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Life After a Stroke Event

With Special Reference to Aspects on Prognosis, Health and Municipality Care Utilization, and Life Satisfaction Among Patients and Their Informal Caregivers

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Abstract
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Objectives. The aim of this thesis was to study the prognosis, health care utilization and health situation in stroke patients, and informal caregiver burden during the first post-stroke year.

 Material and methods. 390 patients, 65 years or older, discharged from hospital after a stroke, were followed with repeated patient interviews, patient record and register data, and hospital staff and informal caregiver questionnaires.

 Results. Prognosis assessments performed by hospital staff at discharge regarding the course of events during the following year were highly accurate and were mainly influenced by the patient's pre- and post-morbid state. The risk of dying or having a new stroke decreased rapidly during the early post-morbid phase. Health care utilization, in hospitals as well as in primary health care, and municipal social service support was considerably higher after the stroke than before, but the utilization of services was lower than previously reported. Health problem prevalence according to interview and record scrutiny was modest, peaked early after discharge and then declined. Support from informal caregivers increased significantly after discharge and remained high during the first post-stroke year. The support given was mainly determined by patient functional ability, distance to patient, relation to patient, municipal social service support provided, and patient sex. The informal caregivers reported considerable strain and burden, with significantly higher levels of anxiety and depression than the stroke patients. Moreover, there was a parallel between the patient's and the caregiver's situation regarding anxiety, emotional and social situation, and home, social and outdoor activities.

 Conclusion. Hospital staff prognosis assessments of patient outcomes during the next year were highly accurate. Risk of recurrence and mortality, and health problem prevalence was high in the early post-stroke period, and than declined. Health care utilization and municipality social support increased over time. Informal caregivers reported considerable strain and burden.

Keywords: stroke, older age, prognosis, care utilization, life situation, informal caregiver, health problems, survival, hazard, nursing

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To My Family

List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

I   Olai L, Omne-Pontén M, Borgquist L, Svärdsudd K. Prognosis assessment in stroke patients at discharge from hospital. *Age and Ageing* 2007;36:184-89.*

II   Olai L, Omne-Pontén M, Borgquist L, Svärdsudd K. Survival, hazard function for a new event, and healthcare utilization among stroke patients ≥ 65 years. *Stroke* 2009;40:3585-90.*

III Olai L, Omne-Pontén M, Borgquist L, Svärdsudd K. Health problems in elderly patients during the first post-stroke year. Submitted.

IV   Olai L, Omne-Pontén M, Borgquist L, Svärdsudd K. Life situation among stroke patients and their informal caregivers. Manuscript.

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Contents

Abbreviations

ADL	Activities in Daily Living
CB	Caregiver Burden scale
CI	Confidence Interval
GQL	Gothenburg Quality of Life instrument
HAD	Hospital Anxiety and Depression scale
HR	Hazard Ratio
ICD	International Classification of Diseases
MMSE	Mini Mental State Examination
N	Number
NHP	Nottingham Health Profile
PHCC	Primary Health Care Centre
PIN	Personal Identification Number
RS	The National Stroke register, Riks-Stroke
SAS	Statistical Analysis System
SD	Standard Deviation
VIPS	Swedish VIPS (Well-being Integrity Prevention and Safety)-model for nursing documentation in patient records

Prologue

When I started to work in hospital in 1975 many stroke patients with severe stroke sequels were staying at the geriatric long-term wards and were regarded as patients with no hope of recovery. They stayed there for several years, most often together in non-single sickrooms. Since that time the stroke treatment, rehabilitation and care have been much more efficient, as advances in basic sciences and clinical research have developed. Knowledge of the human brain capacity of recovery and appropriate treatments applied at the right time and in sufficient amounts has improved the stroke recovery.

This is good message, but questions about what happens after discharge remain. No two patients with stroke present identical symptoms; the consequences are at variance.

Most persons who get a stroke are elderly, but irrespective of age, stroke may be a dramatic event, and most often comes as a 'lightning from a clear sky'. Having a stroke affects many aspects of the lives of the stroke patients and their next-of-kin, other relatives or close friends, *i.e.*, their informal caregivers. Long-term recovery and rehabilitation are often necessary to support stroke patients, adapting them to live with the effects of stroke and to help family members adjust to the caregiver role. During the stroke care process, many elements of the health care continuum are utilised, including emergency and acute care, in- and outpatient rehabilitation, primary health care, municipality social service support, home care, and institutional care. This entails a risk of limited co-operation and transfer of adequate information between the many categories of care professionals that may be involved.

On a mountain tour in Jotunheimen, Norway in the summer of 2009, it was obvious to me how it would be to walk together with someone after a stroke event. After hospital discharge, pathways can be in many different ways for the stroke patient and for the informal caregiver. The path is not always easy to find, but sometimes it can be broad and easy to go. It may go uphill and downhill, the path seems to disappear and it is hard to know where to go. Sometimes there are mounds of stones, but sometimes they had to find their own way. The stroke patients and their caregivers do not always go side by side on the same path or at the same pace.

Since many years I have a special interest in care of older persons, in the boundary of the county council operated care and the municipality social service support. Why is it so difficult to co-operate? All involved should aim to have the stroke patients' and the informal caregivers' welfare as goal:

What is the best for each individual? The health care professional must act as a pathfinder or as a guide to facilitate the stroke patient's and the informal caregiver's way through life.

This thesis aims at describing the situation for the stroke patient after hospital discharge and also to shed light on the informal caregivers' situation from a nursing perspective in primary health care.

Introduction

Stroke is the most common cause of impaired functional capacity in adult persons, and it is also the somatic disease causing the most extensive needs for health care in Sweden [1].

The World Health Organization (WHO) defines stroke as "rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin" [2]. It represents a wide range of clinical manifestations. The two broad categories of cerebral lesions are infarcts and haemorrhages, accounting for 85% and 15% of events, respectively [1].

Stroke is a multi-aetiological disease, and the underlying process is most often atherosclerosis of brain arteries. Depending on location and extent of the brain damage a wide range of clinical manifestations may occur. The symptoms depend on which part of the brain that is injured, and how severely it is affected. The symptoms may be numerous and may affect various parts of the body.

The multitude of symptoms that may affect patients in different ways and the resulting disability varies from complete recovery to devastating impairment or death. Patients may have indistinct difficulties as of cognitive or perceptual nature, which may have at least as great impact on functional ability and on quality of life, as more obvious symptoms. For many of the patients serious health problems may remain after discharge from hospital, and some may persist during several years after the stroke onset [3]. Even hidden dysfunctions may have consequences, less apparent to the general public, although resulting in problems for the stroke patient in daily life.

Incidence and prevalence

As the elderly population is growing in the high-income countries, stable incidence and increasing longevity will result in rapidly increasing numbers of persons suffering stroke. A recent review suggested that the worldwide stroke incidence rate may be higher than previously reported, since community-based studies from new parts of the world have been reported [4]. In Europe, stroke events are expected to increase from 1.1 million per year in 2000 to more than 1.5 million per year in 2025, solely based on demographic changes [5]. In northern and middle Scandinavia incidence rates are signifi-

cantly higher than in other regions, and with an ageing population the burden in the municipality is increasing [6].

The Board of Directors of the National Stroke Register [1] have reported stable stroke incidence rate in Sweden, where approximately 30 000 persons suffer from stroke every year. Of these, 20 000 are first-ever strokes. Studies from various populations show inconsistent time trends regarding incidence and stroke case fatality rates. Worldwide, stroke is more common among men than women. Women get their first stroke about four and a half years later than men, and they have more severe strokes [4, 7]. In Sweden, approximately the same numbers of women as men suffer a stroke. Among persons below 65 years the number of men is twice that of women, and among persons over 85 the number of women is twice that of men [8]. The incidence rates rise sharply with advancing age: in Sweden more than 80%, of stroke cases are over 65 years and the average age for stroke onset is 76 years, 78 among women and 73 among men [1].

It has been suggested that stroke has become less disabling, in Sweden [9, 10] as well as in other western countries [11]. Approximately one third of the patients suffer severe stroke, one forth moderate stroke and the remaining patients have minor symptoms that may be of short duration, although more than half of all patients have persisting disabilities after the stroke [12]. In follow-up studies one year post-stroke, one forth of stroke patients 80 years or older had mild or no disability, one fifth had severe disability, and more than half had died [13].

Risk of mortality and recurrence

On a global level, stroke is the second largest cause of death [14, 15], although stroke mortality rates vary greatly among countries. Differences are apparent, with a high burden in north Asia, Eastern Europe, central Africa, and the south Pacific [16].

During the last decade the advent of thrombolytic therapy [17] and the implementation of stroke units have improved survival and stroke outcomes [18]. The survival rates among stroke patients have increased manifold [11]. Increased long-term stroke survival has been observed in studies in Sweden [10, 19, 20]. Advancing age is associated with high mortality and the burden of ischemic stroke is high in patients 80 years old or older [13]. The outcome is worse for stroke patients, irrespective of age or the duration of follow-up, than for the general population of the same age and gender [21, 22]. In addition, patients with recurrent stroke have poorer outcomes than those with first-ever stroke [23, 24], but those who survived recovered as fast and as well as patients with a first-ever stroke [23].

Medical complications that occur during hospitalization may affect patient mortality far beyond the acute stage [25]. However, most of the high

mortality in ischemic stroke patients appears within the first month [26, 27]. Appelros *et al.* [4] reported recently that the case fatality at one month is higher among women, while Di Carlo *et al.* [7] did not find any significant gender effect on survival rates, at three months follow-up.

Female sex [28], as well as medical and socio-demographic factors, has been shown to significantly influence stroke outcome [29]. Co-morbidity and illness severity among elderly medical patients admitted to hospital significantly affect length of stay, mortality, and readmission, but not discharge destination [30].

Previous attempts to estimate the risk of stroke recurrence or mortality have usually been based on the cumulative hazards (or survival) function provided by various types of life table methods, including proportional hazards regression. However, in cumulative hazards or survival functions fluctuations across time tend to be evened out, making assessment of the risk in various time intervals difficult. Today, the hazard function may fairly easily be computed using modern standard software. No hazard functions (risk level in relation to follow-up time) for stroke recurrences or stroke mortality seem to have been published.

Stroke care

Since admission to hospital in Sweden is free of charge for the patient, virtually all patients with clinical signs and symptoms indicating stroke are admitted, except some already institutionalized [6, 31, 32], and some patients with very mild stroke [32]. Access to Computerised Tomography (CT) investigation is nearly complete [6, 33].

The development of stroke care has focused on establishing stroke units. Care at a stroke unit has been shown to improve stroke survival [34-36], functional outcome after stroke [34, 35] and reduce the need for institutional care [35, 36]. The overall goals for stroke units are evidenced-based acute care with best possible recovery and least possible remaining disability. A stroke unit is characterized by co-ordinated care and rehabilitation using a multidisciplinary team and meetings in common. Disciplines represented are medical care, nursing care, occupational therapy, and physiotherapy, among others. The health care professionals have regular education and training in stroke management, and routine involvement with the carers in the rehabilitation process [37]. Despite strong scientific evidence for stroke units, they are still far from universally implemented [38], and patients are still cared for in general Internal Medicine Wards, in Sweden as well as in other parts of the world.

The stroke unit is the first part of a chain of care efforts in stroke rehabilitation. Successful rehabilitation requires close co-ordination between in-hospital care, outpatient care and municipality-based social service support.

Stroke patients are conventionally referred from the stroke unit or from a medical ward to a rehabilitation unit, where they have a substantial part of their rehabilitation. Alternatively, early discharge support from hospital is organized, with emphasis on rehabilitation and services at home. Rehabilitation has been shown to reduce death and dependency after stroke [39, 40].

Transition

Older persons with continuous multifaceted care needs frequently require care in multiple settings. Therefore, the Swedish government introduced new regulations in 2005 (SOSFS 2005:27) in order to bridge the gap between in-hospital care and care outside hospital, with the purpose to secure the information and communication and to improve the routines connected with discharge planning.

The discharge is a challenging and complex time, for both patients and caregivers, and many issues may be raised. The time period of the transition out of hospital to the home has been found to be a period of uncertainty and of great significance for the future [41]. Inappropriate discharge planning, in conjunction with early discharge, may have an impact on the rehabilitation process of stroke patients and pose increased and unrealistic demands on the informal caregivers [42, 43]. During transitions between settings, elderly stroke patients are particularly vulnerable. The lack of appropriate discharge decisions may cause unnecessary suffering, inefficient use of health care resources, and potentially serious errors in long-term management. This may cause problems such as fragmentation of care and poor care quality.

Prediction of outcome

Accurate information on outcome and the extent of continuing disability after stroke is necessary for the rationale, planning, provision, and allocation of health services for patients with stroke. Therefore, the health care professionals have an important role to mediate information about expected recovery. The stroke patient, the next-of-kin, and those professionals taking over the nursing and medical responsibility and municipality social service support, need information useful for counselling and decision-making.

Problems inherent in clinical prognosis assessment in stroke patients are the heterogeneity of the patient group [44] and the many professional categories involved in the care of patients, possibly causing limited dissemination of important information among staff or a limited knowledge of the patient needs.

A number of models have been developed to improve prognosis assessments [45], some complex others easy to use, and most of them with short

follow-up times. However, in medical practice clinical judgment is most often used. Measures of the ability of the staff to forecast the course for the patient during the next future are needed to improve discharge planning.

After discharge

After discharge from acute or rehabilitation wards, most of the stroke patients return back to their homes [46]. As infirmities set in, the municipal social service may give support, such as personal safety alarms, meals on wheels, transportation service, and home adaptations. As the need for support increases, patients may receive home help and home medical services. Short-term care may be a temporary relief for informal caregivers of severely ill persons. Terminal care in the home is also becoming increasingly common. Elderly people, who need round-the-clock care, may be granted special housing or be admitted to nursing homes. Such homes have generally been operated by the local municipality authorities. In Sweden, primary health care for the elderly can be a task for the county council or for the local authorities [47]. In the study area primary health care was county council operated at the time of the study. Moreover, patient fees for hospital outpatient clinics, general practices, and municipal social service support are heavily subsidized by central and local governments, which means that private financial resources are seldom an obstacle to health care utilization.

With a growing elderly population and improved long-term stroke survival, the health care organizations and the municipalities will be faced with even more extensive care requirements. A number of studies have reported on specific aspects of health care utilization after a stroke event [24, 48], while studies of the total health care utilization panorama before and after the event are needed for a better understanding of the course of events.

Health problems

Stroke patients often experience their process of adjustment to the effects of the disease as difficult and slow, with plateaus in recovery and with unexpected delays [49]. Even patients with mild stroke symptoms, with no visible remaining functional problems, may still have disabilities, such as fatigue, memory and concentration difficulties. It is important to know the nature and timing of complications, during inpatient and outpatient care, and to identify high-risk patients when planning stroke services [50], since many complications can be prevented or treated [3].

Hidden dysfunctions are seldom paid attention to due to short caring episodes, especially for persons with mild strokes [33], and medical and nursing problems after discharge are common. It is important for medical staff, to

have knowledge about the large spectrum of conceivable health problems. Nevertheless, health care professionals may be unaware of many health problems in the elderly [51]. Older people do not report slight or moderately severe disabilities to their physicians, until the condition is advanced [51], as they view the process of ageing as one that is inevitably linked with health problems [52].

Most medical complications develop within the first few weeks of stroke [3, 53] but with reference to shorter hospital stays, it is possible that some problems will not be obvious until after the discharge. Heterogeneous health problems may have different onsets and duration and result in various limitations in function, activity and social life.

Studies on health care problems among stroke patients usually investigate specific problems at each time, with data generally obtained from either registers, patient records or patient reports. The interpretations are most often based on cumulative data, which results in far too high prevalence.

The knowledge of the course of the health situation post stroke, is insufficient. Previous studies have indicated a wide range of health problems after a stroke incident, including pain, fever, infections, falls, depression, anxiety, emotionalism, confusion, fatigue, *etc.* [3, 50, 53-59]. Most of these studies covered hospital patients, a few studies nursing home patients and post-stroke patients living at home. Health problem assessments in post-stroke patients are usually based on clinical examinations with a neurological focus. Studies with a broader approach or with a longitudinal approach where the change of health situation is assessed over time are lacking. There is thus insufficient knowledge of the type, timing, and frequency of health problems during the first post-stroke year.

Informal caregiver

The effects of the stroke are not limited only to the patient, but also the family, neighbours or close friends may be affected to a considerable degree [60]. The post-stroke patient returning home may be a very different person compared to the pre-stroke self [61, 62], and considerable emotional and physical demands may be placed on family members, neighbours or close friends, who take on the caring role [63]. Caring for frail older family members is a challenging and difficult task, especially for the primary caregiver, who bears the main responsibility for the elderly persons' welfare [64]. The caregivers' willingness and ability to support stroke patients appear to have a significant influence on emotional outcome and on the success of rehabilitation [65-68].

A longitudinal Swedish study found that both formal and informal care tended to increase when a person's needs grew [69, 70]. As the rate of institutional living and social service support have decreased in Sweden [71], the

informal caregiver have had to take over most of the responsibility of caring for the stroke patients.

With a continuing shift towards care outside health care institutions, patients and their caregivers may expect more recovery to take place at home and at an even earlier stage. The health care system has a strong expectation that informal caregivers should look after their relatives at home. This may result in increasing demands primarily on families of stroke patients but with no access to psychosocial support systems for the informal caregivers [60]. Many caregivers found it difficult to express their concerns and anxieties, and they may be reluctant to seek help as a sign of failure or inadequacy. Consequently, many caregivers express feelings of exhaustion and isolation [66].

Informal caregivers taking care of post-stroke patients may experience large burdens due to feelings of responsibility, constant anxiety, loneliness, and decreased social activities [72]. Caregivers at risk of burden can be identified early in the process of rehabilitation on the basis of patient characteristics [73-83] and caregiver related factors [72, 77-81]. Probably, factors such as the relationship between the stroke patient and the informal caregiver, the caregiver's own physical health and their psychological health prior to the stroke, have importance for the care giving situation [84]. Failure to recognise the burden on informal caregivers may result in long-term adverse outcomes.

Relation between stroke patient and informal caregiver

To improve support for stroke patients and their informal caregivers, there is a need of better understanding of the situation of both partners. Until now, the majority of studies have been cross-sectional, thereby limiting the understanding of the time course for stroke patients and their informal caregivers. The parallel situation between the stroke patient and the informal caregiver has been studied, but most often for single outcomes such as depression [80, 85], anxiety [80], quality of life [80, 83, 86], and wellbeing [87]. Studies on the life satisfaction in the stroke patient and the spousal caregiver have been published [46, 86-89]. One year after the stroke couples reported significant strain in their relationship, including family functioning and communication. It appears that when the patients gradually adapt to the new circumstances, it become more demanding for caregivers [86, 90].

Even after a mild stroke, remaining limitations can lead to dependence, limited participation and a decrease in life satisfaction affecting both the stroke patient and their spouses [89]. The social network is often reduced for persons with stroke and the altered situation for their families makes it more difficult to maintain friendship and to participate in leisure activities [60, 89, 91, 92].

The relationship between the stroke patient, the informal caregiver and the impact of the care giving experience on the caregiver's situation is complex and dynamic. Thus it is essential to plan and provide more adequate support for the stroke patient and the informal caregiver. For example, the interaction between stroke patients' impairments and spouses' emotional health differ with time after stroke [93]. The assumption that the stroke patient influences the caregiver's well-being is common, although the converse is possible, *i.e.*, family problems may have an effect on the stroke patient's recovery.

The time-course is not well-known and must be investigated and there is a need for clarification of the dynamic relationship between the stroke patient and the caregiver to better understand their situation and to improve appropriate support.

Aim of the thesis

The aim of this thesis was to gain knowledge about the consequences of a stroke event in patients 65 years or older during the first post-stroke year. The knowledge sought related to the patient, the health care provided by hospital and primary health care, the municipality social service support and the informal next of kin caregivers.

Scientific questions

1. At discharge of a stroke patient from the hospital, how correct can physicians, nurses, occupational therapists and physiotherapists predict the person's health situation during the first post-stroke year, and what are the determinants of the prediction accuracy?
2. What are the hazard functions for stroke recurrence and stroke survival? What is the utilization volume of health care and municipal social service support per time unit before and after a stroke incident adjusted for non-exposure due to death and readmission to hospital?
3. How does the health situation develop during the first-post-stroke year as measured by patient interviews and health care record notes and which are the determinants?
4. How much support do informal caregivers provide? What are the determinants for the support given? How are the informal caregivers affected by their support? Are there similarities between the caregivers' and the stroke patients' life situation?

Study population and methods

Setting

The study was performed in a defined geographical area, the cities of Falun (population 55,000) and Borlänge (population 47,000), with both urban and rural areas, in the county of Dalecarlia, central Sweden [94]. In the study area mean age among women was 42.2 years and 40.1 years among men as compared to 42.1 and 39.9 in Swedish national population in 2008 [95]. The employment rate and the median income were both close to that of the Swedish national population. The two cities are served by Falun General Hospital, the only one in the area.

Study population

The study population was recruited from consecutive stroke patients admitted to Falun General Hospital after an acute stroke (index admission), defined as intra-cerebral haemorrhage, brain infarction, or stroke of undetermined pathological type (ICD10 codes I61, I63, and I64) [96]. Other inclusion criteria were 65 years of age or older and discharged alive from the Department of internal medicine (stroke unit or general ward) during the period 1 September, 1999 to 31 May, 2001. The patients were also required to be living in regular housing before admission and have no pre-admission dementia diagnosis. Stroke patients less than 65 years of age were not included to simplify data collection (no need of social insurance or work related data), no institutionalized persons (not always admitted to hospital), and no demented persons (to avoid interview problems).

However, more than 80% of the total stroke population at the time was included in the study [97]. Out of 432 potential participants, 42 died while in the Department of internal medicine, resulting in 390 study subjects.

Case ascertainment

In order to find the cases a registered nurse visited all participating hospital wards twice a week. Moreover, monthly checks with the hospital patient administration system were done, and every second week the study monitor made enquiries to the district nurses and home help auxiliaries on discharged

stroke patients. When the inclusion period was over, a final check-up in the hospital patient administration system was done.

Data collection procedure

Before the study, information was given to hospital staff (physicians, nurses, occupational therapists, and physiotherapists) at relevant hospital wards. Information was also given to staff at PHCCs and nursing homes, temporary housing facilities, and to home help auxiliaries.

During the hospital stay hospital ward nurses gave oral and written information to stroke patients about the study. One week after discharge from hospital one of the study nurses called the stroke patient, and asked for consent for participation in the study. If consent was given, a first face-to-face interview was performed in the patient's home or dwelling by one of two registered nurses within the next few days. Two further interviews were carried out after three and twelve months after the index admission. A flow chart showing the number of participants throughout the study and causes of drop out is presented in Figure 1. The majority of all follow-up interviews with the stroke patients were carried out within 14 days of the ideal interview date. Whenever possible, the same study nurse conducted all follow-up interviews. Approximately 95% of eligible patients were interviewed. The remaining 5% were either too ill or declined the interview. Forty interviews were performed in duplicate by two independent observers with excellent agreement (kappa ≥ 0.95).

Staff questionnaire (Prognosis form)

At each transfer between the stroke unit, internal medicine or geriatric wards and at discharge from the hospital the patient's physician, nurse, occupational therapist and physiotherapist were asked to assess the prognosis regarding 'need of help', 'health situation', and 'dwelling' at three and twelve months after admission to hospital based on their own clinical judgment, or to leave items blank in case of inability to make an assessment. Altogether more than 50 assessors participated; the exact number is unknown because of granted anonymity.

The outcomes to be forecasted were given in three levels based on data from the second or third patient interview or register data. The staff was asked to indicate for each of three outcomes at what level they thought the patient would be at three and twelve months. For the outcome variable 'need of help' the three levels were 'no need of help' (Katz ADL degree A) [98], 'need of some help' (Katz B-E), and 'completely dependent' (Katz F-G). For the outcome variable 'health situation' the levels were 'completely recovered', 'unchanged situation or better but no full recovery', and 'deteriorated
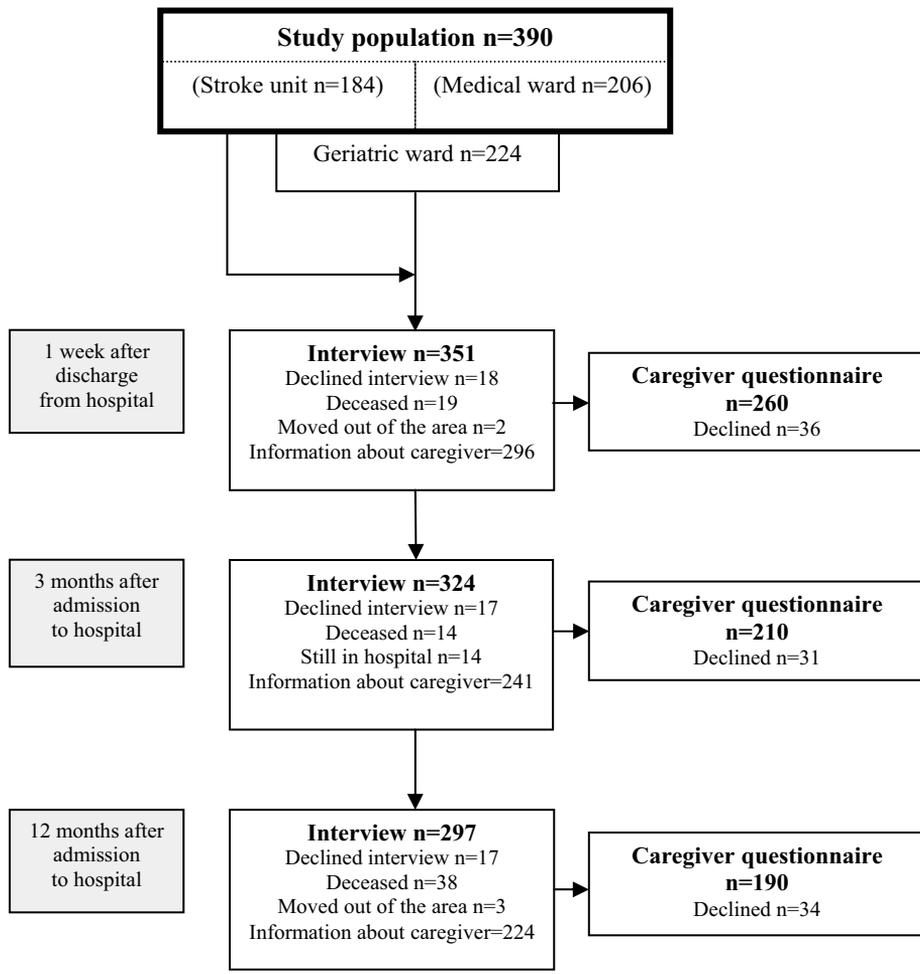
Figure 1. Flow chart of patients and caregivers in the study population

or deceased'. For the outcome variable 'dwelling' the levels were 'living in own apartment or house', 'living in special housing', and 'living in nursing home'.

Finally, the basis for the assessments was sought. Possible responses were medical, nursing, or rehabilitation state, tests, discharge planning information, expected support from next of kin, experience, intuition, other (open-ended alternative), or combinations.

Patient interview data

The various interview and questionnaire instruments used are listed in Table 1. In the first interview demographic information was sought on education, marital status, and cohabitation. In all three interviews Mini Mental State Examination score (MMSE) [99], Hospital Anxiety and Depression scale score (HAD) [100], the Nottingham Health Profile dimension score (NHP) [101], self-rated health score, and prevalent symptoms and health problems were measured. In addition, functional ability was estimated from a Katz ADL assessment [98], ranging from completely independent, grade A (=1) to completely dependent, grade G (=7). The Activity Score subscale in the Gothenburg Quality of Life instrument (GQL-activity) [102] was measured at the first and last interview.

The MMSE [99] is a widely used instrument measuring cognitive ability, with a normal score range of 24-30, lower scores indicate cognitive problems. HAD [100] is a self-rating scale in which the severity of anxiety and depression is rated on four-point verbal rating scales (0-3). The items of the scale have been chosen to be influenced as little as possible by concomitant physical illness. Seven questions are related to anxiety and seven to depression, both with a score range of 0-21, and for overall distress a score range of 0-42. Scores of 8-10 on any of the subscales should be taken as an indication of possible pathology, and scores >11 as 'definite cases'. The HAD scale has been found to be a reliable screening instrument for anxiety and depression [103].

The NHP [101] questionnaire, has been tested in the general population and in various patient populations, including stroke patients. Part I, contains 38 yes/no statements comprising six dimensions of subjective health: physical mobility (8 statements), pain (8), sleep (5), energy (3), emotional reactions (9) and social isolation (5 statements). Within each area statements were weighted, resulting in scores ranging from 0 to 100, with 0 indicating the absence of problems.

Self-rated health have been demonstrated as a predictor of mortality for older persons and has been judged as both reliable and reproducible [104]. The participants were asked to grade their self-reported health on a five-degree ordinal scale, ranging from 1 (poor) to 5 (excellent) and to grade their sense of loneliness, ranging from 0 (never) to 3 (several times a week).

Health problems were measured with a list of 30 medical or nursing problems, and an indefinite number of open alternatives. The patients were asked which of these health problems they had experienced after the stroke or after the previous interview, and whether the symptom was new or exacerbated. Possibly responses were 'yes' or 'no'.

The GQL-activity instrument measured questions on 32 leisure time activities and two open alternatives at the first interview (referring to the pre-admission situation) and at the last interview (referring to the present situation) [102].

Table 1. *Instruments used in the stroke patient interviews and the informal caregiver questionnaires*

	1 week after discharge	3 months after index stroke	12 months after index stroke
Patient interview form	patient	patient	patient
Mini Mental State Examination (MMSE)	patient	patient	patient
Katz Activity of Daily Life (Katz ADL)	patient	patient	patient
Self-rated health	patient	patient	patient
Nottingham Health Profile (NHP)	patient + informal caregiver	patient + informal caregiver	patient + informal caregiver
Hospital Anxiety and Depression scale (HAD)	patient + informal caregiver	patient + informal caregiver	patient + informal caregiver
Gothenburg Quality of Life (GQL-activity)	patient + informal caregiver	-	patient + informal caregiver
Health problems	patient	patient	patient
Informal caregiver questionnaire	informal caregiver	informal caregiver	informal caregiver
Caregiver Burden scale (CB)	informal caregiver	informal caregiver	informal caregiver

Possible responses were never (score=0), occasionally (score=1), or performed often or regularly (score=2). The scores were then summed across three subscales, home activities (score range 0-20), activities outside home (0-28), and social activities (0-16), and to an overall total activity score (0-64) [105].

Informal caregiver questionnaire data

At each interview the respondents were asked who their main informal caregiver was. These received a structured questionnaire in connection with each patient interview with questions about the caregiver's age and sex, relation to the patient (spouse, child, sibling, grandchild, son or daughter in law, neighbour or friend, or other person), distance from the caregiver's to the patient's home (same household, same building, same municipality, or other), the nature and amount of assistance provided, the HAD, NHP, and the Caregiver Burden (CB) scale [81]. In addition, the GQL-activity instrument was included in the questionnaires corresponding to the first and third patient interview, Table 1.

The caregiver was asked whether a number of specified types of assistance had been provided during the previous period, and how much time was spent providing that assistance every week. At the first interview, caregivers were also asked about the care provided in the year before the index admission. Only care specifically focussed on the stroke patients' wellbeing was included. Activities regularly undertaken for the whole household (*e.g.* meal preparation, dish washing, or washing) were included as specific activities, only if the stroke patient was incapable of performing these tasks.

A support score was calculated based on the frequency of the help given from informal caregivers, ranging from no help (score=0) to help several times a day (score=4) in each of 15 different tasks, total score range being 0-60. Moreover, demographic details about the caregivers, such as whether the caregiver was in paid employment before and after the stroke, were recorded.

The CB scale was originally developed to measure perceived burden among family caregivers to patients with stroke and dementia. The scale consists of 22 items, each ranging from no burden (score=0) to high burden (score=4). It is divided into five subscales: general strain (8 items), isolation (3), disappointment (5), emotional involvement (3) and environment (3). The CB scale has been shown to be a valid and reliable instrument to assess caregiver burden [81].

Patient record data

Information on appointments, hospital admissions, and co-morbidity, was obtained by scrutinising hospital patient records. All diagnoses were coded

according to the International Classification of Diseases (ICD), versions 8-10 [96]. Data on age and gender were obtained from the unique 12-digit personal identification number (PIN-code), given in Sweden to all residents at birth or immigration and used in all official documents and registers. The PIN is an excellent and highly reliable tool for record linkage.

Information on date, diagnosis and care provider for appointments with and home calls made by primary health care centre (PHCC) staff (all care-giver categories) and municipal elderly health care was obtained by scrutinising PHCC and municipal elderly health care records regarding health problems, diagnoses, and date of appointment or care given. To avoid classification uncertainty no distinction was made between the concepts complications, sequels or stroke related disability. The health problems documented during the patient interviews, as well as the diagnoses and health problems found after patient record scrutiny were classified into keywords, each coded as yes/no, according to the 'Well-being, Integrity, Prevention and Safety' model (VIPS) for nursing documentation in patient records [106]. The keywords and their contents are presented in Table 2. The information on health problems based on interview data was available at one week after discharge from hospital and at three and twelve months after hospital admission, whereas the information based on patient record scrutiny was available continuously during the first post-stroke year. To facilitate comparison of the two ways of measuring health care problems the patient record based data were computed with the same time frame as the interview data in addition to the continuous mode.

Furthermore, municipal social service support records were scrutinised regarding type of support given and time period, during the year before and the year after admission. Social service support means in this context home help, meals on wheels, transportation service, personal safety alarms and respite services.

National Stroke Register data, Riks-Stroke

The Swedish National Stroke register, Riks-Stroke (RS) is a national quality assessment register for acute stroke, set up in 1994 with the aim to monitor stroke care quality and to improve care by providing comparative feedback data in process and outcome for hospitals treating stroke patients [34]. Since 1998 RS covers all Swedish hospitals with acute stroke patients of all ages and with the stroke diagnoses intra-cerebral haemorrhage, cerebral infarction and unspecified stroke (ICD10 codes I61, I63 and I64). Data collection in RS is kept simple to ensure maximum coverage [28], and the results from individual hospitals may be compared with national data. The questionnaires in RS are updated regularly and new versions of its contents are available online (http://www.riksstroke.org/files/contents.html).

Table 2. *Keywords and their content in the Well-being, Integrity, Prevention, and Safety (VIPS) model for nursing documentation*

Keyword	Content
Communication	Speech impairment, aphasia, apraxia
Cognition, development	Memory deficits, concentration difficulty, understanding of health and illness, lack of initiative or motivation, attention impairment, difficulties with planning and organizing, post stroke dementia
Breathing, circulation	Respiratory problems, aspiration, dyspnoea, coughing, heart problems, deep vein thrombosis, bleeding, body temperature, oedema, cyanosis
Nutrition	Swallowing difficulties, nausea, vomiting, appetite loss, weight loss
Elimination	Urinary tract problem, bladder or bowel incontinence, diarrhoea, constipation
Skin	Integument, lesions, ulcers, wound infection, sweating
Activity	Paralysis, falls, spasticity, contracture, deteriorated condition, activity limitations
Sleep	Fatigue, daytime sleepiness, tiredness, restlessness, sleeping problems
Perception with pain	Shoulder pain, pain syndrome, headache
Perception other than pain	Perception and coordination deficits, vision or hearing limitation, sensibility impairment, balance disturbance, dizziness
Psycho-social	Inability to control emotions, pathological crying, anxiety, uneasiness, stressfulness, social deprivation, personality change, uncertainty, irritability, depression
Well-being	Deterioration, stroke recurrence
Composite assessment	Other health problems

Data on independence regarding transfer, personal hygiene and dressing immediately prior to the stroke incident, available for 365 patients, were obtained from the RS as measures of pre-morbid state.

National Hospital Discharge Register data

The Swedish National Hospital Discharge Register is a register based on all patients discharged from all hospitals in Sweden (www.sos.se/epc). Information from the register on day of admission, day of discharge, and all diagnoses for all admissions to hospital from 1971 until June 2006 was obtained for all patients included in the study, using the PIN-code as means of linkage. All diagnoses were coded according to the ICD versions 8-10 [96].

National Cause of Death Register data

The National Cause of Death Register includes all fatal events among Swedish residents, whether Swedish citizens or not and irrespective of place of death. Information on date of death and underlying cause of death until June 30, 2006 was obtained for the study population from the register. All diagnoses were coded according to the ICD versions 8-10 [96].

Regional Hospital Outpatient Register data

The Dalecarlia Regional Hospital Outpatient Database contains information on all appointments with outpatient clinics at Falun General Hospital. Information on date, diagnosis, caregiver category, and clinic for all hospital outpatient appointments from one year before to one year after the index admission was obtained from the register for the patient study population.

Ethical considerations

All patients in the study population gave oral informed consent to participation and informal caregivers implicit consent, standard procedure at the time. The study complied with the Helsinki Declaration and was approved on several occasions during the planning and data collection, first by the Research Ethics Committee at Uppsala University and later by the National Research Ethics Board.

Statistical considerations

Data were analyzed with the SAS software package, versions 6.12 and 9.1 [107]. Summary statistics, such as means, medians, and measures of dispersion were computed with standard parametric methods. Crude differences between groups in continuous variables were computed with Student's t-test and differences in proportions with the chi-square test. Only 2-tailed tests were used. Survival, health care utilization, diagnoses, and discharge destination data were 100% complete, and post-morbid state data, based on interviews, was 95% complete.

Paper I

Assessment accuracy was measured as number of accurate assessments in relation to total number of assessments done and expressed as a percentage, 33.3% representing chance given the assumption of no knowledge among the staff of the outcome distribution in this patient category.

The analysis of factors influencing the prognosis assessment accuracy was performed with univariate logistic regression with accuracy of individual assessments (yes or no) as the dependent variable and potentially influencing factors as independent variables. Factors affecting at least one outcome were then entered in the final multivariate analyses.

Optimism and pessimism were measured as the proportion of inaccurate assessments more favourable or less favourable than the real outcome. Only two-tailed tests were used. To account for multiple testing p-values <0.005 were regarded as significant.

Paper II

The stroke recurrence and death hazard functions were calculated by means of the SAS 'Lifetest' procedure, providing coordinates for the hazard function and estimates of the influence of various factors on the hazard function. The cumulative survival function was computed with Cox's proportional hazards regression, using age, sex, independence and co-morbidity (prevalent hypertension, myocardial infarction, number of previous strokes, other cardiovascular diseases, and diabetes) as exposure variables, and providing hazards ratios (HR) and their 95% confidence intervals (95%CI).

The proportion of the study population in hospital care any day during the five years before the index admission was calculated. Being an inpatient (=1) or not (=0) was indicated in a set of variables, each variable representing a specific day during the five-year period (day-by-day matrix). Summing the individual matrices and dividing each day variable by the number of exposed patients produced the daily proportion of patients in hospital. The same procedure was used for the five years following the index admission except that exposure to hospital admissions was adjusted for non-survival (a deceased person cannot be admitted to hospital).

The proportion of patients utilizing hospital outpatient and primary health care, and municipal support during the year preceding and following the index admission was computed accordingly. During the year following index admission, exposure was adjusted for hospital admissions and non-survival. All tests on the matrices were done with logistic regression. Only two-tailed tests were used. P-values <0.05 were regarded as significant.

Paper III

Functional ability, MMSE, self-rated health, HAD, and NHP were analysed with linear regression, with each of these variables entered as dependent variable, one at a time, and time of measurement as the independent variable, adjusting for the influence of age, sex, education, marital status, and loneliness (covariates), and providing p-values for trends across time.

The prevalence of the VIPS keywords based on interview data was analysed with logistic regression, with the keyword entered as dependent variable and time and the covariates as independent variables, providing p-values for trends across time. The same procedure was used for patient record data computed with the same time frame as the interview data.

The week-by-week prevalence of the continuously collected VIPS keyword data was calculated using a set of variables, each variable representing a specific week during the year (week-by-week matrix). Having a specific VIPS keyword during a specific week (=1) or not (=0) was indicated in the corresponding week variables. Summing the individual matrices and dividing each week variable by the number of exposed patients produced the weekly proportion of patients with a VIPS keyword, adjusted for non-exposure (being in hospital or deceased). Logistic regression was used to test the prevalence change across the year.

Simultaneous occurrence of more than one VIPS keyword per patient per measurement occasion (co-variation) was analyzed with the 'substring' feature available in the SAS software, and with factor analysis with varimax oblique rotation. Both methods yielded the same results. To account for the many tests performed, $p < 0.005$ was regarded as statistically significant.

Paper IV

The analysis of the determinants of caregiver support score was done with multiple linear regression with support score as the dependent variable and functional ability, distance to the patient, the caregiver's relation to the patient, whether municipal social service support was given, patient's age and sex, MMSE score, caregiver's age and sex, and measurement occasion (time variable) as independent variables, with backward elimination of non-significant independent variables. The analyses of the determinants of CB score and the association between patients' and caregivers' responses to the same type of questionnaires were done accordingly. In all these analyses the time variable was non-significant indicating a stable situation across the first post-stroke year.

The regression surface in Figure 7 was computed from the corresponding analysis model using multiple linear regression analysis with adjustment for the influence of all covariates. P-values < 0.05 were regarded as significant.

Results

Population characteristics

The mean age of the patient study population was 78.7 years, and 223 (57.2%) were females, Table 3. More than half had only compulsory schooling, half of the male group was married and half of the female were widows. Before admission to hospital half of the women and one-third of the men were living alone in regular housing.

Pre-morbid state is shown in Table 3. The majority (84%-90%) could dress, maintain their personal hygiene, transfer without assistance, had some form of help and had contacts with PHCC staff during the twelve months before admission to hospital. More than one-fifth had contacts with the hospital as in- or outpatients.

Based on hospital record data from 1971 and onwards, 174 (78.0%) of the women and 117 (70.1%) of the men were hospitalized for their first-ever-stroke, and a history of hypertension, heart disease or diabetes mellitus was common. Forty-four percent of the women and 51% of the men were cared for in the stroke unit, the remaining in the general internal medicine wards. The dominant diagnosis was cerebral infarction, 88%, equal for men and women. In 97% of the cases a computerised tomography scan was performed.

The average time spent in these wards was 7 days, inter-quartile range 3-9. Forty-three percents of the patients were discharged from the hospital and the remaining were transferred to a geriatric ward where they stayed on average for another 30 days, inter-quartile range 14-41. At the end of the hospital stay 73% were discharged to their homes, while the remaining were discharged to various institutions or died in hospital.

Remaining functional ability measured one week after discharge showed that slightly more than half were in Katz grade A, one-fourth were classified as grade F or G, and the remaining were in B-E. Mean MMSE-score was 22.3, (inter quartile range 19-29), 122 (36.2%) patients scoring <24 points on the MMSE, indicating possible cognitive dysfunction.

On the HAD subscale 'anxiety', 28 (10.0%) patients scored 8-10, indicating possible pathology, and 19 (6.5%), scored 11-31, indicating definite cases. Corresponding values for the subscale 'depression' were 25 (9.6%) patients and 22 (7.5%) patients, respectively.

Table 3. *Socio-economic data and pre-morbid state in the patient study population during twelve months before admission to hospital*

	Women			Men		
	N	Mean or %	SD	N	Mean or %	SD
Age at admission to hospital, years	223	79.8	6.50	167	77.3	6.26
Socio-economic data						
Education						
Elementary school	133	59.4		92	55.4	
Junior secondary /vocational school	30	13.4		29	17.5	
College/university	12	5.4		20	12.0	
Marital status						
Never married	22	9.8		20	12.0	
Married/cohabiting	56	25.0		93	56.0	
Widowed/divorced	110	49.1		31	18.7	
Living alone	110	49.1		53	31.9	
Pre-morbid state						
Independence in						
Transfer	189	84.4		145	87.3	
Personal hygiene	202	90.2		147	88.6	
Dressing	199	88.8		145	87.3	
Community home help [1]	73	32.6		43	25.9	
Help from next of kin	93	41.5		76	45.8	
PHCC[2] visits/home calls [3]	202	90.2		143	86.1	
Hospital in-patient admissions (days)	47	21.0		40	24.1	
Hospital out-patient visits	45	20.1		47	28.3	
Medical history						
Previous cerebro-vascular events	79	35.3		62	37.3	
Hypertension	94	42.0		52	31.3	
Heart disease	122	54.5		94	56.6	
Diabetes mellitus	46	20.5		42	25.3	

[1] On average 1.58 visits per day for women and 1.13 for men among those concerned
[2] Primary Health Care Centre
[3] Out of which 37.4 district nurse home calls for women and 46.1 for men among those concerned

The well-being score was 3.7 (inter quartile range 3-4). The proportion of patients independent in terms of transfer, personal hygiene and dressing was substantially lower at discharge than before admission.

The informal caregiver characteristics are shown in Table 4. Two thirds of the caregivers were women, and mean age was 62 years (range 23-89). Almost half were spouses, and four out of ten were children to the patients. Slightly less than half of the caregivers were living in the same household or the same building as the patient; another 40% were living in the same municipality, while 13% were living in other municipalities. Before the index admission less then half provided some form of care, on average five hours per week and 8-11 support score. The corresponding numbers after discharge were more than six out of ten, 11 hours per week and 13-15 support scores.

Table 4. *Informal caregiver characteristics*

	Women		Men	
	N	Mean (SD) or %	N	Mean (SD) or %
N [1]	169		90	
Age, years		62.2 (13.35)		62.7 (14.36)
Caregiver's relation to patient				
Spouse	82	46.6	40	40.8
Child	67	38.1	47	48.0
Sibling	9	5.1	4	4.1
Neighbour or friend	8	4.6	4	4.1
Grandchild	3	1.7	1	1.0
Son or daughter in law	3	1.7	0	-
Other relative	4	2.3	2	2.0
Distance to patient				
Same household	78	44.3	43	43.9
Same building	6	3.4	2	2.0
Same municipality	73	41.5	37	37.8
Other municipality	19	10.8	16	16.3
Support given to patient				
Before index admission				
Caregivers providing support	74	43.8	48	53.3
Hours per week		5.4 (15.54)		5.8 (13.96)
Support score		10.9 (9.56)		8.5 (7.56)
After index admission				
Caregivers providing support	100	59.2	58	64.4
Hours per week		11.2 (20.30)		10.7 (15.26)
Support score		15.0 (11.62)		13.6 (10.10)

[1] Data on gender missing for one caregiver

Study I

Outcome and prognosis assessments

Outcomes at three and twelve months after admission to hospital are shown in Table 5. More than half of the patients had no need of help, an unchanged health situation or no full recovery, and more than 75% lived in regular housing. The overall accuracy of the assessments in three months was on average 68.4% and for twelve months 61.5%. For three months the accuracy was 64.5% for 'need of help', 62.4% for 'health situation', and 78.4% for 'dwelling'. The corresponding proportions for twelve months were 60.1%, 56.2% and 68.2%, all highly significantly better than chance ($P<0.0001$). Inaccurate assessments were mainly dominated by overly optimistic assessments regarding the 'health situation' and overly pessimistic assessments regarding 'dwelling'.

Table 5. *Outcome 3 and 12 months after admission to hospital, based on interviews and register data*

	3 months after stroke index		12 months after stroke index	
	N	%	N	%
Need of help				
No need of help (level 1)	184	51.8	165	52.5
Need of some help (level 2)	86	24.2	76	24.2
Completely dependent (level 3)	56	15.8	59	18.8
Insufficient information	29	8.2	14	4.5
Deceased or moved	35	-	76	-
Health situation				
Completely recovered (level 1)	72	18.6	61	15.8
No full recovery (level 2)	187	48.2	178	46.2
Deterioration (level 3)	32	8.2	20	5.2
Deceased (level 3)	33	8.5	71	18.4
Insufficient information	64	16.5	55	14.3
Moved	2	-	5	-
Dwelling				
Own housing (level 1)	267	75.2	240	76.4
Special housing (level 2)	52	14.6	53	16.9
Nursing home (level 3)	36	10.1	21	6.7
Deceased or moved	35	-	76	-

In univariate logistic regression analyses patient age, cohabitation, pre-morbid state (activity degree, hypertension history), remaining functional ability, staff occupational experience, ward speciality, and assessment made by a physician all affected the assessment accuracy of one or more outcomes. No influence was found for patient sex, co-morbidity other than hypertension, first or recurrent stroke event, stroke type, time lag between assessment and outcome per assessment period, and staff categories other than physician.

In a set of multivariate logistic regression analyses, with assessment accuracy entered as dependent variable and all the variables univariately affecting outcome accuracy entered as independent variables the effect size and direction of each factor on outcome was fairly consistent in the three and twelve months' perspective, although some were significant and others were not, Table 6. The accuracy of 'need of help' assessments was affected negatively, *i.e.*, made the assessment more difficult, by the factors living alone before admission and need of help at discharge and positively, *i.e.*, facilitated the assessment, by activity degree before admission and hypertension history. The accuracy of 'health situation' assessments was affected negatively by ward speciality (stroke unit), and positively by pre-morbid state (activity degree), and remaining functional ability. The accuracy of 'dwelling' assess-

Table 6. *Adjusted odds ratios for factors influencing the accuracy of prognosis assessment. Significant ratios are in bold text*

|	3 months after stroke index						12 months after stroke index					
	Need of help		Health situation		Dwelling		Need of help		Health situation		Dwelling	
	OR	95%CI	OR	95%CI	OR	95%CI	OR	95%CI	OR	95%CI	OR	95%CI
Assessment in stroke unit	1.15	0.70-1.90	**0.55**	**0.34-0.91**	0.67	0.34-1.33	1.21	0.71-2.07	**0.57**	**0.35-0.92**	0.59	0.31-1.13
Patient age	1.03	0.99-1.06	1.01	0.98-1.04	0.97	0.93-1.01	1.02	0.98-1.05	0.98	0.95-1.01	**0.95**	**0.91-0.99**
Living alone before admission	**0.62**	**0.42-0.91**	1.07	0.72-1.60	0.67	0.40-1.11	0.82	0.55-1.22	1.35	0.92-1.99	**0.50**	**0.31-0.82**
Activity degree before admission	**1.04**	**1.01-1.07**	0.99	0.97-1.02	1.03	0.99-1.07	**1.04**	**1.02-1.07**	**1.03**	**1.01-1.06**	**1.05**	**1.02-1.09**
Hypertension history	**1.54**	**1.04-2.28**	0.98	0.66-1.46	0.90	0.54-1.50	1.05	0.70-1.56	1.08	0.74-1.58	1.43	0.88-2.33
MMSE[1] level at discharge	1.02	0.99-1.05	**1.06**	**1.03-1.10**	**1.06**	**1.02-1.10**	1.02	0.98-1.05	**1.04**	**1.00-1.07**	**1.05**	**1.01-1.09**
Need of help at discharge	0.78	0.59-1.03	**2.45**	**1.81-3.32**	**0.46**	**0.33-0.65**	**0.56**	**0.42-0.73**	**1.90**	**1.44-2.52**	**0.42**	**0.42-0.30**

[1] Mini Mental State Examination
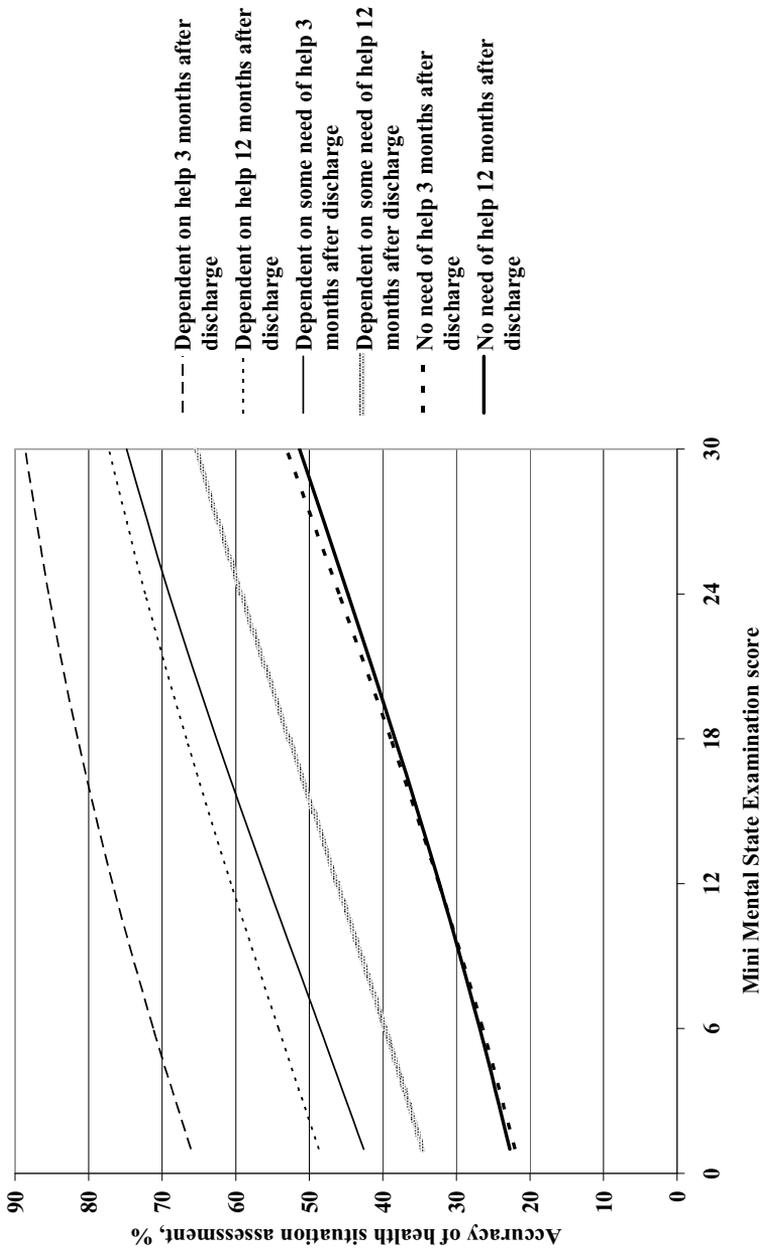
Figure 2. Proportion of accurate health situation prognosis assessments three and twelve months after admission by Mini Mental State Examination score and need of help at discharge

ments was affected negatively by patient age, living alone before admission, and need of help at discharge, and positively by activity degree before admission and MMSE-score at discharge.

Combinations of determinants affected the assessment accuracy markedly. In the example shown in Figure 2 the accuracy of the assessments of 'health situation' at three months ranged from 22% for independent patients with low MMSE score, to 89% for dependent patients with high MMSE score. The corresponding range for twelve months was 23 to 77%.

The overall most common bases for the assessments were rehabilitation status (78.2%), medical status (74.5%), nursing status (60.7%), experience (38.0%), intuition (23.0%), and expected support from next of kin (17.9%).

Study II

Survival and risk of new stroke

During the first year after the index discharge 71 (18.2%) patients died, and altogether 224 (57.4%) died during the first five years. During the first year 55 (14.1%) patients died from cardiovascular disease, whereof 29 (7.4%) from stroke and 18 (4.6%) from myocardial infarction, and 7 (1.8%) died from malignant disease. During the first five years the corresponding numbers were 123 (31.5%), 58 (14.9%), 48 (12.3%), and 25 (6.4%), respectively. All other causes were infrequent.

Mortality during the first five years was significantly influenced by age (HR 1.06, 95%CI 1.04-1.08, p<0.0001) and functional ability (HR 2.15, 95%CI 1.81-2.54, p<0.0001), but not by sex, stroke number, or any co-morbidity. The cumulative mortality rate in groups according to age and functional ability is shown in Figure 3. The cumulative mortality after five years ranged from 32.2% for patients 74 years old at index admission, independent at index discharge, to 94.5% for those 83 years old and completely dependent on help at discharge.

The mortality hazard function is shown in Figure 4. The risk decreased rapidly during the first 90 days from 14.0%, achieved stability on the 4-5% level during the next two and a half years, and then increased slowly. The hazard function for stroke recurrence, also shown in Figure 4, decreased rapidly from 14.1% at discharge to a stable level of approximately 2% from three years on. The risk of stroke recurrence was mainly affected by the number of previous strokes (HR 1.39, 95%CI 1.27-1.53, p<0.0001), a hypertension diagnosis (HR 0.72, 95%CI 0.55-0.94, p=0.02), and sex (male to female HR 0.79, 95%CI 0.66-0.96, p=0.02), whereas functional ability, age, and other co-morbidity variables had no significant effect.
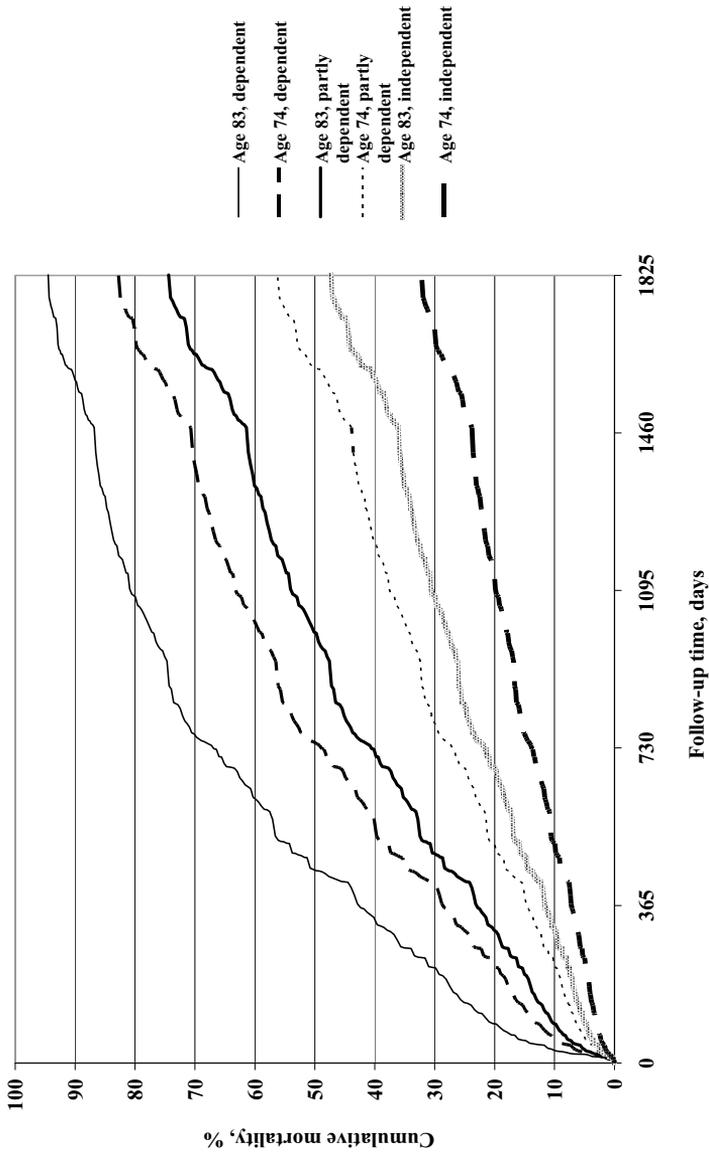
Figure 3. Cumulative mortality during five years following hospital admission for stroke in groups according to age and functional ability (age 74 and 83 was the inter quartile range in the study population)
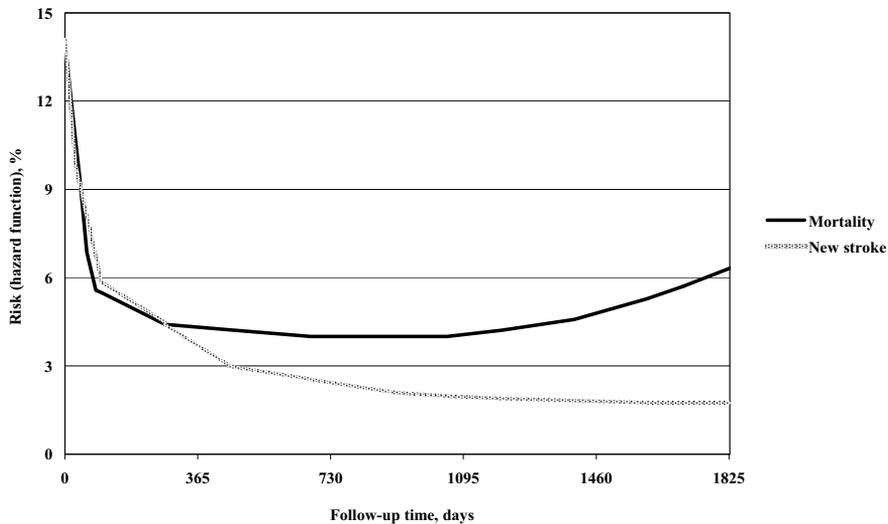
Figure 4. Hazard function for mortality and for stroke recurrence, during five years after the index stroke event

Health care utilization and municipal social service support

During the five years preceding the index admission 269 (69.0%) patients had at least one hospital admission, and 37 (12.1%) patients had a new hospital admission within 28 days after the index admission, 201 (65.5%) within 365 days, and 291 (74.6%) had a new one within five years.

During the five years preceding the index admission 1-2% of the study population were in hospital any given day, Figure 5. At index the proportion became 100% and then fell back to a level of 2-3% five months after index. The corresponding proportions of hospital outpatient and PHCC appointments during the year preceding index increased from 5%-6% in the beginning of the period to 8%-9% toward the end (p for trend <0.0001). After index it fell from 14%-15% to 9%-10% (p for trend <0.0001). The proportion receiving municipal social service support increased during the year preceding index from 31% to 37% (p for trend <0.0001), fell to 0% during the index admission, and then increased rapidly to 60% three months after the index admission, and to 65% over the rest of the year (p for trend <0.0001).

Overall, more than 90% had some contact with PHCC staff before and more than 99% after the index admission, and 58% and 75%, respectively, attended hospital outpatient clinics, Table 7. The most common contacts were with physicians and nurses or district nurses. The corresponding proportions using municipal social service support were 39% and 70%. The type
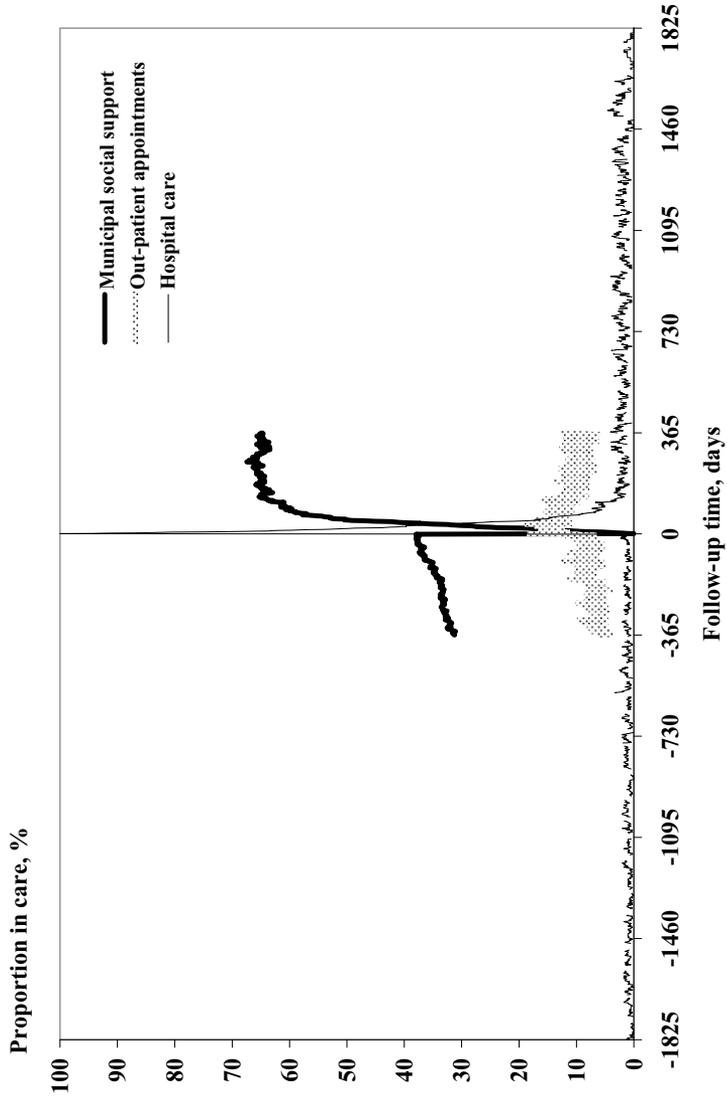
41

Figure 5. Day-by-day proportion of hospitalized subjects, proportion with a hospital outpatient or primary health care appointment, and proportion with municipal social service support during 5 years or 1 year before and after the index stroke admission, adjusted for non-exposure (hospital admissions and mortality)

Table 7. *Type of outpatient care and municipal social service support during the year before and following the index stroke admission*

	12 months before admission		12 months after admission	
	N	%	N	%
PHCC[1] appointments / contacts	352	90.3	388	99.5
General practitioner	302	77.4	381	97.7
District nurse	318	81.5	354	90.8
Rehabilitation staff	105	26.9	271	69.5
Hospital outpatient care / contacts	225	57.7	291	74.6
Physician	202	51.8	235	60.3
Nurse	84	21.5	165	42.3
Rehabilitation staff	4	1.0	31	7.9
Other	8	2.1	60	15.4
Municipal support	153	39.2	273	70.0
Home help	100	25.6	193	49.5
Personal safety alarm	92	23.6	153	39.2
Transportation service	78	20.0	117	30.0
Temporary or permanent special housing	0	0	116	29.7
Other	76	19.5	137	35.1

[1] Primary Health Care Centre

of support given was approximately the same before and after index admission, but the levels were considerably higher after index. The dominant types of support were related to home help, personal safety alarm, and transportation service, as well as special housing services after index. Age, number of previous strokes, and female sex increased the level of municipal social service support provided.

Study III

Change of health situation over time

The levels of functional ability (Katz ADL), MMSE, self-rated health, HAD, and NHP were stable across the first post-stroke year after adjustment for the influence of the covariates, Table 8. The cumulative prevalence of the interview based VIPS keywords since discharge or last interview, and the patient record based keywords arranged in a similar time frame are shown in Table 9. Generally, the prevalence of the interview-based VIPS keywords was higher than the record based ones, with a few exceptions. The most frequently reported VIPS keywords from the interviews were 'Perception', 'Mobility', 'Sleep', and 'Cognition', while the most common findings based on records were 'Pain', 'Elimination', 'Breathing or circulation', 'Perception', and 'Sleep'. Based on interview 97% reported any VIPS keyword at any time

Table 8. *Change during the first post-stroke year of functional ability, Mini Mental State Examination score, Self rated health, Hospital Anxiety and Depression scale, and Nottingham Health Profile dimension after adjustment for the influence of age, sex, education, marital status and loneliness*

	Time of measurement			
	1 week after discharge	3 months after index stroke	12 months after index stroke	p for trend
Functional ability (1-7)	2.4	2.2	2.3	=0.67
MMSE (0-30)	22.3	24.0	22.6	=0.74
Self-rated health (1-5)	2.4	2.3	2.2	=0.04
HAD				
Depression (0-21)	4.3	4.3	4.2	=0.84
Anxiety (0-21)	3.7	3.3	3.3	=0.28
NHP				
Energy (0-100)	38.2	36.4	36.4	=0.66
Physical (0-100)	32.5	30.3	33.4	=0.53
Sleep (0-100)	23.1	22.1	22.8	=0.97
Emotion (0-100)	20.4	20.4	18.4	=0.27
Social (0-100)	18.0	16.6	18.1	=0.76
Pain (0-100)	9.6	10.0	11.2	=0.33

during the last nine months. The corresponding prevalence based on record data was 92%.

To obtain a better view of the timing of problem reporting, VIPS keyword prevalence based on record scrutiny over time is shown in Figure 6. The total VIPS keyword prevalence increased as the patients were discharged from hospital, peaked at 8% 12-18 weeks after index admission, and then gradually decreased to 4%. All individual keywords followed the same pattern, except 'Skin' problems, which were fairly constant from week 12 and onwards.

Based on interviews there was co-variation between the VIPS keywords 'Cognition', 'Mobility', 'Sleep', 'Pain', 'Perception', and 'Psychosocial'. A total of 538 (61.6%) interviews contained various combinations of these keywords. Other combinations were infrequent. Based on patient record data there was similar co-variation between the VIPS keywords 'Breathing or circulation', 'Elimination', 'Sleep', 'Pain', 'Perception', and 'Psychosocial'. A total of 3167 (54.1%) patient record notes contained various combinations of these keywords.

Table 9. *Change during the first post-stroke year of health problems as reported at interview and found in primary health care and municipal elderly health care records, after adjustment for the influence of age, sex, education, marital status, loneliness, and for non-exposure (hospital admissions and mortality)*

	Health problems reported at interviews				Health problems in patient records			
	1 week after discharge	3 months after index stroke	12 months after index stroke	p for trend	1 week after discharge	3 months after index stroke	12 months after index stroke	p for trend
Health problems, total, %	82.2	87.0	97.2	<0.0001	43.3	55.2	91.5	<0.0001
Perception	47.3	51.5	69.6	<0.0001	9.7	13.2	42.4	<0.0001
Mobility	27.9	33.9	64.2	<0.0001	9.6	12.5	35.3	<0.0001
Sleep related problems	36.0	40.6	62.4	<0.0001	10.9	14.4	41.3	<0.0001
Cognition	19.8	23.2	42.5	<0.0001	2.2	2.9	11.0	<0.0001
Pain related problems	19.9	21.8	32.2	<0.0005	12.0	16.5	50.6	<0.0001
Elimination	13.6	16.1	32.1	<0.0001	19.0	23.4	50.4	<0.0001
Nutrition	14.2	16.4	29.3	<0.0001	6.0	7.9	25.4	<0.0001
Breathing or circulation	8.6	10.6	25.4	<0.0001	7.9	11.3	44.3	<0.0001
Communication	12.8	14.5	24.9	<0.0001	3.5	4.2	8.7	=0.005
Psycho-social	12.2	13.4	20.4	<0.0001	8.2	10.5	28.6	<0.0001
Skin	1.6	2.1	6.9	<0.0001	6.1	8.5	32.2	<0.0001
Miscellaneous	2.9	3.5	8.5	<0.0005	1.3	1.9	10.3	<0.0001

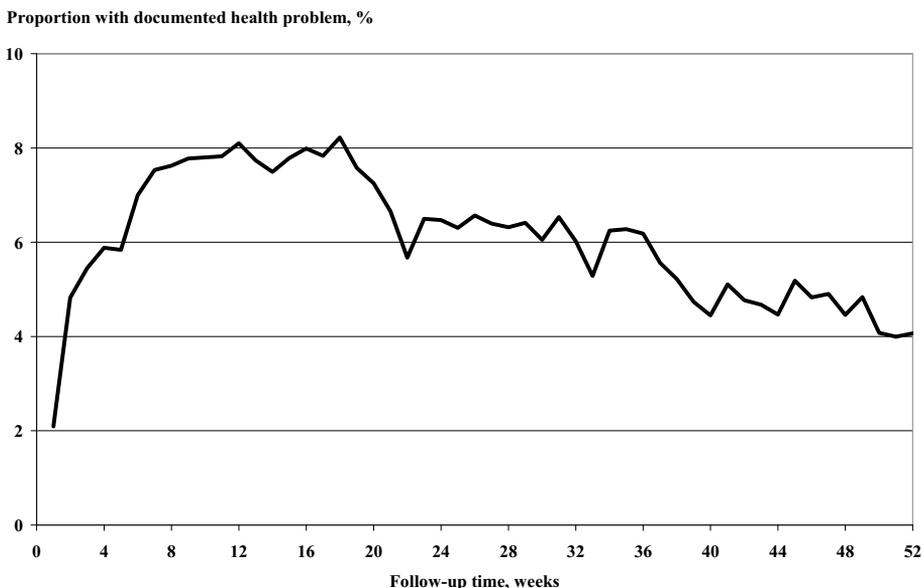Proportion with documented health problem, %

Figure 6. Prevalence of all health problems combined week-by-week, based on primary health care and municipal elderly health care records during the first year post-stroke, adjusted for non-exposure (hospital admissions and mortality)

Study IV

Determinants of support given

The determinants of the amount of support provided are presented in Table 10. The significant determinants were in rank order of importance the patient's functional ability, distance from the patient's to the caregiver's home, the caregiver's relation to the patient, whether the patient was receiving municipality social service support, and patient's sex, whereas patient's age, MMSE, caregiver's age, caregiver's sex, and measurement occasion during the post-stroke year had no significant effect.

The support given increased from 8 support score among independent patients to 16 among those partly or totally dependent. Members of the patient's household provided most support, while that provided by others was smaller. The most frequent caregivers were in rank order spouses, children, neighbours, grandchildren, and other relatives. Patients receiving municipality social service support received more informal caregiver support than those with no municipality social service support, even when the effect of functional ability was taken into account. Finally, male patients received more informal caregiver support than female patients.

Table 10. *Determinants of amount of informal caregiver support given, estimated in multiple linear regression analysis with backward elimination of non-significant variables*[1]

	Mean	95%CI	p
Patient's functional ability			<0.0001
Independent	8.1	5.2-10.9	
Partly dependent	17.6	14.0-21.3	
Dependent	15.2	11.4-19.0	
Distance to patient			<0.0001
Same household	20.7	12.7-28.7	
Same building	10.4	3.1-17.7	
Same municipality	8.7	5.6-11.8	
Other municipality	7.1	2.5-11.6	
Caregiver's relation to patient			<0.005
Spouse	16.4	13.4-19.4	
Child	13.0	10.1-15.9	
Sibling	7.1	1.3-13.0	
Neighbour	12.6	2.3-22.9	
Grandchild	10.6	0.7-20.6	
Son or daughter in law	9.2	1.0-17.4	
Other relative	11.0	5.0-17.1	
Patient receiving municipality social support			<0.005
No	10.6	7.2-14.0	
Yes	12.1	9.2-15.1	
Patient's sex			<0.05
Women	10.6	7.6-13.6	
Men	12.5	9.2-15.7	

[1] The eliminated non-significant variables were informal caregiver's age (p=0.97), MMSE[*] score (p=0.71), measurement occasion (p=0.29), patient's age (p=0.24), and caregiver's sex (p=0.11)
[*] Mini Mental State Examination

Caregiver burden

Mean CB score was 14.9, SD 12.90, median 11, and range 0-55. CB score increased significantly with the amount of support given (p<0.0001), amount of municipality support given (p<0.0001), low patient functional ability (p=0.0005), caregiver's relation to the patient (p=0.001), and patient age (p<0.05), whereas caregiver's age and sex, the patient's functional ability and sex, and the distance between the caregiver's and the patient's home had no significant effect.

The CB levels according to the support given by the informal caregiver and the patient's MMSE score, adjusted for the influence of caregiver-patient relation, patient age, and municipality social service support given, is shown in Figure 7. CB score increased linearly with decreasing MMSE score irrespective of informal caregiver support score. CB score increased non-linearly with support given, with a fast initial increase that levelled off at high support scores, irrespective of MMSE score.
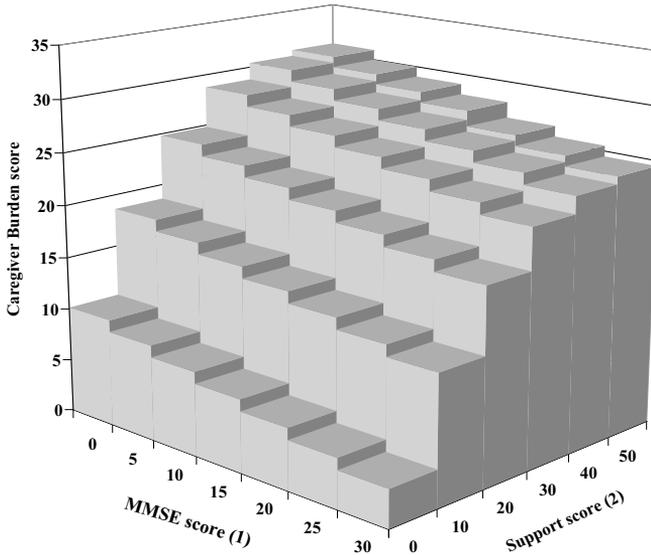
Figure 7. Caregiver burden according to the patients' MMSE[1] and given support[2]

[1] MMSE = Mini Mental State Examination
[2] Support score = The support score is based on the frequency of given help from informal caregivers, no help (=0) to help several times a day (=4) in 15 different tasks

Parallel between caregivers' and patients' situation

Mean values for the patients' and caregivers' responses to the HAD, NHP and GQL-activity instruments are presented in Table 11. Generally, the caregivers had higher HAD anxiety and depression scores, lower scores in all NHP dimensions, and higher GQL-activity scores than the patients. Table 11 also shows associations between individual patients' and their caregivers' scores expressed as regression coefficients of patient scores on caregiver scores, adjusted for the influence of patient functional ability, age and sex, MMSE score, caregiver-patient home distance and relation, caregiver age and sex, and municipality social service support given.

For every unit increase of patient anxiety score, the caregiver anxiety score increased by 0.146 units (p<0.0001). Corresponding associations between patients and caregivers responses were found for the emotion and social dimensions of the NHP instrument, and all the activity subscales of the GQL-activity instrument. For other NHP dimensions there were no significant associations. The highest regression coefficients were found for the activity subscales.

Table 11. *Association between patients' and caregivers' responses to Hospital Anxiety and Depression scale (HAD), Nottingham Health Profile dimension (NHP), and the Gothenburg Quality of Life Activity instrument (GQL-activity), adjusted for the influence of patient functional ability, age and sex, Mini Mental State Examination score (MMSE), caregiver-patient home distance and relation, caregiver age and sex, and municipality social service support given*

	Patients' responses	Caregivers' responses	Regression coefficient of patient's on caregiver's response	p
HAD				
Anxiety score	3.1	6.1	0.146	<0.0001
Depression score	3.9	13.9	-0.022	=0.41
NHP				
Emotion score	15.3	7.5	0.100	=0.0013
Energy score	27.7	10.0	0.055	=0.07
Physical score	24.1	4.3	-0.024	=0.22
Pain score	7.7	5.9	0.029	=0.49
Social score	13.2	3.3	0.065	=0.0072
Sleep score	16.6	10.0	0.061	=0.07
GQL-activity				
Home activity score	2.5	6.2	0.279	<0.0001
Social activity score	5.3	6.7	0.239	<0.0001
Outdoor activity score	3.5	7.8	0.290	<0.0001

Discussion

This study of elderly stroke patients in two Swedish municipalities provides a broad view of the situation of these persons and their informal caregivers, who are often fragile in many respects and in need of different kinds of support. The study demonstrates the challenges that health care and municipal social service support face in meeting the needs of elderly patients and their informal caregivers living with the aftermath of the diversity and complexity of a cerebral stroke.

Prognosis assessment accuracy at discharge from hospital regarding the course of events three and twelve months after admission to hospital was mainly influenced by pre-morbid state, course during the hospital stay and post-morbid state. The risk of dying or having a stroke recurrence decreased rapidly during the early post-morbid phase. Most stroke patients had some health problem during the first year, although the health problems peaked early after discharge and then declined. There were discrepancies between the patients' health complaints and those documented in the records. Health care utilization, both in hospitals, primary health care, and municipal social service support was considerably higher post-stroke. Both time and amount of care provided by informal caregivers increased significantly after discharge, and they were under considerable strain. Another noticeable result is that the more formal support the stroke patient gets the more help from informal caregivers is also given.

Study design and methodological considerations

The study was performed as a prospective longitudinal cohort study of consecutive patients, who survived the acute stroke phase and fulfilled the inclusion criteria. The study results may be limited by the inclusion of only patients 65 years or older, admitted from their own homes and with no documented dementia prior to admission. However, by this restriction a number of problems, such as dementia limiting the interview data reliability, and for patients below 65 years support from social insurance and work rehabilitation authorities would make the study population more homogeneous. In spite of this restriction, more than 80% of the total stroke population was included in the study. With regard to the inclusion criteria there were no differences in age, sex and diagnosis distribution between the study group

and national stroke patient data [8, 108]. No distinction between first-ever or recurrent stroke was made at inclusion, but this information was obtained from the National Hospital Discharge Register and used in the analyses.

As admission to hospital in Sweden is free of charge for the patient, virtually all patients with clinical signs and symptoms indicating stroke are admitted to hospital [6]. Moreover, patient fees in hospital outpatient clinics, general practices, and municipality social service support are all heavily subsidies by central and local governments, avoiding health care utilization hinders by private financial resources. This may weaken the possibility of generalizing the results, as the study was performed in a northern European setting with fairly unlimited access to low-cost health care and municipal social service support. On the other hand, the situation at hand permits a broad review of accurate needs.

Co-morbidity data were based on hospital and PHCC record scrutiny and the National Discharge register, with almost 100% coverage. The National Cause of Death Register has almost 100% coverage and was applied for mortality data. Complete data were obtained from hospital, PHCC, and municipality elderly health records, from doctors as well as nurses, occupational therapists and physiotherapists.

The documentation of health problems in the patient interviews and the complete set of hospital and PHCC medical records and municipality elderly health records during the first post-stroke year, were performed in such a way that all health problems mentioned or noted were recorded. Most of the notes were nursing documentation. No distinction between the concepts of complications, sequels or stroke related disability was made to avoid classification uncertainty. In addition to the interview data, data from health care records may contribute to the image of the complexity in stroke patients' outcome.

The Prognosis form was validated with satisfactory results before the data collection period began. The interview and questionnaire data were collected with validity tested instruments (CB [81], GQL [102], HAD [100], Katz ADL [98], MMSE [99], and NHP [101]), and with a low attrition rate (5%). Some of the interviews were recorded in duplicate with excellent agreement.

De Groot *et al.* [109] suggested that medical chart reviews yield the most complete data, provided that all existing charts for one patient are collected. This may be true for medical diagnosis, but other health problems may not be possible to catch by scrutinizing health records. To get a more comprehensive view, the patients' reports on experienced health problems during the study period should be included. In this study a large number of health problems were recorded. Sometimes presumably identical problems were worded in different ways, and some problem wording overlapped. In order to facilitate the understanding and analysis of the health problems, the VIPS classification was adopted. It was originally created and validity tested to

allow for systematic nursing documentation [106], but it also proved to be suitable for classification of health problems in medical records.

There may be a number of explanations for the decrease over time of health problems prevalence. First, it may be a registration bias, if long-term health problems are no longer reported, although since all but one health problem followed the same course across time, this alternative seems unlikely. A second possibility might be that the health problems were solved and a third related alternative might be that the decreasing prevalence reflects the healing process. The reason why 'Skin' problem prevalence was stable over time may be that it is a reflection of the possibility that most skin problems are not stroke related.

The patients were instructed to report problems occurring after a specific point in time (the day of discharge in the first interview, or the previous interview in the second and third). Persons may have had difficulties in differentiating problems occurring before and after the specified point in time, or may even have reported cumulative data across the year. However, the information obtained from the interviews gave supplementary information to that obtained from patient records.

It may have been difficult for the informal caregivers to distinguish between activities regularly undertaken for the whole household and specific activities that the stroke patient was incapable to perform. It may also be unclear for whom the municipal social service support was aimed, the stroke patient or the informal caregiver. If an informal caregiver is physically able, he or she can perform most care giving tasks. If the caregiver has deteriorated in health or physical ability, additional care should be provided [43, 110]. The results may have been affected by indistinct decisions about home help services, *i.e.,* whether the formal care was provided for the stroke patient, or to help the carer cope with care giving tasks. These two items are inextricably linked.

In conclusion, the strengths of the study include the completeness of the stroke patient segment covered, the reasonably complete coverage of the total stroke population, and the broad and complete coverage of health care utilization data. The population was large enough for the purpose of the study. The population magnitude, the longitudinal study design and the repeated measurements allowed a more comprehensive view of the time course than what was possible in previous studies.

Findings

Predictions

The health care staff at hospital should be aware of the stroke patients' situation after discharge. For optimal post-hospital care, adjusted to the needs of

the individual stroke patient, it is vital that staff from the hospital, PHCC and the municipality social service support together take part in the discharge process and plan the continued care.

Prognosis assessments may appear as some form of 'prophecy' [111], but it has far more important implications in clinical practice. Accurate assessments are needed to guide patient management [44, 45, 112, 113], for clinical decision-making [112, 113], rehabilitation improvement, discharge planning [44, 45, 113], and for the provision of appropriate prognostic information to patients and next-of-kin [45, 112-114]. It is also important for the provision of health care, optimal help and dwelling conditions, planned and given at the right time.

The basis for the prognosis is often unclear. Health care staff relies on their knowledge of the natural history of the disease, clinical judgment, experience, and intuition. Several of the measures used in this study such as living alone, pre-morbid state, event severity and the course during the hospital stay, and remaining functional ability were probably used consciously or unconsciously in clinical judgment.

Factors affecting the accuracy of the prognosis assessments were basically the patients' condition prior to admission, the course during the hospital period, the condition at discharge and level of social support. It is not possible to know exactly what factors the hospital staff were using, but it appears reasonable to assume that factors, such as age, previous stroke, admission ADL score, consciousness at onset, disorientation in time and place, severity of paralysis, sitting balance, urinary continence, level of social support as described by Kwakkel *et al.* [44], were taken into account, since the basis for the assessments mainly included rehabilitation results, medical status and nursing status and only to a small extent intuition or other factors.

One problem inherent in prognosis assessment in stroke patients is the heterogeneity in these patients [44]. Progress and recovery differs for each person with stroke, each of whom has different and complex needs. Elderly stroke patients often suffer from multiple diseases. Co-morbid conditions may also delay the stroke recovery process, and influence the time-course prediction through interruptions due to exacerbations of coexisting diseases, slower progress or increased vulnerability to medical complications [115].

Predictions of living situation seems to be rather simple, since predictors of special accommodation placement mainly are based on functional or underlying cognitive impairment, and associated with lack of assistance and support in daily living [116]. Nevertheless, the health care professionals tended to be overly pessimistic about dwelling, perhaps because of insufficient knowledge of the ability among home help services and the PHCC staff to manage severe illness. In addition, during the past decades the number of rooms in special accommodation has decreased. In contrast, the health care professionals at the hospital tended to be overly optimistic in their assessments of the patients' health situation and long-term need of help, as shown

also by others [117-119]. Forecasts are aggravated by future additional morbidity that is unfeasible to anticipate. Not very surprising, earlier studies have shown that short-term forecasts usually are more accurate than long-term forecasts [118].

The 'health situation' assessments performed by the stroke unit staff were less accurate than assessments performed in other wards, which may be surprising. It might be that patients in the stroke unit were more severe disabled, but the differences were not statistically significant. However, their assessments were done fairly early in the hospital period. The patients' condition may have changed in the later course.

A large number of prognostic models involving a variable number of predictors have been proposed. Most of the 83 models reviewed by Counsell and Dennis [45] had potentially serious deficiencies in internal and statistical validity, many could be generalized only to a limited extent, and none had been adequately validated. Few studies have addressed the issue clinical judgment versus formal decision support. Counsell *et al.* [119] found no model markedly better than clinical judgment. Since the various studies on the accuracy of clinical judgment have used similar outcomes but defined and graded differently, it is difficult to compare the success levels. They reported 65% accurate prognosis assessments in inpatients, approximately the same level as the 56-78% in this study. More recently, König *et al*. [120], developed a prognostic model based on age and the National Institute of Health Stroke Scale (NIHSS) which correctly predicted survival and functional recovery after three months in 70% or more in stroke patients. Function ability at one week strongly predicted the three-month disability outcome, and supplemented by information about initial stroke severity and congestive heart failure history, may provide an early outcome guide useful for patient and family counselling [121]. Unlike the present study, most stroke prognostic models predicts outcome for no more than three months after the stroke onset. In addition, in the present study the three and twelve-month results regarding predicted outcome were fairly consistent.

The small and insignificant differences in assessment accuracy between the staff categories may be due to how long the patients were staying in the ward and how closely the staff category had worked with the patients, *i.e.* the exposure time between patient and staff. In a systematic review it was pointed out that when patients were well-known, the assessments were generally too optimistic as compared to those for less well-known patients [118]. Benner pointed out the importance of experience [122], but in this study the factor experience was competed out by other, more important factors, such as stroke patient activity degree prior to admission and MMSE-score and need of help at discharge. In addition, the patients were referred back to their general practitioners, limiting the information feedback on outcome to the assessing staff.

Another factor involved is the many professional categories involved in the care of the patients, with risk for limited information or holistic perspective of the patient needs. The various staff categories may therefore have different bodies of knowledge for their assessments, possibly causing limited dissemination of important information among staff or a limited knowledge of the patients needs. This is of clinical importance before discharge planning and information transition to other caregivers is performed.

During the hospital stay and at the discharge planning conference, the hospital staff gives their view of the patient and probably their expectations of the future, *i.e.* a prognosis forecast. The discharge planning conference is an opportunity for all involved to get broad and mutual information. The effectiveness of communication between hospital staff and the providers of services outside the hospital setting have been suggested to be of importance [123] for the continued care outside the hospital.

Risk of recurrence and mortality

The risk of recurrent stroke and death among stroke patients after an acute care episode in the study decreased rapidly during the first three months, and then levelled off. The mortality risk also decreased rapidly, but became stable at six months and slowly increased after two and a half year. Although the hazard function is a well-known (and the best) statistical measure of risk relative to follow-up time, it seems not to have been reported previously in stroke patients. The finding in this study is therefore a novel one. Similar shapes of the hazard function for new events have been reported for acute myocardial infarction with similar time frames [124]. Others have drawn similar conclusions based on cumulative survival curves [125]. However, although the survival curve is based on the hazard function, the latter provides a more direct measure of mortality or recurrent event risk over time.

In this study, 47% of all vascular deaths after the first year were caused by recurrent strokes, whereas another Swedish study [22] found 39% during the corresponding time. The modest difference can probably be explained by the age distribution in the population. The cumulative mortality function illustrates the influence of age and independence at discharge on mortality. Similar findings have been reported by others [126]. No significant effect of sex or co-morbidity, such as previous strokes, other cardiovascular disease, or diabetes, was found, although others have found such effects [22, 27, 127, 128].

Health care utilization

The stroke severity affects the care utilization, in hospital as well as outside hospital [129]. In Sweden, the median for length of stay in hospital in acute stroke care has been stable during the last decade, while it has decreased

somewhat for the total in-patient care, due to increased early supported discharge [1]. This means that the demand of care and rehabilitation outside hospital will be higher, including primary health care and particularly municipality social support, *i.e.* home help and special accommodations. In addition, the amount of informal care will be considerable.

The utilization of hospital inpatient care was higher during the years following index than the preceding years. The utilization of outpatient care increased slowly during the year preceding index and fell slowly during the following year but to a somewhat higher level than during the preceding year. The utilization of municipality support was substantially higher than the health care utilization and with a marked increase during the year following index. In spite of their weakened post-morbid state, three quarters of the patients could return to their homes after discharge. In total women received more municipality support then men, but relief services were more common in men. Women were more dependent on others and more often institutionalised [28], while men were more likely to be discharged to their homes, and less likely to be discharged to chronic care facilities than women, similar to previous findings [130]. One explanation might be that the men were younger and often had someone to take care of them when going back home.

In spite of the fact that a majority of the patients were admitted to hospital during the years before and after the index admission, fairly few were hospitalized on any randomly chosen day. The same argument applies to hospital outpatient and primary health care. This is a novel finding, and reflects the fact that most of the patients stay in hospital for fairly short periods, usually only a few days, and outpatient appointments last usually less than an hour. The day-by-day utilization chart gives a more correct view of the 'burden' of these patients on the health care systems than cumulative proportions of patients utilising health care over time.

The care provided by informal caregivers, both time and amount of care giving tasks, increased significantly after discharge as compared to the pre-stroke year. Interestingly, the results indicated that the more formal care, the more informal care. In Sweden, most elderly people rely on help from their families, but many receive help from both formal and informal sources. It has been suggested that if support from one of the sources increases then support from other sources will increase as well [131]. The reason may be that the patients are dependent on several kinds of support, and that many tasks can be performed by informal caregivers, but additional support from formal care are needed as to support the dyad [132]. Moreover, severely disabled persons may be cared for at home if they have support from both informal and formal care, but not if only one form of support is available. In addition, since the number of special accommodations has decreased in Sweden [133], only the frailest and oldest people may have such accommodations.

Health situation

The most frequent diagnoses based on inpatient records during the three years preceding the index admission were cardiovascular disease, neurological disease, musculo-skeletal disease, and endocrine disease including diabetes. One fourth of the patients had a previous cerebro-vascular event, and one fifth had a history of hypertension. It has been reported that at least 80% of people aged 65 years or more have one chronic condition or more, and 65% have multiple chronic conditions, increasing with age [134], and 80% of elderly persons with heart failure have been reported to have four or more co-morbidities. The prevalence of these concomitant disorders differed depending on sex and age [135]. The co-morbidity and recurrent strokes may be an explanation of the deterioration that occurred during the first year, as also has been reported by Pettersen *et al.* [136].

The situation during the first year post stroke is not as bad as previously thought, since most medical complications develop within the first few weeks of stroke [3, 53]. The cumulative reporting method, usually used in studies similar to the present one, indicates a high health problem level. The method used in this study, a continuous time series of health problems as reported in patient records, provides a more straightforward estimate of health problem prevalence. In this study the cumulative method indicated health problems in more than 90% of the study population versus 8% or less using the continuous time series method.

Frequent co-variation was found between the health problems 'Cognition', 'Mobility', 'Sleep, 'Pain', 'Perception', 'Psychosocial', 'Breathing and circulation, and 'Elimination', similar to the findings of Appelros *et al.* [57]. Detection of one health problem should lead to consideration of the others. The awareness of this co-variation may help health care professionals in their assessment of stroke patients' health status.

Differences were found between health problems based on interviews and those based on patient records. Both nurses and doctors are unaware of many health problems in the elderly, perhaps because these disabilities most often are only slightly or moderately severe [51]. Furthermore, vague symptoms such as tiredness, forgetfulness, and low mood are often considered by patients [52] and health care staff to be normal in old age. The elderly may not like to disturb their physician with symptoms they regard as trivial, normal for their age, or for which they think there is no treatment [52]. This implies that elderly people may not inform their doctors [51] or other health care professionals until the condition is advanced.

It has been shown, that of all nursing problems known, one third were documented, another third were known by the staff but not documented, and one third was known only by the patients [137]. Others have found that patients identify severe problems that are unknown to the nursing staff [137-139], and that there is inadequate ability of the staff in identifying unmet

needs [140]. These discrepancies may be attributable to different views of health problems. For instance, problems with elimination, and breathing or circulation can be effectively handled by health care staff, and they may not be very annoying to the patient. On the other hand, perceptive and cognitive problems are not easily communicated, and unvoiced problems will not be addressed [141]. Neither the patient nor the health care professionals have the words or the tools to handle these problems, and the professionals may not ask about problems for which they do not have a solution.

Parallel in stroke patient – caregiver situation

The focus in stroke rehabilitation has shifted from a patient perspective to a patient-and-caregiver dyad approach, in recognition of the fact that caregivers play an essential role in preserving rehabilitation gains and in the long-term well-being of stroke patients [80, 84, 142]. Nevertheless, most studies have been cross-sectional, thereby limiting the understanding of the time-course of the care giving role.

Coping with the situation after discharge can be distressing for the stroke patient as well as for the informal caregiver, as their life situation has been dramatically changed. Both have to master the completely new life situation and try to regain well-being. Even if the stroke was mild, the remaining limitations may lead to dependence, limited participation and a decrease in life satisfaction affecting both the stroke patient and their spouses [89]. Generally, this study showed that the caregivers had lower scores in all NHP dimensions than the stroke patients, with associations between patients and caregivers responses for the emotion and social dimensions, indicating that if one is improving or deteriorating, the other will follow suite.

Some studies have considered life satisfaction in the couple stroke patient and spousal caregiver [80, 86, 89, 92]. It appears that when the patients gradually adapt to the new circumstances, although their self-perceived physical function deteriorates, it become more demanding for caregivers [86]. In contrast, Carlsson *et al.* [89] found stroke patients less satisfied than their spouses while McCullagh *et al.* [80] found that the caregivers had better quality of life, but unlike the stroke patients, their quality of life did not improve over the first year. It has been found that life satisfaction scores are relatively independent between the stoke patient and the informal caregiver, but with a more close association within couples than for parents/children [88].

The interaction between the stroke patients' impairments and spouses' emotional health may be different at different phases after stroke. The functional recovery of the stroke patient and the caregiver's responses over time suggest that the evolution of both parts should be considered [143]. The life situation may be negatively perceived, for the stroke patient as well as the informal caregiver, if the patient is depressed and aggressive [144]. The re-

verse may also be possible, if the informal caregiver is depressed it may worsen the depression of the stroke patient and this will likely result in poor response to rehabilitation. Depression in the informal caregiver might be used as an indicator of a worse outcome for both the stroke patient and the informal caregiver.

Anxiety and depression scores indicated a worse situation in this respect for the informal caregiver than for the stroke patient, during the first year post stroke, indicating caregiver depression. In contrast, Kotila *et al.* [85] found that the frequency and severity of depression was similar in patients and caregivers, and others found that caregivers emotional outcome was associated with the stroke patients' emotional status [145, 146].

The informal caregivers had higher GQL-activity score indicating minor influence of the performed activities after the stroke. Others have shown that the social network often is reduced for persons with stroke, and the altered situation for their families makes it more difficult to maintain friends and to participate in leisure time activities [60, 66, 89, 92, 147]. The stroke patient and the informal caregiver may need support to be able to resume social and leisure time activities. Others found that couples that were able to resume a resemblance of everyday normality had a higher life satisfaction [46, 92].

Informal caregiver situation

Informal caregivers of stroke patients provide care ranging from physical help to psychosocial support. The patient's functional ability, distance from the patient's to the caregiver's home, the caregiver's relation to the stroke patient, patient receiving municipality social service support, and patient's sex were significant determinants of the volume of the support given. Neither patient's age, MMSE, caregiver's age and sex nor measurement occasion during the post-stroke year had any significant effect. The caregivers may experience high levels of burden, associated with the characteristics of the patients and of themselves with deteriorated health, well-being and social life as a result. It was found that informal caregivers were under considerable strain, especially depressive symptoms, according to the HAD scale.

The assumption that the stroke patient influences the caregiver's health and wellbeing is common [66, 81, 145], although the converse is possible, *i.e.*, family problems may have an effect on the stroke patient's recovery. Some researchers have reported aspects of patients characteristics that affect caregivers [81, 145, 146, 148] while others did not find any specific relationship [66]. The results in this study indicated that caregiver burden increased significantly with the amount of support given, whether municipally support was given, relation to the stroke patient, patient functional ability, and patient age. McCullagh *et al.* [80] reported decreasing anxiety levels and care giving burden over time, even though no considerable changes in patients' dependence or support levels occurred. A possible interpretation might be

that these changes represent a shift toward normalization with time. The informal caregivers' anxiety and depression levels could be explained by their continuous worries about the risk of recurrence and concerns about the future, and their perceived burden.

Jönsson *et al.* [86] reported that negative emotional outcome was highest for informal caregivers of stroke patients with moderate dependence. A possible explanation might be that more severely disabled stroke patients usually were provided more municipality support.

Members of the stroke patient's household provided most support, while that provided by others was smaller. Female spouses and male children were most often the primary informal caregiver, and the mean age was lower than for the stroke patients. Patients receiving municipality social service support received more informal caregiver support than those with no municipality social service support, even when the effect of functional ability was taken into account. Finally, male patients received more informal caregiver support than females. The men usually had assistance from their spouses, while many women were living alone after their partner had died [90].

Informal caregivers increased their support to the stroke patients to a large extent, after the stroke incident, both in terms of time and the amount of care giving tasks. It has previously been reported that informal caregivers assist their spouses to a great extent, regardless of the stroke severity [90].

Care giving is a complex and multidimensional activity. The care giving role is often like a significant burden, with physical and emotional draining, which may lead to breakdown in the support provided. The burden is characterized by the objective tasks and amount of time devoted to dealing with the consequences of disability. The caregiver burden evolution over time has been reported to decrease between three and twelve months post-stroke [80]. Others have found a sizeable proportion of carers burdened at 6 months [76, 78, 149] and that the burden levels remained constant over time, as in the present study [76, 78, 143]. In contrast to this opinion, beneficial effects of care giving and an increase in carers' appreciation of life has been suggested [82, 150].

The experience of care giving is fairly similar between husbands' and wives', whereas children's experiences have been found to be somewhat different. The daughters are more likely to take on the caregiver role but once they have become caregivers, they all report similar behaviours and feelings as the spouses [151]. Female spouses have lower quality of life and well-being than the male spouses [152], and experience more care giving stressors [151], appear to be more prone to anxiety [146, 153], while men are reported to have a more negatively affected life situation [144, 154]. On the one hand females caregivers perform household tasks as more time-consuming and difficult than male caregivers. On the other hand 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 per-

form [152]. Possible explanations may be that male caregivers have chosen to take on the care giving role, and the care giving tasks is more likely to be noticed for men, and it might be seen as something new added to the men's life experience. They are also more frequently receiving outside help with housekeeping than female caregivers [152].

More caring difficulties related to behavioural than to the physical sequels of stroke have been reported. This may have implications for the health care professionals, as the behaviour disturbances are not as evident as the physical ones, but must nevertheless be paid attention to [155].

Psychological distress in carers has been reported [43, 66], and the distress starts early in the progress; those caregivers who were distressed 6 weeks post discharge remained distressed 1 year after discharge [43]. This implies that identifying informal caregivers at high risk for poor emotional outcome is of great importance to reduce the negative caregiver emotional outcome [156]. In addition, caregiver strain seems to be a consequence of the fact that caregivers are unable to find time for themselves [74, 157], and relief services should be considered. This will gain both the stroke patient and the informal caregiver.

Implications for clinical practice

Stroke patients in a mobile society and with a non-coherent medical system, and consequently a large number of caregivers, may find themselves 'lost in the system'. One prerequisite for avoiding this situation would be to optimise the transition from hospital and to create a care continuum. It is important that people in the caring professions, irrespective of whether their employers are the county council or the municipality social services, are attuned to the frailty and the risk of impaired health, functional abilities, and participation in the society of their patients. It is also necessary for hospital patients with mild or no obvious problems at discharge to be followed up by the aftercare system.

Care-planning meetings are essential tools for optimum care after discharge, where goals, continued care, planned follow-ups and evaluations are considered. A named person should have the responsibility of the continued care after discharge. Nurses are essential in the ongoing assessment of both functional and psychosocial goal achievement. Knowledge of the stroke patient's experiences throughout the recovery process will also help health professionals in evaluating, planning and providing the care. Close involvement with both the stroke patient and the informal caregiver in teaching and planning enables nurses to early recognize signs of dysfunction, and to initiate appropriate intervention may be essential. Thus, it is important that the care staff has access to expert professionals, both as a resource for support and guidance to staff and as a source of referral for patients. Health care

professionals generally need better knowledge of hidden health problems to be able to understand and detect cognitive and perceptive problems.

Health care professionals as well as social services staff, should be able to identify vulnerable and ineffective dyads to give adequate support. They should improve their awareness of the needs, even unspoken ones, of both the stroke patient and the informal caregiver, even when only one is seeking help. Routine assessments of informal caregivers may be helpful to diminish emotional distress. The health care professionals also need education and practical tools to be more sensitive for the vulnerable position of informal caregivers, although they do not show their vulnerability.

Furthermore, to promote overall wellbeing of stroke patients and their informal caregivers, it is important to bridge the gap between patients' or caregivers' expectations of recovery and residual disability. In addition, in the present study the patients were referred back to their general practitioners, which means that the feed back of information on outcome to hospital staff was limited. One way to further improve the accuracy of prognosis assessment might be create a system for feed-back from PHCC to the hospital staff.

Implications for further research

Interestingly, an increase of health care utilization the year before the stroke incident was found. This utilization increase may be regarded as an early warning sign of the coming stroke event. This might be a subject for further study.

Another subject for further research might be how well not only the hospital staff but also the stroke patients, their informal caregivers, and the assistant nurses may predict the patients' need of help, health situation and dwelling situation at three and twelve months post-stroke. Prediction of informal caregiver burden and distress might be valuable.

Conclusions

Prognosis assessment accuracy at discharge from hospital regarding the course of events three and twelve months after admission to hospital was higher, 56%-78% than expected by chance (33%). The accuracy was mainly influenced by pre-morbid state, course during the hospital stay and post-morbid state. There was a considerable variation in the accuracy of assessments, 22%-89%, due to individual factor combinations.

The risk of dying or having a stroke recurrence decreased rapidly during the early post-morbid phase, implying that stroke patients are frailer in the early phase after the incident than later on. Health care utilization, both in hospitals and primary health care, as well as municipal social service support was considerably higher following the index admission than before. Among the various types of care given, the nursing aspects dominated.

Most stroke patients had some health problem during the first year, but only 4%-8% during a specific week. The health problems peaked early after discharge and then declined. There were discrepancies between the patients' health complaints and those documented in the records, with the largest discrepancies regarding perception, cognition and communication. There was co-variation between some of the health problems, which might be used to identify unvoiced health problems.

Both time and amount of care provided by informal caregivers increased significantly after discharge. The informal caregivers were also under considerable strain. They showed significantly higher levels of anxiety and depression HAD scales than the stroke patients, indicating caregiver depression. Another noticeable result was that the more formal support the stroke patient got, the more help from informal caregivers was also given. If health care professionals and social services staff could identify vulnerable stroke patients and their informal caregivers and give them adequate support, the best possible rehabilitation could be achieved while reducing the economic burden and minimising human suffering.

Summary in Swedish: svensk sammanfattning

Stroke medför en plötslig och påtaglig förändring av livet för den drabbade och försätter både denne och de anhöriga i en ny livssituation. Efter hemkomsten från sjukhuset ställs de inför många nya problem. Det handlar ofta om praktiska problem men även hur de hanterar och bemästrar den nya livssituationen. Eftersom antalet personer som lever efter genomgången stroke ökar, på grund av förbättrad överlevnad, medför det ökade insatser inom vårdens olika grenar. Främst kommunala insatser men också ökade krav och förväntningar på att anhöriga ställer upp som vårdare.

Det övergripande syftet med studien var att öka kunskapen om strokepatienters och deras anhörigas situation efter utskrivning från sjukhus.

Studiepopulationen bestod av 390 konsekutiva strokepatienter, 65 år eller äldre, som vårdades på Falu lasarett under tiden den 1 september 1999 - 31 maj 2001 samt anhöriga som gett hjälp och stöd åt patienten.

Artikel I

Syftet var att undersöka i vilken utsträckning sjukhuspersonalen kunde prognostisera det fortsatta sjukdomsförloppet och dess konsekvenser utanför sjukhuset under det första året efter insjuknandet. Sjukhuspersonalen, det vill säga läkare, sjuksköterska, arbetsterapeut och sjukgymnast, fick i samband med utskrivning göra en individuell prognos på tre och tolv månaders sikt efter insjuknandet avseende patientens hälsotillstånd, hjälpbehov samt boendeform. Utfallet baserades på patientintervjuer tre och tolv månader efter insjuknandet. Den prognostiska förmågan hos sjukhuspersonal var signifikant bättre än slumpen. I de fall där prognosen var felaktig var personalen oftare alltför optimistisk än pessimistisk i sina bedömningar. De faktorer som påverkade prognosens korrekthet var framför allt patientens status före insjuknandet, som aktivitetsgrad och ensamboende, samt påverkad kognitiv förmåga och hjälpbehov vid utskrivningen. Att rätt kunna bedöma patientens prognos är viktig för såväl patienter och anhöriga som för vårdpersonalen, bland annat i samband med utskrivningsplanering från sjukhuset.

Artikel II

Avsikten var att beskriva co-morbiditeten vid insjuknandet, naturalförloppet och vilka faktorer som har betydelse för det fortsatta förloppet. Datamaterialet utgjordes av journaldata från sjukhusbunden öppenvård, primärvård och kommunernas äldrevård samt data från slutenvårdsregistret och dödsorsaksregistret. Dödsrisken och risken för återinsjuknande minskade kraftigt från cirka 14% tidigt i efterförloppet till en stabil nivå på 2-5% efter ett halvår. Cirka 2% av patienterna krävde sjukhusvård vid ett givet tillfälle under det första året efter strokeinsjuknandet. Motsvarande vårdutnyttjande inom primärvården var 6% och i den kommunala äldreomsorgen 60%. Den kommunala vården svarade således för den största vårdinsatsen efter utskrivningen.

Artikel III

Studien syftade till att undersöka och beskriva förändringar i hälsosituationen under det första året efter strokeinsjuknandet. Analysen baserades på uppgifter från patientintervjuer en vecka efter utskrivning och tre och tolv månader efter insjuknandet, samt journaluppgifter från primärvård och äldreomsorg. Hälsoproblemen baserade på intervju- och journaldata klassificerades enhetligt i 15 problemområden, enligt VIPS. De vanligaste intervjubaserade problemområdena var perception, rörlighet och sömn, medan de vanligaste journalbaserade problemen var smärta, inkontinens och problem med andning och cirkulation. Kognitions-, rörlighets- och sömnproblem tenderade att samvariera, vilket kan utnyttjas för att identifiera svårfångade problem. Nästan samtliga patienter rapporterade problem någon gång under året, men få vid ett givet tillfälle. Problemen var mera vanliga tidigt efter utskrivningen från sjukhuset, 8% noterades tidigt i förloppet och minskade därefter till 4% mot slutet av året.

Artikel IV

Syftet var att mäta och jämföra livssituationen för personer som drabbats av stroke och för deras anhöriga efter insjuknandet. Arbetet är baserat på de tre patientintervjuerna och anhörigenkäter besvarade vid motsvarande tidpunkter. Patienterna fick ett betydande anhörigstöd redan före indexinsjuknandet, i genomsnitt 5 timmar per vecka. Under det första året efter strokeinsjuknandet var motsvarande insats 11 timmar per vecka. De faktorer som bestämde insatsens storlek var patientens kognitiva förmåga, vårdgivarens släktskap med patienten, om patienten fått kommunal äldrevård, samt patientens kön. De anhörigas upplevda börda ökade med den givna hjälpinsatsen, om kommunal äldrevård getts, vårdgivarens relation till patienten, låg Mini Mental

Test-poäng och patientens ålder. Både informell och formell vård ökade. Slutligen fanns det en påtaglig parallellitet mellan patients och vårdgivarens situation avseende ångest och depression och livskvalitet, som innebar att ju mer ansträngd patientens situation var, desto värre var vårdgivarens.

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On a beautiful, sunny day in January 2010

Lena Olai

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