

# **Persons with stroke and their nursing care in nursing homes**

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## **ABSTRACT**

The overall aim of this thesis was to describe and explore the health status and health care needs of persons with stroke in relation to care planning following acute hospital care, as well as health status in persons living in nursing homes (NHs), focusing on those with stroke, their nursing care needs and nursing care. The RAI, a multidimensional instrument, was used to assess the health status of the persons. Patients (n=114) from two acute stroke wards were assessed at time for discharge decision. Reason for further care planning were collected from the patients' case records. 519 persons from thirteen NHs, of whom 100 suffered from a stroke, were assessed according to RAI, as well as 40 persons with a stroke living in 5 NHs. Registered nurses (RNs) (n=30) were interviewed about the persons with stroke (n=40) and the nursing care provided. In addition these person's nursing records were reviewed. Statistical analyses were used to test differences in health status among the patients in relation to discharge placement, and in relation to diagnose groups among the 519 persons in NHs. Results showed that discharge decision from acute care was uncertain for some of the most severely impaired patients often discharged to a nursing home, due to a very short time before the decision (mean 5.6 days). Bowel and bladder incontinence and eating and feeding problems were seldom recorded in the discharge summary and for some patients discharged to a NH further care planning were insufficient. There were significant differences between the diagnose groups in many functions, and frequency of very/severely impaired cognition were 30% in persons with stroke, more than half in persons with dementia and 15% in the rest. Persons with stroke were most in need of extensive or total assistance in many of the activities of daily life (ADL). Qualitative content analyses was used to analyse the interviews and nursing records. Cognition, mood, eating, feeding, nutrition, pain, urinary elimination and transfer were areas that became the focus for the analyse. The RNs descriptions of such care in nursing homes elucidated the complexity arising from these disorders in the individual's daily life. The RNs' descriptions of the persons' disabilities and disorders often lacked a diagnostic reasoning and like there interventions, were expressed in everyday language. Uncertainty was expressed about the persons' disorders and disabilities, their causes and treatment. This was probably aggravated by communication difficulties with many of the patients, lack of knowledge of stroke care, lack of time to observe and interact with these persons, not using any instrument to help achieve a better description and differentiation of the disorders, poor access to or collaboration with multiprofessional staff. There was also a contrasting picture, mostly from the RNs with special training in stroke care and collaboration with paramedical staff. Thus several of the nursing homes appeared not to provide adequate care for stroke patients. There is a risk that some old, severely impaired stroke patients, discharged to a nursing home shortly after the onset and with a vague care plan, do not get the care needed and fail to rehabilitate to maximum potential or to preserve function. Keywords: Stroke, nursing home, Resident Assessment Instrument, nursing care, cognition, communication, mood disorders, eating, nutrition, pain, urinary elimination, transfer

## LIST OF PAPERS

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

- I Kumlien S, Axelsson K, Ljunggren G, Winblad B. (1999) Stroke patients ready for discharge from acute care – a multi-dimensional assessment of functions and further care. *Disability and Rehabilitation*, **21**, (1), 31-38.
- II Kumlien S, Ljunggren G, Axelsson K. Health status among persons living in nursing homes with focus on persons with stroke (Manuscript).
- III Kumlien S. & Axelsson K. (2000) The nursing care of stroke patients in nursing homes. Nurses' descriptions and experiences relating to cognition and mood. *Journal of Clinical Nursing*, **9**, 489-497.
- IV Kumlien S. & Axelsson K. (2002) Stroke patients in nursing homes: eating, feeding, nutrition and related care. *Journal of Clinical Nursing*, **11**, 498-509.
- V Kumlien S, Ljunggren G, Axelsson K. Stroke patients in nursing homes: their state of health and related care, focusing on pain, urinary elimination and transfer. (Submitted)

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## INTRODUCTION

### **Being affected by a stroke and nursing care needs**

The impact that stroke has on the individual is unique and varies widely depending on the injury and involvement of essential functions such as cognition (Hochstenbach et al. 1998; Kase et al. 1998), communication (Sundin et al. 2000) and physical functioning (Tennant et al. 1997), the person's experiences of the disease and the care given. Even if recovery from stroke is successful many persons have some symptoms remaining for the rest of their life after a stroke. Others have serious functional deficits and may need long time for rehabilitation, and during that time they may also need advanced nursing and medical care.

During the acute phase the persons may suffer from fluctuating consciousness, acute confusion (National Board of Health and Welfare, 2000; Gustafson et al. 1991) and severe cognitive and neurological impairments. The nursing care during this period is to maintain vital functions, early mobilisation and optimal nutrition. Furthermore it is crucial to prevent secondary complications such as pneumonia, aspiration, urinary retention, urinary tract infection, deep vein thrombosis, pulmonary embolus, pressure ulcers, agitation, seizures, stroke progression (National Board of Health and Welfare, 2000; Karla et al. 1995), falls and fractures (Ramnemark et al. 1998) which might lead to deterioration. There are few studies on the affected person's experiences of their situation during this phase, probably because of impaired cognition followed by communication difficulties. However, in a case study by Burton (2000a) the person affected described tremendous feelings of fear, helplessness and sensations as if his body were falling away from him. When elderly Chinese patients were asked about their experiences in the acute care period after a stroke they expressed the need for information about the cause of illness and treatment, need for psychological care e.g. sharing feelings, as well as needs concerning hygiene, mobilisation, sleep, rest and therapy (Lin & Mackenzie, 1999). They also expressed it as stressful to adapt to another environment and new staff, as the stay was short (3-7 days) in the acute ward, and needs for a sense of security were also expressed.

Descriptions of affected persons' experiences during the first year after the onset were concerned with eagerness to know exactly what had caused the stroke, strange sensation and loss of body control, and decreased capacity to concentrate, retain knowledge and remember

(Bendz, 2003; Burton, 2000a). There was also description of lost energy, a kind of fatigue that influenced their whole life. After a while persons expressed an insight that the stroke accident was not only a time-limited life event, as some had thought in the beginning (Kirkevold, 2002), and their experiences had much to do with physical training and coming home (Bendz, 2003; Kirkevold, 2002). The major psychological support valued by the informants during institutional rehabilitation included giving them a sense of security and reassurance, listening to their worries, offering verbal encouragement and respecting them as individuals (Lin & Mackenzie, 1999). Discharge from hospital is an important event, where the situation changes, and adaptation to a different environment and often another life.

Stroke rehabilitation has focused on the physical manifestation, although cognitive disorders, emotional disturbances and social disadvantages are often problems which offer the person great difficulties in daily life, as well as making the rehabilitation more difficult (Foster & Young, 1992). Early diagnosis and adequate therapy may be crucial to the success of rehabilitation. In the first four to six months after stroke onset when rehabilitation treatment is most promising, both primary and secondary depression have a negative effect on motivation and progress. Impaired compliance and lack of progress due to depression could contribute to increased depression (Herman & Wallesch 1993).

### **Stroke demographic**

Stroke is known to be a major global health problem and is the third most common cause of death after heart disease and cancer in most industrialised countries, including Sweden (National Board of Health and Welfare, 2000). According to the World Health Organisation (WHO) stroke is defined as ‘rapidly developing signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or leading to death, with no apparent cause other than of vascular origin’ (WHO MONIKA project, 1988). The incidence of stroke in Sweden is estimated at 25,000-30,000 individuals yearly (National Board of Health and Welfare, 2000). There has been a progressive fall in deaths from stroke in many western countries including Sweden over the last decades (Peltonen et al. 1998), which is explained partly by improved care (Stegmayr, 1996) but also by less serious symptoms at onset resulting from prevention and treatment based on new knowledge.

The risk of a stroke accident increases with age, and the mean age at onset is 75 years, for women 77.5 and for men 73.2 (Stegmayr et al. 1999a). Johansson et al. (2000) found in a hospital-based study of first-ever stroke incidence from 1983 to 1985 and from 1993 to 1995 that the total incident rate increased. Furthermore the incidence for persons aged 75 years or older was stable, although persons under 75 years had an increased incidence. They suggested that even a stable incidence rate, as in the case of those 75 years or older, will lead to an increased absolute number of patients with stroke due to the growing elderly part of the population. It has also been shown that there has been an increase in stroke incidence among persons aged 30 to 65 years and the greatest increase has been among women (Medin et al. 2004).

Thus this indicates that the incidence of stroke will be even larger than had earlier been expected. The stroke prevalence in the US population 25 to 74 years of age showed an average increase of 7.5 % for each 5-year period during 1971 to 1994 (Muntner et al. 2002). The number discharged from hospitals remained relatively constant, although the number and percentage of the persons discharged directly to a long-term care facility increased, with a rate of 6.3 % in 1981 compared to 8.9 % in 1994. Thus as the incidence of stroke increases the consequence will be more persons living with a life-long disease with various degrees of handicap. This highlights the importance of the quality of care and rehabilitation in a growing stroke survivor population to maintain wellbeing among the affected, but also to minimise the burden on the survivor's family and for society.

### **Recovery after a stroke**

Stroke is described as a chronic disease with a particular biological course, including acute onset, initial rapid improvement that gradually is slowing to a steady course. The acute phase may vary from a couple of days to a couple of weeks. Kotila et al. (1984) showed that a clear improvement in neurological as well as in neuropsychological deficit was assessed from the acute stage to three months and continued to twelve months, although to a lesser degree. In addition some researchers agree that maximum motor recovery occurs in the first month following a stroke and is complete by 3 months (Gray et al. 1990). Ferrucci et al. (1993) found that in stroke patients with severe neural damage, further functional improvements occurred even after completion of a rehabilitation programme, and that older patients may be more

likely to employ compensatory strategies to overcome some of the neural impairment that remains after a stroke.

### **Length of stay in hospitals and discharge decision**

During the past 15 years, the health services have been required to be more cost-effective. One result is shorter length of stay in emergency care for stroke victims, with a variation from 7 to 24 days in Sweden (Riks-Stroke, 1995). In addition, the length of stay in geriatric rehabilitation has also decreased and the total length of stay within hospital care was from 11 days to 28 days. Furthermore, those county councils having the shortest length of stay were those who discharged most stroke victims to special housing (a generic phrase for accommodations that include nursing homes, homes for the elderly, service houses and group residencies) (Bergmark et al. 2000). This places constraints on discharge decisions and the planning of further care, to ensure an optimal level for stroke patients. Aspects of planning involve the patient's history and state of health from medical, physical, psychological and social points of view. Other aspects are the need for nursing care, the viewpoints of the patients and their relatives, priorities for beds in the acute care setting and the availability of care alternatives, as well as economic demands on the hospital department. The last aspect is ensuring that the patient's status will be followed up (Styrborn 1994). At discharge, written information concerning the patient's medical, nursing and rehabilitative treatments and their results, the patient's actual state of health and proposals for further treatment and rehabilitation should be sent to the next caregiver, according to the National Board of Health and Welfare (SOSFS 1996).

### **Stroke care at different levels**

At onset, most stroke victims are admitted to emergency hospitals (Peltonen et al. 1998). According to the national stroke register (Riks-Stroke, 1995) 73 % of the patients were cared for in stroke units, although there was large difference between the hospitals in the country. Moreover it was shown that patients admitted to stroke units had a less severe stroke than those who were admitted to general wards (Stegmayr et al. 1999 b). However, the evidence of the benefits of this care includes all categories of stroke patients at the acute stage and is well documented (Stroke Unit Trialists' Collaboration, 2000; Indredavik, 1999).

In addition Jorgensen et al. (2000) concluded from a study of completely unselected stroke patients that those who had the most severe strokes appeared to benefit most and those who benefited least were those with mild or moderate strokes, as well as patients <75 years of age. Patients with the most severe strokes were the only subgroup in whom the length of stay was not reduced, but comparable with those of the general wards. According to the result of the study they suggested that all patients with acute stroke should have access to treatment and rehabilitation in a dedicated stroke unit. However, they call attention to the fact that the marked improvement in outcome shown in this and in other studies (Jorgensen et al. 1999; Indredavik et al. 1997) is connected with stroke units emphasizing a team approach to nursing, rehabilitation and family participation. and not acute intensive monitoring.

Depending on the patients' state of health and potential for rehabilitation they are discharged from emergency hospitals to their home, to medical or geriatric rehabilitation (depending on age), and to special housing. However, there were great differences between the county councils as well as within them as to percentage of patients discharged to geriatric rehabilitation, from less than 10 % to more than 20 %, and to special housing, from less than 10 % to more than 30 % (Riks-Stroke, 1995). Those who discharged most patients to geriatric rehabilitation discharged fewer patients to special housing. These differences might partly be explained by different organisations, for example as to resources for rehabilitation in special housing. However, among the patients who lived at home without any help before the stroke accident, the percentage of patients who lived at home 3 months after the accident was slightly higher among those who had first been discharged to geriatric rehabilitation. Furthermore, it has been shown that persons affected by a stroke who were cared for in a combined emergency and rehabilitation ward had shorter length of stay and better functional status at discharge than those who were cared for in separate wards (Ang et al. 2003).

Persons who are severely impaired and in need of advanced nursing care and rehabilitation either for an extensive period of time or for the rest of their lives are mostly discharged to a nursing home. Some nursing homes have special wards for rehabilitation, although resources differ widely (National Board of Health and Welfare, 2003a; Gurner, 1995). For stroke care of good quality, it is necessary that all levels of care and their collaboration function well. However, according to the National Board of Health and Welfare (2000) special strategies are required to improve stroke care for persons discharged to nursing homes or to their own

homes. Studies have also shown a marked loss of ADL in persons referred to long-term care (Reutter-Bernays & Rentsch, 1993).

In Sweden the county council provides most of the acute stroke care in hospitals, rehabilitation care in hospitals and primary health care. Stroke care in special housing is provided by the municipalities, excluding physicians' care. In addition, care teams and day-care centres are available to assist stroke patients living at home.

### **Persons with stroke in nursing homes**

Among all persons being cared for in nursing homes, those who suffer from a stroke amount to about a fourth. The main reason to move to a nursing home (NH) is mostly the need for advanced nursing care, too extensive to handle at home (National Board of Health and Welfare 2003b). Furthermore, as the number of beds in nursing homes has decreased (National Board of Health and Welfare 2003c) at the same time that qualification criteria have increased, and more persons are taken care of in their homes, those entering nursing homes are in need of advanced nursing care related to cognitive disorders and physical disabilities (Bergmark et al. 2000). Thus, persons with stroke are cared for together with other persons with a complexity of diagnosis. Furthermore they are admitted at different phases of their disease.

### **Competence in nursing home care**

During the past few years there has been a shortage of RNs in nursing homes, and furthermore most of them lack specialist competence in elderly care (Szebehely, 2000). When the National Board of Health and Welfare (2001) conducted an investigation concerning the need for competence recruitment of staff to the municipalities in Sweden, three out of four municipalities answered that recruitment of RNs was very or rather difficult. Corresponding responses from other nursing staff (licensed practical nurses and nurses' aides) revealed that four out of ten municipalities and for physiotherapists and occupational therapists about half of the municipalities answered that it was very or rather difficult to recruit. In general small municipalities found it easier to recruit staff than municipalities in larger or medium cities. About six out of ten municipalities hired staff from companies, mostly RNs, in order to manage the situation (a.a.).

The Local Authority (2004) reported that among the nursing staff recruited in 2003, half had education in nursing care and among those who already worked in the municipalities, about six out of ten were educated in nursing care. According to staff turnover 71,200 worked by the hour. Twenty percent of the staff who were recruited to perform nursing care in the municipalities in 2003 were born abroad and most of them were born outside the Nordic countries and the European Union (a.a.).

### **Registered nurses working in nursing homes**

RNs working in nursing homes often work with few colleagues and limited resources as to paramedical competence; furthermore this could be aggravated by staff who lack basic competence in nursing care. They may also have to make advanced decisions concerning the person's situation and decide, for example, when there is need of a physician.

When RNs were interviewed as an expert panel about their view of their profession within elderly care in the municipalities, they emphasized that long clinical experience from different specialities was important to carry out assessment and care planning for the elderly (Tunedal & Fagerberg, 2001). They also believed that educating nursing staff was stimulating for the RNs, which led to an opportunity to reflect on their own work; it increased nearness to and cooperation with the nursing staff and thus better relations. Furthermore, it increased confidence towards the nursing staff as the RNs receive knowledge about the staff's competence. Deep knowledge of geriatric nursing care based on nursing research as well as geriatric and gerontological knowledge was also important for the profession. However, the greatest obstacle to their profession was lack of time, where the lack of nursing staff influenced the amount of time that RNs could spend on the work that demands an RN (a.a.).

When 210 RNs responded to questions on their working situation in nursing homes or similar facilities, the results showed that almost half of them expressed discontent with their working situation (Weman et al. 2004). The RNs experienced lack of time, lack of stimulation or lack of support in their working situation. The authors concluded that there was a risk that nurses with long experience in caring for older people would leave their employment for other work with better working conditions. In some municipalities in Sweden the municipalities have changed the RNs' work in nursing homes, where the RNs work as consultants on request from the nursing staff.

## **Nursing care of persons with stroke**

Several views on and definitions of nursing care are to be found in the literature (Sjöstedt, 1997), where the task or instrumental aspects have dominated, although in the past decade much focus has been on the interaction between the person cared for and the nurse, the expressive part of nursing. Nursing care consists of two integrated parts, the task to be performed and the relationship within which it is performed. Thus the task and relationship require one another and are present at the same time (Norberg et al. 1992). Sometimes the relationship may be more important than the task or *vice versa*, and sometimes the task and relationship are of equal importance. There are two levels of communication, the content and the meta-level constituting the quality of communication. This is often performed through wordless communication (a.a.).

Jacono (1993) states that to care for a person in a professional way depends on the RNs performing this instrumentally and in an expressive interaction based on the person's resources, problems and needs; and furthermore, that the care is based on evident theoretical and methodological knowledge and the process is mostly assessable and observable. Roach (1992) defines five categories which characterised professional nursing: *compassion*, which creates a relation sensitive to the suffering of others; *competence*, which contains knowledge, judgement, experience and motivation to meet demands on the professional responsibility; *confidence*, a quality that develops a confident relationship; *conscience*, a moral conciseness that directs the behaviour according to a moral competence; and *commitment*, which is defined as a composite of emotional responsibility.

The role of RNs in rehabilitation has been discussed over the decades (Burton, 2000b; O'Connor, 2000; Kirkevold, 1997; Nolan et al. 1997;) and described as technical, therapeutic or managerial. Sherwood (1997) acknowledges the importance of technical caregiving by nurses as a part of the total healthcare experience, but emphasizes that the manner in which this is performed is central to therapeutic nursing. According to Sherwood (1997) the manner in this respect is derived from an in-depth knowledge of the person cared for and is constructed between the parties over time. Equally Kirkevold (1997) and Burton (2003) describe therapeutic nursing as a process rather than outcome, focusing on education and emotional support, which requires an active partnership between the affected person and the nurse.

The Royal College of Nursing (RCN) (2000) presents a view of rehabilitation in their gerontological programme, where they emphasise that rehabilitation needs to involve all the individual's daily activities with three main focal points: enhancing and maintaining quality of life, restoring physical, psychological and social functioning by recognising the health potential of each individual, preventing disease and illness. This view seems to be suitable for persons with stroke in nursing homes (RCN, 2000).

The impact that stroke has on the individual demands a holistic view of healthcare (Nolan & Nolan, 1997; Doolittle, 1988), where individual consequences in daily life (Lewinter & Mikkelsen, 1995) are important for nursing care. The range and the extent of dysfunction following a stroke accident are unique to the person. Thus nursing care depends upon accurate and unique assessment of the individual's needs, which was emphasized by Davis and co-workers (1997). When a systematic assessment instrument was used by the nurses in nursing homes it was found that this increased their awareness of the person cared for as to her/his needs, wishes and resources (Hansebo et al. 1999). Equal findings have been reported by Lockwood & Marshal (1999); Ruland et al. (1997). However, to be able to individualize a person's nursing care needs one must understand how that person experiences the disorder and, through communication, meets his or her needs as well as extending motivation and encouraging participation (Jacobsson et al. 2000, 1997).

### **Rationale of the study**

Today persons with stroke are admitted to nursing homes in different phases of their disease and with great nursing care needs. According to the national Board of Health and Welfare (2000), it is important that stroke victims receive stroke care of good quality through all levels of care so as to reach optimal health; yet there is little focus on the care planning for those discharged from acute hospital to nursing homes and almost no research on persons with stroke in nursing homes as to their health situation, nursing care needs and care. Thus, it seems important to know more about these persons' health and nursing care, as a basis for further care improvement with the aim of minimizing the need for permanent nursing home residence.

## AIM

The overall aim of this thesis was to describe and explore the health status and health care needs of persons with stroke in relation to care planning following acute hospital care, as well as health status in persons living in nursing homes, focusing on those with stroke, their nursing care needs and nursing care.

### Specific aims

- Paper I      to describe actual functions, performance of activities and need for further care in patients with a stroke in acute care wards at the time the physicians decided that the patients were ready for discharge, in relation to placement after discharge and the motives for the decision.
- Paper II     to describe health status in persons living in nursing homes with a special focus on those with stroke.
- Paper III    to identify registered nurses' descriptions and experiences of stroke patients and their nursing care, focusing on cognition and mood.
- Paper IV    to explore eating, feeding and nutrition among stroke patients in nursing homes, as described by their nurses and by assessments.
- Paper V     to describe pain, urinary elimination, transfer and related care among stroke patients in nursing homes, as expressed by their registered nurses and by assessments.

## METHOD

### Design

Quantitative descriptive consecutive (I) and cross-sectional studies were performed (II), at time of decision from acute care hospital. The health status and length of stay of stroke patients were compared in relation to placement after discharge (I). In Paper II the comparison of health status was between persons with stroke, dementia and those with other diagnosis living at nursing homes. The focus was on those with stroke, although we found it interesting to compare them with other persons living in the same context and often cared for

by the same nurses. To obtain a deeper insight about the health situation, nursing care needs and nursing care of persons with stroke in nursing homes, a descriptive multi-method component design was used (IV-V) where results from one method were clarified by results from other methods (cf. Green & Carelli, 1997). Thus interviews, nursing-record reviews and RAI assessments were used in Papers IV-V. In Paper III only one method, interviews, was used (Table I).

**Table I. Overview of the studies, participants and method**

<b>Study</b>	<b>Main content of the studies</b>	<b>Participants</b>	<b>Method of data collection</b>	<b>Method of data analysis</b>
I	Descriptions of patients when decided ready for discharge related to placement and motives for decision	114 patients from 2 acute care hospital wards	RAI assessments Records reviews	Descriptive statistics Chi-squared test Kruskal-Wallis ANOVA
II	Descriptions of persons with stroke, dementia and other diagnosis	519 persons in nursing homes	RAI assessments	Descriptive statistics Chi-squared test Kruskal-Wallis ANOVA
III	Descriptions of patients and their nursing care focusing on cognition and mood	30 RNs from 5 nursing homes responsible for 40 patients	Interviews	Qualitative content analysis
IV	Descriptions of patients and their nursing care focusing on eating, feeding and nutrition	30 RNs from 5 nursing homes responsible for 40 patients	Interviews Records reviews RAI assessment	Qualitative content analysis Descriptive statistics
V	Descriptions of patients their nursing care focusing on pain urinary elimination and transfer	30 RNs from 5 nursing homes responsible for 40 patients	Interviews Records reviews RAI assessments	Qualitative content analysis Descriptive statistics

## **Research setting and participants**

Two acute care wards (one neurological and one medical) in the Stockholm County Council area were the settings for Paper **I** (Table I). During the period of data collection these wards admitted stroke patients acute without selection and they also represented two different catchment areas in the Stockholm County. They specialised in stroke care and conducted primary nursing which could increase RNs' knowledge about the individual patient. The patients were included in the study consecutively over two months. The inclusion criteria were length of ward stay of 3 days or more and a diagnosis of stroke according to the International Classification of Diseases, Ninth revision (ICD-9) (WHO, 1976). Patients with transitory ischaemic attack (TIA) were excluded. Mean age of the stroke patients was 73.2 years, ranging from 44 to 92 years (Table II). Mean length of stay in days before the discharge decision was 6.7 days, and total mean length of stay was 13.4 days.

Thirteen nursing homes were the settings for Study **II**. They were all situated in the municipality of a large city in Sweden. No random selection was made; instead these 13 nursing homes chose to participate after an information meeting about a planned follow-up concerning quality of care. Data was collected in a cross-sectional study during the years 1997-1998. The sample consisted of 1,267 persons living in these nursing homes and they covered about 20 % of all nursing homes in this municipality. From the total sample, those with a length of stay of more than one year were excluded. Thus 519 persons were included (Table I).

The settings for Studies **III-IV** were five nursing homes in the Stockholm area selected since many of the stroke patients in Study **I** were discharged to them. RNs working in these nursing homes and responsible for a stroke patient included in the study were selected as participants. Included were all stroke patients in accordance with ICD-9, (WHO, 1976) with a length of stay in the nursing home of no more than one year. Patients with a diagnosis of dementia were excluded. Thus 30 RNs were interviewed about 40 patients. The mean age of the RNs was 41 years (range 23-60 years). The stroke patients' mean age was 78 years (range 55-92 years) (Table II), and their mean length of stay in the nursing home at the time for data collection was 126 days (range 22-378 days).

**Table II. Persons' age, sex and from where they were admitted.**

Variables	Acute care discharge to home	Acute care discharged to rehabilitation	Acute care discharged to nursing homes	Nursing homes persons with stroke	Nursing homes persons with dementia	Nursing homes persons with other diagnosis	Nursing homes persons with stroke
	<b>Paper I</b> n=44	<b>Paper I</b> n=46	<b>Paper I</b> N=24	<b>Paper II</b> n=100	<b>Paper II</b> n=168	<b>Paper II</b> n=251	<b>Paper IV, V</b> n=40
<b>Age (years)</b>							
Median	<b>72.5</b>	<b>74</b>	<b>84.5</b>	<b>83</b>	<b>85</b>	<b>86</b>	<b>80</b>
Range	<b>(44-88)</b>	<b>(47-90)</b>	<b>(66-92)</b>	<b>(62-97)</b>	<b>(52-100)</b>	<b>(53-102)</b>	<b>(55-92)</b>
<b>Sex (%)</b>							
Female	<b>39</b>	<b>48</b>	<b>79</b>	<b>58.6<sup>1</sup></b>	<b>76.5<sup>2</sup></b>	<b>73.4<sup>3</sup></b>	<b>67.5</b>
Male	<b>61</b>	<b>52</b>	<b>21</b>	<b>41.4</b>	<b>23.5</b>	<b>26.6</b>	<b>32.5</b>
<b>Admitted * from (%)</b>				*	*	*	
<b>Acute care ward</b>				<b>12.2</b>	<b>6.6</b>	<b>14.5</b>	<b>35.0</b>
<b>Rehabilitation ward</b>				<b>50.0</b>	<b>25.5</b>	<b>45.0</b>	<b>57.5</b>
<b>Own home</b>	<b>68</b>	<b>83</b>	<b>75</b>	<b>14.6</b>	<b>27.7</b>	<b>21.0</b>	<b>0.0</b>
<b>Residential home</b>	<b>18</b>	<b>13</b>	<b>25</b>	<b>19.5</b>	<b>38.7</b>	<b>16.5</b>	<b>0.0</b>
<b>Other</b>	<b>14</b>	<b>7</b>	<b>0</b>	<b>3.7</b>	<b>1.5</b>	<b>3.0</b>	<b>7.5</b>

1 One patient is missing, 2 one person is missing, 3 three persons is missing \* 19 % of the data were missing

## Data collection

### Interviews

Interviewing RNs about the person with stroke and her/his care was used as a method of obtaining a deeper insight into these persons' health situation, care needs and care. The choice of RNs was twofold: as responsible for the nursing care they are obligated to make assessments, plan and perform interventions and evaluate the care of these persons. Thus, their descriptions are important considering the quality of the care given. Furthermore their descriptions can be used to increase understanding of what assessed health data may involve in daily life. In addition, persons with cognitive and communicative restrictions are often excluded from research; thus this was a way to obtain more knowledge about persons with stroke in nursing homes.

A semi-structured interview, which has a sequence of themes to be covered and also suggested questions, was performed. Usually an interview guide is used, which can include just some rough topics or it can be more detailed (Kvale, 1996). The guide in our interviews was following the structure of the nursing process (cf. Yura & Walsh, 1998). Thus RNs were asked to describe “their” person cared for and the nursing care provided, starting with an open question: “tell me what you know about the person or will you describe the person“. They were encouraged to express in their own words their experience of caring for the person in case. The RNs’ descriptions were supported by questions such as: ”what kind of resources does the person have “? “Does the person have any other problems”? “What do you do about those problems”? “Tell me more about this”. A few questions were about the RNs’ experience and knowledge of stroke care. The tape-recorded interviews lasted for about one hour and they were later transcribed verbatim (III, IV, V).

#### *Assessments and instrument*

In Study I the Resident Assessment Instrument (RAI) (Kumlien & Ljunggren, 1994; Morris et al. 1991) was used to assess the stroke patient’s state of health and healthcare needs when the physician considered the patient ready for discharge from the acute care. The persons with stroke in the nursing homes were also assessed with the RAI in close connection to the interviews with RNs (IV and V). In Study II the nursing homes resident were assessed with the RAI version 2.0 (Morris et al. 1995).

The RAI is a multidimensional instrument (Morris et al. 1991) consisting of well-defined items in 15 domains, e.g. cognition, communication skills, activities of daily living (ADL), physical functioning, mood and behaviour, nutritional, oral and dental status, pain, and skin condition. The instrument was developed in the USA for care planning and for improvement of care for the elderly. Some of its items are dichotomously scored: memory recall abilities, hemiplegia, trunk balance, chewing problems or having a bad appetite. Other items such as communication skills, daily decision-making and bladder continence, have several response alternatives. For example, activities in daily life could be scored from ‘independent’, via ‘supervision’, ‘limited’, ‘extensive assistance’ to ‘totally dependent’ (0-4). These alternatives are also combined with the support provided, which is scored from ‘no assistance at all’, ‘set up help only’, ‘physical assistance by one person’, to ‘by two or more persons’ (0-3).

The assessment includes the actual health status for each item showing the person's resources and needs, and changes in the domain. The RAI has been extensively tested in the USA (Morris et al. 1990, Hawes et al. 1995) and for example Sweden, Denmark, Iceland, Italy and Japan (Sgadari et al. 1997) for validity and reliability. Many of the items in the RAI achieved an adequate to excellent level of reliability, with no substantial differences across countries.

The sources of information required to make the assessment are communication with and observation of the patient, information from the patient's case record, and when needed information from other staff in the care team as well as the patient's relatives. The RN is responsible for the assessment. Thus, the RAI is collected from several data sources, and the assessments are performed during different timeframes depending on the item and comprising 24 hours (Morris et al. 1991).

The RAI contain several subscales that can be used without any further data collection. The following were used in this study:

#### The Cognitive Performance Scale

To construct the Cognitive Performance Scale (CPS) five items from the RAI were used; 'comatose', 'short-term memory', 'cognitive skills for daily decision-making', 'making oneself understood by others', and 'self- performance in eating' (Morris et al. 1994). Within this system the RAI can be used to assign patients to seven CPS categories, ranging from 0 to 6, where 0 means 'totally intact cognition' and 6 'very severely impaired'. The CPS corresponds highly with two well-known and accepted standard tests of cognition, the Mini-Mental State Examination (MMSE) (Folstein et al. 1975) and the Test for Severe Impairment (TSI) (Albert & Cohen, 1992). The CPS was used in the studies **I**, **II**, **IV** and **V**.

#### ADL summary score

Four items concerning ADL; eating, bed mobility, transfer and ability to manage the toilet, have been combined to a sub-scale (Fries et al. 1994). Scores range from 4, independent in these activities, to 18, total dependence (**II**, **IV** and **V**).

### Depression Rating Scale

The depression rating scale (DRS) comprises seven mood items from the RAI to identify depression e.g., ‘persistent anger and irritability with self or others’, ‘sad, pained, worried facial expressions’ and ‘crying, tearfulness’ (Burrows et al. 2000). Scoring is based on: 0, ‘the behaviour was not exhibited in the last 30 days’, 1, ‘exhibited up to 5 days a week during last month’, 2, ‘exhibited daily or almost daily’. The score runs from 0 to 14 and a cut off score of 3 is suggested for depression. Validation studies were based on a comparison of the DRS with the Hamilton depression rating scale (Hamilton et al. 1967), and the Cornell scale for depression (Alexopoulos et al. 1988). Furthermore, the DRS demonstrated excellent sensitivity and acceptable specificity compared with psychiatric diagnosis based on to DSM-IV criteria (Burrows et al. 2000) (II).

### The index of social engagement

The index of social engagement describes the individual’s sense of initiative and involvement in social activities (Mor et al. 1995). Items from the RAI involved in the index were ‘at ease interacting with others’, ‘at ease doing planned or structured activities’, ‘establishes own goals’, ‘pursues involvement in life of facility e. g., make/keep friends, involved in group activities etc.’, ‘accepts invitations into most group activities’ and ‘time spent in activities’. The scale was validated by comparing its scores with actual time spent in activity programmes. Scores range from 0, ‘severe withdrawal’, to 6, ‘high level of participation and initiative’ (II).

### *The assessment procedure*

In Study I the patients in acute care were assessed by the RAI by the first author (SK), where the RN responsible for each patient was the primary source of information for the author’s assessment. If the RN could not answer a special item, other team members were asked, e.g. a nursing staff or a physiotherapist. The stroke patients in the nursing homes were assessed in the same way (IV and V). In Study II the assessment was performed by the staff at each ward, where the RNs responsible for the single patient were responsible and led the assessment. Training in the RAI assessment was given by RNs who were experienced in the RAI. The training consisted of verbal and written information and instructions to make the assessment, training with individual cases and follow-up, where difficulties in making the assessment were discussed. The assessments were performed after the RNs from the wards were educated

in performing the assessments. The collected data were registered in a database and for this study the patients were selected from the database.

#### *Case records and nursing records*

Reasons for discharge placement and request for further care were collected from the patient's case record in Study **I**. As part of the descriptions of the patients' eating, feeding, nutrition and related nursing care (**IV**), and pain, urinary elimination, transfer and related nursing care (**V**), all text concerning this content was sorted out from the nursing part of the patients' nursing records, focusing on the period two weeks before the interviews (**IV**) and two months before the interview (**V**).

### **Data analysis**

#### *Content analysis*

In nursing research and research focusing on human communication, content analysis is known to be suitable. It has been described as a method for identifying, coding and categorising primary patterns in interviews and observations in an analytical way (Berg 1998). Nursing researchers have used qualitative content analysis for a variety of data and for various depths of interpretation (O'Brian et al. 1997; Söderberg & Lundman, 2001). By a qualitative analysis the visible, obvious, content can be described, while the latent-content analysis deals with the relationship aspect and involves interpretation of the underlying meaning in the text (Donwne-Wambold, 1992; Kondracki et al. 2002).

Qualitative content analysis was chosen for analysing the interviews. After reading the transcribed material through several times, to get a grasp of the overall content, it was obvious that content with regard to cognition and mood was central in the RNs' descriptions, and because of that became the focus for Study **III**. The whole text was searched and all text with descriptions of patients' cognition, mood, related care, and the RNs' reflections on cognition and mood, as well as their knowledge and experience of stroke care, was abstracted from the interviews. That part of the interviews was the unit of analysis. The selected areas in Paper **IV** were eating, feeding, nutrition and related care, and in Paper **V** pain, urinary elimination, transfer and related care.

The text was then divided into meaning units, which includes words, sentences or paragraphs containing aspects related to each other through their content. The meaning unit was then condensed, referring to a process of shortening while still preserving the core. Thus this means that no abstraction, interception on a higher logical level, was done. After that, content areas and specific topics sharing the same content were put together into subcategories. Finally the material was categorized. A category could be seen as a group of content that shares a commonality (cf. Krippendorff, 1998). According to Graneheim & Lundman (2004) a category refers mainly to a descriptive level of content, which can be seen as an expression of the content of the text and they often include a number of subcategories. Furthermore the analysis also includes numerical results.

### *Statistics*

Descriptive statistics were used in Study **I** and **II**. Chi-squared tests were performed for dichotomized items from the RAI, and Kruskal-Wallis tests for scale values to test the differences between the three patient groups. Analysis of variance was performed to test the differences in age and length of stay between the three patient groups. The statistical analyses **I**, **II** were made using SAS software (SAS Institute Inc. 1987).

### *Nursing-record reviews*

The review of nursing records in our study focused on the domains of eating, feeding, nutrition, and related care (**IV**) and pain, urinary elimination, transfer and related care (**V**). The nursing records of the persons living in nursing homes were copied after being unidentified. A content analysis was performed with the text from the records in the same mode as for the interviews. However the text reviewed in Paper **IV** focused on the period two weeks before the interviews. This timeframe was increased to two months in Paper **V** due to the fact that recording was often not so frequent.

The interviews, the RAI assessments and nursing records were analysed separately, and combining the qualitative and quantitative components occurred during the interpretation and reporting phases (**IV**, **V**).

## **Ethical considerations**

The research ethics committee at the Karolinska Institute approved the studies No 94:77 (I) and No 94:341(III-V). The ethical question to be considered was the individual's right to integrity and autonomy. Informed (oral and descriptive) consent was obtained from the patients or their relatives and from the nurses. The data (interview, patient record, nursing record and RAI assessment) of a patient were marked, whereafter all personal identities were removed and there was no code list. Permission to carry out the study was given by the heads of the acute care departments and the managers of the nursing homes. In Paper II primary data collection took place in the years 1997-1998 and was asked for by the local municipality as a follow-up of the quality of care. The RNs in the participating wards performed the RAI after informed consent from the persons living in these nursing homes and in some cases from their relatives. This study is based on secondary data, where the information on the persons only involves gender, and age as to year and month of birth.

## **RESULTS**

### **Acute care discharge of persons with stroke**

There were significant differences between those discharged from the acute care hospital to home to rehabilitation wards or to nursing homes in many functions and disabilities (I). The persons for whom the decision was to be discharged to a nursing home were the most severely impaired (Table III) as to cognition, communication and activities of daily living (ADL). Sad or anxious mood occurred in 33% and 29% respectively for those discharged to a rehabilitation ward and to a nursing home. Improvement in ADL during the care period before the discharge decision was assessed in more than 75% of those discharged home or to a rehabilitation ward, and in 42% of those discharged to a nursing home. For the latter swallowing was a frequent problem (42%) (Table IV) as was leaving at least 25% of the food, having a poor appetite or an insufficient fluid intake (60%) (I).

The persons with stroke discharged to nursing homes (I) had significantly shorter mean length of stay (mean=5.6 days) before the physicians considered them ready for discharge, than discharged to a rehabilitation ward, but not than those discharged home.

### **Health status of persons with stroke in nursing homes**

The health status in persons with stroke in the acute care hospital as well as in the nursing homes showed a complexity of different impaired functions and disabilities (Table III and IV) according to the RAI (**I-II, IV-V**). This also indicates great and complex nursing care needs. The RAI assessment in nursing homes showed that the majority of persons with stroke had impaired cognition, although the degree varied widely (**II, IV, V**). Severely or very severely impaired cognition was found in 30% of persons with stroke, in more than half of those with dementia and just over 15% of the rest, when 519 persons in nursing homes were assessed according to the RAI (**II**), although in Study **V** it was 13% (Table III). When persons with stroke were referred to be discharged to a nursing home, 70% were assessed as severely or very severely cognitive impaired (**I**). In Paper **II** 15% of the persons with stroke were assessed as depressed according to the depression rating scale (DRS), while in Paper **IV** 55% were assessed as having at least one mood disorder. About one third of the persons with stroke and dementia (**II**) only sometimes, rarely or never made themselves understood, which was the case in 11% of the persons without any of these diagnoses; however, there were fewer (15%) among the persons with stroke in Paper **V**. Decreased ability to understand other persons (sometimes, rarely or never) dominated among those with dementia (42%) compared to those with stroke (19%) and the rest (9%). Aphasia was found in 22% of the persons with stroke, while the proportion in persons with dementia was 5% and for the rest 2%.

About half of the persons with stroke had a rather extensive need to a total need in the ADL-sum 13-18 in the four activities; eating, bed mobility, transfer and ability to manage toilet use (**II, IV**), which was the case in 30% in those with dementia and the others (28%) (**II**) although it was more than 70% in those discharged to a nursing home (**I**). (Table III). About 80% of the persons with stroke were dependent on eating when set-up help was counted as some kind of dependency (**II, IV**) and this was also frequent among those with dementia (73%) and those with other diagnosis (80%), although the prevalence of different impairments, known to have a negative influence on eating capacity, dominated in those with stroke (**II**). According to the RAI about 60% of the persons with stroke were assessed that weight loss was uncertain (**II**). Between 43% - 47% of the persons with stroke were assessed as suffering from pain (**II, V**). Bladder and bowel incontinence were also a frequent problem especially in those discharged to a NH or living at a NH (**I, II, V**).

**Table III.** Percentage of persons with impaired functions and disabilities in those with stroke at time of discharge decision from acute care and in persons with stroke, dementia and other diagnosis living in nursing homes.

	Acute care discharge to Home		Acute care Discharged to rehabilitation wards		Acute care discharged to nursing homes		Nursing homes Persons with Stroke		Nursing homes Persons with Dementia		Nursing homes Persons with others diagnosis		Nursing homes Persons with Stroke	
	Paper I (n=44)	%	Paper I (n=46)	%	Paper I (n=24)	%	Paper II (n=100)	%	Paper II (n=168)	%	Paper II (n=251)	%	Paper IV, V (n=40)	%
Impaired cognition a)	11		15		70		30		51		15		13	
Mood disorders	14		33		29		15 <sup>1</sup>		24 <sup>1</sup>		17 <sup>1</sup>		55	
Making oneself understood never/rarely or sometimes	5		28		71		34		33		11		15	
Understand others never/rarely or sometimes	2		20		71		19		42		9		20	
ADL-sum dependency b)	7		28		67		51		30		28		48	
Transfer Dependency c)	18		61		88		77		49		57		78	
Bladder Incontinence d)	11		48		75		64		67		50		60	
Bowel incontinence d)	2		17		58		53		60		35		38	
Daily pain	18 <sup>3</sup>		15 <sup>3</sup>		21 <sup>3</sup>		25 <sup>2</sup>		26 <sup>2</sup>		31 <sup>2</sup>		38 <sup>3</sup>	

a) Severe, very severe (5-6) according to CPS, b) Rather extensive to total need as to eating, bed mobility, transfer and toileting (ADL-sum 13-18), c) Dependency 2-4 according to RAI, d) Sometimes, often, always incontinent 1 according to DRS scale. 2 daily pain. 3 daily almost daily pain.

**Table IV.** Percentage of persons with impaired functions, disabilities, falls, use of aids devices, nutritional approaches and interventions connected with urinary elimination, in those with stroke at time of discharge decision from acute care as well as in persons with stroke, dementia and other diagnosis living in nursing homes.

	Acute care discharge to home		Acute care Discharged to rehabilitation wards		Acute care discharged to nursing homes		Nursing homes Persons with stroke		Nursing homes persons with dementia		Nursing homes persons with other diagnosis		Nursing homes Persons with stroke	
	Paper I (n=44)	%	Paper I (n=46)	%	Paper I (n=24)	%	Paper II (n=100)	%	Paper II (n=168)	%	Paper II (n=251)	%	Paper IV, V (n=40)	%
Limited arm Movement a)	16		46		67		65*		25*		24*		70	
Limited leg Movement a)	20		48		65		77		48		49		73	
Impaired trunk Balance b)	2 <sup>3)</sup>		26 <sup>3)</sup>		54 <sup>3)</sup>		57 <sup>2)</sup> §		36 <sup>2)</sup> §		36 <sup>2)</sup>		28 <sup>3)</sup>	
Fall within last month	32		33		43		12		23		15		20	
Bedfast mostly	2		30		54		14		4		18		18	
Use of lift	0		7		17		30		13		8		18	
Swallowing problems	7		26		42		17		6		9		23	
Chewing problems	0		7		8		10		22		12		15	
Parenteral feeding	2		11		38		0		1		1		0	
Tube feeding	0		4		4		5		2		1		8	
Mechanically altered diet	9		22		33		19		26		17		33	
Plate guard etc	0		0		0		9		2		2		8	
Indwelling catheter	2		15		8		13		5		12		15	
Scheduled toiling	0		0		0		17		30		8		5	
Use of pads	11		50		96		81		74		66		80	

a) Partly or total loss of voluntary movement. \* 18 persons with stroke, 31 with dementia and 52 with other diagnosis were not assessed.

b) Partly or total loss of balance: 2) according to balance test, 3) according to observation. § 1 person with stroke and 5 with dementia were not assessed.

More than half of the persons studied in the nursing homes had no or almost no participation or initiative to social engagement (II)

### **Registered nurses' descriptions of persons with stroke and related care**

When registered nurses were interviewed about persons suffering from stroke and their care, certain areas stood out as important (Table V) (III, IV, V).

#### *About the persons and related care*

The RNs' descriptions concerning cognition were sorted into nine categories; *clarity, confusion/orientation, strange behaviour, forgetfulness/remembrance, alertness, awareness, verbal/nonverbal expressions, making oneself understood and understanding others* (III) (Table V). Each category contained different disabilities, degrees of disability and changes in disability, as well as descriptions of patients with normal functioning. Sixty-five percent of the patients were described as having disabilities in at least one category, although many patients were ascribed several disabilities. Fifteen patients out of forty showed cognitive improvement since their admittance to the nursing home, while deterioration was reported for four.

The descriptions of mood (68 %) included patients who were interpreted as being depressed or showing signs associated with depression as well as other mood changes (III). The descriptions of patients' mood were categorised as, *expression, action and will* (Table V). Improvements in the condition of 17 patients were reported, while the condition of five had deteriorated since their arrival in the nursing home.

The described nursing care related to impaired cognition and mood disorders were sorted into three categories: *compensatory care* e.g., looking after, reminding, assisting, using devices for communication, arrangements of the environment; *emotional and social supportive care* e.g., encouraging and treating with respect, integrity and patience, listening to the patient, always informing the patient what you plan to do, trying to find out things for the patient to do and *physical rehabilitative care* e.g., guiding, showing, instructing and training movements (III). The nursing care intended to meet a specific patient's needs often contained interventions from more than one category. There were also suggestions for other nonconventional methods e.g. playing for patients who were unable to follow instructions.

**Table V.** Categorisation of registered nurses' descriptions from interviews and nursing records of persons with stroke, and numbers of persons in the different categories as to impaired cognition, mood disorders, pain as well as disabilities in eating feeding, nutrition, urinary elimination and transfer.

<b>Number</b>	<b>Interviews</b>	<b>Nursing records</b>
<b>Paper III</b>		
<b>Cognition</b>		
Clarity	10	
Confusion/ orientation	9	
Strange behaviour	13	
Forgetfulness	9	
Alertness	1	
Awareness	6	
Non-/verbal expressions	23	
Making oneself understood	19	
Understanding others	12	
<b>Mood</b>		
Expression	8	
Action	14	
Will	10	
<b>Paper IV</b>		
Eating, feeding, nutrition		
Handling food on plate/table	5	1
Manipulating food in mouth	11	8
Other disabilities	7	11
Nutrition	3	4
<b>Paper V</b>		
<b>Pain</b>		
Location	14	20
Aetiology	8	11
Persons' verbal expression	2	6
Behaviour interpreted as pain	7	2
Intensity	5	4
Causes of onset or relief	4	4
Frequency	3	2
<b>Urinary elimination</b>		
Degree of continence	7	3
Causes of incontinence	2	3
Problems related to urinary elimination	5	7
Description of toilet use	9	2
<b>Transfer</b>		
Descriptions of transfer	20	18

Eating and feeding disability were categorised as *handling food on the plate or table*, *manipulating food in the mouth*, *other disabilities and signs of undernutrition (IV)* (Table V). The number of eating disabilities in individual patients ranged from 1 to 7 in the severely dependent group as to eating and 1 to 3 in the moderately dependent group. RNs described some persons with swallowing problems as having severe problems, a lot of coughing, repeated pneumonia, and there were also reports of patients who became frightened and panic-stricken at aspiration. Various teeth problems were mentioned, although for some no chewing problems were assessed or described. RNs' explanation for persons having a poor intake of food, liquid or a poor appetite were pneumonia, dysphagia, and having forgotten to eat and drink. Few descriptions related to the patients' nutrition e.g., being rather thin. There were also complains about patients being undernourished and thin, on arrival from acute care.

The RNs gave examples of nursing care interventions for different disorders related to eating, feeding and nutrition (IV). Adjusting the environment as well as different kinds of assistance and supervision were described in connection with *handling food on the plate/table*. Tube feeding, adjusting food consistency, feeding techniques, mouth care and emotional support were examples of descriptions related to disabilities concerning *manipulating food in the mouth*. Examples of described care connected with *other disabilities* were adjusting food amount, preventing nausea, assistance/supervision and persuading. Some RNs emphasized that emotional support and efforts to communicate were especially important for those who were tube-fed, as there could be a risk that these patients were neglected if the RNs just put on a drip to the tube. Three patients were reported as receiving nutritious liquids as nutritional support.

Descriptions of pain (68%) were sorted into seven categories; *localisation*, *aetiology*, *persons' verbal expressions*, *behaviour interpreted as pain*, *intensity*, *causes of onset or relief and frequency* (Table V). Localisation was the most frequently described, and the paralysed half of the body, leg, arm, and shoulder/neck dominated (V). These patients were all assessed as hemiplegic and 8 of them suffered from contractures. Contractures, sitting in a bad position or expressed as pain related to stroke were the most commonly described aetiologies of pain. Behaviour and body expressions interpreted by the RNs as expressions of patients' pain were more frequently described in the interviews. Fifteen patients were assessed as suffering from daily or almost daily pain, though frequency was only described in five patients.

Interventions to relieve pain were described in 56% of those recognised with pain (V). The most common described intervention was drugs. Other described interventions were physiotherapy, positioning, activities adapted to pain and specialist consultation, although they were sparse. Described physiotherapy was heat treatment, massage, transcutaneous electric neurological stimulation (TENS) and prophylactic care to prevent contractures, and these treatments were mostly performed by the therapists. RNs also described their efforts to help the patients find a comfortable position, which was described as a difficult task.

There were few descriptions (35%) about urinary incontinence and continence in the persons with stroke and they were sorted in the categories; *degree of urinary continence, causes of incontinence, problems related to urinary elimination, and descriptions of toilet use (V)* (Table V). Devices for urinary elimination were sometimes the only thing mentioned and 17.5% of the persons were described as to degree. There were no reports concerning when the person started being incontinent. Few descriptions were about what caused the incontinence and for two persons no explanation was described for the use of an indwelling catheter (IC). Problems related to the use of IC, such as discomfort or repeated urinary tract infection, and to the use of pads, such as infections, itching skin problems, discomfort or embarrassment, were described. Ability to manage toilet use was only described in nine persons, of those who were assessed by the RAI as in need of some assistance. In the interviews RNs also emphasised that some patients were at risk of falling or fell when they used the toilet because they were not aware of their physical limitations, although those risks were not recorded.

Described interventions related to urinary elimination were few (15%) and among those persons 10% received scheduled toileting (ST) (V). The RNs' descriptions of ST varied; some followed a strict scheduled list for toileting, while others took the patients regularly to the toilet in connection with certain routines. Some RNs described how they worked to get the patient to do without his/her (IC) after being admitted to the nursing home, and removed it if there were no reasons to contradict this. There were descriptions of successful results, although the patient had had an IC for several months. In contrast there were patients who had had their IC for a long time without any expressed reason. Only 37.5% of the patients were described as to care related to toilet use and just two were recorded. Common expressions were helping or supervising the patient with toilet use. Physical training (e.g. walking) was described as a part of the process of improving patients' ability to manage toilet use.

Transfer was described in 50% of those in need of some assistance (V) (Table V). For some patients there was no specific report of transfer but a common expression about all the daily activities, e.g., “Needs help with almost everything”. Other descriptions varied in specificity, for example, “needs help in transfer” or “He can sit up in bed independently and almost transfer from bed to chair”. There were few explanations for the reason for needed assistance; those given were ‘impaired cognition’, ‘impaired balance’ and ‘paralysis’.

In the interviews 52.5% of the persons were described as receiving care by the RNs as to transfer (V). The descriptions varied in specificity for example descriptions were about how RNs avoided the use of a lift when helping the patients in need of assistance in transferring, because it was important to let the patient stand up, to train muscle strength, balance and movement when transferring. Care was also concerned with teaching the patient about transferring, with the aim of getting as much co-operation as possible. Using the belt when assisting transferring in order to prevent pulling the arms was pointed out as important by some RNs. Other descriptions just expressed that the patient need help in transferring.

When RNs described the persons with stroke they often used a common language that lacked specificity e.g., being fairly clear in the head, having swallowing problems, being in some pain, using pads (III, IV, V). However, their descriptions gave examples of how the disability affected the patients’ ADL. No guidelines or instruments were described to be used when assessing the patients’ state of health or in connection with special disabilities.

Although there were examples of detailed descriptions of care interventions in relation to the different disabilities and problems many were commonly described and lack specifics (III, IV, V). No guidelines for management of, for example, pain, eating, nutrition, urinary elimination were described (IV, V). Some of the described nursing care, such as emotional supportive care, were only described in the interviews.

### **Reflections on care**

Some RNs expressed difficulties in understanding written reports of assessment e.g., from the speech therapist. They also spoke of their tremendous frustration when they could not understand the persons and their feelings. They expressed understanding for the persons who were in a depressed mood due to their life situation or because the nursing home could not meet the patients’ need for meaningful activities (III).

RNs' reflections were about difficulties in knowing the state of the patients e.g., cognition, whether the person were in pain or not, and also uncertainty about the causes (III, V). Uncertainty and frustration were expressed about how to approach some persons with stroke, as the RNs did not know what they required of them or what the actual problem was (III).

RNs were critical of the persons' bad states of health on arrival at the nursing home and the RNs believed that they had been discharged from the acute care too early. Furthermore they expressed dissatisfaction with difficulties in receiving different consultations e.g. speech therapist, dietician or other specialists, because of costs or lack of interest due to the age of the person. Dissatisfaction was also voiced about nursing staff members in the nursing homes without proper education and training, with poor Swedish and an attitude of assisting the persons too much. However, satisfaction with staff was also expressed. The RNs were stimulated in their work when the patients improved and this was seen as a credit to the treatment received, although deterioration in a patient's condition raised doubts about the meaning of rehabilitation. Lack of resources was described as a risk that often resulted in neglect of patients' psychological and social needs, as well as the withdrawal of rehabilitation opportunities when the patients did not improve quickly enough (III, IV, V).

The RNs' descriptions and reflections elucidated different views on the care, where some nurses expressed a restorative or rehabilitative care, while others were more passive (V). One RN emphasised that in her ward they had ST for all patients who were able to participate. In contrast some RNs merely stated that the patients were incontinent or forgot to ask to be assisted to the toilet. Some RNs expressed the opinion that training transfer with the patients was not their work, as this was done by the paramedic staff. However, other RNs expressed how they integrated training as a part of their care, and felt that this was important since the therapist had limited resources (V).

Many of the RNs' reflections were about the need to be more active in the direct clinical care of the patients. They emphasized that when one meets and observes the patient during the caring process, one knows her/him in another way and the options for assessing their resources and needs were much better. RNs claimed that they were responsible for the care and yet they often had to rely on staff with poor or no education. Furthermore RNs stated that participation in the clinical care together with other "nursing staff" also provided natural

occasions to teach and supervise them on specific topics that were detected during their caring process. These were also occasions to stimulate and enthuse the staff. However, lack of RNs, a lot of administrative work, and too much time spent on drug distribution led to stress at work (V).

### **Documentation on care of persons with stroke**

Physical improvement was the most common reason given in the patients' records for choice of placement for those discharged home or to rehabilitation ward (I). Many of the patients discharged to a rehabilitation ward were described as cognitively intact, though this was not often clearly expressed as a reason for further rehabilitation. For nursing home placement, the most common reasons were major stroke and severe functional loss with dense hemiplegia. The planning for further care among those discharged to nursing homes varied as to long-term rehabilitation. Bowel and bladder incontinence, and eating and feeding problems were seldom recorded in the discharge summary. A copy of a nursing summary was rarely found in the patients' records (I).

Documentation about handling food on the plate/table, behaviour interpreted as pain as well as descriptions of toilet use were very sparse (IV, V) (Table V). However, localisation of pain was more frequent described in the records as daily notes, for example "pain in the shoulder".. This was also the case as to interventions against pain, where the notes of drugs against pain dominated. One note expressed the person's metaphoric way of describing the pain. Continued recorded evaluations of pain-relieving treatment were sparse, and for some persons there were none (IV). Two persons with swallowing problems were not recorded. Evaluation of the amount of fluid intake by daily recordings was given about four persons of whom two were tube-fed. Notes on food intake in the nursing records were often vague e.g. "eats poorly". Mostly notes on food and eating in nursing records concerned the prescribed diet. No nutritional records or advice from a dietician were found in the records (IV). Described and evaluated interventions appeared seldom in the nursing records and there were few care plans; mostly daily notes were used (IV, V).

### **Communicating care through different methods**

Study IV elucidated that some eating disorders were not recorded at all and that the RAI detected chewing problems, bad appetite and poor intake better than did the interviews and

nursing records. The degree of urinary continence was assessed according to the RAI in 100% of the patients, compared to 25% in the interviews and nursing records (V). Equally ability to manage toilet use and transfer were assessed in 100% compared to 30% and 65% respectively by interviews and nursing records. Although pain was assessed in 68% of the patients and described in 96% by the interviews and nursing records. The interviews more often described the patients' resources and gave a less impaired view of the patients, while the nursing records more frequently described patients' need for help. Moreover, behaviour and body expressions interpreted by the RNs as expressions of pain e.g., anxiety, guarding behaviour, were more frequently described in the interviews (V) as were many of the instances of eating behaviour (IV).

Furthermore, some of the interventions elucidated in a comprehensive way that the RNs made many efforts in their nursing care e.g., positioning, transferring; however, this was almost invisible in the nursing records (III, IV, V). The interviews more frequently expressed a restorative/rehabilitative view of the care given than did the records. Described and evaluated interventions appeared seldom in the nursing records; for example, there were few notes about the patients' food intake, except for the patients who were tube-fed (III, IV, V).

## **DISCUSSION**

The overall aim of this thesis was to explore health status and healthcare needs among persons with stroke, in relation to care planning at emergency hospitals, as well as health status, nursing care needs and nursing care in those living in nursing homes.

Cognition, mood, eating, feeding, nutrition, pain, elimination and transfer became areas of special focus, showing a high frequency of impairment and disabilities, especially in those discharged to a nursing home or living in one (I-V).

### **Knowing the person**

In the interviews a striking matter was the RNs' descriptions of their tremendous frustration when they could not understand the person cared for. Such difficulties created a sense of frustration as the RNs believed that this led to difficulties in knowing the person cared for and understanding her/his feelings; and thus they did not know what the person wanted (III). The concept of knowing the patient in therapeutic decision-making has been identified in several

studies, where knowing the patient is a process of understanding and treating the person as a unique individual (Radwin, 1996. Tanner et al. (1993) presented five aspects of knowing the patient: responses to therapeutic measures, routines and habits, coping resources, physical capacities and endurance, and body typology and characteristics. Knowledge of patient's experiences, behaviours, feelings and perceptions were other categories of the concept described by Radwin, (1995).

Deep knowledge about the person cared for is important for the way in which care is performed according to Sherwood (1997) and this is established between the nurse and person cared for over time. Several RNs in our study also emphasized the need to be more active in direct clinical care and were of the opinion that during the caring process one got to know the person more in depth (V). When one saw how they looked, whether they radiated wellbeing, how they behaved etc, then one's capacity to assess their resources and needs was stated to be much better. Nurses with long clinical experience of cognitively impaired persons described how they could identify specific pain cues by knowing the person. Clusters of individually defined pain cues in the persons cared for are shown to become the recognition feature for pain in cognitively impaired elderly persons (Parke, 1998). In addition RNs expressed that they were responsible for the care, yet due to shortages of RNs often had to rely on staff with an often poor education (V).

Knowing the patient is supported by continuity of care, spending time with the person cared for, and providing more than physical aspects of care (Luker et. al. 2000). Thus, shortage of resources often lead to little time spent in direct clinical care and lack of continuity, which most certainly jeopardized the RNs' ability to get to know the person cared for. In addition some RNs expressed that information from earlier caregivers was not satisfactory, and written reports, for example, from the speech therapist, or of assessment of cognitive state were sometimes difficult to understand (III).

There were few descriptions on the persons' own experiences of their condition but examples provided were expressions of tremendous fear related to swallowing, discomfort and embarrassment as to urinary incontinence and a metaphorical expression from a person in pain (IV-V). This could be explained by the fact that the persons with stroke were assessed and described with different degrees and variations of communicational ability (I-V) In

addition 22% of persons with stroke have aphasia, recognised as an important predictor of depression (Åström et al. 1993). The consequences of aphasia have also been described as extremely depressing and frustrating connected with anger, chaos, isolation, and as being a person nobody knows how to relate with (Parr et al. 1997), as well as loss of one's sense of self (Brumfitt, 1993).

When Sundin et al. (2002) studied communication between care providers and persons with aphasia, they found that when care providers lacked knowledge about the person's abilities, losses and experience of the current situation, as well as knowledge of the patient's history, they felt insecure. In our study RNs also expressed a feeling of insufficiency and uncertainty as to how to approach the person, as they did not know them well enough (III). Studies have also shown that caregivers who feel they are unable to make contact with severely demented persons experience care as meaningless and therefore spending less time with those persons (Ekman et al. 1991). Thus there may be a risk that those persons become very isolated, having no one to relate to.

To achieve understanding and being understood, especially for those severely communicatively impaired, an inter-subjective presence in the parties' meeting is needed, where the persons' experiences and feelings are shared by the carers in a silent dialogue guided by those feelings (Sundin & Jansson, 2003). The interpretation of facial expression (Asplund et al. 1995), also described by the RNs (III, V), or by completing a puzzle by combining attuned affects with observations of behaviour and with knowledge about the person's previous reactions (Häggström et al. 1998) are also ways of understanding communication in this group. Furthermore, Athlin & Norberg (1987, 1998) found that the problems with feeding severely demented persons decreased, and interactive actions increased, when they were fed by staff who had a good knowledge of the patient and their eating based on a patient-assignment system instead of a task-assignment system.

### **Discharge from acute care**

The interviewed RNs in the nursing homes expressed criticism about the stroke patients' bad state of health at arrival to the nursing home, when they were discharged from acute care hospitals. Their descriptions included for example stroke patients who were confused, drowsy, malnourished, not able to swallow, with a missed diagnosis of diabetes, being very

depressed, having bad contractures or who just had started the oral intake of fluids and were looking very thin (III-IV). This was in line with what Styrborn & Thorslund (1993) found among elderly patients referred to be discharged from acute care hospitals, where one-third were in need of further rehabilitation, another one-third needed further medical attention, a number of them were not in a stable medical state and 16% died before discharge. Also in our study (I) we found that the stroke patients decided to be discharged directly to a nursing home from the acute care hospital were still in need of special nursing care, medical care and rehabilitation due to swallowing problems, eating and feeding disorders, mood disorders and other physical impairments. Furthermore, some of these patients were not in a stable state: eight were somnolent, of whom five died before the discharge.

Impaired cognition influencing all mental and bodily functions of the patient (Tatemichi et al. 1994) as well as a state of acute confusion, which is common during the first weeks after the stroke onset (Gustafson et al. 1991), might have made the assessment more uncertain for these patients. Notes about difficulties in reaching agreements between the physicians and the representatives from the nursing home, whether the patients were medically ready for discharge or not, were also found in patients' records (I). It was concluded from the study by Styrborn & Thorslund (1993) that it is crucial when and on what grounds the physician judges a patient to be medically ready for discharge from an acute care hospital, whether other sections of the care system were prepared to take over and if those persons needs could be met.

Earlier research emphasized longer time as optimal to ensure a good discharge decision for severely impaired stroke patients (Karla, 1993; Hulter-Åsberg & Nydevik, 1991). Karla & Crome (1993) concluded that an assessment one week after the onset of a stroke may predict the possibility to be discharged home early but is not predictive enough for patients needing longer rehabilitation. The findings in our study indicate that discharge decisions from acute care hospitals for the most severely impaired stroke patients were made after only a few days, as they had a very short mean length of stay at discharge decision (I).

According to the complexity of disorders and the care needs of many persons with stroke, it seems to be especially important with a discharge decision based on knowledge from different professions' assessments of the person, where the individual's multidimensional needs and

wishes are considered as well as how they may be met. However, for most of the persons discharged to a nursing home the length of stay at the time of discharge decision was probably too short to give the team members sufficient time to meet and interact with the persons and their relatives as well as discuss the affected persons' different problems from different professionals' points of view and plan together for further care. Although these persons had the highest mean age and were most impaired, a geriatric consultant was only used in 33% of the cases (I).

The benefits of stroke units with special stroke team maintaining vital functions, preventing deterioration and early mobilisation is evident and well documented (Stroke Units Trialists' Collaboration, 2000; Jorgensen et al. 2000). However, there is no evidence that treatment in a stroke unit is beneficial if the care is limited to one week (National Board of Health and Welfare, 2000). Furthermore, according to Jorgensen et al. (2000) those with most severe stroke appeared to benefit most. Thus, the persons with stroke discharged directly to a nursing home after a very short length of stay (I) might not receive the optimal care.

Proposal for further treatment and rehabilitation should be noted in the discharge summary as well as the actual state of health of the patient, according to the Swedish authorities (SOSFS 1996a). Further care was planned for those discharged to home, such as receiving rehabilitation at a day care unit or in the patient's home, as well as receiving help from the municipality. Although it is not possible to draw any conclusion about the number receiving rehabilitation and help (I), it is important to include the restoration of psychological and social abilities according to the needs and desires of the patients and their families. In a report from the National Board of Health and Welfare (2004), where 5,000 persons were followed up in their homes two years after their stroke onset, more than 30% did not receive rehabilitation though they were in need.

Several studies has also shown that persons' quality of life is worse compared with a general population the first year after a stroke (Strum et al. 2004) especially regarding physical factors and vitality (Bugge et al. 2001). However, quality of life is complex and difficult to measure. Wyller & Kirkevold (1999) found when interviewing persons 3 years after stroke that the reduced quality of life was not interpreted as a direct consequence of body changes, but as a result of the individual's interpretation and evaluation of the changes. It was essential whether

the person compared the present situation to life prior to the stroke, or to a post-stroke reference point.

Tyson and Turner (2000) found when investigating the discharge of stroke patients from hospitals and follow-up that the treatment was all geared towards getting the patient out of hospital, rather than a rehabilitation process and focused on discharge as the end. This way of acting seemed to have been present for some of the patients being discharged to a nursing home (I), probably due to strong economic demands on the acute care hospitals. Lundh and William (1997) found several shortcomings when investigating discharge planning of elderly people from hospitals in Sweden and UK, and they concluded that discharge must be seen as a continuum, as part of the patient's care. Thus it is important to ensure that patients' needs can be met at all levels of care by professional care; this is necessary and also emphasized by the growing evidence that various therapies can improve mobility, activities of daily living and quality of life long after a stroke (Clarke & Ahren, 1994; Drummond & Walker, 1994).

### **Complexity in persons with stroke**

The health status according to the RAI among the persons with stroke in our studies showed a high prevalence of very severely or severely impaired cognition (70%) at time of discharge decision (I), which varied between 30-13% in the nursing homes (II, IV-V). One explanation of this variation might be the increased qualification criteria for entering nursing homes in the last past years (Bergmark et al. 2000), increased rates of cognitive dysfunction in nursing homes have also been reported in USA (Fries et al. 2000). However, when including all persons with stroke assessed as having some degree of impaired cognition the prevalence was high in all except those discharged to home (I-II, IV-V), and there were a great variation of the degree of impaired cognition. In addition cognition is a complex function which in various ways influences the individual's daily life in various ways in most activities. RNs also expressed uncertainty and difficulties in knowing the state of patients' cognition (III).

Depression was assessed in 15% according to the DRS used in Paper II, while only different signs of mood disorders (55%) were assessed in the other papers (I, IV-V), thus this was not possible to compare. Depression has been reported from 10 to 60% during the first year after a stroke (Gresham et al. 1997; Gordon & Hibbard, 1997). The rather low prevalence of depression (II) may be caused by the fact that about a third never, rarely or just sometimes

were able to make oneself understood. Although RNs' descriptions of mood disorders correspond with those found by Bennet (1996) while interviewing skilled nurses about this topic, and also with the diagnostic criteria for major depressive disorders (American Psychiatric Association, 1994) they found these difficult to distinguish from the actual brain damage or as a result of the current situation (III).

Persons with stroke were in most need of extensive assistance in many of the activities, e.g. transfer due to significantly more loss of will-conducted movements (I, II, V). The low percentage of independence as to toilet use, dressing and personal hygiene among those with stroke and dementia is probably explained by the influence of impaired cognition, added by motor dysfunction among those with stroke (II). The dependency as to eating was high in those with stroke (II, III) as well as in those with other diagnosis (II), when set-up help was included. Impaired sitting balance, hand/arm movement, swallowing problems (Table IV), side vision problems, all known to be associated with eating problems (McLaren & Dickerson, 2000; Jacobsson et al. 1996 ) dominated among those with stroke. Furthermore McLaren & Dickerson, (2000) also found that impaired arm movement was the most powerful predictor of protein and energy consumption. Yet, in nearly 60% of the persons with stroke and in over half of those with other diagnosis there was an uncertainty whether they had lost in weight (II). The number of different eating disabilities in individual persons with stroke, varied from one to seven (III).

The prevalence of pain in the persons with stroke in nursing homes varied between 43% (V) to 47% (II), which is lower than was reported from other studies of persons living in nursing homes (60- 88%) (Blomqvist, 2002). However, pain has been reported even up to 93% in long-term care of stroke patients (Nydevik et al. 1993), when including physical examination. Furthermore, when three sources of information were used the RAI, interviews and documentation the prevalence increased from 43 to 63% (V). Thus it is reasonable to assume that pain was undetected, a risk that has been reported, especially in those who suffer from impaired speech, disturbed cognition and distorted body image (Pickering et al. 2000; Kaasalainen et al. 1998). Thus this is important to prevent, detect and treat. Some of the RNs described that it was difficult to decide whether persons with cognitive and communicative impairments were in pain or not (V).

The highest prevalence in urinary incontinence was assessed in persons with stroke discharged to a nursing home (**I**), followed by persons with dementia and stroke in nursing homes (**II, V**). This was not surprising since incontinence was shown to be a clinical factor after stroke that was associated with greater disability among those in nursing homes (Bean et al. 2003). Impaired cognition, communicative or mobility deficit have also been reported to be barriers to maintaining continence (Brittain et al. 1998).

The RAI assessments as a multidimensional instrument elucidated an extreme complexity of different functional impairments, disabilities, mood disorders and other symptoms important to care planning. In addition this complexity is increased by how different impairments, disabilities and health problems may interact with each other. For example pain has been connected with reduced ADL, sleep disturbance, participation in social activities (Ferrell et al. 1990), depression (Parmelee et al. 1991). Depression might lead to poor food intake (Herbert, 1996) as well as hindering rehabilitation.

### **Communication about care**

A primary goal of the record is continuity in care for the patients and facilitation of follow-up of the care process, especially for chronically ill patients with multiple diseases. Thus the record should hold valid and reliable information (SOSFS 1996b). However, though eating and feeding as well as incontinence were frequent problems in the acute care hospital, little attention was paid to that in the patients' records (**I**). RNs have to define these and other care aspects in the patients' case records for the purpose of further care. A copy of a nursing discharge summary was rarely found in the patients' case records (**I**).

Ehrenberg & Ehnfors (1999) found, when reviewing 120 patients' records in nursing home, no evidence of a systematic and comprehensive assessment of the patients' problems based on established criteria or the use of any instrument. This was also the case in our study (**IV-V**) when reviewing the nursing records of eating, feeding, nutrition, pain, urinary elimination and transfer, and has also been recognised in nursing homes earlier (Hansebo et al. 1999) and primary care (Törnquist, 1998). Many of the described conditions were not documented at all in the nursing records (**IV-V**), which could be a risk when staff continuity is bad. A striking result from the study was the very few notes of weight found in the records, especially with many patients known to have poor food intake and appetite, to look thin and described as in a

bad nutritional state on arrival. Furthermore there was no adequate documentation of follow-up of the persons' food or nutritional intake, except for those who were tube-fed.

RNs have been recognised to assess patients more than was recorded (Ehrenberg & Ehnfors, 2001). The authors thought that this had to do with accumulated knowledge about the patient and therefore not noted. In this study (VI-V) some descriptions, for example, behaviour interpreted as pain and nursing care related to the studied domains were also more frequently described in the interviews than recorded. When they were recorded, sometimes a less specific view of the interventions were given compared to interviews (IV-V). Lack of carefully recorded care plans may contribute towards care perhaps not being communicated and thus not recognised. For example the described risk of falling when using the toilet was not recorded, which might have contributed to the number of falls in these persons (V). Transfer in relation to toilet use was the most common activity related to falls in elderly residents (Jensen et al. 2002). The restorative care, which more often was expressed in interviews than in the records, contributed to making the RNs' care invisible and accordingly less communicated. There is also a risk of ineffective interventions, were nursing staff may perform care differently, leading to uncertainty in the person cared for and thus hinder progress.

### **RNs' care of persons with stroke in a nursing home**

When reporting the health status of the person cared for the RNs usually described concrete situations from daily life. Some also described the person's capability although most of them reported care needs (III-V). Thus for food handling on the table or plate they gave examples from the meal situation where behaviour could be interpreted as related to impaired attention, initiation, conceptualisation, visuospatial ability or memory (IV). Many of these eating disabilities have also been recognised in persons with dementia (Tully et al. 1997) but have not often been described in persons with stroke, probably because there have been few studies.

Depending on the complexity of these persons with stroke there is a need for comprehensive assessments in the studied domains. For example as to eating, Jacobsson et al. (1996, 1997) and Westergren et al. (1999) emphasized the importance of a test meal based on a model developed by Axelsson et al. (1986), where the person's ability to eat food of different

consistencies is observed. Through systematic observations of the person's eating behaviour, sitting position, types of coughing, RNs receive valuable information for diagnostic reasoning and ideas on suitable interventions. Furthermore detection of different risks is important in order to prevent secondary complications. Dysphagia was a common problem among the studied persons (**I, II, IV**). Some of the persons were also described as suffering from repeated pneumonia or a great deal of coughing, and were extremely frightened about aspiration their breathing (**IV**).

Short hospital stays and poor care planning, including insufficient information between healthcare levels, magnify the risk that problems such as dysphagia may not be addressed (**I**). Furthermore, many of the studied patients suffered from decreased alertness, attention and impulsiveness as well as fatigue (**III**) which is reported as risks for aspiration of food and liquids (Fienberg et al. 1990). Thus RNs must become competent in eating assessment including swallowing assessment to avoid aspiration of food and liquids known to be associated with pneumonia, sepsis, and increased morbidity and mortality (Caruthers, 1990). In addition eating difficulties with strongest predictive value as to nutritional status were found to be 'dysphagia', 'eats three-quarters or less of served food', 'alertness' and 'aberrant eating speed', when stroke patients admitted to a rehabilitation ward were studied according to eating, nutritional status, activities of daily living and pressure ulcers (Westergren et al. 2001); thus indicating that several persons in our study were at risk of undernutrition (**IV**). Yet only a few weights were recorded as follow up.

Today there are many guidelines and instruments based on nursing research in most of the domains studied that help RNs to perform comprehensive assessments, including those developed especially for persons cognitively and communicatively impaired. However, in the present study the RNs' descriptions of the persons' disabilities and problems were often expressed in ordinary terms, lacking comprehensiveness and a diagnostic reasoning process (**III-V**). Furthermore there were no descriptions of the use of any guidelines or instruments related to the different areas studied, which probably would have helped them in the diagnostic process, detection of risks and care planning. This might have been one reason for few expressed causes of the different disabilities, and often unspecific described care given (**III-V**), although there was a tendency that the few specific descriptions were given by the RNs with education or experience in stroke care or good collaboration with therapists.

There is a growing knowledge about the brain plasticity and the influence of different stimuli. Thus the poor engagement in social activities shown in our studies is a further threat to these persons' health and wellbeing (II-III). Persons in nursing homes have also been reported as being occupied by few meaningful activities (Bircall & Waters, 1996; Nolan et al. 1995).

The interviews elucidated that instrumental and expressive care often were combined to meet the persons' needs (III-IV). The importance of the recognition of both these components in nursing care (Sjöstedt, 1997) and in stroke rehabilitation is growing (Burton, 2003; O'Connor, 2000; Kirekevold, 1997). Recently it was also shown in an experimental study of elderly stroke survivors that when nursing interventions related to affective domains and cognitive domains were added to the usual routine rehabilitation programme in the intervention group, they showed better scores in functional, psychological and emotional variables than those who only received the usual routine programme (Nir et al. 2004). In addition this effect had both short- and long-term effects. In our study the RNs were obstructed by insufficient time spent with the person to get to know her/him well enough. This was also aggravated by the extreme complexity in those persons, often added by the cognitive and communicative impairments. Furthermore, there were expressions about insufficient theoretical and methodological knowledge among some of the nurses. Thus it was not surprising that RNs' descriptions of their care interventions often were common and lacked specifics (II-V).

## **Methodological consideration**

### *Interviews*

Interviewing RNs about their perception of the person cared for as well as the care given and changes in their health status was a method to get better insight (III-V). As these persons suffer from a variety of impairment and disabilities, our semi-structured questions aimed at getting a holistic view of their health situation, which is the situation that confronts RNs and nursing staff. If the interviews had been about specific topics, the answer might have been more specific. However, asking follow-up questions such as "could you tell me more about this" or "how do you meet these needs" was a way to richer answers. In an interview situation it might be more special descriptions that stick out and probably the most urgent and for

example more obvious nursing care might not have been addressed. To minimise this the interviewer asked follow-up questions such as “is there any other care needed?”.

In the analysis of the different papers (III-V) texts were abstracted from all interviews, which might risk losing coherence; however by working with all interviews several times during a long period, reading them several times and also listening to them during the analysis, this risk decreased.

In a qualitative study *credibility* refers to whether results give a credible depiction of the respondents' reality and not merely the researcher's subjective view (Polit & Beck 2004). In Papers III-V no confirmation of the results has been obtained from the interviewed. Although when discussing this result with RNs working in nursing homes as well as students practising in nursing homes, they often confirm results from interviews.

*Transferability* has to do with whether the original context is similar to the context where results are to be transferred. The RNs interviewed represented a wide range of age, and of experience working in elderly care. A few had a specialist competence and they worked at different kinds of the nursing homes. Thus they and the nursing homes may be representative at least for big cities but maybe not for the countryside (III-V).

*Dependability* refers to the stability of data over time and conditions. Assessing the dependability of the data can be done by carrying out a procedure of stepwise replication. Another researcher should be able to assume similar results but not the contrary to achieve dependability. In Papers III-V the first author (SK) carried out the categorisation, although the two nurse researchers met regularly during the analysis to discuss the meaning units and the categories. This was an analytical process sometimes included re-sorting and reaching agreement on the categories.

#### *The Resident Assessment Instrument*

A multidimensional instrument, the Resident Assessment Instrument, RAI, was used in Papers I-II and IV-V to give a comprehensive description of the persons with stroke as to their health status and care needs. Other instruments, focusing on specific areas, might have given a deeper knowledge in the various areas addressed, but as these instruments are often

limited to a narrow function, too many instruments would have had to be used to cover all the areas that were now covered by the RAI.

When using an instrument there are many aspects to consider. The *internal validity* concerns the truth value of a quantitative study and addresses whether the study investigates what was intended (Polit & Beck, 2004). In our study there are several aspects of the RAI that are important for the question on internal validity. The *content validity* concerns the degree to which an instrument really assesses what is supposed to be assessed, and the clinical relevance of the data. The implementation of the RAI was a U.S. Congress mandate, based on the insight of varying quality in U.S. nursing homes and lack of care planning support for the staff in these institutions. Based on the relevance of the clinical needs the residents showed, this comprehensive needs assessment was developed. Constructing the RAI was a process over several years, including research, opinions from experts in many clinical fields, and several clinical tests (Drugovich & Mor, 1989; Morris et al. 1990, Hawes et al. 1995). When the international research community started to use the RAI, a more systematic approach was developed, including translations and back-translations and testing for validity and reliability in other countries.

Up to now, the RAI has been used in more than 20 languages in about 30 countries in various settings, e.g., long-term care facilities, home care, palliative care, psychiatric settings, and acute care hospitals. The RAI is legally mandated to use in the U.S., in several parts of Canada and Japan and in all of Iceland. It is also extensively used in Finland in nursing homes as well as in home care. But even if an instrument that has been translated to another language could be less reliable, due to translation as well as differences in cultural contexts, the RAI has showed high reliability when tested in several countries and in various settings (Sgadari et al. 1997; Carpenter et al. 2001, Hirdes et al. 2002, Mor, 2004) and a high content validity in several countries including all the Scandinavian countries (El Kohly et al. 1994; Jensdóttir et al. 1995; Ljunggren, 2000; Grue et al. 2001; Noro et al. 2005). In total, more than 500 scientific articles have been presented, using the RAI, and world-wide a large number of national, regional or local reports have been written. The research organisation responsible for these instruments, interRAI, is actively promoting further development of the clinical use of them and recently launched an updated suite of instruments that have been tested for reliability in eleven countries with good results (unpublished) [www.interrai.org](http://www.interrai.org)

Instead of adding separate scales of important issues, such as cognitive and physical dysfunction, depression or social engagement, the research within interRAI has taken the path to cross-walk golden standards with variables within the RAI instruments. For example the CPS scale correlates with the MMSE and the DRS correlates with the Hamilton and Cornell scales (see the section on Methods). This approach thus minimizes the need to use extra scales or instruments if the RAI is implemented.

It is also important to consider that an instrument is not valid or reliable in itself, but in relation to the population it is used for. Obviously, the RAI was not especially developed for persons with stroke, but since it was developed for addressing the needs of all kinds of residents in long-term care institutions, it was used also for persons with stroke (**II, IV-V**). Most items in the instrument should be assessed over a full week and all shifts to provide safer information. However, in Paper **I** the context was two acute-care hospitals with an often short length of stay. To overcome the problems with this, the assessment was performed by one of the researchers assessing the actual health status within the last 24 hours but in careful dialogue with the responsible RNs to minimise the risk of assessing a temporary functioning that diverged from the patient's overall function within the intended time frame.

Factors that might have increased the validity and reliability of the assessment (**I, IV-V**) were the fact that the first author (SK) had a long experience in using the RAI, but still worked together with the responsible RNs for the actual person assessed, and used the other suggested sources of information to complete the assessment. That the RNs and other nursing staff were carefully trained in the RAI also contributes to the quality of the assessment, although different conditions in the nursing homes as to the number of RNs, educational levels in the nursing staff, the continuity of staff, etc. might on the other hand have jeopardised the assessments (**II**). This is, however, balanced by the fact that the RAI consists primarily of clinically important issues for the RNs, responsible for the care planning and documentation. The motivation to collect relevant information is therefore strengthened.

The aspect of *external validity* concerns the sampling design adequacy, whether the studied sample is representative for the population and thus the results could be generalized (Polit & Beck, 2004). There was no known selection bias of the patients with stroke in the two acute

care wards studied, representing two different catchment areas in the municipality. Therefore, it seems reasonable to consider the patients representative for the population (I). The population of nursing homes represented thirteen different nursing homes, including mostly care given by the municipalities, but also some private care givers; they covered about 20% of all nursing homes in the municipality (II). In Papers IV-V five different nursing homes in the municipality were included. No randomised selection was used in these studies (II, IV-V). However, there was a mix of wards as to size, kind of care provided, and geographical distribution, which probably made the sample representative for the municipality. However, since large differences were reported as to discharge to nursing homes from the acute care hospitals, as well as different care organisations, it is not possible to consider whether the studied population is representative for the whole country.

#### *Other aspects*

The drop-outs in Paper I were almost 25%, but most of these patients were discharged to home (84%) and also had a shorter length of stay compared to all patients in the study. Since the data collection was done 2-3 times/week, this was probably one reason for missing some patients with short length of stay. However, the main target of this study was persons discharged to nursing homes, not to home. The inclusion of more short-staying persons discharged to home would not have changed the results of study I.

There may also be differences between interviews, documentation and actual nursing practice, which could only be resolved by observing these nurses at work (III-V). However, the use of interviews, documentation and assessments, a method triangulation, provided a basis for convergence and reduction of missed data. The combination of methods also elucidated interesting differences regarding the details of data, which contributed to knowledge about how RNs communicated nursing care.

## CONCLUSION

Persons with stroke in nursing homes were in need of advanced nursing care because of extremely complex nursing care needs. This was elucidated by the RNs' descriptions of these persons and also by assessment of their health status according to the multidimensional RAI. These persons had a variety of impairments as to cognition, communication and paralyses as well as symptoms such as pain, mood disorders and depression, which except for the possibility of interfering with each other, influenced the person's daily life in many different ways.

The discharge decision might be uncertain for some of the most severely impaired stroke patients, who were often decided to be discharged to a nursing home after a very short stay. Written information about the stroke patients from acute care to the next caregiver was not as full as recommended by the authorities and desired by the nursing home RNs.

Uncertainty was expressed by the RNs in the nursing homes about the patients' health conditions and descriptions were often expressed in ordinary terms that lacked a diagnostic reasoning process and specific interventions. This may be related to the expressed insufficiency of time in clinical care, leading to less ability to knowing the person more deeply, which was especially important when understanding those with communication difficulties. The RNs did not use instruments to achieve a better description and differentiation of the disabilities, insufficient knowledge in stroke care and poor access to or collaboration with multi-professional staff might have aggravated their uncertainty. However, there was also a contrasting picture, mostly from the RNs with special training in stroke care and access to or good collaboration with paramedical staff.

Thus several of the nursing homes appeared not to provide adequate care for the persons with stroke, which may lead to less improvement or failure to preserve functions, perhaps even lead to serious threat to their health. It may also indicate that some discharge decisions by acute care hospitals are uncertain and that communication between care providers as well as between caregivers was insufficient.

### **Implications for education**

The needs of older people are extremely heterogeneous and further aggravated by a disease such as stroke. Thus RNs working in nursing homes need to learn more about research-based and comprehensive assessments, strategies and ways of interacting with persons cognitively and communicatively impaired. There is also a need to increase the knowledge of how to maintain or increase persons' capabilities, which is important to integrate in daily care. In training programmes learning to consider a holistic view that recognises the health potential physically, psychologically and socially could be an important repertoire for nurses in nursing home care. Thus there is a need to further develop gerontological nursing both in nursing programmes and also the gerontological specialist programme.

### **Implications for further research**

There is a need for more experimental studies to test the effects of different nursing interventions, for example the use of both expressive and instrumental nursing. Furthermore, different organisations should be tested and evaluated, for example RNs working as consultant compared to RNs working in the daily clinical practice. Also studies to evaluate if RNs specialising in gerontology nursing make any difference compared to those without. It is important to show what makes a difference to these frail persons.

### **Implications for clinical care**

This study indicates the needs of sufficient RNs to make it possible for them to practice clinical care, which is crucial with respect to knowing the person cared for. Furthermore it is important to view the other nursing staff working, to integrate supervision and continues education to increase the quality of care. Crucial knowledge is developed over time in clinical care and there is a serious risk if RNs with short clinical experiences rarely meet and care for the persons in nursing homes. When considering these complex persons with a stroke it is not possible to assume that nursing staff with poor education should be able to decide when they should ask for help. Furthermore the needs of multi-professional assistance need to be better considered by the municipalities.

## **POPULÄRVETENSKAPLIG SAMMANFATTNING**

### **Personer med stroke och deras omvårdnad på sjukhem**

Att drabbas av stroke innebär olika nedsättningar för den enskilde individen, beroende på vilken del eller delar av hjärnan som har drabbats. När olika kognitiva funktioner såsom minne, associationsförmåga, uppfattningsförmåga, talförmåga, förmågan att förstå tal drabbas påverkas det dagliga livet dramatiskt med svåra förluster för den enskilde att kunna klara sitt dagliga liv. Fysiska nedsättningar är också vanliga t ex förlamning eller nedsatt rörlighet i halva kroppen eller arm eller ben. Nedsatt känsel, synfältsbortfall eller omedvetenhet om sin ena kroppshalva förändrar också den enskildes liv i hög grad.

Vissa personer återhämtar sig snabbt, från några dagar till veckor, för andra kan det ta lång tid och det är inte ovanligt att nedsättningar kan bli bestående. Stroke är också den vanligaste orsaken till invaliditet och tar i anspråk flest vårddagar på svenska sjukhus och en stor andel av kommunens resurser. Personer som drabbats av omfattande funktionsnedsättningar behöver ofta omvårdnad och rehabilitering under lång tid för att uppnå optimal funktionsnivå. Emellertid har vårdtiderna inom såväl akutvård som geriatrisk rehabilitering förkortats kraftigt under det senaste decenniet, vilket ställer stora krav på fortsatt vårdplanering för att tillgodose en god vård i hela vårdkedjan. Möjligheter till en långsiktig rehabilitering och specifik omvårdnad varierar mellan olika kommuner.

Sjuksköterskor ansvarar för omvårdnaden av personer med stroke inom olika nivåer i vårdkedjan, vilket innebär att kvaliteten på deras arbete är av stor betydelse för hur den stroke drabbade kan återhämta eller förbättra sin hälsa efter insjuknandet. Komplexiteten i de konsekvenser som sjukdomen kan medföra ställer stora krav på sjuksköterskor att förstå och vårda dessa personer. Trots att personer med stroke utgör ca 25 % av dem som vårdas på sjukhem har lite forskning ägnats åt denna grupp.

Målsättningen med studierna har varit att kartlägga stroke drabbades hälsostatus och vårdbehov i relation till vårdplanering vid beslut om utskrivning från akutsjukhus, samt även hälsostatus på de personer som vistas på sjukhem, med ett fokus på dem med stroke, deras vårdbehov och omvårdnad. Resultatet är tänkt att kunna utgöra en grund för

kvalitetsförbättringar inom sjukhemsvården samt för utveckling av utbildning av sjuksköterskor och specialistsjuksköterskor inom vård av äldre.

**Studie I** har till syfte att beskriva hälsostatus bland personer som drabbats av stroke när beslut fattades om att de var 'medicinskt färdigbehandlade' och beskriva hälsostatus i relation till vart patienten skrevs ut och hur länge hon/han vårdades. Alla patienter med diagnosen stroke från två akuta strokeavdelningar och med en vårdtid på minst 3 dagar inkluderades konsekutivt under två månader. Patienter med TIA exkluderades. Patienternas (n=114) hälsostatus bedömdes med The Resident Assessment Instrument (RAI) och samtliga journaler granskades med avseende på fortsatt vårdplanering och motiv för val av vårdform samt vårdtid. Skillnader i hälsostatus, vårdtid m.m. mellan patienter som skrevs hem, till rehabiliteringsavdelning eller till sjukhem prövades med statistiska metoder.

Resultatet visade att de strokepatienter som skrevs ut direkt till sjukhem hade signifikant kortare medelvårdtid (5,6 dagar) innan beslut om "medicinskt färdigbehandlad" togs jämfört med dem som skrevs ut till geriatrisk rehabilitering (7,5 dagar). Vid beslut om utskrivning till rehabiliteringsavdelning konsulterades alltid en geriatiker, vilket förekom i 33 % i samband med utskrivning till sjukhem. Strokepatienterna som skrevs ut till sjukhem hade de största funktionsnedsättningarna vad gäller kognition, kommunikation samt i det dagliga livets aktiviteter. I denna grupp var sväljproblem vanligt förekommande (42 %) liksom förekomst av dålig aptit och/eller otillfredsställande födointag (60 %). Tecken på depression och sänkt sinnesstämning förekom i ca 30 % hos de patienter som skrevs ut till rehabiliteringsavdelning eller till sjukhem. Uttryck för planerad fortsatt långsiktig rehabilitering för de patienter som skrevs ut till sjukhem kunde endast återfinnas i de medicinska epikriserna från den ena strokeavdelningen, där man också skickade dessa patienter till de sjukhem som hade speciella avdelningar för rehabilitering. Urininkontinens, ät- och nutritionsproblem var sällan noterade i den medicinska epikrisen och omvårdnadsepikriser skickades endast i undantagsfall.

**Studie II** har som syfte att beskriva hälsostatus för personer som vistas på sjukhem med ett särskilt fokus på dem som drabbats av stroke. Den undersökta gruppen utgjordes av 519 sjukhemsboende från 13 sjukhem, vilket motsvarar ca 20 % av alla sjukhem i en stor stad. De flesta avdelningar var ordinärt sjukhemsboende. Korttidsboende, långtidsrehabilitering och demensboende förekom också samt enstaka inriktning mot palliativ eller psykiatrisk vård. De boende delades in i 3 grupper efter huvuddiagnos; 19,3 % med stroke (n=100), 32,4 %

med demens (n=168) och 48,3 % utan de två tidigare diagnoserna (n=251). Beskrivande statistik användes för att analysera skillnader mellan grupperna.

Resultatet visade att alvarligt eller mycket alvarligt nedsatt kognitiv förmåga förekom hos 30 % av dem med stroke, i mer än hälften hos dem med demens och i 15 % hos övriga.

Majoriteten i alla 3 grupperna hade också kognitiva nedsättningar av lindrigare grad.

Förekomst av depression varierade mellan 15 % hos dem med stroke, de med demens (24 %) och övriga (17 %). Över en tredjedel av dem med stroke och demens kunde inte eller hade stora svårigheter att göra sig förstådd, vilket var fallet i 11 % hos de övriga. Däremot var andelen mindre hos dem med stroke som hade svårigheter att förstå andra (19 %), än hos dem med demens (42 %).

Mer än hälften av dem med stroke hade behov av omfattande hjälp vad gäller toalett besök, förflyttning mellan säng och stol, sängrorlighet och ätande, vilket förekom i 30 % hos dem med demens och övriga. Omkring tre fjärdedelar av samtliga grupper hade något hjälpbehov i samband med ätande om man också räknade med förberedande åtgärder inför måltid, däremot dominerade olika fysiska nedsättningar såsom nedsatt rörlighet i arm, hand, dålig sittbalans, sväljproblem hos dem med stroke. Smärta bedömdes hos 47 % hos dem med stroke, de med demens (54 %) och övriga (66 %). Andelen med urininkontinens varierade mellan 64-75 % mellan grupperna. Mer än hälften av samtliga grupper hade inget eller nästan inget deltagande eller initiativ i socialt engagemang. Studien visade på komplexa vårdbehov, där personer med stroke har ett stort behov av fysisk assistans. Behovet av kommunikation var stor hos dem med stroke och demens.

**Studie III** har som syfte att beskriva personer med stroke och deras vård på sjukhem med fokus på kognition och sinnesstämning. Alla boende med en stroke diagnos (de med demens diagnos exkluderades) på fem sjukhem inom Stockholms län och med en vårdtid som ej översteg 1 år ingick i studien (n=40). Sjuksköterskor (n=30) ombads berätta om de inkluderade personer för vilka de var omvårdnadsansvariga. I intervjuguiden som användes ingick frågeområden om den strokedrabbades aktuella hälsosituation, vårdbehov, given vård och förändringar i hälsotillståndet liksom frågeområden om sjuksköterskans erfarenhet och kunskap i strokevård. Från de ordagrant utskrivna intervjuerna analyserades all text med beskrivningar om individens kognition, sinnesstämning, och relaterad vård, samt sjuksköterskornas beskrivningar av sin kompetens i strokevård med innehållsanalys.

Resultatet visade att sjuksköterskorna beskrev kognitiva problem hos 65 % och tecken på sänkt sinnesstämning hos 68 % av de boende. Kognition delades in i 9 kategorier; *klarhet, förvirring/orientering, konstigt beteende, glömska/minnas, vakenhet, medvetenhet, verbala/icke verbala uttryck, göra sig själv förstådd och förstå andra*. Kategorierna innehöll olika nedsättningar, grad av nedsättning, förändring liksom normal funktion. Sinnesstämning beskrevs hos 68 % och delades in i 3 kategorier; *uttryck, aktivitet och vilja*. Kategorierna inkluderade personer som tolkades vara deprimerade eller olika tecken som kan vara förknippade med depression. Sjuksköterskornas beskrivningar präglades av ett allmänt språk, som ofta beskrev hur dessa nedsättningar inverkar på individens dagliga liv och synliggjorde komplexa och varierande vårdbehov. Beskriven vård relaterad till nedsatt kognition och sänkt sinnesstämning var; *kompensatorisk vård* t ex se efter, påminna, assistera, anpassa miljön, *emotionellt och socialt stödjande vård* t ex uppmuntra, behandla med respekt, integritet och tålmod, lyssna, informera och försöka finna något meningsfullt att göra, *rehabiliterande vård*; t ex guida, visa instruera träna rörelser. Sjuksköterskorna beskrev ej några kriterier för sina bedömningar eller att de använde några bedömningsinstrument. Sjuksköterskornas erfarenhet och utbildning i strokevård varierade i hög grad, liksom innehåll och omfattning av beskrivningar angående omvårdnadsåtgärder, där vissa sjuksköterskor gav exempel på mer specifika åtgärder, medan andra uttryckte åtgärder på ett mycket generellt sätt.

Sjuksköterskornas reflektioner visade på en stor frustration, när de ej kunde förstå vad personen med stroke önskade eller kände, beroende på kognitiva eller kommunikativa problem. De uttryckte förståelse för individer som visade tecken på depression på grund av sin livssituation, men också för att de ansåg att sjukhemmen inte kunde möta deras behov av meningsfulla aktiviteter och stimulans. Osäkerhet om den strokedrabbades kognitiva status uttrycktes också, liksom huruvida orsaken till tillståndet berodde på hjärnskadan i sig eller t.ex. infektion, trötthet eller brist på stimulans. Det fanns ett missnöje hos sjuksköterskorna som ansåg att personerna med stroke ej var färdigbehandlade och att de kom till sjukhemmen i ett mycket dåligt skick. Bristande resurser beskrevs som en risk för att dessa boende ej fick den vård de behövde. Sjuksköterskorna uttryckte önskemål om mer utbildning inom strokevård. De menade att delar av personalen hade för låg kompetens att vårda dessa personer med komplexa problem. Det fanns också ett missnöje med att möjligheter till rehabilitering av sjukgymnast och arbetsterapeut drogs bort om den strokedrabbade inte förbättrades tillräckligt fort.

**Studie IV** har som syfte att beskriva personer med stroke och deras vård på sjukhem med fokus på ätande och nutrition. Samma intervjuer som i studie III har analyserats men i denna studie har även de strokedrabbades (n=40) omvårdnadsjournaler liksom gjorda RAI bedömningar analyserats med fokus på ätande och nutrition. En innehållsanalys har gjorts på liknande sätt som i studie III

Resultaten visade att nästan 83 % av de strokedrabbade beskrevs behöva någon form av hjälp i samband med ätande, varav 22,5 % hade ett omfattande hjälpbehov medan 60 % hade ett begränsad hjälpbehov. Kommunikativa och kognitiva nedsättningar var allvarligast hos dem som hade störst hjälpbehov, men stora skillnader förekom inom grupperna. Beskrivna ät-och nutritionens problem kategoriserades i 4 kategorier; *hantering av mat på tallrik eller bord* t ex svårt att hitta maten, lustigt plockande med glas och tallrik, kom sig inte för att börja äta, *hantering av mat i munnen* tuggproblem, läckage från munnen, sväljproblem, mat kvar i munnen, *andra svårigheter* avvikande tid för ätande, dålig aptit och födointag, *tecken på undernäring* viktminskning, mager. Antalet ätproblem hos enskilda individer varierade från 1 till 7. Beskrivningarna var ofta allmänna och någon mera utförlig bedömning av t.ex. patientens sväljsvårigheter, orsak till läckage av mat och vätska från munnen eller tuggproblem gjordes ej. Olika ätproblem var sällan noterade i omvårdnadsjournalen med undantag för sväljproblem. Några vårdtagare hade allvarliga sväljproblem med upprepade pneumonier. Dålig aptit liksom för litet födointag var vanligt förekommande hos dem som hade behov av någon form av assistans vid födointag, vilket RAI-bedömningarna fångade upp i högre utsträckning än vad intervjuerna eller dokumentationen gjorde.

Beskrivna omvårdnadsåtgärder liksom utvärdering av dem var sällan noterade i omvårdnadsjournalen. Intervjuerna gav exempel på interventioner kopplade till de olika ätproblemen såsom tillsyn, guidning och hjälp, emotionellt stöd, anpassning av olika konsistens på mat och matningstekniker. Emellertid varierade kvaliteten i dessa beskrivningar, där endast ett fåtal var mer specifika. Det fanns få beskrivningar kopplade till patientens nutrition. Några sjuksköterskor beskrev patienten som tunn eller mager, ibland utan att ha någon vikt eller annan bedömning av individen. Dokumenterad uppföljning av födointag förekom endast hos ett fåtal vårdtagare förutom hos dem som sondmatades. Nutritionsjournal fanns inte dokumenterad hos någon, och vikt fanns noterad i endast sex omvårdnadsjournaler. Sjuksköterskorna beskrev inget samarbete med dietist. Man menade att de fanns på sjukhusen och att det kostade pengar att konsultera dem.

**Studie V** baseras på samma material som studie IV (intervjuer, omvårdnadsjournaler och RAI-bedömningar) och syftet var att beskriva personer med stroke och deras vård på sjukhem med fokus på smärta, urininkontinens och förflyttningar mellan säng till stol. Intervjuer och omvårdnadsjournaler analyserades med innehållsanalys och RAI med beskrivande statistik. Vidare jämfördes beskrivningarna från intervjuerna, journalerna och RAI med avseende på frekvens och kvalitet.

Resultatet visade att 62,5 % av de strokedrabbade beskrevs och bedömdes ha smärta, 82,5% var urininkontinenta och 85% var i olika grad beroende av hjälp vid förflyttning. Den vanligaste beskrivna lokaliseringen av smärta var arm/ben och skuldra/axel (37,5 %). RAI identifierade alla vårdtagare vad gäller grad av inkontinens vilket bara skedde i 25 % om man räknade ihop beskrivningar från intervjuer och journaler. Intervjuerna beskrev oftare än vad som var dokumenterat vårdtagarnas resurser, beteenden som sjuksköterskorna tolkade som smärta, liksom olika omvårdnadsåtgärder, vilket följaktligen blev sämre kommunicerat. Det fanns en brist på systematiska bedömningar baserade på vedertagna/vetenskapliga kriterier inom de studerade områdena liksom få beskrivningar över orsaker till besvären och specifika omvårdnadsåtgärder samt vårdplaner. Intervjuerna belyste också att vissa sjuksköterskor hade en mer aktivt bevarande/rehabiliterande omvårdnad, medan andra uttryckte en mer passiv syn där rehabilitering var paramedicinarnas arbete.

Sjuksköterskornas beskrivningar och RAI-bedömningar av personer med stroke synliggjorde vilka komplexa vårdbehov dessa individer har. Sjuksköterskorna beskrev också en osäkerhet i att förstå och vårda dessa personer, vilket framgick i deras ofta generella beskrivningar av den stroke drabbades hälsoproblem och vård. Flera orsaker kan bidra till detta; för lite tid för att kunna medverka i den kliniska vården och lära känna den vårdade, vilket var speciellt viktigt för dem med kommunikationsproblem, att sjuksköterskorna ej använde några instrument eller guidelines som hjälp i sina bedömningar, att samarbete och tillgång på paramedicinska resurser varierade samt att många sjuksköterskor upplevde sig ha för lite kunskaper i strokevård. Korta vårdtider på akutsjukhus och en vag vårdplanering med en kanske dålig uppföljning för dem som skickas till sjukhem ökar risken för att dessa personer inte får den vård och rehabilitering de skulle behöva. Studierna visar på en rad områden där omvårdnaden behöver utvecklas för att dessa personer ska nå optimal hälsa.

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