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# PSYCHOLOGICAL HEALTH AND LIFE SITUATION IN SPOUSES OF STROKE PATIENTS

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*Den första dagen under resten av mitt liv  
var helt annorlunda än vad jag hittills upplevt  
jag såg den först som märkligast av märkliga ting  
att falla utan egentlig tyngd, att flyta utan kraft  
att virvla bort utan ljud, att se utan att förstå....  
Just så var den första dagen i mitt nya liv  
det gamla har jag för alltid lämnat bakom mig....*

*Bo Gustaf Swebilius*

# 1 ABSTRACT

About 30,000 people in Sweden are affected by stroke each year. The effect on physical functioning, and also consequences such as depression and aphasia, are likely to affect not only the life of the patient, but also the life of the spouse and family.

The aims of the thesis were to identify factors of importance for the life situation of spouses of stroke patients and to evaluate the effect of a support- and education programme on the spouses' psychological health.

The participants in this thesis were gathered from three different populations.

Participants in Paper I were significant others of depressed stroke patients. The aim of this study was to describe the life situation among significant others to patients with post stroke depression (PSD) and to identify associations between the life situation of the significant other in relation to patient characteristics. In Paper II the participants were significant others of depressed or aphasic stroke patients. The aim was to describe and compare predictors of the life situation of significant others of depressed or aphasic stroke patients. In Papers III and IV the participants were spouses of stroke patients consecutively approached and invited to participate in a randomised controlled trial (RCT) intervention programme. The aim of Paper III was to explore if a nurse-led support- and education programme for spouses of persons affected by stroke improved the psychological health in the spouses, and the aim of Paper IV was to identify predictors of psychological health and to examine if these predictors change over time in spouses of stroke patients during the first year after stroke. A second aim was to identify gender differences in psychological health among the spouses.

Perceived need of assistance was the only common predictor of the life situation of the significant other of both significant others of depressed and aphasic stroke patients.

Amongst the aphasic patients, perceived personality change and living with the patient were factors that had a negative effect on the life situation of the significant other.

General well-being and presence of illness in the spouse were the most prominent predictors of psychological health, throughout the first year.

Significant others of stroke patients participating in a support- and education programme had significantly more knowledge about stroke after 12 months compared to the controls. No difference in psychological health was found. However, the

participants appreciated the group sessions and the attention from the health professionals. Significant others of male stroke patients reported a more negative impact on their life situation, than did significant others of female stroke patients. There was a significant relation between the patient's level of depression and physical function (ADL); those with less impaired ADL had more major depression than those with more impaired ADL.

This thesis highlights the importance of assessing the situation of spouses of stroke patients. The perception of the patient's need of assistance is an important factor affecting the life situation of spouses of both depressed and aphasic stroke patients. An intervention programme increases the spouses' knowledge about stroke, but a combination of group meetings and individualised support may be necessary in order to gain effect also on the psychological health. Assessments of the spouses' perception as well as of the patients' factual situation may identify spouses at risk. Enhancing the psychological health and supporting those in need may enable the patient to continue to live at home without risking the health of the spouse.

Key words: stroke, spouse, life situation, psychological health, support programme.

## 2 LIST OF PUBLICATIONS

### I

Å. Franzén-Dahlin, E. Billing, P. Näsman, B. Mårtensson,  
R. Wredling, V. Murray,  
Post-stroke depression - Effect on the life situation of the significant other.  
Scandinavian Journal of Caring Science, 2006; 20; 412-416.

### II

Å. Franzén-Dahlin, A-C. Laska, J. Larson, R. Wredling, E. Billing, V. Murray,  
Predictors of life situation among significant others of depressed or aphasic  
stroke patients.  
(submitted)

### III

Å. Franzén-Dahlin, J. Larson, V. Murray, R. Wredling, E. Billing,  
A randomised controlled trial evaluating the effect of a support- and education  
programme for spouses of persons affected by stroke.  
(submitted)

### IV

Å. Franzén-Dahlin, J. Larson, V. Murray, R. Wredling, E. Billing,  
Predictors of psychological health in spouses of persons affected by stroke.  
Journal of Clinical Nursing, 2007; 16; 5; 885-891

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### **3 LIST OF ABBREVIATIONS**

ADL	Activities of Daily Living
ANELT	Amsterdam Nijmegen Everyday Language Test
ANOVA	Analysis of variance
AVAT	Availability of attachment
AVSI	Availability of social integration
BI	Barthel Index
CPRS-S-A	The Comprehensive Psychopathological Rating Scale-Self-Affective
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders
MADRS	Montgomery-Åsberg Depression Rating Scale
PSD	Post-Stroke Depression
QoL	Quality of Life
RCT	Randomised Controlled Trial
SD	Standard Deviation
SOC	Sense of Coherence
SPSS	Statistical Package Social Sciences
VAS	Visual Analogue Scale
WHO	World Health Organization



## 4 INTRODUCTION

According to the World Health Organization (WHO), stroke is defined as a “rapidly developing clinical sign of focal or global disturbance of cerebral function, with symptoms lasting for 24 hours or longer, or leading to death, with no apparent cause other than vascular origin” [1]. Stroke is the general term for cerebral infarction (85%), intracerebral haemorrhage (10%), and subarachnoidal haemorrhage (5%). Globally, cerebrovascular disease is the second leading cause of death. In the year 2005, stroke accounted for 5.7 million deaths worldwide, equivalent to approximately 10% of all deaths [2].

A stroke may present a wide range of symptoms, depending on the localisation and extent of the brain damage. The most well-known is a sudden onset of paresis on one side of the body. The hemiparesis is often accompanied by impaired higher cerebral functions like aphasia or neglect, depending on in which hemisphere the lesion is located. A hemiparesis without involvement of cortical functions can occur when the small central penetrating arteries are affected. Stroke is the third most common cause of death in Sweden (15% after three months) and the most common cause of neurological handicap [3]. After three months, 22% of the stroke patients are dependent on their ADL among those who were independent before their stroke. The effects on physical functioning, as well as consequences such as depression and aphasia, are likely to affect not only the life of the patient, but also the life of the spouse and family [4, 5].

## **5 BACKGROUND**

The incidence of stroke in Sweden is about 300/100,000 per year, which results in about 30,000 persons being affected by stroke each year. Men and women are almost equally affected. Around 700 stroke patients are treated at the Stroke Unit at Danderyd Hospital each year. The average time of stay is seven days, and the mean age is 73 years among men and 78.5 among women. Three months after the stroke event, 60% of those who survived and who lived at home before their stroke were back home without home-care service. Another 14% were able to return home with assistance from home-help service. In addition to this, 60% of the patients report that they are partly or totally dependent on assistance from their spouse/family [3].

### **5.1 TREATMENT**

Treatment in a stroke unit has been shown to be of benefit for all patients with suspected stroke, and increases the combined effect measurement of independent survival with at least 4-5% [6]. The acute medical treatment after stroke differs depending on the cause of the stroke, but is guided by three important objectives: preservation of life, preservation of neurological function, and prevention of complications and recurrence [7]. In intracerebral haemorrhage, the aim is to prevent further bleeding and other complications. In ischaemic stroke, all patients can be treated with aspirin with an increase of independent survival of around 1%, maybe mainly due to its early secondary preventive effects. Ischaemic stroke can also be treated with thrombolysis if the treatment can start within three hours from onset of symptoms but so far only in highly selected patients. Long-term treatment is directed at the potential risk factors such as hypertension, atrial fibrillation, and diabetes and aimed at avoiding a new stroke. Also lifestyle factors, i.e. cigarette smoking, lack of physical exercise, stress, and an improved diet, should also be discussed with the patient [8].

### **5.2 THE PATIENT**

#### **5.2.1 Physical symptoms**

Physical deficits can occur after the stroke. Sudden onset of weakness or paresis in arm and/or leg on one side of the body is common, and so is one-sided sensory loss. Speech difficulties and visual impairments, such as blindness in one eye or loss of field of

vision on one side, can also occur. Other symptoms may be vertigo in combination with double vision or walking difficulties. Sudden severe headache and sudden disorientation and nausea/vomiting can also be symptoms of a stroke [8]. As many as half of the stroke survivors are left with physical disabilities [9].

### **5.2.2 Depression**

Around one third of the stroke patients are affected by depression after their stroke. In the general population there is a risk of 17-18% that a person during his/her lifetime will suffer a depression [10]. It is important to identify patients at risk as a post-stroke depression (PSD) may have a negative impact on functional recovery [11], quality of life, and mortality [12].

### **5.2.3 Aphasia**

Speech difficulties are also common after stroke. Around 33% of the stroke patients are affected by some form of aphasia. During the first three months after the stroke event, great improvements are seen in most of the aphasic patients. In those with initial mild aphasia, 70% recovered totally [13]. Still, 50-65% of the patients with initial aphasia have some speech difficulty after six to 12 months [14].

### **5.2.4 Cognitive impairment**

Cognitive functions include different skills such as learning, memory, verbal ability, visuospatial skill, logical thinking, problem solving, and attention. Dementia after stroke has been found to affect around 25% of the patients. Cognitive impairment is even more common; 61% of the non-demented stroke patients have been found to have some cognitive impairment compared to 31% in non-demented controls [15]. Formal and informal care in carrying out ADL is more common in patients with cognitive impairments, and thus influences the situation of both the patient and the spouse [16]. Neglect may also be a sequel after stroke and appears as impairment in attention to one side of the body or unawareness to the left or right in space.

### **5.2.5 Personality change**

Change in personality, perceived by the caregiver, has been reported by Stone et al. as having a negative effect on frustration, dissatisfaction, patience, and worrying [17]. Stroke patients often describe themselves in more negative terms after, than prior to,

their stroke [18], and these changes in self-appreciation may also be experienced by the significant other.

### **5.2.6 Rehabilitation**

In 2004, 80% of the stroke patients in Sweden were treated at a stroke unit in the acute phase [19]. A stroke unit is characterised by coordinated multidisciplinary rehabilitation, with medical, nursing, physiotherapy, occupational therapy, speech therapy, and social work disciplines involved [20]. Patients treated at a stroke unit are more likely to be alive, independent, and living at home one year after the stroke [21]. Following discharge from the hospital, stroke rehabilitation is provided as outpatient rehabilitation, day care or domiciliary rehabilitation. Stroke team consisting of physiotherapist, occupational therapist, speech therapist and social worker are available resources in primary care in many communities. General practitioner and district nurses are also often involved in the care after discharge from the hospital

### **5.3 THE SPOUSE/SIGNIFICANT OTHER**

The important role of the spouses in maintaining their disabled family member in the community is becoming increasingly recognised [22]. The aim of the health services is to discharge as many patients as possible back home. Earlier discharge means that the care has to continue in the community which in turn often means informal, unpaid care provided by a spouse, not being given a choice whether to take on the role or not [23]. Living with a person affected by stroke can influence the situation of the spouse in many different ways. Physical deficits in the stroke patient can be challenging for the spouse, who can experience limited physical strength themselves due to age and their own illnesses. Depression in the patient has been associated with impaired QoL and poor mental health in the caregiving spouse [24]. Communication problems negatively affect the mental health in the spouse and are also associated with more task difficulty and with negative stroke-related caregiver outcomes (i.e., social functioning, subjective well-being, and physical health) [25]. Memory and behavioural changes after stroke affect not only the patient but also the spouse. These changes have been shown to be associated with poorer mental health in spouses [26]. The situation of spouses of stroke patients has incurred more interest during the latest decade. So far, neither the determinants of the life situation nor the best ways to improve the psychological health in the spouses is known.

Problems related to physical aspects of care are more easily recognised by health professionals, than are emotional and behavioral disturbances [27]. Despite evidence of burden on the spouse, support and care directed at the spouse are not standard in most stroke services. In the Swedish National Guidelines for stroke [6], it is discussed that the family also is affected by a stroke, but no guidelines of how to care for the carers are presented. Other countries have developed practical guidelines for how to improve the professional support for this group [28, 29]. The Dutch guidelines consist of 13 areas that should be considered regarding the spouses' situation. These includes identifying spouses at risk, assessment of burden, interventions for carers, providing information and education, differences in complaints between patient and spouse, depression, primary care, involvement of spouses in the rehabilitation process, long-term consequences, fellow sufferers, young children of stroke patients, sexuality and intimacy, and societal involvement. Based on these guidelines, implementation of some of these areas is present in this thesis.

### **5.3.1 Life situation**

Life situation is a broad concept that involves several aspects of life. A qualitative study identified six descriptions that were involved in how the subjects experienced their life situation: a feeling of confinement, a feeling of social isolation, a feeling that the way of life has changed, a feeling of security in life, a feeling of a threatening future, and promoting health [30]. In this thesis the concept of life situation covers aspects of social life, coping, routines at home, feelings of burden and depression, and feeling worried.

### **5.3.2 Psychological health**

Depression is common not only in the stroke patient but also in the spouse. An incidence rate of around one third, which is at the same level as for the patients themselves, has been reported [31, 32]. Depressive symptoms are more common when caring for stroke survivors who exhibit memory and behavioural deficits [33]. More lifestyle interference and poor family functioning are other aspects that have been shown to have a negative impact on the mental health of the spouse [26]. Depression in the spouse has been associated with subjective and objective burdens [31], but has been shown to be possibly ameliorated by a greater sense of control [33]. In this thesis, depression in the spouses is defined by a score of 10 points or more on the CPRS-S-A scale. The economic situation may also affect the psychological health. Costs for

medications and visits to the hospital and doctors can put pressure on one's economic situation, as well as loss of income of the patient and/or caregiver [34, 35].

### **5.3.3 Sense of coherence**

Sense of coherence (SOC) is a "global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement" [36]. These three domains are called: comprehensibility, manageability and meaningfulness. SOC considers one's ability to respond to stressors by the appropriate use of an effective coping strategy [37]. A person with a strong SOC is expected to have a greater ability to handle stress. Previous studies have shown that a strong SOC was associated with lower levels of burden [38], a better self-rated QoL [39, 40], and that spouses with a weaker SOC were more likely to have a low psychological well-being and a more pessimistic view of their life in the future [41].

### **5.3.4 Social network**

Social network describes the structure of the individual's social relationships to other individuals within the network. It also includes the inter-relationship between these individuals [42]. The impact of having social support has been shown to contribute to a significantly better and progressively improved functional status in the stroke patients [43]. Also in the significant other, a higher level of social support was found to be associated with lower levels of caregiver depression and higher levels of well-being and general health [44]. Upholding the social contacts can be a difficult task when physical and communicative difficulties limit the possibilities to move and to participate in even trivial discussions. For the significant other it might be difficult to leave the stroke patient alone, and thus opportunities to integrate in the society can be limited.

## 6 INTERVENTION PROGRAMMES

The vulnerable situation of significant others of stroke patients has been recognised and attempts have been made to meet the demands of this group. One neglected area has been identified as need of information of the disease. Lack of knowledge increases the uncertainty and anxiety in the significant other [45]. Interventions directed at improving knowledge have shown positive results, but they were not associated with improvement in the perceived health status [46, 47]. Another area of interest is depression in the significant other. Reduction of the depressive symptoms after an intervention programme have been shown, but unfortunately did not this improvement persist when the intervention ended [48, 49].

Higher levels of social support have been shown to be associated with lower levels of depression and higher levels of well-being and general health in the significant other [44]. Interventions may have a positive effect on social support in making the participants aware of possible sources of support [50].

In addition to benefits to the patient and significant other, availability and training of family caregivers of stroke patients have been shown to have a considerable positive impact on professional care and health care cost reduction [51].

Taken together, there is a need for better understanding of the spouse's situation and offering better support to caregivers as well as stroke patients, thus facilitating for the patient to continue living at home [52].

## 7 AIMS

The overall aims of the thesis were to identify factors of importance for the life situation and the psychological health of spouses of stroke patients and to evaluate the effect of a support- and education programme on the spouses' psychological health.

The specific aims of the studies included in this thesis were:

**Paper I.** To describe the life situation among significant others to patients with post-stroke depression (PSD) and to identify associations between the life situation of the significant other in relation to patient characteristics.

**Paper II.** To describe and compare predictors of the life situation of significant others of depressed or aphasic stroke patients.

**Paper III.** To explore if a nurse-led support- and education programme for spouses of persons affected by stroke improved the psychological health in the spouses.

**Paper IV.** To identify predictors of psychological health and to examine if these predictors change over time in spouses of stroke patients during the first year after stroke. A second aim was to identify gender differences in psychological health among the spouses.



## 8 METHODS

### 8.1 PARTICIPANTS AND DESIGN

Data used in this thesis originated from three different cohorts. Participants in Paper I consist of 71 depressed stroke patients and their significant other from a randomised placebo-controlled antidepressant trial [53].

Participants in Paper II are the same as in Paper I, but also include 77 aphasic patients and their significant other, in a randomised placebo-controlled trial investigating the effect of an antidepressant agent on aphasia regression [54]. In these papers, the significant other is someone pointed out by the patient as a person being close to him/her. In both studies patients who did not have a significant other or did not want their significant other to participate were excluded. Also, depressed patients were excluded if they had aphasia prohibiting communication and aphasic patients were excluded if they were suffering from an overt depression.

Papers III and IV consist of 100 spouses of consecutive stroke patients treated at the Stroke Unit at Danderyd Hospital between November 2001 and May 2004. One hundred spouses were needed for the study, assuming that the detected increase in psychological health among spouses in an intervention group compared to the control group was 25%, giving a sufficient power of 80% with a two-tailed test, with a Type-I error probability of 0.05. Fifty spouses were randomised to an intervention programme, with six meetings during six months and a follow-up meeting after 12 months, in groups of ten spouses. The 50 remaining spouses constituted a control group that received standard treatment, which consisted of regular information during the patient's hospital stay and the possibility to attend an open session for one-and-a-half hours held by one of the stroke-specialist physicians at the stroke unit. In these papers, the definition of a spouse is someone that lives in the same household as the person affected by stroke. One hundred fifty-three spouses chose not to participate in the study (Figure 1).

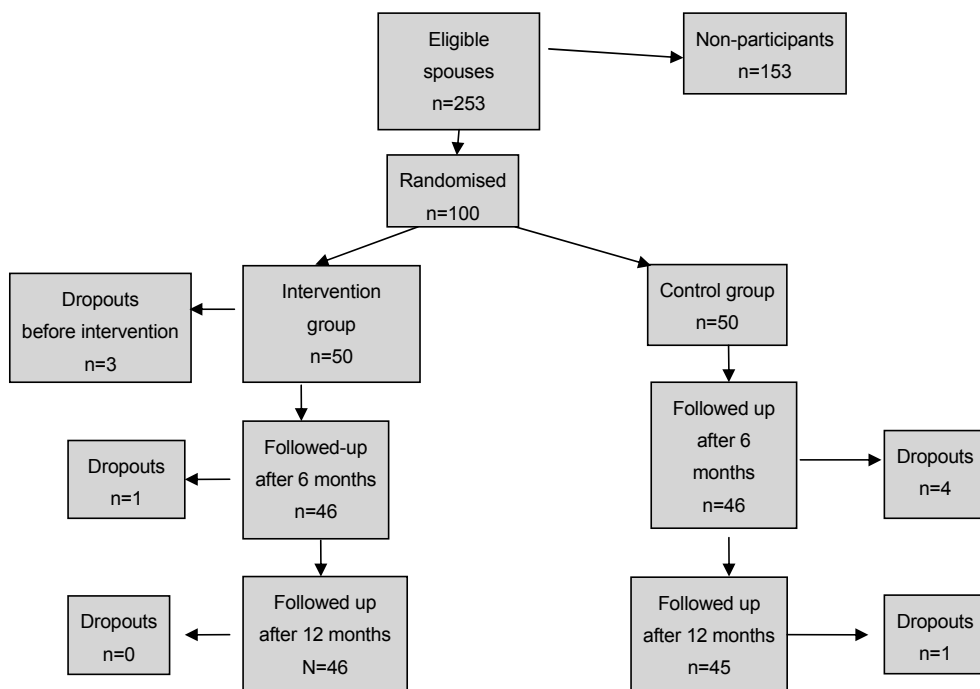


Fig. 1. Flow chart of participants and dropouts in the randomised controlled intervention trial.

## 8.2 PROCEDURE

The inclusion period for patients in Papers I and II took place between June 1996 and March 2002. The degree of depression and aphasia were evaluated by specifically trained staff; for the degree of depression by use of the depression rating scale MADRS and for the grade of aphasia according to the verbal communication test ANELT. The level of functional ability (Barthel Index) was assessed by the study nurses. All other assessments were made by the significant other. The life situation instrument evaluated the significant others' opinion about their own situation. Need of assistance, personality change, state of depression and aggression concerns the significant other's opinion about the patient. The aphasic patients were evaluated at six months after their stroke event, so that they should have experienced how it is to live with speech difficulties. For the depressed patients the assessment was made when they sought help for their depression, which was at any time from stroke onset up to one year post-stroke. At this time they had already experienced the suffering caused by the condition. This means that the situations of the significant other of the aphasic and the depressed patients are

comparable, since both groups have experienced how it is to live with severe sequels, or consequences of stroke. By definition the time lapse from stroke onset to assessment in this study was longer for the aphasic patients.

In Papers III and IV, participants were identified through the patients treated at the Stroke Unit at Danderyd Hospital, and they were recruited between November 2001 and May 2004. Those who were randomised to the intervention participated in six meetings with 10 spouses in each group. The sessions started with a 20-30 minutes lecture on different topics: risk factors, treatment, prevention, personality changes, and social aspects. The lecture was followed by group discussions. The aim of the intervention was to improve knowledge about stroke and to give the spouses the opportunity to discuss stroke-related topics and their own problems related to the informal caregiving, with specialist nurses and other spouses in the same situation. Evaluation was made at baseline and after six and 12 months. The significant other assessed their own situation concerning psychological health, well-being, social network, sense of coherence, knowledge about stroke, and economic situation. The Barthel Index score of the patient was a joint estimate by the study nurse and the significant other.

### **8.3 INSTRUMENTS**

Activities of daily living (ADL) was assessed by the Barthel Index [55]. This scale evaluates basic activities of daily living such as feeding, grooming, transfer, dressing, toileting, bathing, walking, incontinence of bowel and bladder, and stair walking. The ADL-item scores range from 0 (complete functional impairment) to 100 (complete functional independence). The study nurses made the assessment in papers I and II, and in papers III and IV the assessment was made by the study nurses together with the significant other. Internal consistency reliability in the study, measured with Chronbach's alpha coefficient, was 0.91-0.94.

The severity of depression was assessed by the Montgomery-Åsberg Depression Rating Scale (MADRS) [56]. The MADRS consists of ten items of which one is observed and the reminders are assessed as reported by the patient. The items are depressed mood, anxiety, reduced sleep, reduced appetite, inability to feel, difficulties in concentrating and taking initiatives, pessimistic thoughts, thoughts of suicide, and a pessimistic outlook. Each item rates from 0-6 based on a predefined increasing severity scale. Scores on individual items are summed to yield a total score reflecting the severity of

depression. The higher the total score, the more severe is the depression. The assessments were made by specially trained study nurses/physicians. Internal consistency reliability, measured with Chronbach's alpha coefficient, was 0.85 in the present study.

Depression was diagnosed as either a major or minor depressive episode according to the DSM-IV criteria (Diagnostic and Statistical Manual of Mental Disorders) [57].

The spouses' psychological health was evaluated by a self-assessment scale, the Comprehensive Psychopathological Rating Scale–Self-Affective (CPRS-S-A) [58]. This scale consists of 20 items regarding mood, sleep, appetite, worry over trifles, physical discomfort, and zest for life. Possible scores range from 0 to 60, the higher the score the worse the self-assessed psychological health. Based on clinical experience, the cut-off score for risk of depression was set to 10 points (personal communication; B. Mårtensson, 2001). Internal consistency, measured with Chronbach's alpha, was 0.90-0.92 in the present study.

Well-being was measured with the short form of Bradley's Well-being Questionnaire, consisting of 12 questions regarding negative well-being, energy, and positive well-being. The answering options are given on a four-point Likert Scale, ranging from 0, "not at all", to 3, "all the time". The total score ranges from 0 to 36, the higher the score the better the perceived well-being. The internal consistency reliability for the scale in the present study was 0.87, as measured with Cronbach's alpha coefficient. The Well-being Questionnaire has earlier been tested in a Swedish setting by Wredling et al. [59].

The patient's need of assistance [60] was assessed by 15 questions concerning help with dressing, taking medication, shopping, cooking, housecleaning, laundry, and social contacts. The questions were to be answered by yes or no, range 0-15. The more "yes" scores, the larger the need of assistance. The significant other made this assessment. Internal consistency reliability measured with Chronbach's alpha coefficient was 0.93-0.95 in the present study.

The significant other also assessed change in the patient's personality by 10 questions. These questions evaluated changes in patience, mood, and temper. The answer alternatives were "yes" or "no". The more "yes" answers, the more the patient had

changed in personality, range 0-10. This scale has been developed for the randomised controlled trial of depressed stroke patients (VM). Internal consistency reliability measured with Chronbach's alpha coefficient, was 0.80 in the present study.

Perceived social support was measured with an abbreviated Swedish version of the Interview Schedule for Social Interaction [61]. Six items measure availability of social integration (AVSI), indicating how many people who are available for social support, and seven items measure availability of attachment (AVAT), indicating occurrence of emotional contacts. The AVSI total scores range from 6 to 36, and the AVAT total scores range from 1 to 7 (the higher the score, the better for both scales). In the present study, both AVSI and AVAT showed a high internal consistency, measured with Cronbach's alpha coefficient, and were 0.90 and 0.78, respectively.

The level of knowledge of stroke among spouses was measured with a questionnaire consisting of 13 questions developed for this study. The questionnaire has been tested regarding face validity, among stroke-unit specialist nurses, physicians and paramedics, and was revised in relation to received comments. The scores range between 0 and 30, the higher the score the more knowledge about stroke.

Sense of coherence (SOC) was measured with the short version of Antonovsky's questionnaire (13 questions) [62]. The concept of SOC includes three components: the perception of comprehensibility, manageability and meaningfulness. SOC is suggested to serve as an overall ability to cope with stressors. Possible scores range from 13 to 91. A higher score indicates a stronger sense of coherence. The questionnaire has been tested in Sweden by Langius et al. [63]. In the present study internal consistency, measured with Cronbach's alpha coefficient, was 0.71-0.85.

A proxy assessment of the patient's mood ("State of depression") was evaluated by a 10 cm horizontal non-graded visual analogue scale (VAS) with "happy" as one end point and "sad" as the other end point. The patient's level of aggression ("State of aggression") was measured by the same method, with "calm" as one end point and "angry/irritated" as the other. Possible scores range from 0-100; the higher the score, the more sad/the higher level of aggression/hostile feelings. This VAS scale has been developed for a post-stroke depression project by one of the authors (VM). The patient's significant other made these assessments.

The life situation of significant others was measured by a questionnaire, “Life situation among spouses after the stroke event”, that has been developed from an instrument originally designed to evaluate the life situation among relatives of schizophrenic patients, Care Burden Scales for Relatives [60]. The questionnaire consists of 10 questions concerning social life, coping, routines at home, and feelings of depression. The answer options are “yes” or “no”. The more “yes” answers, the more the life situation of significant others is affected, range 0-10. In Papers I and II, internal consistency reliability measured with Chronbach's alpha coefficient was 0.81. The instrument was further refined and validated, and this version was used in Paper IV. The number of items in this later version is 13, and Chronbach's alpha coefficient is now 0.80 [64].

**Table 1. Instruments used in Papers I-IV.**

<b>Instruments</b>	<b>Paper I</b>	<b>Paper II</b>	<b>Paper III</b>	<b>Paper IV</b>
▪ Barthel Index	X	X	X	X
▪ MADRS	X	X		
▪ DSM-IV	X	X		
▪ CPRS-S-A			X	X
▪ Well-being			X	X
▪ Need of assistance	X	X		
▪ Personality change	X	X		
▪ Social network			X	X
▪ Knowledge about stroke			X	X
▪ Sense of coherence			X	X
▪ State of depression	X	X		
▪ State of aggression	X	X		
▪ Life situation	X	X	X	
▪ Economic situation			X	X

The perceived economic situation was measured with a visual analogue scale, consisting of two non-graded vertical lines (100 mm). The spouse was asked to mark

the perceived economic situation before the patient’s stroke on the left line and on the right line the perceived present economic situation. The scores range from 0 “the worst possible economic situation” to 100 “the best possible economic situation”. This instrument has been developed for this study by the authors, based on the validated double bar VAS technique for measuring Quality of Life [65].

#### 8.4 STATISTICAL ANALYSES

Descriptive statistics are used in all papers to describe the mean values and standard deviation of participants or used instruments. Chronbach’s alpha has been calculated for the instruments used in the studies. The Mann-Whitney U-test, independent sample t-test or the Chi-square test have been used when comparing groups of participants. Spearman’s rank order correlation has been used when associations between variables have been examined. The regression analyses have been performed with the stepwise forward multiple linear regression analysis. This method was chosen, as the dependent variable is a continuous variable. The regression model is based on the Pearson correlation, why the order of inserting the independent variables was calculated with this method, and also to avoid entering variables highly correlated to each other. Paired t-test was used in examining the change over time for the instruments used. Analysis of variance, ANOVA, was used to test for significant differences between means. The use of different statistical methods is shown in Table 2.

**Table 2. Statistical analysis used in Papers I-IV.**

<b>Method</b>	<b>Paper I</b>	<b>Paper II</b>	<b>Paper III</b>	<b>Paper IV</b>
Descriptive	X	X	X	X
Chronbach’s alpha coefficient	X	X	X	X
Mann-Whitney U-test	X		X	
Chi-Square	X		X	
Spearman’s rank order correlation	X			
Forward stepwise multiple regression analysis		X		X
Pearson correlation		X		X
ANOVA			X	
Independent sample t-test				X
Paired Student’s t-test				X

All statistical analyses were carried out using the statistical package SPSS for Windows version 12.0-14.

## **8.5 ETHICAL CONSIDERATIONS**

The Local and Regional Ethics Committees, as appropriate, of the Karolinska Hospital approved the studies. The participants were informed verbally and in writing, and in the pharmacological randomised controlled trial gave their written informed consent, or in the case that the patient was incapable to do so, the next of kin was allowed to give informed written assent. In Papers I and II, the significant other was assigned by the stroke-affected patient. In Papers III and IV, the spouses of stroke patients treated at the Stroke Unit at Danderyd Hospital were invited to participate in the study.

At the intervention meetings, the patient's issues were discussed in general terms, and it was emphasised that everything that was said should remain confidential within the group. In order to allow the participants to speak freely about problems in relation to the patient, we chose to direct the intervention only to the spouses and not to both the spouse and patient.



## **9 SUMMARY OF FINDINGS**

### **9.1 IMPACT ON LIFE SITUATION (PAPER I-II)**

The life situation of spouses of depressed stroke patients was significantly correlated with the patient's need of assistance ( $p<0.01$ ), personality change ( $p<0.05$ ), state of aggression ( $p<0.05$ ), state of depression ( $p<0.05$ ), and gender ( $p<0.05$ ) (Paper I). When examining predictors of the life situation of the significant others (Paper II), the patients' need of assistance turned out to be significant for both depressed ( $p<0.001$ ) and aphasic ( $p<0.001$ ) stroke patients. Perceived personality change was a statistically significant predictor of the life situation among significant others of aphasic stroke patients ( $p<0.001$ ). This factor was not significant among significant others of depressed stroke patients ( $p=0.079$ ), but was kept as it improved the regression model. Depressed patients who were more dependent on ADL had significant others that tended to be more affected in their life situation, although this was not statistically significant ( $p=0.114$ ). Among significant others of aphasic stroke patients who were living together with the patient, this had a negative impact on the life situation ( $p=0.004$ ), and with increased time after stroke the life situation became less affected ( $p=0.063$ ). For significant others of both depressed and aphasic stroke patients, the life situation was more affected if the patient was a man, although this finding was not significant in the regression model ( $p=0.066$  and  $p=0.677$ ). The regression model explained 48% of the variance in the life situation in spouses of depressed stroke patients and 63% of the variance in spouses of aphasic stroke patients.

### **9.2 IMPACT ON PSYCHOLOGICAL HEALTH (PAPERS III-IV)**

In Paper III, there was no significant difference in psychological health between those participating in the support- and education programme and those in the control group. The spouse's general well-being was shown to be a significant, positive predictor of psychological health at baseline, six and 12 months ( $p<0.001$ ). At the baseline assessment, age was a positive predictor of psychological health in the spouse ( $p=0.023$ ) (the older the spouse, the better the psychological health). A negative predictor was the spouse's own illness ( $p<0.001$ ) (if the spouse was ill, the psychological health deteriorated). Knowledge was a non-significant predictor that improved the model ( $p=0.432$ ) (the less knowledge, the worse the psychological health). The patient's needs of assistance from the district nurse ( $p=0.029$ ) and GP ( $p=0.890$ ) were positive predictors of the spouses' psychological health that improved

the regression model, although only need of assistance from a district nurse was significant. This model explained 48% of the variance in the perceived psychological health at baseline.

After six months the psychological health was negatively predicted by the spouse's own need of assistance from the GP ( $p=0.003$ ) and district nurse ( $p=0.046$ ) (the more need of assistance, the worse the psychological health), and the patient's need of assistance from the GP ( $p=0.023$ ) (the more need of assistance, the worse the psychological health in the spouse). The patient's need of assistance from the district nurse and the patient's Barthel Index score were non-significant negative predictors that improved the model. This model explained 53% of the variance in the perceived psychological health. Also, after six months, the psychological health was significantly more affected in female spouses ( $p=0.049$ ).

At the 12 months' assessment, the spouse's own illness was a negative predictor of psychological health (if the spouse suffered from any illness, the psychological health was worse). Non-significant positive predictors that improved the model were AVAT, new stroke in patient, spouse's need of assistance from the district nurse, knowledge about the stroke disease, and age. Negative, non-significant, predictors were AVSI, handicap of spouse, and the number of days the patient was hospitalised during the year. This model explained 47% of the variance in the perceived psychological health (Paper IV).

### **9.3 OTHER FINDINGS**

In Paper I, depression in the patient was significantly correlated to the Barthel Index score ( $p=0.007$ ), where those who had less impaired functional ability were more likely to suffer from major depression.

In Paper III, the level of knowledge about stroke increased in both the intervention and in the control groups over time, but after 12 months knowledge was significantly higher in the intervention group. When evaluating the impact of attendance at the sessions, we found a significant relationship between the attendance rate and Barthel Index score at six months (spouses of patients with higher Barthel Index score participated more often in the sessions) ( $p<0.05$ ), and between attendance rate and the patient's need for assistance from the district nurse (spouses of patients with more frequent visits to the district nurse participated more often in the sessions) ( $p<0.05$ ).

An evaluation was performed regarding the experiences of the participants in the intervention group which revealed expressions of great satisfaction. On a scale ranging from 1 (very bad/very dissatisfied) to 7 (very good/very satisfied), the mean scores ranged from 6.26 to 6.73 based on 11 questions regarding the content and design of the intervention. Additional comments received from the participants ranged from “very informative lectures”, “good to have the opportunity to listen to the experiences of others and also to discuss your own”, to “less lectures and more group discussions” and “long lectures, not always relevant for me”. Some participants wanted more male and also younger participants. Most participants appreciated the discussions within the group, although wishes for talking alone with a nurse were also presented.

#### 9.4 THESIS

The life situation of the significant other of depressed stroke patients was significant correlated to the patient’s need of assistance ( $p<0.01$ ), personality change ( $p<0.05$ ), state of depression ( $p<0.05$ ), state of aggression ( $p<0.05$ ), and gender ( $p<0.05$ ) (Table 3).

**Table 3. Correlation between life situation of significant others and characteristics of depressed stroke patients.**

Major/minor depression	-0.054
Sex	-0.292*
State of depression	0.325*
State of aggression	0.336*
Personality change	0.450*
Need of assistance	0.557**
Barthel Index	-0.156

\*  $p < 0.05$ , \*\*  $p < 0.01$

The corresponding findings for the significant other of aphasic stroke patients were: for the patient’s need of assistance ( $p<0.01$ ), personality change ( $p<0.01$ ), state of depression ( $p<0.01$ ), and state of aggression ( $p<0.05$ ). In this group there was also a significant correlation between life situation, Barthel Index ( $p<0.01$ ) and age ( $p<0.01$ ) (Table 4).

**Table 4. Correlation between life situation of significant others and characteristics of aphasic stroke patients.**

Sex	-0.233
State of depression	0.418**
State of aggression	0.313*
Personality change	0.496**
Need of assistance	0.589**
Barthel Index	-0.446**

\*  $p < 0.05$ , \*\*  $p < 0.01$

The psychological health in the spouses of stroke patients was significantly correlated to the economic situation ( $p < 0.01$ ), sense of coherence ( $p < 0.01$ ), and health state of the patient ( $p < 0.01$  at baseline and six months and  $p < 0.05$  at 12 months) at the same measure points. The availability of social integration (AVSI) was significantly correlated to the psychological health in the spouse at six ( $p < 0.05$ ) and 12 months ( $p < 0.05$ ) (the less the availability of social contacts, the worse the psychological health). At 12 months a significant correlation was found between psychological health in the spouse and availability of attachment (AVAT) ( $p < 0.05$ ); the fewer the occurrences of emotional contacts, the worse the psychological health (Table 5).

**Table 5. Spearman's rank correlation coefficients between the psychological health in spouses and variables included in the ANOVA analysis.**

	Economic situation	SOC	Knowledge test	Barthel Index	AVAT	AVSI	Health state of patient
CPRS-S-A							
Baseline	-0.388**	-0.436**	0.083	-0.032	-0.067	-0.128	-0.488**
Six months	-0.404**	-0.517**	-0.022	-0.002	-0.068	-0.224*	-0.521**
Twelve months	-0.357**	-0.559**	-0.141	-0.080	-0.244*	-0.249*	-0.474*

\*  $p < 0.05$ , \*\*  $p < 0.01$

CPRS-S-A, comprehensive psychopathological rating scale self-affective; AVAT, availability of attachment; AVSI, availability of social integration.

In a comparison of univariate data of depressed and aphasic stroke patients we found significant differences between the MADRS-score, state of depression, state of aggression, and personality change (Table 6).

**Table 6. Comparison of univariate data of depressed and aphasic patients.**

Variable	Depressed group mean ( $\pm$ SD) (n=71)	Aphasic group mean ( $\pm$ SD) (n=77)	<i>p</i> -value
MADRS-score <sup>a</sup>	18.51 (5.68)	4.36 (5.40)	<b>&lt;0.001</b>
ADL <sup>a</sup>	91.76 (17.91)	86.49 (24.40)	0.154
State of depression <sup>b</sup>	64.48 (19.08)	35.08 (23.98)	<b>&lt;0.001</b>
State of aggression <sup>b</sup>	43.19 (28.39)	30.14 (24.80)	<b>0.036</b>
Personality change <sup>b</sup>	3.31 (2.34)	1.49 (1.90)	<b>&lt;0.001</b>
Need of assistance <sup>b</sup>	4.80 (4.81)	7.02 (5.79)	0.068
Life situation of spouse <sup>c</sup>	3.44 (2.67)	3.06 (2.84)	0.302

<sup>a</sup> assessment of patient made by health staff; <sup>b</sup> assessment of patient made by significant other; <sup>c</sup> self-assessment made by significant other.

## 10 DISCUSSION

When a person is struck by a stroke, the whole family is affected. This means that not only the patient but also the significant others are highly likely to need attention and support. With the long-term survival after stroke increasing and with an ageing population, the burden of stroke for the society and for the significant others is likely to increase; this will most certainly also affect the situation of the significant others [66]. The overall aim of this thesis was to increase knowledge about factors of importance for the psychological health and life situation of spouses of stroke patients, and to evaluate the effect of a support- and education programme for the spouses.

### *Life situation*

Major findings revealed that depressed stroke patients were perceived as more aggressive and more changed in personality than were the aphasic patients by their respective significant other. The need of assistance was the only common predictor of the life situation of the significant other for both patient groups. Regarding the aphasic stroke patients, personality change and living together were factors that made the life situation of the significant other more affected. In the aphasic group, two patients had developed a major depression at the time of assessment.

Even though there are differences in patient characteristics of depressed and aphasic patients, the life situation of significant others of these groups of stroke patients were almost similarly affected. This may be explained by the patients' need of assistance, the main predictor of the life situation for both groups. Our studies confirm findings from earlier studies that both depressed and aphasic patients experience impairment in social activities [25, 67]. Although in different ways, both conditions yield an increase in the need of assistance, the very factor which affected the life situation of the significant other.

Perceived personality change was significantly higher in depressed stroke patients. Amongst the aphasics the perceived personality change turned out to be a significant predictor in the regression analysis. This may stress the importance of further analyses of the depression profile in stroke patients. It is also possible that both groups do have some change in personality, but that this is perceived as having a larger impact on the

life situation of the significant other amongst aphasic patients due to the higher degree of communication difficulties.

If the aphasic stroke patient was living together with someone, the effect on the life situation of the significant other was more affected. This is concordant with findings of others where spousal caregivers reported more burden than caregivers not living with the chronically ill or stroke-affected person [68, 69]. This may indicate that although depression is hard to share in cohabitation, communication difficulties are even harder on the significant other. In the aphasic group, the proportion of patients living alone was larger than in the depressed group. This may be an effect of chance, but also of the aphasic patients generally being older. Further, the sample size of depressed stroke patients living alone may have been too small to turn out to be a predictor in this analysis.

Regression analyses for both groups showed that significant others of female stroke patients tend to be less affected in their life situation, even though this is not statistically significant. Previous studies have also shown that female caregivers are more burdened after their partner's stroke [70, 71]. Men have a tendency to instrumental approaches in solving problems and coping with stress, while female caregiver seem to be more apt to use emotional and avoidant coping styles [72]. However, this can also be explained by the finding that men are more likely to receive help from others with housekeeping [73], and also to be supported by the district nurse; 83% of the male but only 19% of the female caregivers received support from this source [73].

We found that major post-stroke depression is more common among patients with fewer functional deficits. This is not in line with findings in other studies, where increased severity of stroke increased the risk of post-stroke depression [74]. We distinguished between major and minor depression according to the DSM-IV diagnostic criteria. As far as we know, others studies have not looked into how the differences of these two diagnoses differ in relation to ADL. This highlights the importance of assessing all patients for depression also among seemingly recovered patients in order to treat and support those who may be in need thereof.

### *Psychological health*

This is, to our knowledge, the first study which aims to identify changes of predictors over time for the psychological health of spouses of stroke patients during the first year after stroke. We found that self-assessed general well-being is the most prominent predictor of psychological health among spouses.

The psychological well-being has previously been shown to be significantly lower in spouses of stroke patients compared with norm values [75], and that the spouses were apprehensive about increased responsibility, new demanding tasks and fewer opportunities to take part in activities of great value for them [76]. It has been suggested that an important factor for the sense of well-being is the caregiver's ability to look at the situation in a positive manner. An optimistic view will contribute to a higher sense of well-being [77]. Also, caregivers who appraised the caregiving situation as more stressful and threatening were significantly more depressed than those who appraised the situation as more beneficial and less stressful [78].

The spouse's own illness emerged as a significant predictor at baseline and after 12 months. Poorer physical health in caregivers has previously been shown to be associated with greater psychological distress [79]. The physical health has also been shown to deteriorate after taking on the caregiving role, which was reported by 24% of the caregivers in a study by Silliman et al. [80]. This may be an important reminder that the spouses in general are not young and may be faced with a physically as well as psychologically new and seriously burdening demand. This is of outmost importance for the organisation of home-help services which, if provided in an individualised way, may possibly alleviate some of the pressure. This, as mentioned below, has to be further tested but seems plausible. The reasoning is strengthened by the finding that caregivers in poorer health have been found to be under greater strain even when other patient and caregiver characteristics were taken into account [81]. For a caregiver with his/her own health problems the caregiving may affect the caregiving situation as well as the ability to provide care. This is also reflected in the results from our six-month assessment, where increasing frequency of visits to the GP and district nurses for the spouse may indicate a worse physical or psychological health.

Psychiatric morbidity and strain in the spouses were not directly proportional to the degree of disability in the patient in a study by Draper and Brocklehurst [82]. It seems



that it is the spouse's perceptions of the partner's abilities that is the most important factor influencing the well-being of the spouse as well as in our studies as found by Wyller et al. [83].

The impact of the patient's need of assistance from the GP and district nurse changed over time. After six months, a higher frequency of visits to the GP was associated with worse psychological health in the spouse. Directly after the patient's stroke, visits can be supportive, but as time goes on, and if the patient's need of assistance does not diminish, this can reflect a situation where the patient is not improving and the spouse begins to realise that the situation might not get any better.

Age was a significant positive predictor of psychological health at baseline, i.e., the older the spouse, the better the psychological health, and was also kept in the model at 12 months, as it improved the model. The incidence of depression with increasing age has been found to be slightly lower for the elderly population than for younger age groups, but it follows the same female/male ratio [84]. Factors associated with depression are lower income, smaller social network and deterioration of physical health [85, 86]. These factors may also be related to older age such as having a low pension, decreasing number of people in one's network due to deaths, and poorer physical health, all factors which are likely to increase with age. Depression could therefore be expected to increase with age, and not decrease, as we found. One explanation might be that older people have smaller demands on their life as they grow older, and that they find it more natural to accept having a caregiving role. However, it is also possible that older people underestimate their depressive symptoms as found by Dorz et al. [87].

The gender differences in psychological health at six months is in agreement with other findings, where female spouses have been found to be more negatively affected in their caregiving role than male spouses, resulting in poorer psychological well-being for the women [70, 77]. Female spouses are more likely to assist with emotional support as well as household tasks [88], and they also report more interference with family and leisure time [89]. This may influence how the female spouses perceive their situation.

### *The intervention programme*

This study presents results from a support- and education programme for spouses of stroke patients. Despite a hitherto unusually long period for the programme, we did not find any significant difference between the intervention and control groups regarding the main variable psychological health. Both groups increased their knowledge about stroke over time, the intervention group more than the control group, and at 12 months the intervention group had significantly more knowledge about stroke than the control group. One might believe that an increase in knowledge might have a positive effect on the self-confidence of the spouse and thereby contribute to a better life situation.

However, this did not positively influence the perception of the psychological health in the spouses. It is to be noted that the control group also learned more about stroke, which may be explained by repeated contacts with health professionals as well as filling out the same form three times, which could influence the learning process. This general increase in knowledge when taking part in a study is also similar to findings in other studies [46, 47].

When examining the entire group of spouses regarding relationships between psychological health and the variables included in the ANOVA analysis, we found a strong correlation between worse psychological health and low SOC at baseline and after six and 12 months. This association confirms findings in previous studies where a weak SOC was associated with life stress, anxiety, and depression [90, 91]. Assessment of the SOC could therefore be a possible and simple way to identify spouses at risk of psychological distress, and these spouses could then be candidates for extra support.

A deteriorated psychological health of the spouse was also correlated with perceived worse health of the patient at all three measure points. Singh et al. [92] found that the higher the amount of caregiver burden, the greater the lifestyle impact and emotional distress for the caregiver. The impact of a stroke on the caregiver is also influenced by characteristics of the caregiver such as gender, age and physical functioning [93]. This suggests that when planning caregiver support, not only objective measures of the stroke-affected person's physical and psychological limitations should be taken into account, but also the caregiver characteristics.

In our study the Barthel Index was not significantly correlated to the psychological health of the significant other, in contrast to the perceived health state of the patient.

This may be explained by the ceiling effect of the Barthel Index as it only measures basic activities of daily living, and that this assessment was made by both the significant other and the study nurse, while the health state was an assessment of the patient as perceived by the significant other.

Deteriorated psychological health was significantly associated with less social contacts after six and 12 months. After 12 months this correlation was also seen between the psychological health and emotional contacts. Similar correlations have also been found by Grant et al. [44]. A possible explanation can be that taking care of a stroke-affected person consumes both time and energy that otherwise would have been spent on nourishing social contacts.

At all three assessments in our study, worse psychological health correlated with the economic situation. Costs for medications and visits to the hospital and doctors can put pressure on the economic situation, as well as loss of income of the patient and/or caregiver. This finding is congruent with other studies that also have found correlations between both physical and psychological health and lower income [34, 35, 94, 95].

That a higher attendance rate was related to more visits to the district nurse may be explained by the need for more knowledge when the patients needs more assistance, but may also be influenced by a higher awareness of available resources discussed in the group meetings. This is supported by findings of Lincoln et al. [47], who found that caregivers participating in an intervention group, with initial contacts in the hospital and after discharge home visits, had more knowledge about whom to contact for information and about available community services.

Our support and education programme lasted for six months, in an attempt to follow the spouses through the period when the psychological aspects of caregiving and cognitive impairments in the patient would be present. Despite this new approach we could not find that this double intervention, education and support, had any significant effect on the psychological health of the spouse. Possible explanations can be that even longer periods of support are necessary or that the instruments we have used are not sensitive enough to detect differences. We also had a large group of spouses that did not accept the invitation to participate. These spouses may have been those who were in most need of support. Delivering the intervention in the home could be a possible way to reach

these spouses, but the importance of meeting other spouses in the same situation would then not be possible. Also, the opportunity for the spouses to discuss their situation, without the patient overhearing, would be lost.

Information for spouses of stroke patients needs to cover all topics relevant to caring for a person affected by stroke. It should also be an ongoing process, tailor-made to cover all aspects of the need of the caregiver and the patient [96]. This study is a step towards a better understanding of the needs of spouses of stroke patients, but still more knowledge is necessary about how these needs can be met.

## **10.1 METHODOLOGICAL CONSIDERATIONS**

To achieve quality in research, some issues have to be considered. Internal validity refers to the extent to which it is possible to make an inference that the independent variable is truly influencing the dependent variable and that the relationship is not spurious. External validity is when the results can be generalised to situations outside the research setting [97]. In Papers I and II, the participants were pointed out by the stroke-affected patient. Significant others of patients that by any reason did not want their significant other to participate could not take part in the study. In Papers III and IV, spouses of stroke patients were consecutively asked about participation in the study. In Paper III the participants were randomised to either intervention or control groups after the baseline assessment, with help of sealed envelopes, where the result could not be known in advance. In this population (Papers III and IV), we had a large group of primary dropouts (153 out of 253), who were older and more ill themselves, something that limits the generalisability of the findings to the spouses in better physical condition. This naturally influences the external validity for the spouses' group as a whole; but more importantly it indicates that other means are necessary in order to get any opportunity to help the less healthy and/or older spouses. Hence, this finding gives nourishment to the idea that another study must also be undertaken with different approaches for spouses in different life situations.

Reliability is a statistical measure of the stability of an instrument, of its consistency, and of how reproducible the instrument's data are. Instruments used in this study were tested with Cronbach's alpha coefficient to ensure the level of internal consistency. An achieved coefficient above 0.70 is generally considered as acceptable [98]. Instruments

included in this thesis had alpha values between 0.71 and 0.95. It is therefore unlikely that the instruments used should have missed to identifying findings of importance.

VAS scales are frequently used as well as a research and as a clinical tool in different fields of the medical practice and in psychological medicine. The simplicity of the technique and the adaptability to a wide range of research settings has made it an attractive measurement option. A VAS scale is easy and quick to construct [99], easily understood by subjects [100], as long as they have no more important cognitive deficits since the filling in of a VAS demands some certain proportion of abstract thinking. However, the VAS techniques are otherwise suitable for frequent and repeated use [101]. Although Aitken [102] recommended that the VAS scale was more suited to within-subject studies, others have shown that they have been used in both contexts and can effectively discriminate between groups in the predicted direction [103].

Proxy assessments in general report fairly good agreements between subjects and proxies in assessments of functioning, physical health, and cognitive status, although proxies tend to report more impairment in functioning and emotional well-being. Concerning psychological well-being, proxies tend to be less positive than the subjects. Spouses, children and other relatives tend to be capable proxies, although proxy reports may be influenced by caregiver burden [104]. In the studies in this thesis, our interest was directed towards the spouse/significant other. The objective state of the patient was not of main importance to us. By the use of proxy assessments, we got a picture of how the patient was perceived by his/her spouse. It is this perception that is important for the life situation and psychological health in the spouse.

## 11 CONCLUSIONS

Significant others of depressed male stroke patients have a more affected life situation, while female patients were perceived as more changed in their personality.

Major post-stroke depression is more common among patients with limited functional deficits. This highlights the importance of assessment for depression among also seemingly recovered stroke patients in order to treat and support those in need. The perception of the patient's need of assistance is important to predict the life situation among spouses of depressed as well as aphasic stroke patients. More, and specific, factors influence the life situation of the significant others of aphasic stroke patients than of the depressed patients. This finding indicates a more difficult situation for significant others of aphasic patients than those of the depressed.

The most prominent predictors of psychological health over time in spouses of stroke patients were general well-being and presence of illness in the spouse. These areas are the most important to consider, when planning appropriate support for the spouses of stroke patients. Enhancing psychological health and preventing medical problems in the caregiver are essential considerations to enable patients with stroke-related disabilities to continue to live at home.

In this study a hospital-based intervention was used. This requires that the spouse is healthy enough to come to the hospital in order to be able to attend the programme and also demands that the patient can be left alone, or in care of someone else. The programme did indeed increase knowledge about stroke, but it did not improve the psychological health in the spouses even though the intervention programme in this study was extended. To enhance the psychological health, a combination of group meetings and individual counselling might be a solution. Giving support at times when it is asked for and about topics that are appropriate at that time, might be the best way to satisfy the needs for support. The possibility of having time of one's own might help alleviate the strain. A small amount of help from the society may possibly pay off more than the investment, if the spouse can gain strength by having some time of his/her own. This could be further tested with a health-economist. Tools for identifying and monitoring the identified predictors are warranted as a part of standard care to identify problems at an early stage. These would give the necessary focus for clinical nursing interventions on different needs in the significant other.

## **12 LIMITATIONS AND STRENGTHS OF THE STUDY**

A limitation in Papers I and II is that we have no control group with non-depressed and non-aphasic stroke patients. In these papers the stroke patient assigned the significant other. We do not know if the significant other of patients that did not want their significant other to participate perceived their situation differently.

A limitation in Papers III and IV is that we have no control group with non-caregivers, and therefore we cannot draw the conclusion that our findings are unique for spouses of stroke patients. The number of deaths among patients can explain the internal dropout. Due to the high number of external dropouts, results from this study cannot be generalised to the total population of spouses of stroke patients.

### **13 CLINICAL IMPLICATIONS**

Family involvement in the stroke patients' daily activities is almost inevitable as most patients return home after their stroke. This makes the spouses important persons in the rehabilitation process and in the life of the stroke patients. In order to make it possible for the patient to live at home, without risking the physical or psychological health of the spouse, it is of great importance to assess the spouses' perceived physical and psychological health. Appropriate support to the spouse should thus be provided.



## 14 SVENSK SAMMANFATTNING (SUMMARY IN SWEDISH)

Omkring 30 000 personer drabbas av stroke varje år i Sverige. Stroke kan resultera i olika grader av fysiska handikapp, från känselbortfall i arm och/eller ben i ena kroppshalvan, lättare nedsatt kraft eller till halvsidig förlamning. Talsvårigheter är inte heller ovanliga och drabbar ungefär en tredjedel av strokepatienterna och lika många riskerar att drabbas av depression i efterförloppet. Andra kognitiva följder än påverkan på talförmågan kan vara svårigheter med inläring, minne, logiskt tänkande, problemlösning, uppmärksamhet; personlighetsförändring förekommer också. Även neglekt, ouppmärksamhet åt den ena halvan av rummet eller på den ena kroppshalvan förekommer. Alla dessa faktorer påverkar inte bara patienten utan också de närstående.

Syftet med avhandlingen var att identifiera faktorer som påverkar de närståendes livssituation och att undersöka om ett undervisnings- och stödprogram för närstående till strokepatienter kunde förbättra de närståendes psykologiska hälsa. Deltagare var närstående till 71 deprimerade strokepatienter respektive 77 strokepatienter med talsvårigheter i de två första delarbetena. I delstudie III och IV deltog 100 närstående, varav hälften randomiserades till ett undervisningsprogram där deltagarna träffades sex gånger under ett halvår och med ett uppföljande besök efter ett år. Resterande 50 randomiserade utgjorde den jämförande kontrollgruppen.

Vi fann att närstående till manliga patienter (vilka till största delen utgjordes av kvinnor), rapporterade en mer negativ inverkan på sin livssituation än vad närstående till kvinnor (mestadels män) gjorde. Graden av hjälpbehov som de närstående upplevde att patienten hade var en gemensam prediktor av livssituationen för de närstående. Hos närstående till patienter med talsvårigheter fann vi också att upplevd personlighetsförändring hos patienten och att bo tillsammans med denne bidrog till en sämre livssituation för de närstående.

Sett över en tidsperiod på 12 månader fann vi att allmänt välbefinnande och en god hälsa hos den närstående predicerade en bättre psykologiska hälsa. Vad gäller de som deltog i undervisnings- och stödprogrammet framkom att de hade signifikant mer kunskap om stroke efter 12 månader än vad kontrollgruppen hade. Däremot kunde vi inte visa att deltagande i interventionen hade någon effekt på den psykologiska hälsan hos de närstående.

Att göra en bedömning av den närståendes uppfattning av patienten, samtidigt med en bedömning av patientens funktionella och emotionella status, är nödvändig för att kunna hitta de närstående som löper risk att få en försämrad psykisk hälsa och en mer negativt påverkad livssituation. Dessa närstående kan då snabbt fångas upp och erbjudas stöd för att orka med att ta hand om den strokedrabbade i hemmet. En kombination av grupper, där deltagarna kan diskutera sin situation tillsammans med andra med liknande upplevelser och ett individuellt stöd inriktat på den närståendes specifika situation, kan vara ett sätt att förebygga ohälsa hos närstående och möjliggöra att fortsatt boende i hemmet för den strokedrabbade

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