with additional effects on their daily life and psychological well-being and the life satisfaction of the couple. Older spouses may also have other coping resources in terms of the social network and may also have age related problems with physical health and functional ability. This may have an impact on their coping ability and also on their ability to take part in the study.

Patients were recruited to the study over a period of three years. During this long period of time, it can not be ruled out that changes can have had an impact on the study population. However, during the study period, there were no major changes in the organisation in the hospital or the catchment area that might have had an impact on the characteristics of patients included in the study. The patients were all treated at the same ward, which had very little change in the medical and rehabilitation personnel during that time. Furthermore, the ward worked according to the same concept of stroke care.

The neurological characteristics of the stroke patients were heterogeneous. In our material, there were fewer stroke patients with total anterior cerebral infarction than reported in other studies (38, 44, 106, 196). The BI of the study group was higher than the BI of older patients admitted to the same hospital (197). The frequencies of cognitive impairments in terms of aphasia were similar to previous reports (47).

The study included spouses from all of the Scandinavian countries and from several countries in western and southern Europe. Non-Swedish speaking stroke patients and spouses were excluded for practical reasons, however. There will probably be an increase in the numbers of persons from other countries in the future with a weak ability to communicate in Swedish who suffer stroke. Cultural differences and different coping resources may give rise to different experiences among spouses. Studies carried out by persons who speak the different languages in question are necessary to better understand these spouses' need of support.

Withdrawals

In studies of traumatic life events it is common for persons who do not feel themselves to have problems after the event and for persons with severely impaired emotional health to withdraw (198). In the dialogue with the spouses, both at inclusion and in the follow-ups, these types of explanations for withdrawal were seen. There was a trend that more men than women declined to participate in the first interview, although more women than men withdrew in the follow-ups. There was also a trend for spouses of stroke patients with less severe sensorimotor and cognitive impairment to withdraw and for spouses of more severely impaired stroke patients to continue to participate in the study. The statistical analysis of the withdrawals nevertheless showed no significant impact on the conclusions drawn on the basis of the results. However, the sample size of the withdrawals is small, and this may have had an impact on the ability to reach statistical significance. The reasons for withdraw are of clinical importance, however. Several who withdrew during the follow-up period were spouses of patients with mild sensorimotor impairments but they reported experiencing changes in behaviour and emotional problems in their partners after discharge from the hospital for which they were not prepared. This underscores the need of knowledge about "hidden" cognitive impairments, organic mental disorders and emotional problems and how to cope with them (174).

Data collection

Most of the data collection was made in a home-like environment at the hospital. Data were otherwise collected in a place requested by the spouses. It has been shown that collection data only at the hospital poses a risk of bias in that the spouses of patients with severe disabilities are more likely to withdraw due to practical difficulties in participating (199). The flexibility in the actual site of data recording thus reduced the frequency of withdrawals.

The present study used both qualitative and quantitative data. Data were collected in an interview where open questions about experiences of the ongoing life situation were combined with self-rating questionnaires in the course of a regular procedure plan. The advantage of distributing the self-rating questionnaire during the course of the interview was that these questions were incorporated as a natural part of the interview. It also gave the possibility to clarify whether any of the items were perceived as difficult to interpret. It furthermore offered the participants the ability to give greater detail in their answers. Responding to self-rating scales in an interview situation in which there is also time for reflection over the situation and feelings has been indicated to increase the validity of the answers (200). A disadvantage arose when the participants lacked sufficient time. The self-rating scale then had to be given priority in order to reduce the rate of internal drop-outs. It was thus not always possible to achieve the depth desired in the interviews. The qualitative data gave information about the level, change and associations of the chosen variables. The interviews gave deeper insight into the spouses' thoughts and perception of their situation. The final conclusion here is that the combination of the research methods contributed to a deeper understanding of the spouses' experiences in their daily lives after their partners' stroke.

The self-rating scales have been shown in previous studies to be valid and reliable (89, 162, 170). Although it is possible to add the scores of the three sub-components of "comprehensibility", "manageability" and "meaningfulness" in the SOC questionnaire, the questions of whether it is possible to examine each sub-category separately has not been sufficient studied (170, 188, 201, 202). The questionnaire was constructed to measure the concept as a whole and was used in this way in the present study. In agreement with previous longitudinal studies, emotional measures were less stable over time than cognitive measures

(203). In longitudinal studies of life satisfaction, it is inevitable that results of both personality, actual change and temporary evaluations owing to mood swings will be noted (88, 204). Diener *et al.* have shown that the influence of response artefacts such as social desirability and current mood on self-rated life satisfaction seems to be smaller than has previously been suggested but should still not be ignored (94). However, the life satisfaction checklist has been shown in earlier studies to be stable over time in the case of unchanged life situations and to be sensitive to changes in life domains (162). In a number of cases, a tendency was noted during the interview to choose the less negative of two response alternatives in the self-reporting scales, while a more negative picture of daily life and emotional health was reported in conversation. This is a well-known phenomenon when the issue covers questions that can stimulate negative thoughts and feelings in the respondent (200). However, this could have affected the results in a more positive direction.

In qualitative research the trustworthiness of the results depends on a chain of factors including the motivation and capability of the subject to share his or her experiences and thoughts, the relevance of the questions, the qualifications of the interviewer, the means of recording and transcribing data and the analysis and interpretation of the data (205). In the present study, the spouses often expressed that they felt it was valuable for them to express their thoughts and/or for the health care system to gain better knowledge of spouses' experiences. The themes of the questions were developed on the basis of clinical experience and the theoretical assumptions described in the model that guided the study. Great effort was made to develop a physical and emotional environment in which the spouses could feel free to express their thoughts and feelings. Most of the interviews were tape-recorded and a few interviews were transcribed directly after the interview. It was therefore possible to return to the original interviews for a deeper study of the interaction process between the interviewer and the spouses, as it took place during the interviews. The purpose of the present study was not to seek a deeper meaning in the spouses' experiences or to generate theory (180). The data analysis thus remains close to the interview data. Two persons validated the categories that were developed and the categorisation of the spouses according to their degree of pessimism/optimism about the future.

Statistical analysis

Recruitment into the study was completed after three years. Consultation with a statistician concerning the size of the study group indicated that the number of subjects had sufficient statistical power to detect change and associations in the major variables (182, 206). A larger study group would of course have increased the power of the study further. To recruit a larger study group of spouses of stroke patients younger than 75 years would have required a multi-center study. This method has been used in a few studies of larger study groups, but these have included only quantitative data (6, 51, 104, 121). The completeness of the interview data in the whole study group is to our knowledge unique to this study. The interview data have been useful in validating the results of the statistical analyses. It has also offered knowledge about factors in everyday life that are associated with change and the level of psychological well-being and life satisfaction and has provided a deeper and more varied knowledge of the spouses' experience of the variables that were measured than is possible using only the self-rating scales (*unpublished data*).

Because of the rather small study group in combination with multiple statistical analyses, a balance between the risk of a Type I and Type II error must be considered (182). Two different approaches to this problem have been taken. In studies II and III, a probability level of 0.001 was chosen to reduce the risk of Type I errors. Studies IV and V were exploratory in

nature regarding patterns and trends in relationships over time. A level of significance of 0.05 was thus chosen. While there is a risk of Type I errors, trends in relationships between the variables over time are clear.

CONCLUSIONS

- A partner's stroke has a great impact on the spouse's psychological well-being in terms of increased anxiety, sadness and tiredness even in the case of less severe stroke.
- Spouses' psychological well-being in the first weeks after their partners' stroke seems to be more strongly associated with their individual appraisal of the personal impact on their future life and coping abilities than with the objective neurological characteristics of the stroke patients.
- Sense of coherence seemed to be an important factor as regards spouses' coping ability in the first period after stroke onset.
- After some months, most of the spouses' psychological well-being had improved probably in parallel with the lessening anxiety about their partners' lives and hope for further improvement. Between four months and one year, there were individual changes in both a positive and a negative direction.
- A great many of the spouses showed decreased satisfaction in their ratings of valuable domains of life, indicating a widespread impact on everyday life and social relationships.
- In the first period after stroke onset, visible sensorimotor impairments seem to have had a greater impact on spouses' psychological well-being than did cognitive impairments. In everyday life, however, the impact of cognitive and astheno-emotional impairments seems to be more evident in the spouses.
- Different types of impairments appear to have different impacts on different dimensions of the spouses' psychological well-being and on different domains of life. However, there is most often a combination of two or more impairments, which results in a widespread impact on several dimensions of psychological well-being and several domains of life satisfaction.
- The associations between the stroke patients' cognitive impairments, including aphasia, and their level of dependency in self-care and the spouses' psychological well-being were in most cases most marked at four months after stroke onset. The associations between these kinds of impairments and disabilities and the spouses' life satisfaction were most marked at one year. This indicates that the spouses are in need of different types of support at different times in their adaptation process.

CLINICAL IMPLICATIONS

The clinical implications of the study can be summarised in five points:

1. The spouses' thoughts about the disease, the impact on their individual life situations and their coping ability must be the foundation for information, instruction, counselling, treatment and planning, even in the case that the stroke patient has suffered only a mild or moderately serious stroke.
2. Spouses must be given information about "hidden" cognitive, astheno-emotional and emotional impairments and about how to manage them, even in cases of less severe stroke. Spouses need this information before their partners' discharge from hospital as well as in follow-ups after discharge.
3. Spouses are in need of counselling about how to manage their partners' disabilities in everyday life, not least after their discharge from hospital.
4. Spouses of stroke patients with persisting physical and cognitive impairments, including aphasia and/or astheno-emotional syndrome, need support over a long period of time, primarily as concerns their social and leisure situations.
5. Emotional impairments are commonly seen after stroke. The partners' emotional states appear to interact. The emotional health of both partners must thus be taken into consideration in treatment.

In medical care and rehabilitation of the stroke patients, as well as in teaching, counselling and supporting spouses, it is necessary to have knowledge of the complexity of the symptoms and of how different kinds of symptoms and the combinations of symptoms interact with the stroke patients' health, ability to carry out daily activities, communication and social interaction. A team of professionals with specialised knowledge, working together with community service professionals is needed to manage this complex situation. The occupational therapist is an important member of the rehabilitation team. He/she contributes knowledge about evaluation and treatment of patients with an impaired ability to carry out their daily activities in terms of each patient's physical, cognitive and emotional impairments and social and physical environments. Accordingly, the occupational therapist has an important role in teaching and counselling spouses about the impact of different types of impairments on the stroke patients' ability and capacity as well as in giving advice about how to manage disabilities in everyday life in terms of the partners' environmental and social context and their values, habits and roles. This is necessary both in the acute period at the hospital and after discharge. Furthermore, to prevent maladaptation and deteriorations in the health of the spouses, the occupational therapist must consider the spouses' own daily occupations and, as regards caregiving burdens and occupational limitations, must help them to maintain a balance between work and leisure. Giving spouses new life experiences characterised by consistency, participating in shaping outcomes and a load balance in their everyday life may contribute toward maintaining or even strengthening their sense of coherence.

SWEDISH SUMMERY

Introduktion: När en familjemedlem drabbas av sjukdom och funktionsnedsättning påverkas även de övriga familjemedlemmarnas dagliga aktiviteter, roller och emotionella hälsa. En stor grupp av anhöriga med risk för negativ påverkan på sitt psykologiska välbefinnande är makar till strokedrabbade. Stroke är en av våra vanligaste folksjukdomar och orsakas av en propp eller en blödning i hjärnans kärl. Cirka 20 000 personer drabbas årligen i Sverige för första gången av stroke och mer än 100 000 personer lever i samhället med erfarenheten av att ha drabbats av stroke. Stroke kan resultera i en komplex symtombild beroende dels på skadans omfattning, dels på vilket område i hjärnan som drabbats. Sensoriska och/eller motoriska bortfall, nedsatt förmåga att producera och/eller förstå tal, svårigheter att tolka sinnesintryck, minnesproblem, svårigheter med komplext tänkande, nedsatta vitala funktioner såsom urininkontinens, beteendeförändring och nedsatt förmåga till social interaktion, trötthet, irriterabilitet, depression och ångest är vanliga problem efter stroke. De kvarvarande symtomen kan variera från att vara mycket omfattande till inga kvarstående symtom alls. Många av de som drabbats av stroke blir i någon omfattning beroende av en annan persons praktiska och emotionella stöd i det dagliga livet och de anhöriga är de som bidrar med den största andelen av detta stöd. Det har klart uttryckts i WHO's Hälsingborgsdeklaration för stroke vård att de anhöriga skall ses som en viktig resurs i stroke vården, att planering och behandling skall utgå från patientens och den anhöriges intresse och behov samt att hur vård och omsorg till den strokedrabbade påverkar den anhörige emotionellt skall utvärderas. För att ge bättre stöd till anhöriga från den akuta vårdperioden och under rehabiliteringsprocessen finns det behov av fördjupade kunskaper om de anhörigas situation sett ur deras eget perspektiv.

Den föreliggande studien är en longitudinell studie. Studiens design är utformad utifrån en teoretiska modell med antagande att: alla makar till strokedrabbade har sina individuella livserfarenheter och levnadsförhållanden före partners insjuknande. Partners insjuknandet i stroke är en oväntad och hastigt påkommen förändring i både den drabbades och deras makars liv. Stroke medför en förändring i den drabbades hälsa och aktivitetsförmåga vilket har inverkan på bådadas dagliga aktiviteter, roller och relationer. Både själva förändringen av den strokedrabbades hälsa och aktivitetsförmåga och den förändrade vardagen antas påverka makarnas psykologiska välbefinnande och livstillfredsställelse. Individens livserfarenheter och levnadsförhållanden antas ge upphov till hans eller hennes inre och yttre resurser vilka antas vara grunden för hans eller hennes känsla av sammanhang. Känslan av sammanhang antas vara av vikt för hur man kognitivt värderar den situation man befinner sig i och för förmåga till coping. Makarnas kognitiva värdering av situationen och deras förmåga att hantera den känslomässiga påverkan av stroke samt förändringar i det dagliga livet antas ha en medierande effekt mellan konsekvenserna av stroke och upplevt välbefinnande.

Syfte: Studiens huvudsyfte var att longitudinellt undersöka förändring av makarnas psykologiska välbefinnande och livstillfredsställelse mellan den första veckorna efter partners insjuknande, fyra månader och ett år, samt att studera sambandet mellan dessa två variabler och karakteristik av makarna och av de stroke drabbade vid dessa tidpunkter.

Metod: Studien riktar sig till makar/sammanboende till strokedrabbade med ett förstagångsinsjuknande, < 75 år, vårdade vid Neurologiska kliniken, Sahlgrenska Universitetssjukhuset, inga andra snabbt progredierande sjukdomar, bor i Göteborg eller dess närhet och talar och förstår svenska. Etthundrasex par uppfyllde inklusionskriterierna. Åttiotre makar/sammanboende inkluderades konsekutivt i studien. Dessa utgör studiegruppen i studie

I-III. Sextiosju makar deltog vid samtliga tre intervjutillfällen: 10 dagar, fyra månader och ett år efter partners insjuknande. Dessa makar utgör studiegruppen i studie IV-V. Medelåldern för de stroke drabbade var 58 år. Sjuttiofem procent av dessa var män och 25 % kvinnor. Drygt hälften av de strokedrabbade klarade sin personliga vård självständigt redan första veckan efter insjuknandet. Makarnas medelålder var 57 år. Femtiosju procent av dessa var yrkesverksamma. Nitton procent av paren hade minderåriga barn. Data som registrerades angående om makarna omfattade demografiska uppgifter, öppna intervjufrågor om upplevelser och hantering av den nuvarande livssituationen, självskattningsskalor omfattande psykologiskt välbefinnande (the PBWB Index), livstillfredsställelse (Life Satisfaction Checklist) och känsla av sammanhang (Sense of Coherence Questionnaire). Data samlades in vid en semi-strukturerad intervju, oftast genomförd på Sahlgrenska Universitetssjukhuset i en hemliknande miljö. Intervjuerna spelades in på band med makarnas medgivande och tranformerades datanära. Data om den strokedrabbades neurologiska funktionsnedsättningar och förmåga att klara sin personliga vård dokumenterades veckan efter insjuknandet och vid ett år. Vid ett år dokumenterades även förekomst av depression samt asteno-emotionellt syndrom. Intervjodata angående den makarnas framtidssyn analyserades med kvalitativ analysmetod. Kvantitativ data analyserades med icke-parametriska statistiska analysmetoder. Samtliga deltagare gav sitt informerade godkännande till deltagande i studien. Studien har godkänts av Göteborgs Universitets forskningsetikkommitté.

Resultat/Diskussion: Utifrån makarnas intervju utsagor skapades tre med varandra nära förbundna subkomponenter av begreppet Framtidssyn: synen på sjukdomens påverkan på partners framtida hälsa och aktivitetsförmåga; påverkan på egna aktiviteter, roller och livssituation; samt synen på den egna coping förmågan. Fyra olika kategorier av optimism/pessimism inför framtiden kunde definieras och makarna kategoriserades enligt dessa definitioner med hög överensstämmelse vid både inom- och mellanbedömning (*Studie I*). Makarnas syn på sjukdomen och dess personliga konsekvenser för framtiden och deras upplevda psykologiska välbefinnande var starkt associerat, starkare än associationen mellan deras psykologiska välbefinnande och den stroke drabbades objektiva symtombild (*Studie II*). Makarnas känsla av sammanhang var under de första veckorna efter partners insjuknande associerat med deras tillfredsställelse med nära sociala relationer samt med materiella resurser i livet före insjuknande. Makar med en hög känsla av sammanhang hade oftare en optimistisk framtidssyn och högre psykologiska välbefinnande första veckan efter partners insjuknande än makar med låg känsla av sammanhang (*Studie III*).

De första veckorna efter de partners insjuknande var makarnas psykologiska välbefinnande sänkt jämfört med svenska normvärden (*Studie II*). Fyra månader efter partners insjuknande hade deras välbefinnandet ökat, fr. a. rapporterades en längre ångestnivå och ett ökat positivt välbefinnande. Däremot rapporterade många av makarna sänkt tillfredsställelsen med sin daglig sysselsättning, fritid, sexualliv, partner relation och familjeliv. Mellan fyra månader och ett år skedde ingen statistisk signifikant förändring av dessa variabler på gruppnivå, men det förekom individuella förändringar i både positiv och negativ riktning (*IV-V*).

Makar till strokedrabbade med nedsatt förmåga att klara sin personliga vård samt med kognitiva funktionsnedsättningar beskrev oftare en mer pessimistisk framtidssyn de första veckorna efter partners insjuknande än makar till strokedrabbade utan dessa nedsättningar (*Studie I*). Makarnas psykologiska välbefinnande vid denna tidpunkt var dock starkare associerat med den drabbades synliga, motoriska funktionsnedsättningar än med kognitiva, "dolda" funktionsnedsättningar (*Studie II*). I det dagliga livet i hemmet blev konsekvenserna av kognitiva funktionsnedsättningar mer påtagliga (*Studie IV-V*). Olika slags

funktionsnedsättningar hos den drabbade var associerade med olika dimensioner av psykologisk välbefinnande och med olika livsdomäner hos makarna. Den strokedrabbades sensorimotorisk förmåga samt förmåga att klara sin personlig vård var framför allt associerat med dimensionerna ångest och nedstämdhet hos makarnas samt med deras tillfredsställelse med sin daglig sysselsättning och fritidsituation. Kognitiva och asteno-emotionella funktionsnedsättningar hos den strokedrabbade var framför allt associerat med makarnas känsla av glädje och med deras tillfredsställelse med partner relation och familjeliv. Makarnas och den stroke drabbades emotionella hälsa var relaterade till varandra. Sambandet mellan den strokedrabbades funktionsnedsättning, fränsett kvarvarande sensorimotoriska funktionsnedsättningar och makarnas psykologiska välbefinnande var mest tydligt fyra månader efter insjuknandet, medan sambandet mellan den strokedrabbades funktionsnedsättning och makarnas livstillfredsställelse mest markant ett år efter stroke. (Studie IV-V). Omfattande sensorimotoriska funktionsnedsättningar är dock ofta kombinerad med kognitiv, asteno-emotionell och emotionell problematik, vilket medför en komplex påverkan på makarnas psykologiska välbefinnande och livstillfredsställelse.

Resultaten visar att även makar till mildare skadade strokedrabbade påverkades i grad emotionellt i samband med partnerns insjuknande. Tidigare studier har visat att anhörigas emotionella hälsa den första tiden efter partnerns insjuknande är prediktivt för deras emotionella hälsa under det kommande året. Studiens resultat visar på sambandet mellan makarnas kognitiva bild av sjukdomen, dess personliga konsekvenser och av sin egen copingförmåga och deras psykologiska välbefinnande. Genom att stödja makarna till en optimistisk men dock realistisk syn på framtiden och att understödja deras egen coping förmåga kan man som vård- och rehabiliteringspersonal förhoppningsvis bidra till ett förbättrat psykologiskt välbefinnande. Makarnas egen syn på sjukdomens natur, påverkan på den egna livssituationen och de egna resurserna att hantera denna, bör utgöra grunden för information, undervisning och planering. Makarnas känsla av sammanhang var också associerade med deras framtidssyn och optimism. För att stödja denna är det av vikt att bidra till att ge dem nya livserfarenheter av överensstämmelse, delaktighet och balans i belastning i den nya livssituationen, både under den drabbades sjukhusvistelse och i livet efter utskrivningen.

Resultaten visar också på att den strokedrabbades kognitiva och asteno-emotionell problematik kan påverka såväl makarnas psykologiska välbefinnande som partner relation och familjelivet. Asteno-emotionell problematik befanns vara vanligt även hos strokedrabbade med ingen eller lindrig sensorimotorisk problematik. Även makar till mildare skadade strokedrabbade behöver kunskap om denna slags "dolda" problematik samt råd om hantering av dessa problem redan under den drabbades sjukhusvistelse samt rådgivning efter den drabbades utskrivning med fokus på dessa dolda funktionsnedsättnings inverkan på vardagslivet och social interaktion. I de fall den strokedrabbade har kvarstående problem att klara det dagliga livets aktiviteter vid utskrivningen, behöver båda parter uppföljning med inriktning på råd och handledning i att hantera dessa problem i sin sociala och fysiska omgivning. Studien visar också att vid kvarstående sensorimotoriska, kognitiva, asteno-emotionella och/eller emotionella problem är makarna i behov av stöd under en längre tid framför allt med fokus på kommunikation, social situation och fritidssituation.

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APPENDIX I

Definition of the four categories of "View of the future"

Category A: "Very pessimistic"

The spouse experiences the future life as permanently, negatively changed. He/she experiences a great deal of apprehension for recurrence or other medical complications in the stroke victim that may lead to increased disability or death. If the stroke victim suffers impairments, the spouse perceives them as permanent and thinks that the stroke victim will always be in need of great help. The spouse also feels that his/her own possibility to take part in valued activities will be permanently restricted and that the future life situation will involve a great deal of physical and/or psychological burden which will be difficult to cope with.

Category B: "Pessimistic but hope for improvement"

The spouse experiences the future life as uncertain but probably negatively changed. He/she has an apprehension for recurrence or other medical complications of the stroke victim that may lead to increased disability. If the stroke victim suffers from impairments, the spouse feels that they will decrease but that the stroke victim will still be in need of a great deal of help in the future. The spouse also perceives that his/her own possibility to take part in valued activities will be restricted to a great extent and that the future life situation will involve a physical and/or psychological burden but has ideas about how to cope with the problem he/she will face.

Category C: "Optimistic but prepared for alterations"

The spouse experiences the future life as uncertain, but hopes that the current life situation is temporary. He/she experiences some apprehension for recurrence or medical complications of the stroke victim but not to a great extent. If the stroke victim suffers from impairments, the spouse has hope for progress. He/she is nevertheless prepared for the stroke victim to suffer from impairment to some extent and that he/she will be in need of support for some time. The spouse also feels that his/her own possibility to take part in valued activities will be affected to some extent and feels there will be some alterations in his/her own life situation but does not perceive them as a physical and/or psychological burden. He/she has confidence in being able to cope successfully with any consequences that may come.

Category D: "Very optimistic"

The spouse experiences the current life situation as temporary. He/she is aware of the possibility that there could be a recurrence or medical complications of the stroke victim in the future but is not concerned about it today. If the stroke victim suffers from any impairment, the spouse is convinced that he/she will soon recover. The spouse feels that there will be no restrictions to his/her own possibility to take part in valued activities and no future alteration of his/her life situation. The alterations in his/her daily activities that may remain during a short period are not perceived as a physical and/or psychological burden at all and he/she is convinced of his/her ability to cope successfully.

APPENDIX II

Sub-components	Category A: "very pessimistic"	Category B: "pessimistic but hope for improvement"	Category C: "optimistic, but prepared for alterations"	Category D: "very optimistic"
<p>I. Perception of the disease and its impact on future health and ability of the stroke patient</p>	<p>(Expresses her fears that her husband will die) "He's the best thing I have and I can't manage without him and I don't want to manage without him!!!"</p> <p>"I have a hard time seeing that it's going to get better."</p>	<p>"I think about it all the time, I can't deny it: He could have another stroke! But I don't dare say it to anyone. I've almost not dared to say it out loud before now."</p> <p>"I think he can get better, maybe a little if he works at it. Maybe he'll be able to walk with some kind of walking help. But 100%? I don't know..."</p>	<p>"In general I guess I'm hopeful, but of course this thing has to do with something not being good. And I am a little worried all the time. I am."</p> <p>"But it was actually a happy surprise that there was anything (motor function) left at all. There was. Both in the hand and the foot. He can work at that...we have to help him exercise. And of course, if he has support at home it'll be easier...but by the time summer comes anyway I think he'll be able to go with some kind of support, so to speak."</p>	<p>"Of course, if something should happen so that he isn't able to, then we'll have to stay home. But we're planning to travel anyway."</p> <p>"So I knew that this wouldn't get worse anyway. And he works on it by exercising...and it's working, so to speak, because he talks without any trouble and swallows without any trouble, he walks without trouble and so I think it was pretty mild."</p>

APPENDIX II cont.

Sub-components	Category A: "very pessimistic"	Category B: "pessimistic but hope for improvement"	Category C: "optimistic, but prepared for alterations"	Category D: "very optimistic"
<p>2. Perception of changes in daily activities, roles and life circumstances</p>	<p>(Uses earlier experiences of stroke to describe how she expects her own situation to be) "I've seen other people with a stroke and how incredibly much work it takes. Her husband has to work with it constantly. Taking her to the bathroom and everything. It must be a horrible psychological burden to have things like that all the time."</p>	<p>I don't know what's going to happen and there are a lot of problems and there's a lot I have to do...I don't know what I'm going to do. For example, he's never told me what he does when he pays insurance. What should I say? Who do I call?"</p>	<p>"I'd like to go away on vacation to the Canary Islands in the fall since we couldn't do it now. And it's okay if you need a wheelchair. That...you can travel with that. You see that there are people in wheelchairs who travel."</p>	<p>"Now we're just going to take it nice and easy. Celebrate Christmas together with the family. I'll bake my usual Christmas casserole and my aspic that I usually make, so everything will probably be okay."</p>
<p>3. Perception of one's own coping capacity</p>	<p>"I mean, I don't understand how I'm going to manage it. I don't understand !!!"</p>	<p>"It's going to be hard for me. I know that, but I can manage it because I don't work anymore and I'm at home. I'll have to use all my energy for him instead of sitting and sewing. That's just the way it is."</p>	<p>"I'm trying and it's going well. I'm a fairly strong person. You have to take one day at a time. You have to accept that it's going to take time."</p>	<p>"We're going to drive around a little bit in Sweden on vacation..... We'll stay at a hotel in peace and quiet instead of renting a house-trailer or anything that takes work. We think it'll be easier and more comfortable that way."</p>

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