

From the Department of Nursing
Karolinska Institutet, Stockholm, Sweden

Life situation after stroke

-The spouses' perspective

Jenny Larson



Stockholm 2005

All previously published papers were reproduced with permission from the publishers.

Cover front: Hike between Bad Gastein and Sport Gastein, Austria.

Cover back: Sport Gastein, Austria.

Photos by Jenny Larson 2005, layout Patrik Eklund.

© Jenny Larson, 2005.

Published and printed by Universitetsservice US-AB, Stockholm, Sweden 2005.

ISBN 91-7140-457-0.

“Stardust, Lady Stardust,
spread your hair across your universe of magic, let us in.
Let’s fly into the milky-way,
climb these concrete walls and say don’t ever close us in.
Like every city needs a distance,
every sky demands a moon,
every winter needs a snowfall,
every summer wants a June.
Money is just a piece of paper,
gold is blinding – don’t you see.
Fame is just our own illusion, of what life is meant to be.
But I don’t need a perfect mirror,
I don’t care for queens and kings.
We are free and we are perfect, when Lady Stardust sings...”

Lyrics from the song Lady Stardust by Lisa Miskovsky

CONTENTS

ABSTRACT	4
LIST OF ORIGINAL PAPERS	5
LIST OF ABBREVIATIONS AND DEFINITIONS	6
INTRODUCTION.....	7
BACKGROUND.....	8
Incidence	8
Riks-Stroke	8
The stroke patient	9
Informal caregivers.....	10
Transition from hospital to home.....	10
Preparation and information.....	10
Discharge	12
Resources in the community	12
Consequences of caregiving.....	13
Family in a social context.....	14
Models of family caregiving	14
Gender aspects of informal caregiving	14
Changing roles	15
Quality of Life	15
Life situation	15
Coping as informal caregivers.....	16
Existing instruments for assessing the caregivers' situation	17
Supportive nursing interventions	18
Identifying caregivers in need of support	19
AIMS.....	20
METHODS AND MATERIALS.....	21
Design	21
Sample and data collection.....	21
Instruments and questionnaires	21
Quality of Life and Economic Situation	22
Life Situation Among Spouses After the Stroke Event.....	22
Well-being questionnaire short form	22
Health state from the Euro-QoL 5D.....	23
Sense of Coherence	23
The Interview Schedule for Social Interaction	23
The Comprehensive Psychopathological Rating Scale - Self Affective.....	23
Barthel Index	24
Nursing support and education programme for spouses of stroke patients	24
ANALYSES	25
Analyses Paper I	26
Analyses Paper II.....	26
Analyses Paper III	27
Analyses Paper IV	27

ETHICAL CONSIDERATIONS	29
RESULTS.....	30
Paper I	30
Paper II	31
Paper III	32
Paper IV	33
Reliability results	33
Validity results.....	33
DISCUSSION	35
Methodological considerations	35
Internal validity.....	35
External validity.....	36
Construct validity.....	36
Reliability	37
Statistical conclusion validity.....	37
Limitations	37
General discussion of the findings	38
Nursing support intervention.....	38
Gender aspects of informal caregiving	39
Predicting quality of life	40
Identifying spouses with problems in their life situation	42
Interventions aimed at support and education	43
CONCLUSIONS.....	44
FUTURE RESEARCH.....	45
CLINICAL IMPLICATIONS	46
POPULÄRVETENSKAPLIG SAMMANFATTNING.....	47
ACKNOWLEDGEMENTS	50
REFERENCES.....	53
APPENDIX	59

ABSTRACT

In Sweden approximately 30,000 people suffer from stroke every year, of which some 20,000 for the first time. The disease is one of the most disabling chronic diseases in the adult population, with severe consequences for both patients and their families. Living with a person, affected by a chronic illness, is often characterized by a reduced sense of individual freedom and increased sense of responsibility.

The aim of this thesis was to determine the impact of a nurse led support and education programme for improving the spouses' perceived general QoL, life situation, general well-being, and health state (Paper I). It was also to explore gender differences among spouses in perceived psychological well-being, and general life situation, during the first year after the patients' stroke event (Paper II). Another aim was to identify the factors that predict the general quality of life among spouses of stroke patients, and to determine if these predicting factors change during the first year after the patient's stroke event (Paper III). It was also to test the psychometric properties of a questionnaire measuring the life situation among spouses of stroke survivors (Paper IV). The participants were randomly assigned to an intervention group or a control group, 50 in each group (Paper I). In Paper II, the groups consisted of 80 female and 20 male spouses respectively, and in Papers III and IV, the whole sample of 100 spouses was used.

There were no significant differences between intervention and control groups over time (Paper I). The intervention group, attending 5-6 times had decreased their negative well-being significantly after six and 12 months. Their PQoL increased significantly after 12 months. In the group attending 1-4 times, positive well-being decreased significantly the first six months.

There were differences in general well-being and positive well-being between male and female spouses over time (Paper II). Male spouses had a better-perceived general and positive well-being, and lower negative well-being and AVAT than the female spouses. No other significant differences were found between the genders.

Life situation and Present economic situation were the only predictors of QoL that emerged in all three of the regression analyses (Paper III). The emerging predictors of QoL that changed over time were: General Well-being, Own illness, SOC, AVSI, BI, education, and AVAT. The included predictors explained 49%, 54%, and 56% respectively of the variance in QoL in the model.

The LISS-questionnaire showed high psychometric properties in the reliability and validity analyses (Paper IV).

The findings in this thesis demonstrate that spousal informal caregivers of stroke patients have a complex life situation due to the stroke event, and that this has many negative effects on their perceived QoL and psychosocial well-being. The Life Situation Questionnaire can be used by nurses to identify spouses of stroke survivors who are in need of supportive interventions after the stroke event. The results also indicate a need for a continuing development of nurse led support programmes for spouses of stroke patients which also might include individualised support, an empowerment approach, and implementation of coping strategies, in order to facilitate the spouse's roll as an informal caregiver to the stroke patient.

Keywords: Spouse, stroke, quality of life, support programme, nursing intervention, well-being, life situation, gender, predictors, questionnaire.

LIST OF ORIGINAL PAPERS

This thesis is based on the following Papers, which will be referred to in the text by their Roman numerals:

- I. Larson J, Franzén-Dahlin Å, Billing E, von Arbin M, Murray V, Wredling R.
The impact of a nurse led support and education programme for spouses of stroke patients: a randomised controlled trial.
Journal of Clinical Nursing, 2005; 14, 995-1003.
- II. Larson J, Franzén-Dahlin Å, Billing E, von Arbin M, Murray V, Wredling R.
The impact of gender regarding psychosocial well-being and general life situation among spouses of stroke patients.
Advanced manuscript.
- III. Larson J, Franzén-Dahlin Å, Billing E, von Arbin M, Murray V, Wredling R.
Predictors of Quality of Life among Spouses of Stroke Patients during the first year after the stroke event.
Submitted to Scandinavian Journal of Caring Science, 2005.
- IV. Larson J, Franzén-Dahlin Å, Billing E, Murray V, Wredling R.
Spouse's Life Situation after partner's stroke event: Psychometric testing of a questionnaire.
Journal of Advanced Nursing, 2005; 52, 1-7.

LIST OF ABBREVIATIONS AND DEFINITIONS

AVAT	Availability of attachment
AVSI	Availability of social integration
BI	Barthel Index
CPRS-S-A	The Comprehensive Psychopathological Rating Scale - Self Affective
ISSI	The Interview Schedule for Social Interaction
LISS	Life Situation Among Spouses After the Stroke Event
PQoL	Present Quality of Life
RCT	Randomised Controlled Trial
SOC	Sense of Coherence
QoL	Quality of Life
WBQ-12	Well-being Questionnaire, Short form, 12 questions
WHO	World Health Organization
Caregivers	Informal/family caregivers
Formal caregiver	A professional person employed to be a caregiver
Informal caregiver	A person caring for next of kin
Spouse	A person living together with the stroke patient

INTRODUCTION

The World Health Organization defines stroke as “rapidly developing signs of focal or global disturbance of cerebral function lasting >24 hours (unless interrupted by surgery or death), with no apparent nonvascular cause (1). Stroke is the general term for cerebral infarction, 85%; intracerebral haemorrhage, 10%; and subarachnoidal haemorrhage, 5% (2). The disease is the leading cause of death worldwide, and one of the most disabling chronic diseases in the adult population, with severe consequences for both patients and their families (3).

Today, the informal caregivers are required to provide increasingly complex care in the home, to relatives with health problems who previously would have been treated by formal caregivers in hospitals (4, 5). The need for this informal care will increase because people today are living longer, with an improved health, although many diseases have their onset during this long life, and may affect the person’s functional ability.

The relatives, primarily spouses, often feel obligated to care for the patient at home, providing psychological and/or physical support (6). Living with a person, affected by a chronic illness, is often characterized by a reduced sense of individual freedom and increased sense of responsibility. The informal care often takes a great amount of time and energy, and may cause overwhelming emotions (7). Among patients with the most severe strokes, the existence of a spouse at home is one of the factors related to achievement of a good functional outcome and recovery in this group (8, 9).

BACKGROUND

Stroke is the single physiological condition that requires the most bed days in Swedish hospitals, with almost a million bed days a year at an estimated total cost to society of at least SEK 14 billion a year (2). Stroke patients also utilise a large proportion of healthcare and resources in municipal assisted living facilities, and home healthcare services. Approximately 75% of all the stroke patients are treated at stroke care units in the acute setting (2). One of the features, which is believed to distinguish stroke care units from conventional care, is the emphasis on the provision of education and information, although the evidence to support this view is not rigorous. However, hospital care at the Stroke care units are evidence based and cost effective, and long-term beneficial effects of treatment in stroke units are shown for patients who were independent in ADL functions before the stroke (2, 10). A meta-analysis of randomised studies has shown that stroke unit care improves survival and functional outcome after stroke (11).

Incidence

Annually, approximately 15 million people suffer from stroke worldwide (3). In Sweden approximately 30,000 people suffer from stroke every year, of which some 20,000 for the first time (2). However, due to new technologies, treatments, and rapid medical response at stroke units, the stroke mortality has decreased over the years, but even with these advanced technologies and facilities available, 60% of the patients die or become dependent (3, 12-14). Approximately 80% of the stroke victims are older than 65 years; the mean age for stroke patients in Sweden is 75.7 years (male 73.4 years, and female 78.0 years) (2). There are equal numbers of men (49.9%) and women (50.1%) that are affected by stroke, although female stroke patient are on average four years older when they suffer from stroke (2).

The percentage of senior citizens in the country is increasing, which is expected to result in significant increased numbers of stroke victims in the future. These numbers are already showing as the stroke incidence has increased between 1989 and 2000, with the largest increase among women (2, 15).

Riks-Stroke

In 2000, the Swedish National Board of Health and Welfare issued National Guidelines for Stroke Care, an electronic document that above all adopts the recommendations given in the

Helsingborg Declaration regarding stroke care (16-18). In 1995, a Pan-European meeting took place in Helsingborg, Sweden, to improve stroke management in Europe, and at the meeting the Helsingborg Declaration on Stroke was adopted. The National Guidelines encourage all hospitals treating stroke patients to participate in Riks-Stroke (2). The Riks-Stroke is a tool for continuous quality monitoring of hospitals and an instrument for follow-up of the National Board of Health and Welfare's guidelines for stroke care. The purpose is to support a high and consistent quality of care for stroke patients throughout Sweden. The number of registrations has successively increased and has now an estimated coverage of approximately 80% of all the stroke events in the country. Data collection and feedback are accomplished online, and the database now contains more than 170,000 care episodes. A national, annotated Annual Report is issued along with an Analytical Report (2).

The stroke patient

The stroke patients' problems are diverse and complex, and they change over time from initially mostly being practical, and later becoming psychological. The most common acute symptom of stroke is a one-sided sudden loss of function in the arm, leg and/or face. Other symptoms are a sudden onset of numbness, confusion, difficulty speaking or understanding speech, dizziness, loss of balance or coordination, severe headache, fainting or unconsciousness. The symptoms of stroke depend on which part of the brain is injured, and how severely it is affected, i.e., a stroke may completely paralyse one side of the body, or just affect one part of the body, such as an arm or a leg (3).

One of the most important preventable causes of stroke is high blood pressure, defined as a systolic blood pressure higher or equal to 140 mmHg and/or a diastolic blood pressure above or equal to 90 mmHg. Four of every ten people that die from stroke could have been saved if their high blood pressure had been prevented or medically treated (3). Half of the Swedish patients affected by stroke during 2003 had medical treatment due to high blood pressure (2). Other serious risk factors that they were affected by were diabetes (20%), smoking (15%), heart fibrillation (25%), physical inactivity, obesity, unhealthy diet with a high salt intake, stress, heightened blood lipids, and underlying cardiovascular disease.

Stroke survivors often experience depression, feelings of worthlessness, loss of friends, communication problems, altered personality, disruptive behaviours and dependency on their

caregiver. And the process of adjustment to life after stroke is often experienced by the stroke patient as difficult and slow, with plateaus in recovery and with unexpected setbacks (19, 20).

Informal caregivers

In Sweden, an extensive part of the care provided to elderly persons is by informal caregivers (21). The typical informal caregiver is female, either a spouse or an adult child of the care recipient, and seldom shares the responsibilities of caregiving with other family members (22). An informal caregiver is a person caring for the next of kin. In this care the concept consists of three words: “informal”, indicating that it is outside the frames of the formal healthcare system; “care”, which is *what* a person does for another to help; and “giver”, which refers to *the person* giving this help. However, the concept of informal caregiving also means something more than just a caring person; it implies that it is based on relationships and that it is voluntary (23). Parker expresses that “all the factors which transform an impairment into a disability also tend to transform family members and friends into informal carers” (24).

In this thesis, the informal caregivers are the spouses of the stroke patients, and spouse is defined as a person living in the same household as the stroke patient.

Transition from hospital to home

Patients and their spouses are exposed to major adjustments when the patient is discharged from the hospital or rehabilitation ward and return home. At the hospital the environment is modified for disabled persons, with wide doorways, handles at strategic points, specific aids for disabled persons and, above all, formal caregivers are available 24 hours a day. At home this safety net surrounding the patient at the hospital is not available, and suddenly the patient and spouse shall function in their home setting with all that this implies in terms of living with, for example, an added handicap, insecurity and fear, and this may require major adjustments few are prepared for.

In a study by Grant et al. the first week after the stroke patients’ discharge was characterised as very hectic and overwhelming in managing caregiving problems, household responsibilities, and scheduling appointments to assure therapeutic healthcare services for stroke survivors. Often, caregivers had multiple different healthcare professionals in the home simultaneously (25).

Preparation and information

Stroke care is given in three settings or phases: acute care, rehabilitation, and in the community; each phase presents the informal caregivers with different challenges. Information regarding how

the carers manage each phase might provide nurses with useful insights that could serve as a basis for discharge educational materials, and assistance for informal caregivers to develop strategies to adapt to their new roles.

It is of great importance to provide the informal caregiver with information because of the complexity of the disease, with possible cognitive disorders, emotional problems, and behavioural changes among the stroke patients. The lack of information is repeatedly emphasised as a problem by informal caregivers, when they face the circular difficulty of not knowing what they do not know until they have found it out themselves (26). Several studies show that both stroke patients and their informal caregivers feel that they are inadequately informed about the stroke, its consequences, and the available support. They want more individualised medical information, information regarding home care, and the impact of the stroke on themselves as caregivers (26-31). Informal caregivers are in need of support for a long time after the patients' stroke event. However, the areas of concern change over time, as shown in a study by Hanger et al., where patients and carers continued to have unanswered questions for a long time (27). During the patients' hospitalisation, they received a minimum of information, leaving them with unanswered questions even three years after the stroke event (32-34).

Two weeks after the stroke event the most frequently asked questions were about the causes and nature of stroke, association between stress and stroke, and recovery. At six months, the questions regarded risk of recurrence, causes and nature of stroke and medication. After two years, the areas of interest included poor memory or concentration, recurrence of stroke, and balance problems (32-34).

A common belief among professional stroke care providers is that the informal caregivers are not able to absorb information given due to their emotional state, and that they may forget the information given in the early stages after the stroke event (35). The stroke patients and their informal caregivers, on the other hand, wish to be informed about all aspects of care and be involved in decisions. However, they experience difficulties obtaining the information required due to the fact that the staff is perceived as too busy or not available, and the information given is too complicated or does not address their personal concerns (27, 33).

The healthcare system's trend of reducing the length of the patients' stay in hospitals incurs several problems, such as that the informal caregivers perceive lack of choice to take on the role

of caregiving, and they often receive little or no preparation for the caregiving role at home (36-38).

Discharge

In 2003, 55% of the patients were directly discharged to their home from stroke care units in Sweden (2). The average number of days that the patient was hospitalised was 12.1, with a median of 8 days. The patients that were discharged to their own home were hospitalised for 10 days, with a median of 7 days (2). Men, aged 75 or younger, were higher represented (60%), than women (less than 40%), among patients that were discharged back to their own home after the hospitalisation (2). Of the patients living at home without help from the community before onset of stroke, 71.5% had returned home within three months, and of those, 13.6% now received help from the community (2).

The discharge from hospital is a stressful event for the stroke patients and their informal caregivers due to lack of information about stroke and the long-term outcome of stroke, as well as uncertainty in relation to healthcare services (29, 36). Stressed caregivers can slow down the rehabilitation process of the stroke patients, and might also increase the need for long-term hospitalisation (31). Thirteen percent of the Swedish patients state that they receive no or not enough support after discharge from hospital (2).

The physical deficits of the stroke patient are apparent already in the hospital ward, while cognitive-behavioural deficits may not be recognised until after discharge. Therefore, problems related to marital disharmony and emotional and behavioural dysfunctions in the stroke patient are less recognised and addressed by healthcare professionals (19, 39).

Resources in the community

During the 1980s, the community care was rationalised, emphasising cost-effectiveness. Thus, informal caregivers were seen as a resource to social agencies at a low cost, as only small amounts of formal resources were needed to ensure extensive inputs from the informal caregivers (26). In the community today, informal or family care often represents the greater part of the help and support given to older and disabled people at home, and the support given from the community is given when informal care is not available (40). Neither the community services nor the spouses themselves tend to formally recognise the spouses' role as caregivers until a considerable period of time has passed, and therefore the well-being of the informal carer is not actively considered for a long time (41). Supporting carers has not traditionally been one of the aims of home care, but

providing the informal caregivers with support may increase the likelihood of the stroke survivors remaining in the community (42).

Service providers in the community do, or potentially do, offer caregivers hands-on help in order to lighten their workload, giving emotional support, and also with referrals to other service providers (26). However, one feature of the personal care tasks is that they need to be performed on demand when the need arises for the patient, for example toileting, which makes service on this basis impossible for the community to provide.

Support for the carer incorporated directly in the homecare is rare. Most carers who receive help do so because they themselves are elderly, and because the homecare tend to focus at the level of the household, with little distinction being made between the carer and the disabled person (26).

Sixty-four percent of the stroke patients in Sweden reported in 2003 that after discharge they received support from the healthcare personnel or the community, and 8% wanted support, but did not receive any (2). The national Riks-Stroke register shows that in 2003 only between 10 and 20% of the stroke patients, returning home after discharge, received some sort of home care from the community (2). The dependency of caregivers among the stroke patients turned out to be extensive: 62% of the patients were totally or partly dependent, and only 35% were independent (2).

Consequences of caregiving

The involuntary caregiving role often takes a great amount of time and energy and is frequently characterised by a reduced sense of individual freedom and an increased sense of responsibility, with concerns about the ill relative and the consequences the disease might have on the spouse's own life (7, 43). The worries seem to vary with gender and disease (43). Informal caregiving can result in lifestyle changes, and social, physical, emotional, and financial problems for the caregiver (26, 44).

Elderly informal caregivers, taking care of an ill spouse at home, probably have more or less severe health problems of their own, which might affect both the ability to provide care, and the caregiving situation in a negative way. When the caregiver subordinates his or her life to that of the stroke patient, caring becomes the centre of the informal caregiver's life, and his/her self-identity. This makes it hard for the informal caregiver to distance her/himself from the pain and

suffering of the patient. This phenomena is more often seen among female rather than male informal caregivers, where the woman also is a spouse (26).

Family in a social context

Family members are the main source of support for adults, making them an important part of one's social network (21). To be able to obtain social support, having a social network is essential. Social network can be defined as the quantity and density of a person's social relationships, i.e., the number of persons available and included in the social network, and the closeness in the relationships (45). Social support can, in the case of being an informal caregiver or patient, be obtained from healthcare personnel as well as from the social network.

Many networks often give short-term aid and support. However, support for a longer period of time, as needed by the informal caregivers, may not be possible to obtain from the social network (46). Formal caregivers can provide the informal caregivers with informational support; family members often give emotional support; and friends contribute with social support.

Models of family caregiving

The informal caregivers are often seen as resources by healthcare services, and it is taken for granted that spouses will care for their ill partners as a result of marital obligations (41). The different family members are affected by the illness in different ways, and it is important to acknowledge that the caregiving spouse has a shared life history with the person cared for. The informal caregiver can also be seen as a co-worker, working alongside the formal caregivers to help care for the ill partner (40). The community focuses upon giving the informal caregiver help to continue caring, instead of giving the opportunity to decide whether or not to take on the role of informal caregiving in the first place.

Gender aspects of informal caregiving

It is often difficult to distinguish between informal caregiving and the patterns of personal care within family and gender relations. Many women traditionally perform tasks for their spouses and families that would be classified as "caring" if provided by men in reverse (26). Female caregivers are often found to perceive their own health status as poorer than men do, although they live longer (47). Emotional support, behavioural management, and carrying out household tasks are seen as significantly more time-consuming and difficult by the women, than male caregivers perceive them, and the women also express frustration in response to the stroke regarding taking care of their partner (48-50). Being a female family caregiver of a stroke patient increases the risk

for caregiver burn-out (51). The physical strain may be worse for female caregivers, since they don't have the same physical strength as the male spouses, and they also in many cases care for men, heavier than themselves. Male spouses deal with changing roles due to the stroke event, and learn new skills and behaviours as they take over tasks that women traditionally perform (49, 52). The home-help service is often modelled on the female domestic role, and therefore the home help may be of little or no use for female caregivers in traditionally male tasks that they find daunting (26).

Changing roles

As many as 95% of the caregivers experienced changes in their life situation after the stroke event, having to cope with the patient's change of personality, physical and cognitive impairments, and emotional and behavioural changes (44). These might lead to tensions, decline in family communication, decrease in marital satisfaction, deterioration in the family's ability to solve problems, and increased problems as family members struggle to adapt to their new roles and responsibilities (19, 53, 54). Role transitions due to becoming an informal caregiver may be stressful and difficult, when the formerly strong person in the relationship suddenly becomes the weaker party, or the formerly weaker party has to take on new responsibilities far beyond his/her own resources (55).

Quality of Life

Many attempts have been made to define the term "Quality of Life" (QoL); however, most researchers agree that QoL is a multidimensional construct (56). The definitions of QoL are often linked to health and emphasise such components as happiness, personal well-being, life satisfaction, and impact of illness on social, emotional, occupational, and family domains. The World Health Organization Quality of Life Group (WHOQOL 1993) defines QoL as the individual's perception of his/her position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. The overall QoL can be described as the dynamic interaction between the external conditions of the individual's life and the internal perception of those conditions (57). Assessment of QoL may be included in randomised controlled studies, to identify those aspects of QoL that may be effected by the therapy or trials that are expected to improve QoL (56).

Life situation

With time, the burden of informal caregiving contributes to physical, psychological, and social stress among the informal caregivers, leading to depression, anxiety, and decline in the quality

of life (QoL) (6, 58). Six months after stroke, 37% of the stroke patients' informal caregivers experience considerable strain; the frequency slightly decreases to 30% three years after stroke; but 21% are still under strain five years after the stroke event (59-61). Strained caregivers also have significantly lower self-esteem, and increased negatively affected mood (62).

In several studies, caregivers of stroke patients report reduced social life, upset household routines, sleep disturbances, and a great burden of care (6, 58, 63, 64). The burden might be physical as well as psychological, and it seems to be influenced by the characteristics of both the patient and the carer (19, 58).

Lack of a social network and feelings of isolation affect the informal caregivers negatively, and may convey depression and deteriorated health as possible outcomes (19, 65, 66). Many informal caregivers feel restricted because they are unable to leave the cared-for person or because they feel a general anxiety about what might happen in their absence. Spousal informal caregivers have a dilemma, often expressing the need to get away from the claustrophobic feeling of the other person's constant company, and yet the person they most want to go out with is their ill spouse (26). Wanting relief, i.e., getting away from the ill spouse for a period of time, can also seem disloyal to the partner. Sometimes carers call upon the support of their families to give them a break from the caring situation; however, not all have such support networks (26). Many informal caregivers find erosion in their social networks due to the caring situation, which makes it hard to call on such support.

Coping as informal caregivers

Most caregivers develop their own strategies when trying to cope in the new role. Initially many new caregivers try to deal with the uncertainty of the situation and the shock by taking one day at a time, trying to be positive, believing that the stroke patient will improve, and still have realistic expectations on the patient's level of recovery (37). Most informal carers are strengthened and comforted by comparing their own situation to the situation of other stroke survivors more affected by stroke than their own relative.

The informal caregivers have a desire to maintain normality in daily living, and to take part in social activities, but also to be able to take a time out and switch off emotionally from the caregiver role to recharge their batteries. This involves taking a break from the stroke patient and being able to engage in some activity apart from caring for the patient, without feelings of guilt (37, 51). Support from other family members and friends, like assistance with housework, help in the caregiving role, and emotional support are highlighted as valuable by many informal

caregivers. Needs of support, identified by the informal caregivers themselves, include access to advisers, respite care, day care, regular checkups of the patient, and support groups (67).

Existing instruments for assessing the caregivers' situation

There are already several existing instruments that measure different parts of the caregiver's experiences of how being an informal caregiver affect his/her own life. This means that to be able to get a broad picture of the informal caregivers' life situation as a whole, several questionnaires are needed. Some of the existing instruments, which are often used in the research concerning informal caregivers of stroke patients, are presented below.

The Sense of Competence Questionnaire measures the burden of caregiving, and it is divided into three subscales: (1) satisfaction with the impaired person as a recipient of care; (2) satisfaction with one's own performance as a caregiver; and (3) consequences of involvement in care for the personal life of the caregiver (68). This instrument was used in a study by Sholte op Reimer et al., to describe the level and specific nature of the burden of caregiving as experienced by stroke patients' partners (6). In a review article by Deeken et al., with the purpose of identifying and critically evaluating instruments assessing various aspects of the caregiving experience, seventeen instruments measuring burden were found, of which six had not been originally tested for validity, and two were not tested for reliability (69). Deeken also found eight instruments for assessing the caregiving needs, and three instruments for measuring QoL.

Strain in relation to caregiving can be measured by the Caregiving Strain Index (70). This instrument consists of questions regarding sleep disturbance, physical strain, confining feelings, family adjustments, changed personal plans, demands, emotional adjustments, financial strain and overwhelming emotions. van den Heuvel used this instrument to identify risk factors for burn-out in caregivers of stroke patients (51). The results showed that severe cognitive, behavioural and emotional changes in the patient constitute the main risk factors for caregiver burn-out.

The caregivers' psychological well-being can be assessed with the Psychological General Well-being Index, which measures the sense of subjective well-being during the most recent week, including anxiety, depressed mood, positive well-being, self-control, general health and vitality (71). Forsberg-Wärleby used this instrument in a study evaluating the first phase after stroke, from the spouses' perspective (72).

However, there is to our knowledge, a lack of short and concise questionnaires for assessing the general life situation of the stroke patients' spouses. The ideal instrument should be short, easy and fast to complete, and give a broad picture of the problems that the informal caregiver may experience.

Supportive nursing interventions

Informal caregivers are rarely the direct focus of interventions; they feature within the service system by virtue of their relationship with the ill spouse (i.e., in this thesis, the stroke patient) (26).

There are a few different studies regarding information interventions for stroke patients and their informal caregivers, and the results are not that convincing (73-75). In 1987, Lomer and McLellan evaluated the effectiveness of written information in a study where patients and relatives were randomised to receive a 12-page booklet, addressing etiology, risk factors, treatment, recovery, and community services, or standard care (73). The results showed that patients who received the booklet knew more about the etiology and risk factors after one week, but despite having been given the booklet 35% of the patients and 38% of the relatives stated that they had received no information, i.e., booklets with general information about stroke seem to be of limited efficacy. Further, a small RCT (n=36) evaluated personalised booklets containing individualised information regarding symptoms, rehabilitation, ADL and exercising advice and local and national contacts (74). However, only 50% of the patients felt that the booklet was useful, although the informal caregivers of the patients given the booklets had a better-perceived mental health.

Grant et al. developed a telephone intervention for family caregivers of stroke patients, in the form of social problem-solving therapy, to help the individuals manage negative emotional responses to caregiving, to solving problems optimistically, and to using effective problem-solving skills to address issues arising in the caregiving situation (76). This intervention resulted in significant improvements in the intervention group regarding vitality, mental health, role limitations related to emotional problems, and also social problem-solving skills.

Evans et al. evaluated in an American RCT an education programme for carers of stroke patients (77). The programme consisted of two one-hour classes three weeks post-admission, and in addition to the programme seven hours of counselling during admission and after discharge were also assessed. The comparison was made between (a) an education programme, covering the basic principles of stroke, (b) counselling sessions and education programme, and (c) conventional care.

At six and 12 months after the stroke event both interventions significantly improved some aspects of family function. Counselling was consistently more effective than education alone.

There is also a study made to evaluate a multi-disciplinary stroke education programme for spouses of stroke patients, with a rolling programme of one-hour small group sessions, of which six were provided after discharge (29). The programme increased the knowledge about stroke and satisfaction with services, but was not associated with improved health status.

Identifying caregivers in need of support

Quality of life is an important outcome for the increasing number of unprepared spouses of stroke patients that become informal caregivers at home after the stroke event. The spouses experience a great burden of care, and predicting such an outcome is essential in order to be able to develop effective nursing support interventions. It is of great importance to identify these informal caregivers of stroke patients, and what kind of support they need. Seeing the informal caregiver as part of the family which, based on the person's past experiences and history, affect his or her actions, may ease designing individual nursing interventions for the caregiver. In summary, further knowledge is needed about the impact of caregiving on the informal caregivers' QoL, psychosocial well-being and general life situation, and these must be considered to fully understand the caregiving situation.

AIMS

The overall aim of this study was to investigate spousal caregivers of stroke patients regarding their quality of life, life situation, well-being, health state, social network, and gender differences, and to determine if and how a nurse led support and intervention programme had an impact on these variables.

The specific aims were:

- To determine the impact of a nurse led support and education programme for improving the spouses' perceived general quality of life, life situation, general well-being, and health state (Paper I).
- To explore gender differences among spouses in perceived psychological well-being, and general life situation, during the first year after the patients' stroke event (Paper II).
- To identify the factors that predict the general quality of life among spouses of stroke patients, and to determine if these predicting factors change during the first year after the patients' stroke event (Paper III).
- To test the psychometric properties of a questionnaire measuring the life situation among spouses of stroke survivors (Paper IV).

METHODS AND MATERIALS

Design

This thesis used a longitudinal design, with three cross-sectional assessments made at given points in time (Papers I-IV). Descriptive analyses were also applied (Papers I-IV). To detect differences and similarities between different groups in the sample, a comparative design was used (Papers I and II). In Paper I, spouses of stroke patients attending the intervention programme were compared to a control group with spouses not attending the programme, and intervention subgroups attending 1-4 times are compared to those attending 5-6 times. In Paper II, a comparison of men and women was made.

Sample and data collection

Two hundred and fifty-three significant others of stroke patients admitted to the stroke unit at Danderyd University Hospital between November 2000 and July 2002 were identified prospectively for this study. All the caregivers included in this study were the spouses of the patient, with the exception of one daughter who lived with her mother. In this study, spouse is defined as a person living in the same household as the stroke patient. The spouses were excluded from the study when it was not possible to obtain information from them and/or if the stroke patients were not able to return home after the hospitalisation. One hundred spouses (20 men and 80 women) of the eligible 253, accepted the invitation to participate, i.e., a self-selected sample.

The participants were randomly assigned to an intervention group or a control group, 50 in each group (Paper I). The spouses were randomised after the patients' discharge from the hospital. To ensure close balance of the numbers in each group at any time during the trial, randomisation was performed by the authors using blocks of 20 participants, where 10 would be allocated to each arm of the trial, and the sequence could not be predicted. Three participants that were randomised to the intervention group dropped out before the start of the programme.

In Papers III and IV, the whole sample of 100 spouses was used.

Instruments and questionnaires

The instruments used in Papers I-IV were chosen to reflect different aspects of the spouses' general life situation. The collected background data included age and sex of the spouse and

patient, and educational level and medical history of the spouse. The spouses' educational level was broken down into two categories: school attendance for 12 years or for more than 12 years. Presence of spouses' own illness was rated with a "yes" or "no" question; if "yes", they were asked to specify the illness from which they suffered.

Quality of Life and Economic Situation

(Papers I-IV)

The general quality of life was measured with a visual analogue scale consisting of two non-numerical vertical lines (100 millimetres) with the verbal extreme point markers, "the worst possible quality of life" and "the best possible quality of life" (78). The spouse was asked to mark the quality of life before the onset of the patient's stroke on the left line, and the present quality of life on the right line. This instrument was tested in a Swedish population of stroke patients, and it provided an individually perceived general assessment on aspects of life (78). Present economic situation was measured in the same way, with the verbal extreme point markers, "the worst possible economic situation" and "the best possible economic situation".

Life Situation Among Spouses After the Stroke Event

(Papers I-IV)

Life situation was measured by the Life Situation among Spouses after the Stroke Event questionnaire (LISS), which consists of four subscales: worries, powerlessness, personal adjustment, and social isolation (79). The score ranges from 13 to 65 points, where the score of 65 describes a very good general life situation, and 13 the worst possible life situation. In the present study, Cronbach's Alpha coefficient for the four subscales and the total score was 0.86, 0.86, 0.84, 0.86 and 0.80, respectively (79).

Well-being questionnaire short form

(Papers I-V)

Well-being was measured by the short form of Bradley's Well-being Questionnaire, which consists of the following subscales: negative well-being, energy, and positive well-being (80). The overall scale, general well-being, is based on these three subscales. The score of general well-being ranges from 0 to 36. The Well-being Questionnaire was previously tested in a Swedish setting by Wredling et al. (81). In the present study, the internal consistency reliability for the subscales and general well-being was 0.85, 0.78, 0.89 and 0.87, respectively, as measured with Cronbach's Alpha coefficient.

Health state from the Euro-QoL 5D

(Papers I and III)

The health state of the spouses was evaluated with the graded visual analogue scale part of the EuroQoL-instrument (82). The scale ranges from 0, “the worst imaginable health state”, to 100, “the best imaginable health state”.

Sense of Coherence

(Papers II and III)

Sense of coherence (SOC) was measured with the short version of the instrument (83). Possible scores range from 13 to 91. A higher score indicates a strong sense of coherence. In the present study, Cronbach’s Alpha coefficient was 0.71. In Sweden, the questionnaire was tested for validity and reliability by Langius et al. (84).

The Interview Schedule for Social Interaction

(Papers II and III)

Perceived social support was measured by an abbreviated Swedish version of the Interview Schedule for Social Interaction (85, 86). Six items measure the availability of social integration (AVSI), which indicates the number of people who are available for social support. Seven of the items measure availability of attachment (AVAT), which indicates the occurrence of emotional contacts. The AVSI score ranges from 6 to 36, and the AVAT score ranges from 0 to 7. In the present study, both AVSI and AVAT showed a high internal consistency, with a Cronbach’s Alpha coefficient of 0.90 and 0.78, respectively. This questionnaire has been tested for validity and reliability in Sweden (85).

The Comprehensive Psychopathological Rating Scale - Self Affective

(Papers II and III)

The Comprehensive Psychopathological Rating Scale - Self Affective (CPRS-S-A) was used to measure the psychiatric health during the past three days. Possible scores range from 0 to 60. A high score indicates a deteriorated psychiatric health. This scale has been tested for validity and reliability in a Swedish study (87). In the present study internal consistency, measured with Cronbach’s Alpha coefficient, was 0.90.

Barthel Index

(Paper III)

The patient's level of self-care was assessed with the Barthel Index (BI), with scores ranging from 0 (total dependence) to 100 (independence) (88). The questions concern the patient's ability to independent perform feeding, moving from wheelchair to bed and return, personal toilet, getting on and off toilet, bathing self, walking on level surface, ascend and descend stairs, dressing, and controlling bowels and bladder. In the present study the instrument showed a high internal consistency with Cronbach's Alpha coefficient 0.91. The instrument is earlier used in Swedish settings (89, 90).

Nursing support and education programme for spouses of stroke patients

(Paper I)

The intervention consisted of a support and education programme undertaken in smaller groups of 10 participants each at the hospital, six times during six months. Stroke specialist nurses led the sessions. The topics for the sessions were the nature of stroke, treatment and recovery, the psychological and social effects of stroke, and how to prevent recurrence of stroke. The sessions started with a lecture on one of the topics for 20-30 minutes. After the lecture the group discussions took place, with issues raised by the participants. The participants also had the possibility to call the stroke specialist nurses between the sessions to get extra information or support. The programme aimed at providing an opportunity for spouses to ask questions and to discuss their experiences of caring for a person that has suffered from stroke, with people in the same situation as well as with the stroke specialist nurses, and also at improving the spouses' knowledge about the stroke disease.

The control group received only regular information during the patients' hospitalisation and at the discharge. They also had the possibility to attend one open session for one and a half hours by a stroke specialist physician on the ward; only three of the participants in the control group chose this option. Apart from this, they did not receive any support or information. The questionnaires were sent by mail to the control group, with a prepaid reply envelope enclosed.

Both groups were followed for 12 months, with assessments at baseline and after six and 12 months. The outcomes were assessed by self-rated questionnaires.

ANALYSES

A number of different analyses were conducted in this thesis. To describe the sample and dropouts, descriptive statistics were used. Chi square test was used on nominal data, and *t*-test, Mann-Whitney and ANOVA when applicable. A comparison was performed between those attending the study and those that chose not to attend, regarding age of spouse and patient, sex distribution, and number of strokes that the patient had suffered (Papers I and II). Since a few participants did not fill out all of the questionnaires, the analyses were restricted only to those from whom data was available for all assessments, i.e., “per protocol” analyses. In all statistical analyses, probability values of <0.05 were considered as statistically significant. The statistical analyses were performed using the Statistical Package for Social Sciences software (SPSS) 12.0 for Windows. An overview of the preformed analyses used in Papers I-IV is shown in Table 1.

Table 1. Analyses used in the four Papers included in this thesis.

Analysis	Paper I	Paper II	Paper III	Paper IV
Chi ²	X	X	X	
Independent student's <i>t</i> -test	X	X	X	
Mann-Whitney <i>U</i> -test	X	X	X	
ANOVA	X	X	X	
Paired student's <i>t</i> -test	X			
Wilcoxon signed rank test	X			
Stepwise forward multiple linear regression			X	
Pearson's correlation			X	
Exploratory factor analysis				X
Item analysis				X
Cronbach's Alpha coefficient	X	X	X	X
Inter-correlation matrix				X
Spearman's rank order correlation				X

Analyses Paper I

The attendance rate was calculated for the participants in the programme, that is, the sum of how many times all attendants participated divided by the sum of how many times they had the possibility to participate.

Analyses were done to compare the control and intervention groups, regarding age of spouse and patient, sex distribution, number of strokes that the patient had suffered, and the number of days between the patient's onset of stroke and inclusion of the spouse in the intervention.

To compare the control and intervention groups over time (baseline, six months and 12 months), analysis of variance (ANOVA) with repeated measures was performed for each of the main outcome variables regarding a) Present Quality of Life (PQoL); b) general well-being and the subscales; c) life situation and the subscales; and d) health state. Interaction effect has been studied between within-subjects factor (i.e., baseline, after six months, and after 12 months) and between-subjects factor (i.e., control or intervention group).

To further analyse the changes over time in depth, a paired Student's *t*-test, and Wilcoxon signed rank test, when applicable, were performed within 1) the intervention group, 2) the control group, 3) those attending the intervention 5-6 times, and 4) those attending the intervention 1-4 times (baseline-6 months and baseline-12 months).

Analyses Paper II

A comparison was made between male and female spouses attending the study, regarding age of spouse and patient, sex distribution, and number of strokes that the patient had suffered.

Analysis of variance (ANOVA), with repeated measures, was performed for all main outcome variables: PQoL, WB, LISS-questionnaire, SOC, AVSI, AVAT and health state, comparing male and female spouses over time (baseline, six months and 12 months). In the analyses we also adjusted for age and education. Interaction effect has been studied between within-subjects factor (i.e., baseline, after six months, and after 12 months) and between-subjects factor (i.e., male or female spouse).

To further analyse the changes over time in depth, Student's independent *t*-test and Mann-Whitney *U*-test, when applicable, were conducted to cross-sectionally compare male and female spouses regarding the baseline-, six month- and 12 month-assessments.

Analyses Paper III

Stepwise forward multiple linear regression analyses were conducted to determine the variables that would best predict QoL at baseline, six months, and 12 months, respectively, with present QoL as the dependent variable. Independent variables entered stepwise in the analysis were age, sex, education, own illness, present economic situation, general well-being, life situation, sense of coherence, AVSI, AVAT, and Barthel ADL Index (patient). To eliminate the collinearity risk and avoid entering variables highly correlated with each other, Pearson's correlation was conducted between the variables.

Analyses Paper IV

An item analysis was conducted on the four subscales in the LISS-questionnaire, to evaluate the underlying constructs, and to provide information about how well each individual item related to the other items in the subscale (91). The corrected inter-item correlation in each subscale should generally show a spread of 0.2 as a maximum. To confirm the individual items belonging in the different subscales, a Spearman's rank order correlation was used to calculate the association between each item and the three subscales in which the item was not included.

The response options were dichotomised as scores 1-3 (low scores), i.e., the worst life situation, and 4-5 (high scores), i.e., the best life situation, to evaluate the frequency of spouses responding with low scores in the LISS-questionnaire. This was also done to evaluate the difficulty level of the items, i.e., the proportion (percentage) of respondents answering the question in a particular way, in this case the response options 1-3. In general, the opinion is that the proportion should range from 30 to 80%, and the ideal value is halfway in between, in this case 55% (92).

To establish the internal consistency in the instrument and subscales, Cronbach's Alpha coefficient was calculated for the total score and the subscales. Values of 0.80 or greater are highly desirable (93).

An inter-correlation matrix was computed for all subscales and the total score of the LISS-questionnaire.

Congruent validity was tested by Spearman's rank order correlation (ρ) of the total score and four subscales in the LISS-questionnaire with the total score and three subscales of the Well-being instrument.

An exploratory factor analysis was performed for the 13 items, using principal component analysis for extraction and varimax orthogonal rotation. To evaluate the constructed subscales, four factors were chosen in the extraction of the factor analysis.

ETHICAL CONSIDERATIONS

This study was conducted in accordance with the ethical principles approved in the Declaration of Helsinki (94). The study was approved by the Local Ethic's Committee of the Karolinska Hospital (No. 01-142).

The respondents agreed to participate after receiving written and verbal descriptions of the study. These included information about the participants' right to end their participation in the study at any time. All data was handled anonymously.

The battery of questionnaires included in the study was quite extensive, which may have been troublesome for the frailest participants. However, since the knowledge regarding the life situation among spouses of stroke patients in Sweden needs to be improved, the amount of instruments was considered necessary and beneficial for spouses of stroke patients in the future.

Only the spouses of stroke patients were invited to participate in this study, not the duads consisting of spouse and patient, which for the patient may have led to feelings of neglect and envy. However, we felt that it was necessary to focus only on the spouses, as it may be difficult or impossible for the spouse to speak freely in the group about perceived problems in the relationship with the stroke patient, if the patient also participate, and also because the spouses are, and have been for a long time, a neglected group in the healthcare system. Our belief is that the study should focus on the spouse, which in the long run also may give a positive input in the relationship with the patient.

RESULTS

One hundred and fifty-three spouses chose not to participate (spouses, $n=151$, children, $n=1$, and parents, $n=1$). Their age ranged from 34 to 95 years (mean age 72.1 years), and the majority were women (68%). The spouses that chose not to participate in the study were significantly older than the participants (mean age 67.4 years, men 72.1 and women 66.2) ($p<0.01$). No other significant differences were found between these two groups of spouses, regarding sex distribution, number of strokes that the patients had suffered, and the patients' age.

The three most common reasons for non-participation among the men were their own illness (22%), no need of support (18%), and other reasons (16%). Among the women, their own illness (24%), no reasons given (18%), and no need of support (14%) were given as explanations for non-participation. Nine participants dropped out from the study (five at six months, and four at 12 months). They had a mean age of 68 years (median 70 years), and eight of them were women. The dropouts were equally divided in the two groups, four from the intervention group, and five from the control group, and the male spouse dropped out from the intervention group. Most dropouts from the intervention group felt that they could not leave the ill spouse at home alone.

The mean number of days from the stroke event to completion of the questionnaire was 83 ($SD=45.16$), with a range of 11-251 days. Twenty-four percent of the spouses had an educational level of >12 years and 65% stated that they were affected by their own illnesses.

Paper I

The attendance rate for the support and education programme was 71%. There were no significant differences between the control and the intervention groups regarding demographic data.

The ANOVA showed no statistically significant differences in any of the outcome variables between intervention and control groups over time (p -values ranging between 0.37 and 0.99). However, there were significant differences over time within groups regarding PQoL ($p<0.01$) and positive well-being ($p=0.02$). Significant interaction was found in general well-being ($p=0.01$).

Participants in the support and education programme decreased their negative well-being ($p<0.01$) directly after the programme was finished, although after 12 months the scores returned to the same level as in the baseline assessment. PQoL had increased significantly after 12 months ($p=0.02$), but no differences were found regarding life situation and health state.

The control group had a decrease in their positive well-being ($p<0.01$) and their general well-being ($p=0.04$) during the first six months, although after 12 months the scores returned to the same level as in the baseline assessment. After 12 months their energy had increased significantly ($p=0.04$).

When analysing the intervention group in subgroups, attending 1-4 times and attending 5-6 times, we found that the group which attended 5-6 times had decreased their negative well-being significantly during the first six months ($p<0.01$) as well as after 12 months ($p=0.01$). Their PQoL also increased significantly after 12 months ($p=0.02$).

In the group attending the support and education programme 1-4 times, positive well-being decreased significantly the first six months ($p<0.01$). After 12 months the health state had decreased significantly ($p=0.03$).

Paper II

Among the participants, there were significant differences ($p=0.02$) in age, between the male (mean age 72.10 years, SD=11.94) and female spouses (mean age 66.24 years, SD=9.31), but no other significant differences were found regarding demographic data.

The ANOVA (Table 2) showed significant differences between male and female spouses over time, in general well-being ($p=0.03$), and positive well-being ($p=0.04$), when adjusted for age and education. Male spouses had a better perceived general and positive well-being, and lower negative well-being and AVAT than the female spouses. No other significant differences were found between the genders. The ANOVA also showed significant differences over time within groups regarding Barthel Index ($p=0.04$), and energy ($p=0.04$).

When analysing the male and female groups cross-sectionally at baseline, the analyses showed that the female spouses had a lower general well-being ($p=0.02$), energy ($p=0.03$), and higher AVAT ($p=0.02$) than the male spouses.

After six months the female spouses had statistically significant lower general well-being ($p<0.01$), energy ($p=0.04$), positive well-being ($p=0.01$), and SOC ($p=0.02$) than the male spouses. However, the female spouses had a higher negative well-being ($p=0.04$), AVAT ($p<0.01$), and CPRS-S-A ($p=0.04$) than the male spouses.

At the 12-month assessment, female spouses continued to have a higher negative well-being ($p=0.02$) and AVAT ($p=0.02$) than the male spouses.

Paper III

The multiple stepwise regression analysis shows that several variables contributed to the outcome measure, i.e., PQoL, during the first year after the patient's stroke event. Predictors with non-significant p -values >0.05 were kept in the analysis because they still improved the regression model. Life situation was the only significant predictor of QoL that emerged in all three of the regression analyses (at baseline, six months, and 12 months). Present economic situation also emerged in all the analyses over time, although with a p -value >0.05 at baseline and after 6 months.

At baseline, life situation, general well-being, and own illness were significantly related to QoL, and present economic situation, sense of coherence, and AVSI also improved the regression model, although with p -values >0.05 , explaining 49% of the variance in QoL.

After six months, life situation and general well-being significantly predicted the QoL, while present economic situation, BI (patient), and education were non-significant predictors that improved the model. The included predictors explained 54% of the variance in QoL.

Life situation and present economic situation were significant predictors of QoL after 12 months. Non-significant predictors were AVSI, AVAT, Barthel ADL Index (patient) and education. The predictors explained 56% of the variance in QoL in the model.

Paper IV

The total score on the LISS-questionnaire ranged from 26 to 65, with a mean of 47.01 (SD 9.82) and a median of 46.00. The mean of the Well-being instrument's total score was 25.28 (SD 5.16), with a median of 25.00.

Reliability results

In the item analysis, the corrected item total correlation ranged from 0.63-0.78, with the exception of Item 8 in 'Personal adjustment', which had a correlation of 0.56. The corrected item correlation for the three subscales 'Worries', 'Powerlessness', and 'Social isolation' had a spread of less than 0.2, whereas the third subscale 'Personal adjustment' had a spread of 0.22 due to the item mentioned above.

The summary of the item analysis shows a highly corrected inter-item correlation for all subscales. All items showed a correlation >0.40 with at least one other subscale, although they had the highest correlation with their own subscale, which indicates that the subscales are related to each other. All but two items in the item analysis showed a lower Cronbach's Alpha value for the subscale if the item was deleted, verifying the four subscales. The subscale 'Social isolation' includes only two items, and Cronbach's Alpha if an item is deleted therefore cannot be calculated.

The proportions of respondents answering with one of the response options 1-3 (low scores) ranged from 31.3% to 79.8% for the 13 items, 11 within the desirable 30-80% range. All the individual items had the highest correlation with their own subscale, although all items had a correlation >0.4 with one or more of the other subscales.

Cronbach's Alpha coefficient showed high internal consistency reliability in the four subscales 'Worries', 'Powerlessness', 'Personal adjustments' and 'Social isolation', ranging from 0.84 to 0.86 and for the total score 0.80.

Validity results

The inter-correlation matrix for the subscales and the total score for the questionnaire showed a high correlation at the $p=0.01$ level, ranging from 0.41 to 0.88.

The LISS-questionnaire showed reasonable high congruent validity when correlated with the Well-being instrument, with the exception of the subscale 'Positive well-being'. The total scores

of the instruments showed a Spearman's rank order correlation of 0.59 ($p=0.01$). The subscale 'Negative well-being' in the Well-being instrument had a negative correlation with all subscales and total score of the LISS-questionnaire, ranging from -0.59 to -0.38 ($p=0.01$), while the subscale 'Energy' had positive correlations ($\rho=0.28-0.52$, $p=0.01$). The subscale 'Positive well-being' had a modest correlation ($\rho=0.21$, $p=0.05$) with the subscale 'Powerlessness' in the LISS-questionnaire.

The four factors accounted for 77% of the variance (49%, 12%, 9% and 7%, respectively), which confirms the distinctiveness of the four subscales. All but three items had the highest factor loadings on their own subscale. Items 5 and 6 had higher loadings on the subscale 'Social isolation' and Item 8 had a higher loading on the subscale 'Powerlessness' than in their own subscales.

DISCUSSION

Methodological considerations

The ambition of the quantitative, cross-sectional and comparative design used in this thesis is to obtain results which as truly as possible render the conditions in the empirical world, which can be generalised. In every step of the research process there are threats to the validity and the reliability, which all may affect the results, conclusions, and external validity. These threats have been considered and will be further discussed under paragraphs 11.1.1 to 11.1.5.

Internal validity

Internal validity refers to the degree to which it can be inferred that the independent variable, rather than the uncontrolled, extraneous factors (for example maturation and attrition), is responsible for observed effects (93). An example of this is whether the instruments used measure what they are supposed to, and if it is possible to draw conclusions. If these threats are minimised, the study is considered internally valid.

Due to the use of control procedures, for instance RCT, true experiments possess a high degree of internal consistency, which enables the researcher to rule out most alternative explanations for the results (93). In this kind of study, selection bias could be a threat to the internal validity. Such risk is supposed to be minimised since randomisation, (used in Paper I) within the context of a repeated measures design is an especially powerful method of ensuring equivalence between groups being compared, that is, of controlling all extraneous subject characteristics (93). However, the population in this thesis consists of a self-selected sample, that is, the informal caregivers' participation in the study was voluntary, which also limits the selection.

Attrition refers to the loss of subjects, which restricts the possibilities for generalisations. In general, the higher the rate of attrition, the greater the likelihood of bias, and biases are generally of concern if the rate exceeds 20% (93). In this study population (Papers I-IV) only 9% of the participants dropped out during the period of 12 months, which means that the risk of biases due to attrition in this study is very low.

This can be seen in a slightly different perspective when comparing the participating group in the study with those that did not accept the invitation to participate. Those spouses not participating

were to a higher degree men, and significantly older, than participating spouses. This might imply that some results may not be very applicable outside the context (Papers I-IV).

Another threat to internal validity is maturation, a process that occurs within the subjects during the course of the study as a result of the passage of time rather than as a result of treatment or independent variable, and this might affect the results in the two later assessments in this study (93). Things might have happened to the respondents between the baseline assessments and the two following assessments, such as the patients may have suffered a new stroke, or the spouses might have become ill themselves, etcetera. This is hard to control for, but only six patients had suffered a new stroke during the 12-month period of the study reported in this thesis (Papers I-IV).

External validity

The term external validity refers to the generalisability of the research findings to other settings or samples (93). An important question is whether the intervention (Paper I) will work in another setting, with different participants. Researchers should routinely ask themselves to what populations, environments, and conditions the results of the study can be applied (93). The population in this study is representative of the general population of spouses of stroke patients regarding percentage when it comes to the gender aspect. However, the target population in this study somewhat limits the generalisability of the results, due to the fact that it consists of only co-residential spousal caregivers of stroke patients, which means that it may be difficult to draw conclusions regarding informal caregivers in general.

The action taken to minimise the threats and biases, such as describing drop-outs and the use of psychometrically tested instruments, indicates that the findings of this thesis may be valid for spousal caregivers of stroke patients.

Construct validity

It is a difficult and challenging task to validate an instrument in terms of construct validity. Construct validity concerns the questions regarding what the measuring device really measures, and if the abstract concept under investigation is being adequately measured with this instrument (93). Despite the obstacles and difficulties encountered in assessing the construct validity of instruments, it is a vital component in the scientific process to do so. The construct validation has an emphasis on logical analysis, empirical procedures, and testing of relationships predicated on the basis of theoretical considerations. Construct validity is linked to a theory or conceptual framework.

The instruments used in this thesis are earlier thoroughly investigated in several scientific studies, showing good psychometric properties, that is, the construct validity of the instruments is high (Papers I-IV). The LISS-questionnaire (Paper IV) was tested in an exploratory factor analysis, and four subscales that emerged. Identifying subscales that are logical and fit well with a theory indicates good construct validity.

Reliability

The reliability of instruments that yield quantitative data is a major criterion for assessing its quality and adequacy. Essentially, the reliability of an instrument is the degree of the consistency, that is, how the items relate to each other (93). An instrument can also be said to be reliable if its measures accurately reflect the true scores of the attribute under investigation. The errors of measurement that impinge on the instrument's accuracy also affect its consistency. All instruments used in this thesis show a high internal consistency, with Alpha values ranging from 0.71 to 0.91 (Papers I-IV).

Statistical conclusion validity

The most vulnerable part of quantitative research is statistical conclusion validity. It is defined as “the extent to which a relation between independent and dependent variables can be shown on the basis of quantitative and statistical considerations of the investigation” (95). The statistical analyses are done to test the null hypothesis, that there are no differences between the groups compared (participants in the intervention vs. non-participants or men vs. women). The null hypothesis can be rejected if there are differences between the groups or accepted if there is none, and the decision-making process is based on selecting a probability level that specifies the degree of risk of reaching a false conclusion (95). The risk is that the null hypothesis is incorrectly rejected (Type I error), or incorrectly accepted (Type II error). In this thesis the chosen probability level was >0.05 for significance, to minimize the risk of Type I error.

Limitations

There are some limitations in this study that should be mentioned. We have no “non-caregiver control group” to compare our results with, which would reveal if our findings are unique for caregivers. The participants in this study are mainly women. However, similar sex distribution is found in several other studies regarding spouses of stroke patients (51, 58). The participants are also live-in spouses of the patient, and most participants were spouses of patients that had suffered mild strokes, which implies that the results cannot be generalised to caregivers in general (i.e. son/daughter in law, siblings, friends, as well as informal caregivers of patients living in nursing

homes). Further, the group size of male spouses is only one fourth of the female group size; however studies of this kind of population tend to have similar sex distribution.

General discussion of the findings

Nurses must ensure that the informal caregivers are assisted in the transition of care from the structured hospital care to home settings and to provide support, so that the caregivers can adapt to their new role and be comfortable and effective as informal caregivers (59). The leading cause of costly long-term institutionalisation of stroke patients is negative health effects, experienced by family caregivers. Nursing interventions are needed to reduce these negative health effects, and to inform the caregivers on how to care for the stroke patient as well as for themselves (96, 97).

Nursing support intervention

We tested the hypothesis that an extended nurse led support and education programme would improve the intervention groups' a) PQoL; b) general well-being; c) life situation; and d) health state. However, we did not find differences between the groups.

The absence of differences between the control and intervention groups in our study may be due to a number of reasons, such as the small number of participants, a bi-polar dilution effect, or that the instruments used are not sensitive enough to detect changes in these variables over time. Since this is an almost virgin field of research, there has been no hard data on which to calculate numbers needed to achieve sufficient statistical power to give evidence. The findings with several trends, however, may be indicative that a larger sample size might have given a clear difference between the participants in each arm of the trial. Although we had a reasonable high attendance rate (71%), the 'dilution effect' might be due to the fact that 50% of the participants in the intervention group attended less than five times. An indication of the dilution effect can be seen when comparing the intervention subgroups, i.e., the group attending 1-4 times with the group attending 5-6 times. The group attending 5-6 times had a significant decrease in negative well-being and increased quality of life over time, while the group attending fewer times had a significant decrease in positive well-being and health state, similar to the control group, which also had a significant decrease in negative and general well-being. The caregivers attending less than five times in the intervention need more focus in future research, since they may represent caregivers with more problems related to the stroke patient, and they may also be in greater need of nursing support. The non-significant differences between intervention and control groups might also depend on another 'dilution effect', i.e., the participants in the control group of the study may have become more aware of problems arising after the stroke event and of gaps in their own

knowledge. This might have led the participants to seek information on their own, which might have been a confounding factor.

The participants in the intervention group decreased their negative well-being during the ongoing support and education programme, although this only gave a temporary improvement, since the negative well-being increased again after the programme had finished. This contradicts the findings in a study regarding a group support programme and an individual support programme for informal caregivers of stroke patients, whereas the intervention had no effect on the caregivers' physical or mental well-being (98).

When asked to evaluate the present intervention programme, the participants were overall positive, and expressed the importance of meeting people in the same situation, exchanging experiences and being able to talk about their own life situation. Talking with others in the same situation about the caregiving situation and the relation with the stroke patient can also reinforce the carers' perceptions of themselves as such, helping them to establish their right to think of themselves and their own needs. Similar opinions were expressed in a study by Rodgers et al., by participants in a comprehensive stroke education programme for patients and caregivers (29).

Gender aspects of informal caregiving

Our results, presented in this thesis, reveal gender differences over time, among spouses of stroke patients, regarding general, negative, and positive well-being, as well as in the social network.

These findings show that the female spouses are more negatively affected in their caregiver role than the male spouses, resulting in a poor psychological well-being for the women, which is also supported by other studies (99, 100). According to Goode's theory of role strain, women have a limited amount of time, energy, and commitment to dedicate to role responsibilities, trying to balance multiple roles of being a mother, wife, employee, and caregiver, which might result in role strain and burden (101). This is also found in a more recent study, where the spouses of patients with a chronic disease expressed feelings of being like a mother to their relative, and how they also felt like a nurse with responsibility for the care at home around the clock (7). Furthermore, men are more emotionally removed from the caregiving experience, more stoic, and more likely to focus on problem resolution, striving to gain mastery and control over the situation, while the women focus on emotional resolution (102).

Many spouses have feelings of loneliness and experience social limitations, that is, contacts with relatives, friends, and family members are considerably reduced (7, 49). Our findings revealed that female spouses, already at baseline, have a significantly higher perceived social support when it comes to occurrence of emotional contacts (AVAT) than male spouses. This finding is in agreement with the results in a study of spouses of patients with Alzheimer's disease, where wives were more likely to report having a confidant than the husbands (103). Contrary to our findings, where female spouses report a low psychological well-being despite perceived available social support, another study reported that the social support was identified as an important factor for the caregivers' psychosocial health, and that it had a positive impact on caregivers' health (104).

Both genders increased their perceived general quality of life during the 12 months, although the male spouses consistently had a higher quality of life than the women. This might depend on the fact that male caregivers are more likely to feel needed, useful and appreciated, and they also feel that they have chosen to take on the caregiving role, a role that gives more meaning to their lives (105, 106). Male caregivers also receive outside help with housekeeping more frequently than female caregivers (106). Furthermore, viewed from a gender perspective, caring is a new task for elderly men, but not for women; hence, it could be seen as something new added to the men's life experience. The caregiving role is generally not expected of men and, due to that, others are more likely to notice and to assist them in this role to a greater degree than they would for women (38).

A demographic difference found in the present study applies that male spouses are statistically significantly older than the female spouses, which can be explained by the fact that women are, on average, several years older than men when they suffer their first stroke, i.e., male spouses are often older than female spouses (107). The same tendency is also found among male and female spouses of patients with Alzheimer's disease (103).

Predicting quality of life

This study is unique in that it focuses on QoL among spouses of stroke patients over time. The experience of informal caregiving is a complex phenomenon. It has an impact on all aspects of the caregiver's life and also greatly affects the psychosocial aspects of the spouse's QoL. Only two of the predictors of QoL, life situation and present economic situation, emerged during the year after the patient's stroke event. A weak economic situation predicted low QoL, which is not surprising, as one or both partners may be forced to give up work, and costly medications for the patient and alterations to the home may be required (108). A poor life situation is equivalent to a great burden among the spouses, which is also shown to have a negative effect on the QoL. This finding is

equal to the results found in several different studies (38, 51, 109). The strongest predictors at baseline and after six and 12 months were the spouse's perceived illness, life situation, and education, respectively. Although most participants in our study were spouses of patients with high scores in the Barthel Index, indicating that the patients were independent in their ADL ability, it is well known that not only the patient's characteristics, but also the spouse's characteristics, such as his or her illness, affect the level of the spouse's perceived burden (6).

It is not surprising that AVAT emerged as a positive predictor of QoL, showing that the existence of emotional contacts in the spouse's social life has a positive effect on their QoL. Emotional support is important for reassuring the spouse, sharing emotional burdens through sympathy or empathy, expressing concern, and providing encouragement. It also contributes to the feeling of being loved and cared about, which helps to sustain self-esteem and reinforces feelings of self-worth (110). Many spouses feel lonely and experience social limitations, that is, contacts with relatives, friends, and family members are considerably reduced (7, 49). They may also experience social disruption because of an unwillingness to attend social events, thereby leaving the patient alone at home (108). A study regarding the impact of social support on the general health of family caregivers of stroke patients showed that, without assistance or support in the informal caregiving, these caregivers are likely to become the second patient in the family (104).

Our results showed that increased numbers of people available for social support had a negative impact on the spouses' QoL. In a study by van den Heuvel et al., caregivers who were less satisfied with their social support were under greater strain and experienced lower mental well-being (51). They also concluded that caregivers are under less strain if they know how to make time for themselves and their social life and where to ask for support.

Contradictory to most studies regarding the QoL of patients, which demonstrate a strong positive correlation between sense of coherence and the patients' QoL, we found that higher scores for sense of coherence had a negative impact on the spouses' QoL. This might be an indicator of the problems that arise when spouses have to make proxy decisions on behalf of the patient and must balance their own needs and those of the patient. The spouses' substantial contribution of informal care to the patients does not happen without consequences for the spouses' own health, and interference with, their own lives (6).

Sit et al. found that educational level has implications for access to information, that is, those with higher education may find it easier to seek information and apply it to their own situation (104).

This might also lead to an awareness of the negative consequences of the stroke disease on the family, which may serve to explain the negative effect of higher education on the QoL of the spouses in our study.

Identifying spouses with problems in their life situation

The LISS-questionnaire clearly identifies stroke survivors' spouses with problems in their life situations. The four constructed subscales concerning 'Worries', 'Powerlessness', 'Personal adjustment', and 'Social isolation' reflect problem areas for this population, which is in accordance with the findings of several studies (66, 111, 112).

Response options 1-3, 'all the time', 'almost all the time', and 'sometimes', were chosen for dichotomisation because these options best indicate the severe conditions of a spouse's life situation. It is not surprising that 79.8% of the respondents agreed with the item 'I worry about my significant other'. This is a natural reaction to the stroke event, and is confirmed in similar studies by other researchers (19, 31, 113, 114).

Although both items in the subscale 'Social isolation' had a lower percentage of respondents answering with one of the response options 1-3 (19.1% and 22.3%, respectively), we have chosen to keep the items in the LISS-questionnaire due to the fact that social isolation is a major problem reported in other studies with this population. One fifth of the spouses in our study felt isolated and withdrew from their social lives, which supports the findings of a study by Thommessen et al (2001), in which 19% of the relatives stated that their social life had been affected.

The exploratory factor analysis of the 13 items gave satisfactory confirmation of the four new subscales in the instrument, although three items had a higher factor loading on another subscale than their own. However, we have chosen to keep them in the subscales defined by the authors, because the factor loadings for the three items exceeded 0.40 in these scales.

The LISS-questionnaire shows high congruent validity when compared to the Well-being instrument. A high correlation was found between the LISS-questionnaire's total score and three subscales and the Well-being instrument's total score and two out of three subscales. The subscale 'Positive well-being' in the Well-being instrument did not correlate with the LISS-questionnaire, except for the subscale 'Powerlessness', which showed a modest correlation. The explanation for this might be that the four questions in the 'Positive well-being' subscale are

written in past tense, while the remaining questions in the Well-being instrument and all the questions in the LISS-questionnaire are in present tense.

Interventions aimed at support and education

Because of the growing dependence on informal caregivers to support individuals with disability in the community, it is important to develop effective intervention programmes to support the carers in adapting to and managing their new roles (37). It is reported that spouses of stroke patients have different needs for support at different times after the stroke, and express need for more attention from health care professionals (20, 31).

CONCLUSIONS

The findings in our studies demonstrate that spousal informal caregivers of stroke patients have a complex life situation due to the stroke event, and that this has many negative effects on their perceived QoL and psychosocial well-being.

In the first study we found no significant differences between the control and intervention groups after a six months' support and education programme for spouses of stroke patients. The intervention group which attended 5-6 times increased their quality of life and decreased their negative well-being over time, while the group which attended only 1-4 times decreased their positive well-being and health state over time.

The results from the second study presented in this thesis show that female spouses of stroke patients have a negative impact on their psychological well-being, while the male spouses have a lower occurrence of emotional contacts in their social network, which generates the hypotheses that there are gender differences among spousal caregivers of stroke patients. Due to the unequal sex distribution the results cannot be generalized to caregivers in general, i.e., the findings are valid for the sample in this study only.

The findings in the third study indicate that psychosocial factors – general life situation, well-being, social network, education, and economy – are important in predicting quality of life among spouses of stroke patients over time, and that changes of predicting factors do occur over time. Determining such predictors at an early stage, and re-evaluating the predictors over time, will help to focus clinical nursing interventions on changes in the spouses' different needs over time.

The Life Situation Questionnaire evaluated and tested in the fourth study can be used by nurses to identify spouses of stroke survivors who are in need of supportive interventions after the stroke event, and can also be used to measure individual life situation as well as at group level. Depending on the study objectives, the questionnaire could be used as a cross-sectional or longitudinal measurement when evaluating an intervention programme.

FUTURE RESEARCH

The results from this study indicate a need for a continuing development of nurse led support programmes for spouses of stroke patients which also might include individualised support, an empowerment approach, and implementation of coping strategies, in order to facilitate the spouse's roll as an informal caregiver to the stroke patient. It is possible that the support intervention may benefit most spouses if it is individualised after the spouses' own needs.

The gender differences found in Paper II regarding social network are interesting, and it would be of interest to further explore them in a repetition of this study in a similar population, with more male participants (i.e., an equal proportion men and women). This study generates the hypotheses that there are gender differences among spousal caregivers of stroke patients.

The BI scores of the stroke affected partners, of the spouses included in this study, were high, indicating that most patients were independent in their abilities of daily living. However, the clinical experience from the nursing intervention raises questions regarding the cognitive and behavioural deficits of the patients and their effect on the spouses' life situation.

CLINICAL IMPLICATIONS

Nurses must ensure that the informal caregivers are assisted in the transition of care from the structured hospital care to home settings and to provide support, so that the caregivers can adapt to their new role and be comfortable and effective as informal caregivers (59). The leading cause of costly long-term institutionalisation of stroke patients is negative health effects, experienced by family caregivers. Nursing interventions are needed to reduce these negative health effects, and to inform the caregivers on how to care for the stroke patient as well as for themselves (96, 97).

The interventions can consist of nursing led group sessions for the spouses of newly diagnosed stroke patients, aimed at increasing disease specific knowledge and giving support, in order to cope with the changed life situation, but also for referrals to the community service, district nurses, home care, welfare officers, and so on, depending of the problems that arise.

Identifying at an early stage, the psychosocial factors that affect the general quality of life among spouses of stroke patients, as well as their general life situation, well-being, social network, education, economy, and also the changes that do occur over time, will help to focus the clinical nursing interventions for the spouses' different needs over time.

POPULÄRVETENSKAPLIG SAMMANFATTNING

Stroke är en sjukdom med stora konsekvenser för de strokedrabbade och deras familjer. I dag är vårdtiderna på sjukhus korta, och de närstående förväntas oförberedda ta sig an rollen som informella vårdare när den strokedrabbade skrivs ut till hemmet. Sammanboende närstående känner ofta också en skyldighet att vårda patienten efter hemkomst från sjukhuset och tillhandahålla emotionellt stöd och assistans vid ADL. De måste också hantera patientens eventuella fysiska och kognitiva handikapp, vilket kan leda till ökade problem för den närstående då familjemedlemmarna också försöker anpassa sig till nya roller och ansvarsområden. I förlängningen kan sjukdomen också för de närstående medföra ett reducerat socialt liv, samt ge sömnproblem, depression, ångest och försämrad livskvalitet.

Både patienter och närstående upplever att utskrivningen från sjukhuset är mycket stressande, med känslor av övergivenhet och osäkerhet rörande vart de ska vända sig för information och praktisk hjälp. Antalet telefonsamtal från närstående och patienter efter utskrivning visar på kunskapsbrist angående medicinering och förflyttningar, samt problem och osäkerhet i hemmiljön. Detta tyder på ett behov av utbildningsprogram specifikt riktade till de närstående.

Studiepopulationen i denna avhandling består av sammanboende närstående till strokepatienter som vårdats på en strokeenhet på ett Stockholmssjukhus. Av 253 tillfrågade närstående valde 80 kvinnor och 20 män att acceptera inbjudan till deltagande i studien. Medelåldern bland deltagarna var 67 år, männen var något äldre (72 år i genomsnitt) än kvinnorna (66 år i genomsnitt). Bland de 153 som valde att inte delta i studien (68 % kvinnor) var medelåldern något högre, 72 år. De vanligast förekommande anledningarna till icke-deltagande var egen sjukdom samt inget behov av stöd.

Syftet med den första delstudien var att undersöka om ett stöd- och utbildningsprogram lett av strokesjuksköterskor har betydelse för de närståendes livskvalitet, livssituation, generellt välbefinnande och hälsosituation, med mätningar vid studiens start samt efter sex och 12 månader. Etthundra närstående randomiserades till interventions- eller kontrollgrupp, med 50 i varje grupp. Interventionsgruppen deltog i stöd- och utbildningsprogram sex gånger under sex månader. Det framkom inga signifikanta skillnader över tid mellan interventions- och kontrollgruppen. I subanalyser fann vi att de som deltog i interventionen 5-6 gånger signifikant förbättrades över tid i

negativt välbefinnande och livskvalitet, medan de som deltog färre än fem gånger signifikant försämrades i positivt välbefinnande och hälsosituation, vilket liknar kontrollgruppens resultat, med försämrat negativt och generellt välbefinnande. Eftersom de som deltog 5-6 gånger i interventionen signifikant förbättrades i negativt välbefinnande och livskvalitet, indikerar resultatet ett behov av sjuksköterskeledda stödprogram för närstående till strokepatienter för att underlätta de närståendes roll som informella vårdare till den strokedrabbade.

I den andra delstudien var syftet att undersöka om det finns skillnader mellan könen beträffande närståendes upplevelse av psykologiskt välbefinnande och generell livssituation under det första året efter patientens strokeinsjuknande. Etthundra närstående följdes vid tre tillfällen under ett år gällande psykologiskt välbefinnande och generell livssituation. Resultaten visar att kvinnliga närstående upplever en negativ påverkan på sitt psykologiska välbefinnande, medan manliga närstående har färre emotionella kontakter i sitt sociala nätverk. Redan vid studiens start och fortsatt över tid rapporterar de kvinnliga närstående lägre livskvalitet och välbefinnande än manliga närstående. Det är viktigt att individanpassa sjuksköterskeinterventioner, för att möta de olika behoven och önskemålen från manliga och kvinnliga närstående i rollen som informella vårdgivare.

Syftet med den tredje delstudien var att undersöka vad som predicerar livskvalitet hos anhöriga till strokepatienter, och om prediktorerna förändras under det första året efter patientens strokeinsjuknande. Etthundra närstående följdes vid tre tillfällen: studiestart, samt efter sex och 12 månader, med självskattningar av livskvalitet, egen sjukdom, ekonomisk situation, generellt välbefinnande, livssituation, känsla av sammanhang, socialt nätverk samt en proxyskattning (utförd av närstående och sjuksköterska) av patientens ADL-förmåga. Den närståendes livssituation och ekonomiska situation predicerade livskvaliteten vid samtliga mättillfällen, medan välbefinnande, utbildning, egen sjukdom, socialt nätverk och patientens ADL-förmåga var prediktorer för livskvalitet vid ett eller två tillfällen under året. Resultaten indikerar att psykosociala faktorer som generell livssituation, välbefinnande, socialt nätverk, utbildning och ekonomi är viktiga prediktorer för livskvalitet hos närstående till strokepatienter, och att dessa prediktorer förändras över tid. Om man tidigt efter patientens strokeinsjuknande kan identifiera dessa faktorer kan kliniska sjuksköterskeinterventioner fokusera på de närståendes förändrade behov över tid för att på så sätt ge dem ett ultimatum stöd i rollen som informella vårdare.

Syftet med den fjärde delstudien var att vetenskapligt utvärdera ett frågeformulär, konstruerat för att utvärdera livssituationen för strokepatienters närstående efter stroketillbudet. Nittionio närstående till strokepatienter deltog i studien. I det ursprungliga instrumentet ingick 20 frågor, som efter statistiska analyser reducerades till 13 frågor. Dessa 13 frågor indelades i fyra subskalor: ”Oro”, ”Maktlöshet”, ”Personlig anpassning” och ”Social isolering”. Instrumentet visade korrekta mätningar i samtliga analyser och slutsatsen är att Livssituationformuläret har en hög validitet och reliabilitet, och är ett instrument som kan användas efter patientens stroke för att identifiera närstående som upplever problem i sin livssituation och som är i behov av stöd från sjukvårdspersonalen.

Resultaten i avhandlingen visar att strokepatienters närstående i rollen som informella vårdare har en komplex livssituation relaterat till patientens strokesjukdom, och att detta kan ha negativa effekter på den närståendes upplevda livskvalitet och psykosociala välbefinnande. Resultaten visar också på ett behov av fortsatt utveckling och utvärdering av sjuksköterskeledda stödprogram för närstående till strokepatienter. Dessa stödprogram kan inkludera individuellt stöd utifrån den närståendes upplevda behov, empowerment, och implementering av copingstrategier, för att stärka den närstående i rollen som informell vårdare till strokepatienten.

ACKNOWLEDGEMENTS

This thesis was carried out at the Department of Nursing, Karolinska Institutet, and Danderyd University Hospital, in Stockholm. I would like to express my sincere gratitude to everyone who had any part in this work and, in particular, I would like to thank **all the spouses** of stroke patients that participated in this study, who gave me an invaluable insight into their situation as informal caregivers.

My supervisor Professor **Regina Wredling**, thank you for believing in me in the first place, and for excellent and critical supervision, helping me reach goals far beyond what I ever thought possible.

Med. Dr. **Ewa Billing**, my co-supervisor, thank you for the invaluable encouragement, support, interest, and understanding in both research, and outside of work. You have an amazing ability to put things in the right perspective.

My co-supervisor, Med. Dr. **Veronica Murray**, thank you for giving constructive criticism on my work, and so generously sharing your scientific knowledge.

My co-supervisor, Med. Dr. **Magnus von Arbin**, thank you for the interesting discussions, giving useful perspective to the obvious nursing point of view of this thesis.

Healthcare Sciences Postgraduate School (NFVO), and **Jan Ekstrand**, thank you for giving me a great opportunity to complete my PhD, including meetings with fellow PhD students and senior researchers, giving great opportunities for networking! Thank you also **all fellow PhD students at NFVO**, mainly all of you in **HK01**, for all the interesting discussions, nice get-togethers, and enjoyable social events during the years.

Helena Fabian, Ulrika Shüldt-Håård, Ulrika Einarsson, and Malin Bruce, my friends (and colleagues at NFVO, and Karolinska Institutet). You all have a big place in my heart! Without you all I don't think that I would have made it to this day, however "exceptional" I might have been ☺. The (almost) daily phone calls regarding everything in life, big or small, personal or work related, what would I have done without them? **Helena**, you have always been there for me, when

I have had my share of ups and downs in life, thank you for all the pep talks! **Ulrika S-H**, thank you for sharing my experiences, always listening to my problems, for giving me the opportunity to listen to yours, and for all the laughs at the stand-up comedy and theatres. **Ulrika E**, you are my teasing, critical thinking, analysing, big-hearted, caring, “stay-up-last (with me) at the NFVO PhD student and supervisor days” friend. You are just as busy as me, but hopefully we’ll have more time now, when we are finished?! **Malin**, you are the best PRAO I have had during these years (and the ONLY prao as well!) ☺. Let us go to Smulan in Norrtälje sometimes soon for a coffee and cake!!

Carl-Göran Ericsson, Head of the Division of Medicine, Danderyd University Hospital, thank you for your encouragement, and for giving me excellent working conditions. My friends and **all colleagues** at the stroke care unit, Danderyd University Hospital, but especially **Bitte Arnald** (the best “kasta gris-U2 forever-finlandsfärja i Köpenhamn”-friend anyone could ask for!), **Linnéa Josefsson** (you do look good in braids! ☺), **Kerstin Lindholm** (Borås, Borås...! ;-)), **Hedvig Bruno** (the never ending Duracell Rabbit), **Idah Arodi** (my dear friend, thank you for finding our house, for giving me a wonderful godson and for your love and friendship), **Kenneth Hammar-Larsson** (Porridge-war, say no more!), **Mari Partinen**, and **Ylva Hasslund** for your never ending support and encouragement.

Susanne Amsberg, **Therese Anderbro**, **Åsa Franzén-Dahlin**, and **Monika Rydell-Karlsson**, my colleagues at the Division of Nursing Research at Danderyd University Hospital, for sharing the everyday life at work, and for giving me the opportunities not only to discuss research, but also for sharing recipes, walks at lunchtime, and coffee breaks when the “paltkoma” after lunch sets in, and **Monika** also for the countdown of hours left until DISSERTATION DAY (every Friday, for the last seven months).

My colleagues at the Department of Nursing at Karolinska Institutet. **Johanna Ulfvarson** and **Anna Carin Wahlberg**, thank you for your support, pep talks, encouragement, and last but not least, your invaluable friendship! **Christina Johnsson**, **Lars E Eriksson**, **Kerstin Nilsson-Kajermo**, **Susanne Georgsson-Öhman**, **Barbro Mendel**, **Mia Jirve**, **Catharina Widmark**, **Karin Gottvall**, **Anna Cristensson**, **Anette Forss**, **Joakim Larsen**, **Agneta Wennman-Larsen**, **Catrin Björvell**, **Lena Wettergren**, and **all the others**, thanks for all the talks, important discussions, inspiring visions, and laughs. In this group I also want to include **Claes Cederfjäll**, who is no longer with us.

Petter Gustavsson at the Department of Nursing, Karolinska Institutet, **Gunilla Rudander**, and **Hans Pettersson**, SPSS, for help and discussions regarding statistical analyses. **Lynn Stevenson** for excellent language review. **Tim Gaston** for many hours of help with my sometimes troublesome computer. **Patrik Eklund**, thank you for helping me with the transformation of my ideas from thoughts to reality, regarding the cover of this thesis, and for great help with the layout (sorry that you had to work a couple of days during your vacation!). **Åsa Windahl**, thank you for your contagious enthusiasm when I was trying to get the pictures I wanted for the cover of this thesis, and thank you for lending me your hiking sticks when the hiking finally became reality!

Thank you to **all of my friends (no one forgotten!)**, particularly **Sanna Annesdotter** for always being my “Sobril i kakorna”, and for forcing me to take a break from work now and then, to do the important things in life, like go for walks, talk for hours, drink coffee or beer, and talk some more. You are truly a treasured friend. **Daga Bäfverfeldt**, no one of my friends can talk as much as you! Thank you for giving me blisters in my ears!! **Heidi Kapstad**, my friend from the EANS summer course, I am always enjoying our discussions and conversations in Svorsk, as well as our group works at Smulan, including the FIKA of course! **Tara Beesley**, my dear friend from “Downunder”, your letters, photos of my Australian family, and e-mails keep brightening my day!

Alexander “Sander” Lundin, my godson who taught me to enjoy life, his kisses, and busses, during the last three and a half years. **The “Larson” Family**, thank you all for your support, and for continuing to call me, even though I haven’t been calling you back frequently during these years. My sister **Annika Jensen**, for not giving me a hard time when I did not seem to have enough time to spend with you, and for your never ending encouragement. My mother **Britt Lindqvist**, who has taught me to reach for the stars, and to believe that everything is possible. Thank you for your love and for helping with our garden and home when I didn’t find the time during these years!

Niclas, we’ve been travelling around the world and back again on several trips during these years, which have given me a much-needed break from the research work now and then. Thank you for giving me the opportunity to complete my PhD, and for believing in me.

This study was supported by grants from the Health Care Sciences Postgraduate School (NFVO), the Swedish Association of Neurologically Disabled (NHR), and the Swedish Stroke Association.

REFERENCES

1. The World Health Organization MONICA Project (monitoring trends and determinants in cardiovascular disease): a major international collaboration. WHO MONICA Project Principal Investigators. *Journal of Clinical Epidemiology* 1988;41(2):105-14.
2. Analyserande rapport. Riks-Stroke. För helåret 2003 (in Swedish). Riks-Stroke - A national quality register for acute stroke: Västerbottens Läns Landsting; 2003.
3. Mackay J, Mensah G. Atlas of Heart Disease and Stroke. [Internet] 2004 [cited 2005; Available from: http://www.who.int/cardiovascular_diseases/resources/atlas/en/index.html
4. Bereton L, Nolan M. 'You do know he's had a stroke, don't you?' Preparation for family-caregiving - the neglected dimension. *Journal of Clinical Nursing* 2000;9:498-506.
5. Sims SL, Boland DL, O'Neill C A. Decision making in home health care. *Western Journal of Nursing Research* 1992;14:186-200.
6. Scholte op Reimer WJ, de Haan RJ, Rijnders PT, Limburg M, van den Bos GA. The burden of caregiving in partners of long-term stroke survivors. *Stroke* 1998;29(8):1605-11.
7. Öhman M, Söderberg S. The experiences of close relatives living with a person with serious chronic illness. *Qualitative Health Research* 2004;14(3):396-410.
8. Jorgensen HS, Reith J, Nakayama H, Kammersgaard LP, Raaschou HO, Olsen TS. What determines good recovery in patients with the most severe strokes? The Copenhagen Stroke Study. *Stroke* 1999;30(10):2008-12.
9. Tsouna-Hadjis E, Vemmos KN, Zakopoulos N, Stamatelopoulos S. First-stroke recovery process: the role of family social support. *Archives of Physical Medicine and Rehabilitation* 2000;81(7):881-7.
10. Glader EL, Stegmayr B, Johansson L, Hulter-Asberg K, Wester PO. Differences in long-term outcome between patients treated in stroke units and in general wards: a 2-year follow-up of stroke patients in Sweden. *Stroke* 2001;32(9):2124-30.
11. Organised inpatient (stroke unit) care for stroke. Stroke Unit Trialists' Collaboration. *Cochrane Database Syst Rev* 2000(2):CD000197.
12. Peltonen M, Stegmayr B, Asplund K. Time trends in long-term survival after stroke: the Northern Sweden Multinational Monitoring of Trends and Determinants in Cardiovascular Disease (MONICA) study, 1985-1994. *Stroke* 1998;29(7):1358-65.
13. Thorvaldsen P, Davidsen M, Bronnum-Hansen H, Schroll M. Stable stroke occurrence despite incidence reduction in an aging population: stroke trends in the danish monitoring trends and determinants in cardiovascular disease (MONICA) population. *Stroke* 1999;30(12):2529-34.
14. Tuomilehto J, Rastenyte D, Sivenius J, Sarti C, Immonen-Raiha P, Kaarsalo E, Kuulasmaa K, Narva EV, Salomaa V, Salmi K, Torppa J. Ten-year trends in stroke incidence and mortality in the FINMONICA Stroke Study. *Stroke* 1996;27(5):825-32.
15. Medin J, Nordlund A, Ekberg K. Increasing Stroke Incidence in Sweden Between 1989 and 2000 Among Persons Aged 30 to 65 Years: Evidence From the Swedish Hospital Discharge Register. *Stroke* 2004;35:1047-1051.
16. National Guidelines for Stroke Care. The Swedish National Board of Health and Welfare. 2005 [cited; Available from: <http://www.sos.se>
17. Adams HP, Jr. The importance of the Helsingborg declaration on stroke management in Europe. *Journal of Internal Medicine* 1996;240(4):169-71.
18. Aboderin I, Venables G. Stroke management in Europe. Pan European Consensus Meeting on Stroke Management. *Journal of Internal Medicine* 1996;240(4):173-80.
19. Anderson CS, Linto J, Stewart-Wynne EG. A population-based assessment of the impact and burden of caregiving for long-term stroke survivors. *Stroke* 1995;26(5):843-9.
20. Bakas T, Austin JK, Okonkwo KF, Lewis RR, Chadwick L. Needs, concerns, strategies, and advice of stroke caregivers the first 6 months after discharge. *Journal of Neuroscience Nursing* 2002;34(5):242-51.
21. Hellström Y, Hallberg IR. Perspectives of elderly people receiving home help on health, care and quality of life. *Health and Social Care in the Community* 2001;9:61-71.

22. McCann J, Christiansen K. Home Care. In: Luecckenotte AG, editor. *Gerontologic Nursing*. St. Louis: C.V. Mosby; 1996. p. 913-943.
23. Ekwall AK. Informal caregiving at old age. Content, coping, difficulties and satisfaction. [Doctoral thesis]. Lund: Lund University; 2004.
24. Parker G. Counting care: numbers and types of informal carers. In: Twigg J, editor. *Carers, Research and Practice*. London: HMSO; 1992.
25. Grant JS, Glandon GL, Elliott TR, Giger J, Weaver M. Caregiving problems and feelings experienced by family caregivers of stroke survivors the first month after discharge. *International Journal of Rehabilitation Research* 2004;27(2):105-111.
26. Twigg J, Atkin K. *Carers perceived: policy and practice in Informal Care*. Buckingham: Open University Press; 1994.
27. Hanger HC, Walker G, Paterson LA, McBride S, Sainsbury R. What do patients and their carers want to know about stroke? A two-year follow-up study. *Clinical Rehabilitation* 1998;12(1):45-52.
28. Hanger HC, Wilkinson TJ. Stroke education: can we rise to the challenge? *Age and Ageing* 2001;30(2):113-4.
29. Rodgers H, Atkinson C, Bond S, Suddes M, Dobson R, Curless R. Randomized controlled trial of a comprehensive stroke education program for patients and caregivers. *Stroke* 1999;30(12):2585-91.
30. Rodgers H, Bond S, Curless R. Inadequacies in the provision of information to stroke patients and their families. *Age and Ageing* 2001;30(2):129-33.
31. Low JT, Payne S, Roderick P. The impact of stroke on informal carers: a literature review. *Social Science & Medicine* 1999;49(6):711-25.
32. Hanger HC, Mulley GP. Questions people ask about stroke. *Stroke* 1993;24(4):536-8.
33. Wellwood I, Dennis MS, Warlow CP. Perceptions and knowledge of stroke among surviving patients with stroke and their carers. *Age and Ageing* 1994;23(4):293-8.
34. Clark MS. Patient and spouse perceptions of stroke and its rehabilitation. *International Journal of Rehabilitation Research* 2000;23(1):19-29.
35. Braithwaite V, McGown A. Caregivers' emotional well-being and their capacity to learn about stroke. *Journal of Advanced Nursing* 1993;18:195-202.
36. O'Connell B, Baker L, Prosser A. The educational needs of caregivers of stroke survivors in acute and community settings. *Journal of Neuroscience Nursing* 2003;35(1):21-8.
37. O'Connell B, Baker L. Managing as carers of stroke survivors: strategies from the field. *International Journal of Nursing Practice* 2004;10(3):121-6.
38. Ekwall A, Sivberg B, Hallberg IR. Dimensions of informal care and quality of life among elderly family caregivers. *Scandinavian Journal of Caring Sciences* 2004;18(3):239-48.
39. Wright LK, Hickey JV, Buckwalter KC, Clipp EC. Human development in the context of aging and chronic illness: the role of attachment in Alzheimer's disease and stroke. *International Journal of Aging Human Development* 1995;41(2):133-50.
40. Twigg J. Carers in the service system. In: *Carers Research and Practice*. London: HMSO; 1992. p. 59-94.
41. Hanson EJ, Tetley J, Clarke A. Respite care for frail older people and their family carers: concept analysis and user focus group findings of a pan-European nursing research project. *Journal of Advanced Nursing* 1999;30(6):1396-407.
42. Draper B, Poulos C, Cole A, Poulos R, Ehrlich F. A comparison of caregivers for elderly stroke and dementia victims. *Journal of American Geriatric Society* 1992;40:896-901.
43. Kuyper MB, Wester F. In the shadow: the impact of chronic illness on the patient's partner. *Qualitative Health Research* 1998;8(2):237-53.
44. Periard ME, Ames BD. Lifestyle changes and coping patterns among caregivers of stroke survivors. *Public Health Nursing* 1993;10(4):252-6.
45. Hall A, Wellman B. In: Cohen S, S. Leonard, editor. *Social support and Health*. New York: Academic Press Inc.; 1985.
46. Cohen S, Syme SL. *Social support and Health*. New York: Academic Press Inc.; 1985.
47. SCB. *Statistisk Årsbok (Statistical Yearbook)*. Stockholm: Statistiska Centralbyrån; 2001.
48. Bakas T, Austin JK, Jessup SL, Williams LS, Oberst MT. Time and difficulty of tasks provided by family caregivers of stroke survivors. *Journal Neuroscience Nursing* 2004;36(2):95-106.
49. Robinson-Smith G, Mahoney C. Coping and marital equilibrium after stroke. *Journal of Neuroscience Nursing* 1995;27(2):83-9.

50. Hopman WM, Towheed T, Anastassiades T, Tenenhouse A, Poliquin S, Berger C, Joseph L, Brown JP, Murray TM, Adachi JD, Hanley DA, Papadimitropoulos E. Canadian normative data for the SF-36 health survey. Canadian Multicentre Osteoporosis Study Research Group. *Canadian Medical Association Journal* 2000;163(3):265-71.
51. van den Heuvel ET, de Witte LP, Schure LM, Sanderma R, Meyboom-de Jong B. Risk factors for burn-out in caregivers of stroke patients, and possibilities for intervention. *Clinical Rehabilitation* 2001;15(6):669-77.
52. Pierce LL, Steiner V. What are male caregivers talking about? *Top Stroke Rehabilitation* 2004;11(2):77-83.
53. Clark MS, Smith DS. Changes in family functioning for stroke rehabilitation patients and their families. *International Journal of Rehabilitation Research* 1999;22(3):171-9.
54. Bethoux F, Calmels P, Gautheron V, Minaire P. Quality of life of the spouses of stroke patients: a preliminary study. *International Journal of Rehabilitation Research* 1996;19(4):291-9.
55. Wennman-Larsen A, Tishelman C. Advanced home care for cancer patients at the end of life: a qualitative study of hopes and expectations of family caregivers. *Scandinavian Journal of Caring Sciences* 2002;16(3):240-7.
56. Fayers PM, Machin D. *Quality of Life. Assessment, Analysis and Interpretation*. West Sussex: John Wiley & Sons, LTD; 2000.
57. Browne JP, O'Boyle CA, McGee HM, Joyce CR, McDonald NJ, O'Malley K, Hiltbrunner B. Individual quality of life in the healthy elderly. *Quality of Life Research* 1994;3(4):235-44.
58. Dennis M, O'Rourke S, Lewis S, Sharpe M, Warlow C. A quantitative study of the emotional outcome of people caring for stroke survivors. *Stroke* 1998;29(9):1867-72.
59. Bugge C, Alexander H, Hagen S. Stroke patients' informal caregivers. Patient, caregiver, and service factors that affect caregiver strain. *Stroke* 1999;30(8):1517-23.
60. Greveson GC, Gray CS, French JM, James OF. Long-term outcome for patients and carers following hospital admission for stroke. *Age and Ageing* 1991;20(5):337-44.
61. Wilkinson PR, Wolfe CD, Warburton FG, Rudd AG, Howard RS, Ross-Russell RW, Beech RR. A long-term follow-up of stroke patients. *Stroke* 1997;28(3):507-12.
62. Blake H, Lincoln NB. Factors associated with strain in co-resident spouses of patients following stroke. *Clinical Rehabilitation* 2000;14(3):307-14.
63. Thommessen B, Wyller TB, Bautz-Holter E, Laake K. Acute phase predictors of subsequent psychosocial burden in carers of elderly stroke patients. *Cerebrovascular Diseases* 2001;11(3):201-6.
64. Boter H, Rinkel GJ, de Haan RJ. Outreach nurse support after stroke: a descriptive study on patients' and carers' needs, and applied nursing interventions. *Clinical Rehabilitation* 2004;18(2):156-63.
65. Coen RF, O'Boyle CA, Coakley D, Lawlor BA. Individual quality of life factors distinguishing low-burden and high-burden caregivers of dementia patients. *Dementia and Geriatric Cognitive Disorders* 2002;13(3):164-70.
66. Elmståhl S, Malmberg B, Annerstedt L. Caregiver's burden of patients 3 years after stroke assessed by a novel caregiver burden scale. *Archives of Physical Medicine and Rehabilitation* 1996;77(2):177-82.
67. Denman A. Determining needs of spouses caring for aphasic partners. *Disability Rehabilitation* 1998;20:411-423.
68. Vernooij-Dassen MJ, Persoon JM, Felling AJ. Predictors of sense of competence in caregivers of demented persons. *Social Science & Medicine* 1996;43(1):41-9.
69. Deeken JF, Taylor KL, Mangan P, Yabroff KR, Ingham JM. Care for the caregivers: a review of self-report instruments developed to measure the burden, needs, and quality of life of informal caregivers. *Journal of Pain and Symptom Management* 2003;26(4):922-53.
70. Robinson BC. Validation of a Caregiver Strain Index. *Journal of Gerontology Nursing* 1983;38(3):344-8.
71. Dupuy HJ. The Psychological General Well-being (PGWB) Index. In: Wenger NK, Mattson ME, Furberg CD, Elinson J, editors. *Assessment of Quality of Life in clinical trials of cardiovascular therapies*. New York: Le Jacq Publishing; 1984. p. 170-183.
72. Forsberg-Warleby G, Moller A, Blomstrand C. Spouses of first-ever stroke victims: sense of coherence in the first phase after stroke. *Journal of Rehabilitation Medicine* 2002;34(3):128-33.

73. Lomer M, McLellan DL. Informing hospital patients and their relatives about stroke. *Clinical Rehabilitation* 1987;1(33-37).
74. Pain HSB, McLellan DL. The use of individualised booklets after a stroke. *Clinical Rehabilitation* 1990;4:265-272.
75. Mant J, Carter J, Wade DT, Winner S. The impact of an information pack on patients with stroke and their carers: a randomised controlled trial. *Clinical Rehabilitation* 1998;12:465-476.
76. Grant JS, Elliott TR, Weaver M, Bartolucci AA, Newman Giger J. Telephone Intervention With Family Caregivers of Stroke Survivors After Rehabilitation. *Stroke* 2002;33:2060-2065.
77. Evans RL, Matlock A-L, Bishop DS. Family intervention after stroke: does counselling or education help. *Stroke* 1988;19:1243-1249.
78. Ahlsjö B, Britton M, Murray V, Theorell T. Disablement and quality of life after stroke. *Stroke* 1984;15(5):886-90.
79. Larson J, Franzén-Dahlin Å, Billing E, von Arbin M, Murray V, Wredling R. Spouse's life situation after partner's stroke event: Psychometric testing of a questionnaire. *Journal of Advanced Nursing* 2005;In press.
80. Bradley C. The Well-being questionnaire. In: Bradley C, editor. *Handbook of Psychology and diabetes*. Chur, Switzerland: Harwood Academic Publishers; 1994. p. 89-109.
81. Wredling R, Stalhammar J, Adamson U, Berne C, Larsson Y, Ostman J. Well-being and treatment satisfaction in adults with diabetes: a Swedish population-based study. *Quality of Life Research* 1995;4(6):515-22.
82. EuroQolGroup. EuroQol--a new facility for the measurement of health-related quality of life. *The EuroQol Group. Health Policy* 1990;16(3):199-208.
83. Antonovsky A. The structure and properties of the sense of coherence scale. *Social Science & Medicine* 1993;36(6):725-33.
84. Langius A, Björvell H, Antonovsky A. The sense of coherence concept and its relation to personality traits in Swedish samples. *Scandinavian Journal of Caring Sciences* 1992;6(3):165-71.
85. Undén AL, Orth-Gomer K. Development of a social support instrument for use in population surveys. *Social Science & Medicine* 1989;29(12):1387-92.
86. Henderson S, Duncan-Jones P, Byrne DG, Scott R. Measuring social relationships. *The Interview Schedule for Social Interaction. Psychological Medicine* 1980;10(4):723-34.
87. Svanborg P, Åsberg M. A new self-rating scale for depression and anxiety states based on the Comprehensive Psychopathological Rating Scale. *Acta Psychiatrica Scandinavica* 1994;89(1):21-8.
88. Mahoney FI, Barthel DW. Functional Evaluation: The Barthel Index. *Maryland State Medical Journal* 1965;14:61-65.
89. von Heideken Wågert P, Rönmark B, Rosendahl E, Lundin-Olsson L, Gustavsson JM, Nygren B, Lundman B, Norberg A, Gustafson Y. Morale in the oldest old: the Umea 85+ study. *Age and Ageing* 2005;34(3):249-55.
90. Sommerfeld DK, von Arbin MH. The impact of somatosensory function on activity performance and length of hospital stay in geriatric patients with stroke. *Clinical Rehabilitation* 2004;18(2):149-55.
91. Spector P. Summated rating scale construction. An introduction. Paper number 82. Iowa City: Sage Publications, Inc.; 1992.
92. Jerard K. Basic item analysis for Multiple-choice tests. *Practical Assessment, Research & Evaluation (PAREonline.net)* <http://pareonline.net/getvn.asp?v=4&n=10> ISSN 1531-7714 1995.
93. Polit D, Hungler B. *Nursing Research. Principles and Methods*. 6th ed. Philadelphia: Lippincott Williams & Wilkins; 1999.
94. World Medical Association declaration of Helsinki. *Ethical Principles for Medical Research Involving Human Subjects*. 1964 [cited; Available from: <http://www.wma.net/e/policy/pdf/17c.pdf>
95. Kazdin AE. *Research design in clinical psychology*. 3rd ed. Boston: Allyn And Bacon; 1998.
96. Han B, Haley WE. Family caregiving for patients with stroke. Review and analysis. *Stroke* 1999;30(7):1478-85.

97. Bakas T, Burgener SC. Predictors of emotional distress, general health, and caregiving outcomes in family caregivers of stroke survivors. *Top Stroke Rehabilitation* 2002;9(1):34-45.
98. van den Heuvel ET, Witte LP, Stewart RE, Schure LM, Sanderman R, Meyboom-de Jong B. Long-term effects of a group support program and an individual support program for informal caregivers of stroke patients: which caregivers benefit the most? *Patient Education and Counseling* 2002;47(4):291-9.
99. Borden W, Berlin S. Gender, coping, and psychological well-being in spouses of older adults with chronic dementia. *American Journal of Orthopsychiatry* 1990;60(4):603-10.
100. Wyller TB, Thommessen B, Sodring KM, Sveen U, Pettersen AM, Bautz-Holter E, Laake K. Emotional well-being of close relatives to stroke survivors. *Clinical Rehabilitation* 2003;17(4):410-7.
101. Goode WJ. A theory of role strain. *American Sociological Review* 1960;25:483-496.
102. Kaye LW, Applegate JS. Men as elder caregivers: a response to changing families. *American Journal of Orthopsychiatry* 1990;60(1):86-95.
103. Pruchno RA, Resch NL. Husbands and wives as caregivers: antecedents of depression and burden. *The Gerontologist* 1989;29(2):159-65.
104. Sit JW, Wong TK, Clinton M, Li LS, Fong YM. Stroke care in the home: the impact of social support on the general health of family caregivers. *Journal of Clinical Nursing* 2004;13(7):816-24.
105. Yee JL, Schulz R. Gender differences in psychiatric morbidity among family caregivers: a review and analysis. *The Gerontologist* 2000;40(2):147-64.
106. Matthews JT, Dunbar-Jacob J, Sereika S, Schulz R, McDowell BJ. Preventive health practices: comparison of family caregivers 50 and older. *Journal of Gerontology Nursing* 2004;30(2):46-54.
107. Wyller TB. Stroke and gender. *Journal of Gender Specific Medicine* 1999;2(3):41-5.
108. Rees J, O'Boyle C, MacDonagh R. Quality of life: impact of chronic illness on the partner. *Journal of the Royal Society of Medicine* 2001;94(11):563-6.
109. Sales E. Family burden and quality of life. *Quality of Life Research* 2003;12 Suppl 1:33-41.
110. Peteet JR. A closer look at the concept of support: some application to the care of patients with cancer. *General Hospital Psychiatry* 1982;4(1):19-23.
111. Williams A. What bothers caregivers of stroke victims? *Journal of Neuroscience Nursing* 1994;26(3):155-61.
112. Smith LN, Lawrence M, Kerr SM, Langhorne P, Lees KR. Informal carers' experience of caring for stroke survivors. *Journal of Advanced Nursing* 2004;46(3):235-44.
113. Scholte op Reimer WJ, de Haan RJ, Pijnenborg JM, Limburg M, van den Bos GA. Assessment of burden in partners of stroke patients with the sense of competence questionnaire. *Stroke* 1998;29(2):373-9.
114. Morimoto T, Schreiner AS, Asano H. Caregiver burden and health-related quality of life among Japanese stroke caregivers. *Age and Ageing* 2003;32(2):218-23.

APPENDIX

LISS-formuläret

Närståendeskattning av egen livssituation efter inträffat stroke

Nr:

Initialer:

Datum:

Stroke kan, liksom annan sjukdom, under en tid påverka hela familjen. Vi vill därför be Dig besvara några frågor om hur Din egen situation påverkats av Din närståendes stroke

Besvarandet av frågorna är helt frivilligt och Du är i Din fulla rätt att avstå utan att detta på något sätt påverkar den behandling som Din närstående får.

Du som fyller i blanketten är (ringa in det som passar):

Make Maka Sambo Barn Syskon

Annan närstående, nämligen:

Frågorna avser situationen under den senaste veckan.

Vi ber Dig att svara genom att ringa in lämpligt svarsalternativ. Om Din strokedrabbade anhöriga fortfarande vårdas på sjukhus kan en del av nedanstående frågor vara svåra att besvara. Vi ber Dig i så fall att lämna dessa frågor obesvarade.

1=hela tiden 2=nästan hela tiden 3=ibland 4=nästan inte alls 5=inte alls

- | | | | | | |
|--|---|---|---|---|---|
| 1. Jag är orolig för min närstående | 1 | 2 | 3 | 4 | 5 |
| 2. Jag känner mig osäker inför situationen | 1 | 2 | 3 | 4 | 5 |
| 3. Jag upplever situationen hemma som oförutsägbart | 1 | 2 | 3 | 4 | 5 |
| 4. Jag känner mig maktlös | 1 | 2 | 3 | 4 | 5 |
| 5. Jag känner mig resignerad | 1 | 2 | 3 | 4 | 5 |
| 6. Jag har svårt att känna glädje | 1 | 2 | 3 | 4 | 5 |
| 7. Jag känner mig förtvivlad | 1 | 2 | 3 | 4 | 5 |
| 8. Jag upplever att stämningssläget hemma växlar | 1 | 2 | 3 | 4 | 5 |
| 9. Jag måste hela tiden tänka på vad jag säger eller gör | 1 | 2 | 3 | 4 | 5 |
| 10. Jag måste hela tiden anpassa mig till min närstående | 1 | 2 | 3 | 4 | 5 |
| 11. Jag är mycket bunden av min närstående nu
efter insjuknandet i stroke | 1 | 2 | 3 | 4 | 5 |
| 12. Jag drar mig undan omvärlden | 1 | 2 | 3 | 4 | 5 |
| 13. Jag känner mig isolerad från omgivningen | 1 | 2 | 3 | 4 | 5 |

