

From Department of Neurobiology, Care Sciences and Society,  
Karolinska Institutet, Stockholm, Sweden

# **Unequal Opportunities for Patients with and without Cognitive Impairment**

Relatives' and significant others' views on  
care and rehabilitation after hip fracture

Ann-Marie Rydholm Hedman



**Karolinska  
Institutet**

Stockholm 2007

Published by Karolinska Institutet. Printed by Universitetservice US-AB  
Nanna Swartz väg, 171 77 Solna, Sweden  
© Ann-Marie Rydholm Hedman, 2007  
ISBN 978-91-7357-118-0

*To My family with love*



## ABSTRACT

The overall aim of the studies that form the basis of this doctoral thesis was to explore how cognitive impairment affects the care and rehabilitation of hip fracture patients, as revealed by their relatives and significant others. A further aim was to investigate to what extent dementia, delirium and other co-morbid conditions in hip fracture patients was put on record in Stockholm County Council's In-patient Care Register (ICR) database.

Study **I** focused on frequencies of dementia and delirium diagnoses in a hip fracture population (**I**). Study **II** focused on the relatives and significant others views on the conditions of rehabilitation for older patients with dementia. Study **III** focused on how relatives to cognitively impaired and cognitively intact hip fracture patients experienced the first six months post fracture, in order to determine whether the patients' cognitive impairment affected the relatives' experiences. Study **IV** focused on cognitively impaired and cognitively intact hip fracture patients' outcomes and their proxies' perceptions of a six-month rehabilitation period.

The results are based on data from 14 993 hip fracture patients (from 1994 to 1999) registered in the ICR, aged 65 years or older (**I**). Moreover, interview data from the 20 relatives (aged 37 to 88 years) to the patients with cognitive impairment (**II**), diaries from 11 relatives to patients with and without cognitive impairment (**III**), and questionnaires from 32 relatives to patients with and without cognitive impairment (**IV**). The Mini Mental State Examination (MMSE) and Katz' Activities of Daily Living Index (ADL) were used to assess the patients. The patients were recruited consecutively, together with their relatives (spouses, children, and other relatives) and other significant persons (friends and staff). The data were analysed with descriptive statistics and correlations (**I**), content analysis (**II**), latent content analysis (**III**) and comparative statistics and manifest content analysis (**IV**).

Based on the result of the four studies in this thesis, it can be concluded that patients with cognitive impairment, i.e. dementia and confusion, are not given the care and attention they need after a hip fracture. This is based on the relatives' views and assertions, which point out that rehabilitation outcomes for cognitively impaired patients are less successful and that their rehabilitation care is less carefully prepared and/or supported by physiotherapists, when compared to cognitively intact patients. This leads to greater dissatisfaction among relatives to hip fracture patients with cognitive impairment. The results indicate that health personnel lack knowledge and strategies that can control and prevent the cognitively impaired patients' behaviour and support them during rehabilitation. Moreover, although the in-patient care register seems to be suitable for planning hip fracture care, it may not be appropriate for patients with comorbid diagnoses, since the register was found to be unreliable in relation to the secondary diagnoses of dementia and delirium. This indicates unequal opportunities for hip fracture patients with and without cognitive impairment. The way forward implicates an improvement in education, guidelines, and support, so that cognitively impaired patients' are given the opportunity to complete their rehabilitation programmes. Furthermore, a more friendly approach is required when dealing with cognitively impaired patients in various care settings.

**Key words:** Hip fractures, Rehabilitation, Unequal care, Relatives, Stockholm County council In-Care Register

## LIST OF PUBLICATIONS

- I. Rydholm Hedman A-M, Ljunggren G, Grafström M and Strömberg L. (2005) Dementia, delirium and other co morbid conditions in acute hip fracture care – traditions, attitudes and local policies rather than actual state guide diagnose making? *Nursing Science and Research in the Nordic Countries* (Vård i Norden) 25 (4):25-9.
- II. Rydholm Hedman A-M & Grafström M. (2001) Conditions for rehabilitation of older patients with dementia and hip fracture – the perspective of their next of kin. *Scandinavian Journal of Caring Sciences* 15 (2):151-8.
- III. Rydholm Hedman A-M, Strömberg L, Grafström M & Heikkilä K. Relatives' experiences of the hip fracture recovery period of older patients with and without cognitive impairment. (Submitted).
- IV. Rydholm Hedman A-M, Heikkilä K, Grafström M & Strömberg L. Hip fractures and cognitive state: Patient outcomes and proxies' perceptions of the rehabilitation period. (Submitted).

Published articles in this thesis have been reprinted with kind permission of the respective publishers: Nursing Science and Research in the Nordic Countries (Article I) and Blackwell Publishing (Article II).

# CONTENTS

1	Background	1
1.1	Care context for hip fracture patients in Sweden	1
1.2	Hip Fracture	1
1.3	Dementia diseases and delirium – co-morbidities in the hip fracture population	2
1.4	Rehabilitation and mobilisation post hip fracture	4
1.5	Cognitively impaired patients' physical outcomes after hip fracture	5
1.6	Lawton's ecological model of adaptation and aging	5
1.7	Informal hip fracture care and proxy reports	6
2	Rationale for the thesis	8
3	Aims of the thesis	9
4	Methods and materials	10
4.1	Sample and participants	10
4.2	Data collection methods	13
4.3	Data analysis methods	16
5	Ethical considerations	19
6	Results	21
6.1	Dementia and delirium diagnoses in a hip fracture population	21
6.2	Competence of older patients with cognitive impairment and hip fracture	21
6.3	Specific needs for support after hip fractures in patients with cognitive impairment	22
6.4	Rehabilitation context of patients with cognitive impairment	22
6.5	Judging the rehabilitation abilities of cognitively impaired patients	23
6.6	Relatives' and significant others' own feelings	23
6.7	Relatives' assessments of the rehabilitation period	24
6.8	ADL-dependence – differences between patients with and without cognitive impairment	25
7	Methodological considerations	26
7.1	The qualitative approach	26
7.2	The quantitative approach	28
7.3	Discussion of the methods	31
8	Discussion	33
8.1	Lack of pain relief and cognitively impaired hip fracture patients' reactions	33
8.2	Physiotherapist-led rehabilitation support	34
8.3	Implication of rehabilitation environment	34
8.4	Physical function outcomes after a hip fracture	35
8.5	Attitudes towards the rehabilitation of cognitively impaired patients	36
8.6	Attitudes towards dementia and delirium diagnoses	37
9	Conclusions	38
10	Acknowledgements	39
11	Populärvetenskaplig sammanfattning	41
12	References	45
13	Original papers I-IV	57

## LIST OF ABBREVIATIONS

<b>ADL</b>	Katz' Activities of Daily Living index
<b>APA</b>	American Psychiatric Association
<b>DSM IV</b>	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition
<b>MMSE</b>	Mini-Mental State Examination
<b>ICD-9</b>	The Statistical International Classification of Diseases, Injuries, and Causes of Death, Ninth Revision
<b>ICD-10</b>	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision
<b>ICR</b>	In-patient care register of Stockholm county council
<b>HSL</b>	Health and Medical Services Act ( <i>Hälso- och sjukvårdslagen</i> )
<b>SCC</b>	Stockholm County Council ( <i>Stockholms läns landsting</i> )
<b>SFS</b>	Swedish Code of Statutes ( <i>Svensk författningssamling</i> )
<b>WHO</b>	World Health Organization



# 1 BACKGROUND

## 1.1 CARE CONTEXT FOR HIP FRACTURE PATIENTS IN SWEDEN

Health care systems cannot be studied in isolation from other aspects of society, or from the social, political and economic organisations (Helman 2000). In Sweden, the Health and Medical Care Act regulates all citizens' rights to health and medical care (*cf.* SFS 1982:763, 2 §). According to 2§, all persons have the right to a high standard of health and medical care, on equal terms, and individuals with the greatest health and medical needs shall be given priority (SFS 1997:142).

Health care and social welfare in Sweden covers all residents, and it is regarded as a public sector responsibility, supported by a national social insurance system. Twenty one County Councils and health-care regions run health care in the acute phases of illness for both inpatients and outpatients (Swedish Government Offices 2006). The municipalities are responsible for the health care and rehabilitation of elderly people, both in their own homes and in sheltered accommodation, but not in acute care situations.

## 1.2 HIP FRACTURE

Hip fracture is an acute injury that mainly occurs after a fall (Sadigh et al. 2004) and it requires a great deal of care and support from both formal and informal caregivers (Parliamentary auditors of Sweden, Report 2001/02:15). Impaired gait and balance, medication, cardiovascular problems and the environment, are common risk factors that contribute to falls and fall injuries (Kallin et al. 2002, Kallin et al. 2004). Cognitive impairment has also been shown to be an independent risk factor (Tinetti, Speechley & Ginter 1988, Stevens et al. 1997, Colón-Emeric, Pieper & Artz 2002, Kallin et al. 2005). Moreover, cognitive function is connected to gait dysfunction, which can contribute to falls. Thus, the risk of hip fracture increases in individuals that suffer from a dementia disease (Ranstam, Elffors & Kanis 1996). It is difficult to prevent falls and pertinent injuries among people with dementia disease (Shaw & Kenny 1998, Shaw et al. 2003)

Hip fractures can be divided into different categories according to their anatomic location, such as; femoral-neck fractures, trochanteric fractures (pre trochanteric or intertrochanteric fractures) and subtrochanteric fractures. Femoral neck and intertrochanteric fractures are the most common type of hip fractures. They account for over 90 percent of hip fractures, while subtrochanteric fractures account for the remaining 5 to 10 percent (Zuckerman 1996, Cserhádi et al. 2002). A hip fracture can be either stable or unstable (Lindskog & Baumgaertner 2004).

Hip fracture is a worldwide cause of morbidity and mortality (Nightingale et al. 2001, Johnell et al. 2004, Johnell & Kanis 2006). There is a large variation in hip fracture incidence in different regions of the world (Kanis et al. 2002). Sweden and Norway belong to the countries with the highest incidence of hip fractures (*ibid.*). A population-based cross-sectional study of the oldest old, the Umea 85+ Study, showed very high prevalence of hypertension, depression, hip fractures, and a high dosage of prescribed

drugs (von Heideken Wågert et al. 2006). In Sweden, approximately 18 000 persons a year suffer from a hip fracture (Löfman et al. 2002, SBU-report 2003). The average age of patients with a hip fracture is approximately 80 years old (Löfman et al. 2002, Thorngren et al. 2002).

Femoral neck fractures can be treated with either primary internal fixation (pins, screws or sliding hip screw and plate) or arthroplasty (artificial joint). A significantly lower failure rate and a good functional outcome, one year after treatment of demented and/or institutionalized patients were shown by Rogmark et al. (2002), when displaced femoral neck fractures were treated with primary hemi-arthroplasty instead of internal fixation. Treatment by means of total hip arthroplasty for vital patients and treatment via hemi-arthroplasty for frail elderly patients is supported by evidence-based rationale (Rogmark & Johnell 2006).

Peoples' experience of pain after a hip fracture varies, when comparing treatment by means of internal fixation or arthroplasty. A primary arthroplasty is associated with less pain and better function during the rehabilitation period (Rogemark & Johnell 2005). Almost half of a population of frail elderly hip fracture patients, living in community-dwellings were found to have persistent pain. The frequency of pain was related to the use of pain medication, symptoms of depression, and skeletal muscle weakness of the fractured leg (Herrick et al. 2004). Undetected or under-treated pain following a hip fracture occurs more frequently among patients with cognitive impairment compared to patients without cognitive impairment (Feldt, Ryden & Miles 1998, Morrison & Siu 2000).

General complications, postoperative infection rate, and re-operation rate, occurred to the same extent in both cognitively impaired and cognitively intact patients (Be-loosesky et al. 2001, Söderqvist et al. 2006).

Roche et al. (2005) found that the presence of three or more comorbidities significantly increased mortality in hip fracture patients. In a Finnish study, a patients' inability to stand up, sit down, or walk, two weeks after the operation, were the main predictors for mortality after a hip fracture (Heinonen et al. 2004). In a Swedish study, which compared hip fracture patients with and without cognitive impairment, significant differences were found in the one-year mortality rate when comparing the two groups. In the cognitively impaired group, the one-year mortality rate was 48 percent compared to 18 percent in the cognitively intact group (Söderqvist 2006a).

### **1.3 DEMENTIA DISEASES AND DELIRIUM – CO-MORBIDITIES IN THE HIP FRACTURE POPULATION**

Many patients with a hip fracture suffer from co-morbidities, such as dementia diseases and acute confusional state/delirium (Holmes & House 2000a, Holmes & House 2000b). Dementia diseases and delirium affect the patient's cognitive function.

*Dementia diseases* include a number of different subtypes, where Alzheimer's disease is the most frequent. The most important risk factor for developing Alzheimer's disease

is increasing age (von Strauss et al. 1999). Other risk factors are a family history of dementia, hyper- and hypotension, high cholesterol, obesity and low physical activity (Kivipelto et al. 2001, Nissinen & Kivipelto 2005, Rovio et al. 2005, Kivipelto et al. 2006). Dementia diseases are progressive and sometimes difficult to differentiate (*cf.* Agüero-Torres, Kivipelto & von Strauss 2006). A clinical diagnosis of dementia disease is usually based on the DSM-IV criteria (APA 2000). In Stockholm County Council's Care Register, the International Classification of Disease, 10<sup>th</sup> revision, ICD-10 (WHO 2004) is used to classify a disease. According to ICD-10, dementia is described as a syndrome caused by disease of the brain, usually of a progressive nature, in which there is disturbance of multiple higher cortical functions. This includes memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Usually, the person's consciousness is not clouded. Impairment of cognitive function is commonly accompanied and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. The described syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and other conditions primarily or secondarily affecting the brain (ICD-10). A definitive diagnosis can only be obtained by post-mortem examination of the patient's brain.

Symptoms of behaviour disturbance are frequently found in nursing home patients with dementia diseases (Schreiner 2001, Zuidema et al. 2006). One symptom of disturbed behaviour is agitation, which can be expressed as physical or verbal aggressiveness, noisemaking and restlessness. Other symptoms are delusion (a misinterpretation of a situation), hallucination (a false perception of objects or events), mood (a pervasive and sustained emotion that colours perception of the world) and obsession and anxiety (Alzheimer's Association, 2006). These symptoms can occur as a direct result of dementia disease, or when patients with dementia disease suffer from a general medical illness, experience pain, or as a reaction to the environment (*cf.* Zeisel et al. 2003). Being aware of environmental factors, the person's life history, and the nature of the disease, can facilitate successful interactions with individuals suffering from dementia disease, which are helpful for understanding their behaviour (Häggström et al. 1998). Ragneskog et al. (1998) showed that patients expressed agitation when they felt discomfort or wanted to communicate with nursing staff. They suggested that agitation is related to experienced stress. Interaction between care providers and patients showing symptoms of disturbed behaviour, means facing chaos, for both the patients (Graneheim & Jansson 2006) and the care providers (Graneheim et al. 2005).

Thus, it is evident that interaction problems such as this can emerge during hip fracture care, since many patients with hip fracture are elderly and also suffer from a dementia disease. Several Swedish studies have focused on the interaction between persons with dementia and their care providers (*i.e.* Hallberg et al. 1990, Graneheim et al. 2001, Skovdahl et al. 2003, Skovdahl et al. 2004). In all types of hip fracture care, either in hospitals or in the patient's own homes with the help of home help services, the health care providers meet people with cognitive impairments. These persons can display unusual behaviour and caregivers can find this extremely challenging.

*Delirium* is a temporary state, classified as mild or severe and the underlying condition should be treated according to ICD (WHO 2004). In the diagnosis system DSM-IV (APA 2000) the term delirium is used to describe the condition of cerebral vascular in-

sufficiencies. According to DSM IV criteria, delirium is a physiological consequence of a medical condition (APA 2000). It is characterised by a disturbance in consciousness and in changing cognition. Delirium is a temporary state that fluctuates and it can last for a couple of hours or several days (*cf.* Strömberg et al. 1997a).

Examples of other terms for delirium used in the English language are: acute confusional state, postoperative psychosis, post-anaesthetic delirium and acute brain syndrome. Older patients hospitalised for a hip fracture, commonly develop delirium (Olofsson et al. 2005). Moreover, delirium is also often found in patients with dementia and/or depression (*ibid.*). This condition is serious and it can cause both mortality and morbidity (Burns, Gallagley & Byrne 2004). Despite the seriousness of the condition, there is a shortage of documentation in hip fracture patients' medical records about their mental state, from both the nurses and the doctors (Gustafson et al. 1991, Söderqvist et al. 2006a).

#### **1.4 REHABILITATION AND MOBILISATION POST HIP FRACTURE**

After the patient has been treated for the hip fracture, rehabilitation is often needed for a long period of time (Lin & Chang 2004, Heikkinen & Jalovaara 2005). This final phase is usually managed by caregivers working in community care, especially for patients with cognitive impairment. For example, if a patient is already living in some form of sheltered housing accommodation, rehabilitation is usually provided in those settings (Thorngren et al. 2005).

Rehabilitation is traditionally associated with training sessions of physiotherapy (Toussant & Kohia 2005) and activities from occupational therapy (*cf.* Hagsten, Svensson & Gardulf 2006). In clinical praxis, professionals such as dieticians, geriatricians, home helps, nurses, nursing staff, occupational therapists, orthopaedic surgeons, and physiotherapists, provide support to the elderly patients.

In sheltered accommodation and nursing homes, the nursing staff carry a heavy load during the rehabilitation period (*cf.* Nolan & Nolan 1997). However, relatives and other significant persons also play a vital role in the rehabilitation process after a hip fracture (Kane et al. 1999, Lin & Lu 2005).

Strategies for and definitions of rehabilitation after hip fracture, seem to vary. Moreover, only a limited number of evidence based studies can be found regarding the effectiveness of physical therapy (Toussant & Kohia 2005). Some studies suggest that after surgical repair, patients with a hip fracture should immediately begin weight-bearing and walking on the treated leg (Koval et al. 1996, Sherrington, Lord & Herbert 2004). Weight-bearing program can improve balance and functional ability among older people after hip fracture (*ibid.*).

Other studies show that early mobilisation and treatment with physical therapy/occupational therapy post-fracture, is associated with better health outcomes (Hoenig et al. 1997, Siu et al. 2006, Oldmeadow et al. 2006). Little evidence is available on the effects of various mobilisation strategies, which begin either in the early post-operative period, or later on during the rehabilitation period (Handoll, Sherrington

& Parker 2004). Health professionals from various disciplines should work consistently to provide specific treatment, based on strong evidence. This can help patients regain their functional ability, enabling them to return to the same living accommodation as prefracture (Cameron 2005a, Cameron 2005b).

### **1.5 COGNITIVELY IMPAIRED PATIENTS' PHYSICAL OUTCOMES AFTER HIP FRACTURE**

Cognitively impaired patients' outcomes of physical training after hip fracture vary. Positive results of physical gain have been shown in randomised studies (Huusko et al. 2000, Naglie et al. 2002), cohort studies (Goldstein et al. 1997, Heruti et al. 1999, Ruchinskas, Singer & Repetz 2000) and in a study with a convenient sample (Resnick 1997). Other measured outcome factors are: discharge destination, mortality and length of stay (Svensson et al. 1996). Many studies show that cognitive status affects the overall progress of the rehabilitation program and the person's functional status to some extent (Landi et al. 2002). However, walking or stair climbing ability is not predictable (Ruchinskas et al. 2000). Hip fracture is associated with mortality, loss of independence, loss of mobility, and residual pain among the oldest old (Lyons 1997, Stenvall et al. 2005).

### **1.6 LAWTON'S ECOLOGICAL MODEL OF ADAPTATION AND AGING**

Lawton and co-workers developed a research model to study the person-environment perspective (Lawton & Nahemow 1973, Lawton 1982). In Lawton's ecological model, a person is defined by her/his competence and the environment is described in terms of demands (Lawton 1982). Adaptation reflects the relationship between a person's competence and environmental pressure. The model separates environmental components into four different classifications, these are: the personal-, the supra personal-, the social- and the physical environment. This model can be helpful for interpreting a person's competence and assessing whether they are able to perform or participate in activities after a hip fracture.

The model focuses on behaviour and well-being. Lawton's work has been widely used in research and it is frequently described in aging literature. Nevertheless, his work has also been criticised for being too theoretical. In an analysis of Lawton's work, one of the criticisms is related to the interpretation of an individual's behaviour, for instance how a person's competence is related to factors within their environment (Schwarz 2003). However, Iwarsson (2005) used Lawton's ecological model of old age and adaptation to demonstrate how the personal component (competence) and the environmental component (press) changed and interacted over time, for older adults living in their own households. Izal, et al. (2005) used Lawton's model to analyse a number of hypotheses, regarding the implications of 'congruence between the self-assessed functional capacity of community-dwelling elderly care receivers and their functional capacity as assessed by their respective family caregivers, for the adaptation of the elderly and for their caregivers' feelings of burden' (p.131).

## 1.7 INFORMAL HIP FRACTURE CARE AND PROXY REPORTS

In a Swedish study, dementia and hip fractures are found to be associated with living in sheltered accommodation (Aguero-Torres et al. 2001). Likewise, Thorngren et al. (2005) found that one third of hip fracture patients lived in nursing homes or old people's homes before the hip fracture, which means that they already had some kind of formal support. After the hip fracture, the patients from nursing homes and old people's homes were rarely discharged to rehabilitation facilities (*ibid*). Despite the fact that many older hip fracture patients live in nursing homes and other sheltered living accommodation, a large part of the care is provided by informal caregivers (Roberto & Bartmann 1993, Williams et al. 1996, Parliamentary auditors of Sweden, Report 2001/02:15, Macleod et al. 2005). The informal care providers are closely related to the patients, especially when the hip fracture patients live in non-institutional settings.

In the studies referred to below, the following terms were used synonymously: caregivers, carers, family, family caregivers, proxy, next of kin, informal support network, informal care and significant others. In one review, significant others were described as, spouses, parents, relatives, and friends. The main idea seems to be that use of the term 'significant others' can apply to many different types of informal caregivers and the term does not apply to health care personnel (Sneeuw, Sprangers & Aaronson 2002).

Several studies have described the effects of caregiving on informal caregivers (Quine et al. 1994, Slauenwhite & Simpson 1998, Crotty et al. 2003, Lin & Lu 2005). These studies deal with quality of life, comparisons of alternative treatment strategies, caregiver burden and the effects of caregiving on the carer's health. In Crotty's study, a significant burden reduction was found among caregivers of patients that received home-based rehabilitation. Lin & Lu (2005) found that burden was higher for caregivers who were unable to gain access to resources designed to help them in their work and/or had provided care to the older person prior to the fracture (Quine et al. 1994).

The family's role in the rehabilitation process and the caregivers' contributions in the early phase of hospital rehabilitation, were found to involve both practical help (helping patients with eating and drinking) and the opportunity for social interaction. Caregivers acted as a link between the external world and the hospital, and offered emotional support to the patients (Macleod et al. 2005). The caregivers were found to have unrealistic expectations regarding the length of the recovery period (Williams et al. 1996). In Williams study, the care recipients lived in their own homes before the fracture and had no history of dementia disease. Mismatched care, especially during periods of transition, was found in one study of patients' and family members' experiences of early discharge from acute care (Slauenwhite & Simpson 1998).

Other studies focus on the concordance between patients' and proxies' assessments of the patients' physical and mental functions (Yasuda et al. 2004, Lum, Lin & Kane 2005). Yasuda et al. (2004) found significant differences between proxy-reports and patients-reports on the changes that occurred during a six-month period, in relation to physical, instrumental, affective, and cognitive functioning of older persons. Proxies overstated improvements and understated deteriorations.

In one study (Lum, Lin & Kane 2005), the residents' daily activities were assessed by the residents themselves and by family members and nursing staff. Then, in order to measure the level of agreement, two different types of data collection were used (Minimum data Set and Activities of daily living). Low to moderate agreement was found, depending on proxy type and method of data collection (*ibid.*).

## 2 RATIONALE FOR THE THESIS

Many hip fracture studies only focus on patients without cognitive impairment. One reason for this might be that patients with cognitive impairment or dementia disease are believed to be unable to participate in verbal and written evaluations. Furthermore, cognitively impaired patients usually have reduced ADL function before the fracture, which may affect conventional outcomes measures after a hip fracture (Atchison, Massman & Doody 2006).

However, some studies have focused on cognitively impaired patients and the outcomes of physical training after a hip fracture (Goldstein et al. 1997, Resnick 1997, Heruti et al. 1999, Ruchinskas, Singer, & Repetz 2000, Huusko et al. 2000, Naglie 2002). Huusko et al. (2000) found that patients with mild to moderate dementia do benefit from physical therapy/occupational therapy, post-fracture. The results of these studies should be considered when planning the care and rehabilitation of hip fracture patients with cognitive impairment. It is also important to gain knowledge about how care providers can support and mobilise patients with cognitive impairment.

Several studies have found inequity in caring post hip fracture, when comparing patients with and without cognitive impairment (Feldt et al. 1998, Morrison & Siu 2000). A comparison of pain relief for patients with and without cognitive impairment showed that those in the impaired group received a smaller dosage of analgesia than those in the intact group (*ibid.*). This means that patients with cognitive impairment often suffer from severe pain postoperatively. This is not acceptable, as all humans are equally valuable and all have the right to high quality health care (*cf.* SFS 1982:763, 2 §). It is crucial that cognitively impaired patients are offered the same conditions for care and rehabilitation as cognitively intact patients, as is stated in Swedish law. Further studies are needed in order to determine whether patients with cognitive impairment are treated differently than patients without cognitive impairment.

It is a well known fact that informal care after a hip fracture is often provided by relatives or other persons close to the patients. Despite this, very few studies focus on the relatives' experiences of hip fracture care and treatment of patients with cognitive impairment. This might be explained, at least to some extent, by the complexity of the issue. Nevertheless, little is known about whether the type of care and rehabilitation services that are offered at the present time are suitable for this group of patients, or whether their relatives are satisfied with the care and rehabilitation of their close ones. Furthermore, it is vital to consider and learn from the experiences of caregivers to hip fracture patients with cognitive impairment. Relatives and significant others have a vast amount of knowledge regarding the care of this group of patients.

Finally, there appears to be a lack of documentation regarding the co-morbidity conditions of cognitively impaired hip fracture patients during their hospital stay. More knowledge is required on this topic, since this is a determining factor for the care and rehabilitation of cognitively impaired patients.



### **3 AIMS OF THE THESIS**

The overall aim of the studies that form the basis of this doctoral thesis was to explore how cognitive impairment affects the care and rehabilitation of hip fracture patients, as revealed by their relatives and significant others. Furthermore, the aim was to investigate to what extent dementia, delirium and other co-morbid conditions in hip fracture patients was put on record in Stockholm County Council's In-patient Care Register (ICR) database.

- I To investigate to what extent dementia, delirium and other co-morbid conditions in hip fracture patients was diagnosed, coded and reported in Stockholm County Council's In-patient Care Register database.
- II To describe the rehabilitation conditions of older patients with dementia and hip fractures, from the perspective of their next of kin.
- III To illuminate how relatives to cognitively impaired and cognitively intact hip fracture patients experienced the first six months post hip fracture, in order to determine whether the patients' cognitive impairment affected their experiences.
- IV To investigate and compare two groups of hip fracture patients outcomes and their proxies' perceptions of a six-month rehabilitation period. One group was cognitively intact while the other was cognitively impaired.

## 4 METHODS AND MATERIALS

Four studies are presented in this thesis, based on two different samples and four data collection methods. In study **I**, the participants consisted of inpatients with a hip fracture registered in the In-patient Care Register database. In studies **II-IV**, the participants consisted of relatives and significant others of hip fracture patients with and without cognitive impairment. In these studies (**II-IV**), relatives/significant others were used as alternative sources of information, since people with cognitive impairment might have difficulties in communicating their own needs. Different terms/words were used in the studies to describe the closest person to the patients. This was based on the fact that it was difficult to find one concept to describe the closest person to the patients. In Study **II** the term 'next of kin' refers to a person's closest relative or relatives, and thereby, the term was used incorrectly, since in some cases, friends and nursing staff from the residential home acted as substitutes for close relatives. Therefore in subsequent studies, the terms 'relatives/significant others' (**III**) and 'proxies' (**IV**) were used to describe the closest person to patients with a hip fracture. In this framework, the term 'relatives and significant others' is used consequently, to describe the closest person to the patients with a hip fracture. 'Significant others' refers to friends and staff closest to patients with a hip fracture.

### 4.1 SAMPLE AND PARTICIPANTS

#### 4.1.1 Sample for Study I

The entire number of participants consisted of 14 993 patients (from 1994 to 1999) from 10 treatment departments in Stockholm County Council. Patients were aged 65 years or older, and all had been diagnosed with a hip fracture.

For patients with a history of serial hip fractures, only the first hospital stay was included, in order to avoid multiple data collection on the same person. Furthermore, patients with a registered hip fracture hospital stay two years preceding the study (1992-1993) were excluded to avoid including patients that had been readmitted due to unsuccessful healing of the hip fracture (Table 1).

Diagnosis codes 820A-X (ICD-9, 1994-1996) and S720.0-2 (ICD-10, 1997-1999) for hip fractures were used to select registered inpatients of Stockholm County Council. Each patient was given an identification number instead of a name or personal identification number before the data collection began.

The hip fracture patients in this study had been treated at either orthopaedic departments or acute geriatric departments, on their first visit. The orthopaedic clinics and two of the geriatric departments were working together on a joint project, which meant that patients were admitted directly from the emergency room to the geriatric unit. Therefore, this particular project was unique, since the orthopaedic surgeon acted only as a consultant for the geriatric departments. The geriatric departments provided the care after surgery. One project took place from 1995 to 1999 while the second project began in 1997 and was still running when the data collection was completed.

Table 1. Number of patients ( $\geq 65$  years) admitted for hip fractures to acute hospitals in SCC, 1994-1999 (I).

Type of departments	1994	1995	1996	1997	1998	1999	$\Sigma$
	N	N	N	N	N	N	N
Orthopaedic and General Surgery	2 641	2 726	2 280	1 739	1 985	1 969	13 340
Geriatric departments*	–	68	252	519	442	372	1 653
Total	2 641	2 794	2 532	2 258	2 427	2 341	14 993

\*Two collaboration projects were included

#### 4.1.2 Sample for Studies II-IV

In Studies II-IV, the sample size was restricted to 40 persons due to the time limits and cost aspects. The recruiting process started by determining the distribution of patients with hip fractures in hospitals belonging to Stockholm County Council. This information was gathered from Stockholm County Council's In-patient Care Register (ICR) as used in Study I. The two hospitals with the highest frequency of hip fractures were selected for Study II-IV.

The inclusion criteria for patients with hip fractures were: 70 to 90 years (a common age range for sustaining a hip fracture), had sustained a hip fracture (cervical fracture/femoral neck fracture, trochanteric fracture/intertrochanteric fracture and subtrochanteric fracture) through a fall accident and had been able to walk pre-fracture. The inclusion criteria for relatives/significant others, stated that participants must be the closest person to the patient and that they were willing to participate in the study.

A consecutive sampling technique was used to recruit 20 patients with cognitive impairment and 20 patients without cognitive impairment. They volunteered to participate in the study together with their relatives/significant others. These persons were preferably spouses, children or other relatives but in some cases, when patients had no close relatives, friends and contact persons from nursing home staff acted as proxies and substitutes for relatives.

The author (A-M.R.H.) personally asked patients that met the inclusion criteria whether they were interested in participating. The patients were asked to give the name of a close relative. When the patient was not able to suggest someone but had agreed to participate, the registered nurse on the orthopaedic ward gave the name of a person who was documented as close to the patient, i.e. a friend or contact person from the nursing home. Their relatives/significant others' were contacted, usually by telephone, *after* the patients gave their consent.

A letter of information was given to the patients and to their relatives/significant others. A total of 77 patients in orthopaedic wards and their relatives/significant others were asked to participate. The patients were also asked to participate in the Mini Mental State Examination (MMSE) before the data collection from relatives began. However, one relative was too busy to take part in the study and 36 patients declined some of the patients explained that they were too exhausted to participate while others did not wish to participate in the MMSE.

After the MMSE, patients were divided into two groups: A cognitively intact group with 20 patients (MMSE  $\geq 24$ ) and a cognitively impaired group with 20 patients (MMSE  $\leq 23$ ). Each group included the patient's relatives/significant others. The 40 relatives and significant others (aged 37 to 88 years) were all interviewed (**II**). Eleven kept a diary (**III**) and 32 completed a questionnaire (**IV**). See Figure 1.

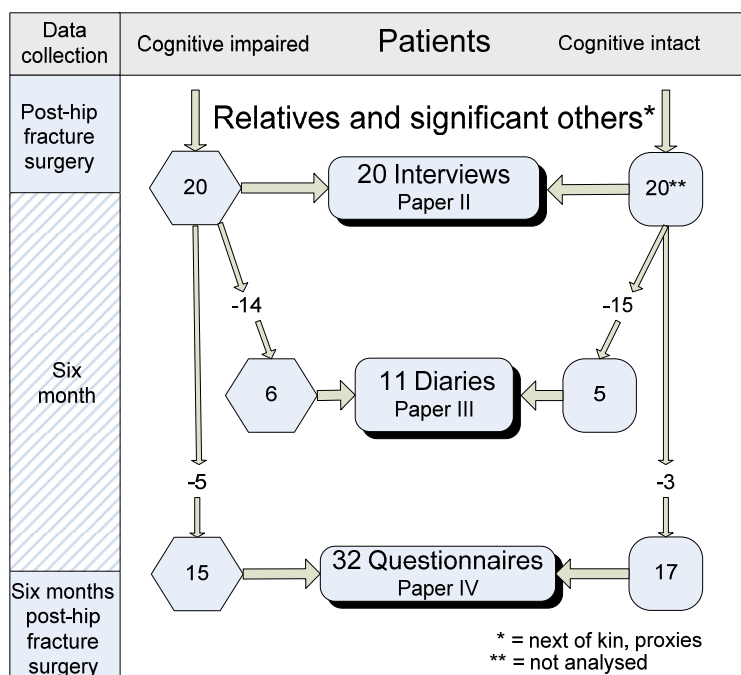


Figure 1. Schematic illustration of sample, recruiting process and number of participants (**II**, **III**, **IV**).

In Study **II**, only the interviews with relatives/significant others of patients with cognitive impairment were analysed according to the focus of the thesis. The main reason given for non-participation in Study **III** was that the relatives/significant others had already participated in an interview. In study **IV**, the withdrawal number was 20%, however this was higher in the group of relatives/significant others of patients with cognitive impairment (33%). This might be due to the fact that patients were generally older and suffered from multiple diseases. Also, because the cognitively impaired group did not always have a relative to represent them, this might have led to additional unanswered questions from those acting as substitutes for relatives. An overview of the participants is shown in Table 2.

Table 2. Overview of participants described in Paper I-IV.

Participants	Paper I	Paper II	Paper III	Paper IV
	14,993 Hip fracture patients. The first hospital stay recorded in the ICR	20 Hip fracture patients with cognitive impairment and 20 relatives-/significant others	11 Hip fracture patients with and without cognitive impairment and 11 relatives/significant others	32 Hip fracture patients with and without cognitive impairment and 32 relatives/significant others
<b>Relation to patients</b>				
Wives	–	–	1	2
Husbands	–	7	1	9
Sons	–	3	2	7
Daughters	–	4	2	5
Other relatives	–	1	1	5
Friends	–	1	2	1
Staff	–	4	2	3
<b>Age, years</b>	<p>≥65 years or older</p> <p>Median of all patients: 82 years</p> <p>Median of patients with registered dementia/acute confusional state diagnosis: 84 years</p> <p>Median of patients without: 82 years</p>	<p>Patients: 70-89 years</p> <p>Relatives/significant others: 37-84 years</p>	<p>Patients: 72- 89 years</p> <p>Relatives/significant others: 37 to 73 years</p>	<p>Patients 70-92 years</p> <p>Relatives/significant others: 37 to 88 years</p>

## 4.2 DATA COLLECTION METHODS

Data was collected from Stockholm County Council's In-patient Care Register (I), and from relatives/significant others by means of an interview (II), diary writing (III) and a questionnaire (IV). The questionnaire was pilot tested and revised before distribution to the relatives/significant others. The patients' physical function (ADL) was retrospectively assessed pre fracture and 6 months post fracture.

#### 4.2.1 The patients' cognitive state and physical function

The Mini Mental State Examination (MMSE): Since a thorough dementia investigation is rarely conducted in acute settings, the preliminary grouping of patients according to cognitive status was based on information from nurses, relatives, and case-sheets. The patient's cognitive status was then verified with the help of a MMSE, which was carried out by the author 0-20 days after the fracture occurred.

The test is a widely used screening test to measure cognitive function, developed by Folstein et al. (1975). The MMSE covers six sections: orientation, registration, attention, calculation, recall, language and coping. The maximum score of 30, whereof 24-30 points is defined as cognitive intact status. A cut-off score  $\leq 23$  was used to define patients as cognitively impaired (Folstein et al. 1975, Tombaugh & McIntyre 1992). A geriatrician assisted with the interpretation of the six above mentioned sections covered by the MMSE form.

Katz' Activities of Daily Living Index (ADL): Katz' ADL is a widely used instrument to describe outcomes after a hip fracture (Svensson et al. 1996, Beloosesky et al. 2002, Gruber-Baldini et al. 2003). According to Katz' ADL (Katz et al. 1963) the interviewees were asked about the patient's *pre* fracture level of physical function, and the same persons answered questions about the patient's *post* fracture level of physical function in the questionnaire.

The personal ADL index measures six functions (bathing, dressing, going to the toilet, transfer, continence and feeding). The individual's ability to perform these functions is expressed as a grade (A-G or "Other"), which summarises the overall performance of the function. The most independent level is classed as grade A and the most dependent to grade G. An individual whose ability is classified as "Other" is more independent than one whose ability is classified as G and more dependent than one whose ability is classified as A or B (Katz et al. 1963). In paper IV the term locomotion is used instead of the term 'transfer'. Some studies differentiate between locomotion (e.g., walking) and mobility (e.g., transfers) (i.e. Goldstein et al. 1997), while others do not (i.e. Eastwood et al. 2002). In Katz' ADL-Index 'transfer' is one of the six functions, which describes a person's mobility.

#### 4.2.2 Register data

All hip fracture inpatients covered by Stockholm County Council are registered in a database (ICR). The following variables were used to process data from the ICR (I): identification number, age, gender, hospital stay, diagnoses, place and date of admission and destination after discharge (own home or other hospitals). Unfortunately, it was not possible to determine whether patients were discharged to nursing homes or to independent living in their own homes. Since each patient was given a unique id-number, it was possible to check whether patients had more than one hospital stay. The register data included the main diagnosis of hip fracture and nine positions of co-diagnosis.

The ICD-codes identify an underlying disease. The following is a description of the codes according to ICD-10 for dementia and delirium diagnoses as used in paper I.

Dementia due to Alzheimer's disease is described with G-codes. Mental and behavioural disorders due to dementia (F00-F03 codes) and delirium (F05-07 codes) are described with F-codes. Delirium is an etiologically non-specific syndrome (code F 05), classified as mild or severe. The R-diagnoses (ICD-10) classifies symptoms and signs relating to cognitive function. Disorientation, confusion (R41.0) as well as unspecified symptoms and signs relating to cognitive function (R41.8) can be used to describe the confusional state when no causative factor can be found.

#### **4.2.3 Interviews**

For Study II, the author contacted the relatives/significant others by phone in order to obtain their verbal informed consent and to determine a suitable time and place for the interview. Semi-structured interviews were conducted, with the help of an interview guide with a predetermined set of topics (*cf.* Polit & Beck 2004). The topics covered background data regarding the relative's/significant other's relationship to the patient, data on the fall and surgery, the rehabilitation environment, the patients' specific needs, and the activities and experiences that were part of the rehabilitation process.

The interviews were conducted 'face-to-face' in a place chosen by the participants, i.e. the patients' home, the first authors' office, the acute hospital or the nursing homes. In order to obtain information, the interviewer (the author) asked the participants certain questions, such as, "Can you describe a good environment for rehabilitation after a hip fracture"? Sometimes clarifying questions were asked by the interviewer, i.e. when the interviewee did not fully understand the question or when the interviewer wished to go deeper into the topic. Brief notes were taken during the interviews, which lasted between 30 and 90 minutes, a typical interview lasting 45 to 60 minutes.

#### **4.2.4 Diaries**

Immediately after the patients and relatives/significant others had agreed to participate in the study, the relatives/ significant others were given a special notebook, here referred to as a diary (III). They were asked to write about important situations relating to the patients and to themselves and to continue writing for the following six months. In addition to the written diaries, they were asked to provide further information about themselves (age and relationship to patient). The participants were given the freedom to describe what they believed to be important information regarding both the patients' and their own lives following a hip fracture.

In practice, the participants began writing diaries no later than one month after the hip fracture occurred. The number of entries varied, from writing almost every day to summing-up the entire six-month post fracture period. In one case, notes were written until the patient died four months after the fracture. As a whole, the relatives and significant others of patients with cognitive impairment made fewer diary entries (mean: 9 situations/person) than relatives and significant others of patients without cognitive impairment (mean: 22 situations/person). The patients' children made the highest number of diary entries. The two contact persons wrote to the same extent as the relatives.

### 4.2.5 Questionnaires

Six months post fracture, a questionnaire was sent to the relatives' and significant others' home addresses together with an addressed return envelope (IV). When participants had completed the questionnaire, which included twenty structured and unstructured questions; it was then sent back to the researcher. The questionnaire consisted of multiple-choice-questions to obtain information about the patient's rehabilitation training sessions. The questions focused on how quickly the sessions began after surgery, the amount of time it took to complete them, the location, and the main person that provided assistance during the rehabilitation process. A single ordered category was used to evaluate the rehabilitation period (1 = very good; 2 = good; 3 = bad; 4 = unacceptable). Before the analysis began, the four categories were dichotomized into answers with a choice of good/bad. Questions regarding whether new falls or complications had occurred were answered with yes/no choices. Finally, an overall assessment of the relatives' and significant others' perceptions of the patients' rehabilitation care was gained by including three open-ended questions, worded as follows:

"What was good with the rehabilitation?"

"What was not so good with the rehabilitation?"

"What kind of help did you want your close relative/ patient to have during the period?"

The open-ended questions allowed relatives and significant others to describe aspects of care giving that might not have been captured by only completing the questionnaire.

## 4.3 DATA ANALYSIS METHODS

### 4.3.1 Design

In this thesis, both a qualitative and quantitative approach was chosen to answer the research questions. Study I was a retrospective total investigation, with a descriptive/comparative design. Study II was a cross-sectional study with a descriptive design. Study III was a prospective/comparative study with a descriptive design. Study IV was a follow-up study of the patients' physical function and a comparison between groups. Mixed methods were used to build up a broad picture of the first six months after a hip fracture for patients with cognitive impairment. Mixed-methods can be used to illustrate, clarify, or amplify the meaning of quantified descriptions or relationships (Polit & Beck 2004).

### 4.3.2 Content Analysis

Content analysis is a useful research technique for text analysis (Downe-Wamboldt 1992, Berg 1995, Graneheim & Lundman 2004). This technique makes it possible to draw replicable and valid inferences to the contexts of their use. The analysis can be either manifest, (quantitative) or latent (qualitative) (*ibid.*). Since analysis processes always imply interpretations, quotations were used to verify the interpretations of raw data and in the description of the results (Sandelowski 1994).

In paper II, data was analysed in accordance with Berg (1995) and Frankfort-Nachmias & Nachmias (1992), but interpretations were also made based on the framework out-



lined in Lawton's ecological model of adaptation and old age (*cf.* Lawton 1982). The data analysis began by reading the texts several times, in order to search for a preliminary understanding of the whole. Then, the words were marked and sorted into groups. These readings generated ideas about how to analyse the data in more detail and then the categorisation process began. Downe-Wamboldt (1992) recommends formulating preliminary categories the very first time when reading material. Gradually, as the coding procedure continued, and the data was condensed to smaller units.

A further analysis was conducted to define the categories more precisely, so that they matched the areas and aspects of Lawton's ecological model (Lawton 1982). Finally, the following four categories were formulated: 1) the competence of older patients with dementia and a hip fracture, 2) specific need of rehabilitation support in the light of competence, 3) environmental factors; and 4) classification of rehabilitation activities. Table 3 illustrates the process of data analysis.

Table 3. Illustration of the data analysis of the interviews based on Lawton's ecological model (II)

Notes from the interviews →	Meaning units marking relevant words →	Aspects →	Areas →	Categories
She has become skinnier after the operation, I will look after her, by preparing her food	She has become <b>skinnier</b> after the operation,	loss of weight	Biological health	The competence of older patients with dementia and hip fracture

In paper III, a qualitative form of content analysis was used to interpret the text from the diaries. Graneheim & Lundman, (2004) describe this form as being latent. The analysis started by reading the texts from both cognition groups separately. Then a series of systematic coding procedures started. The texts were divided into meaning units and then condensed according to the main content. The condensed meaning units were then coded. Codes were sorted into categories according to the patients' successfulness of recovery and the occurrence of complications, since the authors' understanding of the texts was that the patients' conditions affected the relatives' experiences. Then a comparison was made between the two groups based on the different categories. The results consist of the following four main categories: 1) dissatisfied relatives due to health care providers' lack of support 2) satisfied relatives due to patients' successful recovery 3) distressed relatives due to patients' suffering 4) strained relatives due to caring responsibility.

In paper IV, the open-ended questions were analysed with manifest content analysis (Graneheim & Lundman 2004). From a relative/significant other perspective, the whole text from each open-ended question was read separately for both groups, and the text was divided into meaning units based on the descriptions of care and rehabilitation. To find differences in the answers of staff, relatives, or friends, codes from each proxy-group were counted and compared separately. Comments from both staff and family

proxies were of a similar nature. The categories were used to illuminate the statistical results of the rehabilitation period.

### 4.3.3 Statistical Analysis

A majority of the variables were on the nominal or ordinal scales (**I** and **IV**) and therefore, chi-square tests were used to test the levels of differences and associations (*cf.* Bland 1995)

Analysis methods for total investigations were used when analysing data from the ICR (**I**). Pearson's Chi-square test was used to investigate differences over time, differences between hospitals/departments and differences between first and second hospital stay (a chain stay). Pearson's correlation was used to analyse the association between the number of recorded secondary diagnoses and the presence of recorded dementia/delirium diagnoses in hospitals/departments (**I**) (*cf.* Bland 1995).

The Chi-square test was used to investigate differences in outcomes regarding patients *with* and *without* cognitive impairment, but also to examine the differences between relatives'/significant others' assessments of the patients' rehabilitation period after a hip fracture (**IV**). Moreover, age group differences were also investigated.

Table 4 shows the variables and analysis methods that were used to describe the patients physical function both before the hip fracture occurred and six months post-fracture. *P* values lower than 0,05 were considered statistically significant.

Table 4. Analyses of patients' physical function according Katz-ADL Index\*.

Paper	Variables	Analyses
<b>II</b>	Physical function pre fracture	Description of patients' ADL-grades, A-G, Others
<b>IV</b>	Physical function pre- and post fracture. Locomotion pre- and post fracture	Differences between patient groups. Median of ADL-grades A-G pre/post fracture. Pearson Chi-square test

\*Data was collected by interview *pre* fracture and by questionnaire 6 months *post* fracture

## 5 ETHICAL CONSIDERATIONS

The Ethical Committee of Karolinska Institutet in Stockholm approved the project (KI 386/00 and KI 94/286. After obtaining approval, the first author sent in a further application, asking for permission to use a different approach when contacting potential participants and this request was also accepted (10/395). The Data Inspection Board also approved the study (31-486-95). The studies have been designed to follow Swedish research ethics, such as taking into account and protecting the interests of patients and relatives (Gustafsson, Hermerén & Petterson 2006).

A number of ethical issues must be addressed when asking older people to participate in research (Beauchamp & Childress 2001), especially regarding patients with cognitive impairment and their families (Faden & Beauchamp 1986, American Psychiatric Association 2006). Informed consent is required, when recruiting people (Rikkert et al. 1997). In an ethical sense, informed consent means that those asked to participate in research studies must have the capability to make decisions and be informed that they have the right to obtain information on what the study actually entails. Furthermore, participation must always be voluntary. Having capability means that the person is able to make correct decisions, armed with the relevant information (Kim, Cox & Caine 2002).

In our data collection, participants were invited to take part in the study by the first author, in face-to-face meetings. A letter, which aimed at obtaining the person's consent, was handed to each participant. This explained the aim of the study as well as other information stating that participation was voluntary, and that data would be treated confidentially.

After the patients agreed to participate, they took part in a cognitive test (MMSE). The author found that patients with cognitive difficulties sometimes found that participating in the MMSE was exhausting, more so than subjects that were cognitively intact. An important ethical issue is related to making decisions as to how long the examination or i.e. interview should last and whether it is justifiable to interrupt them or continue when difficulties emerge. It was important that the researcher was sensitive to the patients' reactions when they showed signs of concern or agitation. On these occasions, they were allowed to take a break, or in some cases, the interviews were brought to an end. The author had to make this decision based on her intuition, empathy and professionalism. This question was discussed on several occasions amongst those in the researcher group.

When relatives and significant others of the patients had agreed to participate, they were asked to choose a time and place for the interview. The interviews were conducted either in the first author's office, in the acute hospitals, in the nursing homes, or in the relative's own home. Being interviewed in one's own home can be experienced as an intrusion of one's private domain. Therefore, it is important to be sensitive to the relative's feelings and emphasise their right to withdraw participation at any time. Initially, the Dementia Association in Stockholm supported this study and they also identified the research areas and people that were willing to participate in the pilot

study. They, however, did not interfere on the research process or the analyses of the studies conducted. Afterwards, two senior orthopaedic consultants (one at each hospital) acted as gatekeepers, in order to facilitate the project. However, the gatekeepers were not involved in the research project. In the register study which included data from the ICR, all data were coded with numbers making it impossible to identify the patients.

## 6 RESULTS

The main results from the four studies are summarised below.

### 6.1 DEMENTIA AND DELIRIUM DIAGNOSES IN A HIP FRACTURE POPULATION

The first paper focuses on to what extent dementia and delirium and other comorbid conditions are diagnosed and documented in the hip fracture patients records (I). According to the Inpatient Care Register database of Stockholm County Council, the number of hip fracture patients (aged 65+) with a secondary dementia/delirium diagnosis, varied considerably in the ten hospitals (6% to 17%), and the range in one hospital was 1% to 20 % from one year to another. In total, 10% of all 14 993 first hospital stays for a hip fracture, had a recorded secondary dementia diagnosis and only 1% (n=153) had a recorded delirium diagnosis. Among the oldest old patients (aged 90+), one out of ten (12%) was diagnosed with dementia or acute confusional state (I).

In a sub sample of 7 223 patients, who were admitted for a second hospital stay directly after the first (rehab stay), the secondary diagnoses appear to have occurred randomly as the diagnoses were not based on systematic evaluations. The same pattern was found in other reports on secondary diagnoses. Hospitals that tended to keep records of co-existing cognitive disorder diagnoses, usually recorded other co-morbidities (I)

### 6.2 COMPETENCE OF OLDER PATIENTS WITH COGNITIVE IMPAIRMENT AND HIP FRACTURE

According to Lawton's taxonomy, the category which refers to 'the competence of older patients with cognitive impairment and hip fracture' was described in the following *five* areas: cognitive capacity, biological health, sensory-perceptual capacity, motor skills and ego strength (II).

The relatives/significant others considered it to be extremely important to be aware that the patient was vulnerable due to cognitive impairment. The aspects linked to *cognitive capacity* were memory impairment, visuospatial dysfunction, communication problems and language difficulties.

In the area of *biological health* the following aspects were identified: fatigue, weight loss, pain, constipation and fever, during the postoperative period.

Audition and vision were two aspects of patients' *sensory-perceptual capacity*. Some of the relatives explained that they did not know whether a problem was related to a patient's loss of hearing, or to dementia disease. However, the patients were limited in their capacity to interpret impressions.

The patients' *motor skill* was described with aspects from both the pre- and the post operative period. The relatives and significant others meant that, in the rehabilitation process, it was necessary to consider a patient's walking ability pre operatively, and

also consider their fear of falling post operatively, since this affected the patients' motor skills.

A patient's *ego strength* was another area linked to the patient's competence. The relatives and significant others reported that patients with cognitive impairment showed two different ways of dealing with the post fracture period, which was based on their 'ego strength'. Some patients did not take the initiative in joining in rehabilitation activities, while others walked independently, since they were unaware of the hip fracture. These patients seemed unable to relate to the hip fracture and tended to forget about it. Patients need a great deal of support in order to tackle this problematic situation (II).

### **6.3 SPECIFIC NEEDS FOR SUPPORT AFTER HIP FRACTURES IN PATIENTS WITH COGNITIVE IMPAIRMENT**

According to the relatives and significant others, patients with cognitive impairment had specific needs in regard to support after a hip fracture and based on the patient's actual competence (II). These needs were described as: support due to loss of memory, support with physical functions and supervision and encouragement (II and IV). Patients needed to be reminded to use their walking frames for example, or needed to be reminded about other things due to impaired memory. The relatives/ significant others emphasised the need for support and the importance of 'taking one thing at a time' so patients would make good progress during the rehabilitation process. The cognitively impaired patients also needed staff support while participating in physical exercise to improve their muscle strength. They also said exercise sessions should be conducted with people that the patients knew well. Patients also needed supervision from staff when conducting daily activities. Staff and relatives with a positive attitude towards the patients, by showing interest and encouragement were considered especially valuable (II).

### **6.4 REHABILITATION CONTEXT OF PATIENTS WITH COGNITIVE IMPAIRMENT**

According to Lawton's taxonomy, environmental factors are described as: personal area, physical area and social area (II). According to these descriptions, the *personal* environment area was considered from two perspectives: the staff's knowledge of dementia disease and the staff's knowledge of rehabilitation after a hip fracture.

The *physical* environment was described as a traditional environment for cognitively impaired patients, i.e. nursing homes, group dwellings or blocks of service flats. These were considered to be the best places for rehabilitation. However, the relatives emphasised that more staff were needed with specific knowledge of rehabilitation after hip fractures. The rehabilitation activities of patients with cognitive impairment were described in relation to daily activities (II). Three different aspects were focused on during participation in activities: gait training, a general training programme and paying attention to the patients.

Study (IV) showed that patients in the cognitively impaired group mainly participated in rehabilitation sessions in sheltered housing accommodations. Their main support came from nursing staff in contrast to the cognitively intact patient group, whom mainly received help from a physiotherapist. The relatives/significant others complained that there was a shortage of staff and that staff used physical restraints at times, i.e. restraint belts (IV).

The area of *social* environment comprised of three aspects: serviceability for relatives/significant others, cost aspects, and moving from one place of residence to another (II). When patients were already living in nursing homes, the most practical way to provide rehabilitation was to help the patient in the nursing homes and not anywhere else. However, the financial aspect of this had to be considered, since extra resources were needed for supervision and rehabilitation. For example, one of the effects of having a dementia disease meant that patients often became confused, due to a change of environment, and therefore, extra staff were needed. These extra costs were charged to a separate account and not to the group dwellings (II).

### **6.5 JUDGING THE REHABILITATION ABILITIES OF COGNITIVELY IMPAIRED PATIENTS**

In some cases, according to the relatives and significant others, health professionals judged cognitively impaired patients as being incapable of managing rehabilitation. The relatives/significant others believed that this was because the patient was unwilling to take part in physical exercise. The findings showed that some of the patients were unprepared and did not realize why they had to participate in training programmes (II).

The cognitively impaired patients were sent back to nursing homes with no arrangements for rehabilitation activities (III). The decision to discharge a patient did not correspond to the patient's rehabilitation needs, e.g. one person was sent back to the nursing home earlier than planned because staff at the emergency care unit said that the patient was difficult to take care of. Furthermore, the relatives/significant others claimed that staff in acute care discussed the patients in a disrespectful manner and displayed negative attitudes towards both patients and relatives/significant others. They also revealed that one rehabilitation hospital had refused to accept a patient, whom they considered unsuitable for rehabilitation. The relatives/significant others to the cognitively impaired patients, also complained that an evaluation of the patient's physical and mental competence, was based on the opinions of staff in the acute hospitals and that the patient's physical status *before* the hip fracture was not taken into account (III).

### **6.6 RELATIVES' AND SIGNIFICANT OTHERS' OWN FEELINGS**

The patients cognitive status and the recovery period after a hip fracture, was reflected in the relatives/significant others feelings. These were categorised as: satisfaction, dissatisfaction, strain and distress (III).

Relatives/significant others of cognitively intact patients, were *satisfied* when the recovery process was successful and had few complaints (III). On the contrary, rela-

tives/significant others to cognitively impaired patients experienced *dissatisfaction* with the six-month rehabilitation period, even when no complications occurred. These relatives/significant others experienced a lack of support from the health care providers. They felt that staff did not take them seriously at all. They reported poor follow up of the patient after surgery, a lack of adequate rehabilitation activities, such as physical exercise and mobility assistance, and complained of poor medical treatment. The proxies were dissatisfied with staff on the wards when they wanted to discharge patients with cognitive impairment at an early stage, without agreement from the proxies. Relatives/significant others said there was a shortage of information and counselling. The majority of negative experiences came from: the contact persons, the neighbours, and the children, but not from the spouses (III).

When recovery was unsuccessful, both groups of relatives/significant others had negative feelings (III). Relatives/significant others to cognitively intact patients felt *strain* due to their caring responsibilities, since they helped the patients with a variety of tasks.

The relatives/significant others of cognitively impaired patients described their feelings of *distress* due to the patients' suffering. In the impaired group, some patients suffered from complications and became wheelchair-bound or bedridden and the patients' recovery did not go as well as expected. The health care providers did not take the relatives'/significant others' requests seriously, when they asked for treatment and pain relief. The patient's fatigue and fear of falling, together with sleeping disorders and a state of confusion, affected their close relatives deeply. Relatives in the cognitively impaired group, experienced feelings of: sadness, anxiousness, exhaustion, hopelessness, and powerlessness (III).

## **6.7 RELATIVES' ASSESSMENTS OF THE REHABILITATION PERIOD**

Relatives and significant others of patients with cognitive impairment, assessed the rehabilitation period as being of a much lower quality than the group of relatives and significant others to cognitively intact patients (IV). The relatives/significant others to cognitively impaired patients categorised the period in negative terms, when complications occurred, locomotion decreased, and when nursing staff provided most of the help.

There was a significant difference between the two cognitive groups regarding access to physiotherapist-led rehabilitation (IV). According to the relatives and significant others, postoperative complications were reported at a similar rate in both groups.

In the impaired group, relatives described poor follow up after surgery and a lack of communication with staff members in the various settings. Relatives complained that patients lacked adequate rehabilitation activities, such as physical exercise and mobility assistance. Medical treatment was also perceived as poor, especially pain relief (III).



## **6.8 ADL-DEPENDENCE – DIFFERENCES BETWEEN PATIENTS WITH AND WITHOUT COGNITIVE IMPAIRMENT**

The patients' physical function (ADL) was assessed pre- and 6 months post fracture. ADL-dependence was described for each patient, based on the ADL-Index score pre fracture (**II**). Differences between the two groups and differences within the groups were based on changes in the ADL- index score, when measuring physical function before and after the fracture and the ADL median before and after the fracture (**IV**).

The ADL-Index score six months after the hip fracture showed significant differences between the two groups.

In the impaired group, ten patients (91 percent) had a lower score of at least one ADL-grade six months post fracture compared to pre fracture. Only one third of the patients had the same locomotion pre- and 6 months post hip fracture. The ADL-median was rated as grade C pre-fracture and this decreased to grade E post fracture. Eight of fifteen patients (53 percent) were dependent in all six activities (grade G = totally dependent) post fracture (**IV**).

In the cognitively intact group, only five out of seventeen (29 percent) lost one or more degrees of independence on the ADL-grade scale. Both the pre- and post fracture median grade was measured as grade A (range from A–D pre fracture and A–F post fracture). Furthermore, nine out of seventeen cognitively intact patients (53 percent) were independent in all six activities (grade A) six months post fracture, compared to no patients in the cognitively impaired group (**IV**).

## 7 METHODOLOGICAL CONSIDERATIONS

Both qualitative and quantitative data are integrated in this thesis. This integrated approach means gaining insight into a multidimensional reality (Polit & Beck 2004). By investigating, both register data and the experiences of relatives/significant others to hip fracture patients about care and rehabilitation, a more holistic view was gained of the contextual factors connected to the rehabilitation period. Furthermore, comparing the statements of relatives to the cognitively impaired patients with the cognitively intact group's statements, allowed us to illustrate the more specific aspects of care and rehabilitation for the cognitively impaired group. However, this design also has limitations.

### 7.1 THE QUALITATIVE APPROACH

#### 7.1.1 Researchers pre-understanding

An interpretation of human experiences is dependent on the researcher's pre-understanding (Graneheim & Lundman 2004). In study **II-IV**, the intention was to analyse data from relatives' and significant others' experiences/views of hip fracture patients care and rehabilitation.

An understanding of specific underlying assumptions in the fields of 'rehabilitation' or 'orthopaedics', can be lost or misinterpreted when the researcher is not familiar with the care context (as each care context has its own culture code). The first author's medical background as a nurse anaesthetist (surgical) together with experience from the geriatric field as a teacher (elderly care and rehabilitation) contributes to such understanding. In addition, the co-authors experience in various research fields, e.g. orthopaedics, nursing, family and gerontological research, also facilitated the interpretation of the data. The co-authors also contributed by bringing an "outside" perspective to the study, by asking questions about information that might seem self-evident to the first author.

Reflexivity refers to the way in which the researcher's own values, experiences, interests, beliefs or political commitments have formed the research (Maxwell 2005). The present studies (**II-IV**) took place at a time when priority issues were in focus in the Swedish-health care system. An interest group for persons with dementia disease and their relatives initiated the project (The Dementia Association, Stockholm - The National Association for the Rights of the Demented). The goal was to enhance rehabilitation opportunities for dementia patients with a hip fracture and to discuss the obstacles they faced during this process.

The interest group described the following obstacles. There is a lack of knowledge about the work needed for rehabilitation, it is unclear as to who is actually responsible for rehabilitation, dementia patients are a low priority group, resources are not properly allocated and that resources within the buy/sell system are not adjusted to the time-consuming efforts that are necessary for the rehabilitation of dementia patients.

The interest group contacted Professor Bengt Winblad and Margareta Grafström at Stockholm Gerontologic Research Center in order to get their opinions. Then, the au-

thor (A-MR.H.) was asked whether she was interested in joining the project, which she accepted. The researchers were responsible for the design of the project, the data collection, and the data analysis, without being under pressure from any organized associations within the community or other stakeholders. Therefore, the project reflects the needs expressed by members of society, but involvement in the research was objective, i.e. confirmable.

Conformability refers to the objectivity or neutrality of the data (Polit & Beck 2004). To achieve 'conformability' the researcher must remain neutral and keep a good sense of integrity, strictly adhering to professional judgement and scientific and ethic principles. According to Lincoln & Guba (1985) agreement on how well the results are based on the collected data, is more important than the researcher's interpretation of the material.

### **7.1.2 A critical examination of trustworthiness**

The choice of method used in the data collection and analysis will be critically described, based on different aspects related to trustworthiness. The credibility of a study involves aspects such as how to recruit participants, how to select meaning units, how well the categories cover the data, and agreement between researchers, experts and participants (Graneheim & Lundman 2004).

With the intention of comparing patients *with* and *without* cognitive impairment, the patients were included consecutively. The same individuals were asked to participate in an interview (II), write a diary (III) and answer a questionnaire (IV). In this thesis, a triangulation of sources from the interviews, diaries, and questionnaires of significant others, relating to the same topic, was used to reduce the risk of chance association due to the use of a specific method (*cf.* Maxwell 2005). By using this data triangulation, it was possible to enlighten the same phenomenon from different sources and time-periods. However, as time passed, some of the participants withdrew, and therefore, the number of participants in studies III and IV was lower than the original 40 persons. We assume that relatives who were well prepared or felt obligated to write the diaries, were more likely to participate in the diary writing (III). Although, only a small number of participants took part in study III, the patterns between the two groups were apparent. Therefore, at least tentatively, the credibility of the findings should be acceptable.

Patton (2004) means that qualitative research consists of detailed descriptions. The interview study (II) was not tape-recorded. However, during the interview, the researcher wrote short notes and then immediately transcribed them to a data file. Notes concerning the respondents' reactions were added to the information. In the diaries (III), the quality of the texts varied. Some wrote long, rich descriptions on a daily basis, while others wrote retrospective, short condensed sentences. With respect to the above material, content analysis was the most suitable method of analysis, since this method can be applied to several types of documents without philosophical requirements (*ibid*).

One way to prove the dependability of an analysis is to show the procedure of coding (*cf.* Graneheim & Lundman 2004). However, this was not done in papers (II-IV), due to the space limitations. In study II-IV, both the author who conducted the analysis,

(A-MR.H.) and the co-authors, reflected on and discussed the content and categorisation models. Mores et al. (2002) argues that the investigators themselves are responsible for the attainment of reliability and validity rather than depending on external experts. However, 'external member checking' (a neuropsychologist and a geriatrician) was used to confirm the interpretations of data belonging to the experts fields (II). 'Member checking' is a technique used to check an assumption or a particular understanding with informants or co-authors (*ibid.*). In this thesis 'member checking' was used in the analysis process to confirm the interpretations of the data (II-IV). However, direct quotations were presented to give the reader contact with the raw data through excerpts or entire passages from the interviews, diaries and open-ended questions. These illustrated the relatives/significant others emotions, attitudes, beliefs, and thoughts (II-IV). The quotations validate and demonstrate the interpretations of the data (Patton 2004).

In study II, a theoretical model outlined by Lawton was used to sort the data into the final categories. When using a theory or a model, the researcher should be aware that this is associated with both advantages and risk (Maxwell 2005). The advantage of using a theory is that it can simplify, clarify, or explain some aspects of the study phenomena. On the other hand, there is a risk that the researcher does not use the theory adequately, or relies too much on the theory and therefore is uncritical. Not using the theory in a correct way imposes both a practical, scientific and ethical problem (*ibid.*). Having reference to a conceptual framework of person-environment was useful, since it helped us to understand the underlying assumptions of the cognitively impaired patients' conditions for rehabilitation (II).

### **7.1.3 Transferability of the findings**

Transferability refers to the extent to which findings from data can be transferred to other settings (Polit & Beck 2004). There are reasons to believe that the findings of the present studies can be transferable to other settings (not only the two Stockholm hospitals). For example, to other patient groups (acute illness in combination with cognitive impairment), or to staff with limited knowledge of dementia diseases and/or rehabilitation, and to other settings within or outside the country. Descriptions of the data collection context can be helpful when setting up new studies to confirm the results. Finally, it is always up to the reader to decide whether it is possible and/or suitable to transfer outcomes from qualitative studies to other environments or contexts (*cf.* Graneheim & Lundman 2004).

## **7.2 THE QUANTITATIVE APPROACH**

### **7.2.1 The Mini Mental State Examination**

The Mini mental State Examination (MMSE) is a widely used method for assessing cognitive impairment (Folstein et al. 1975) although it cannot be used to diagnose dementia (Tombaugh & McIntyre 1992). One review found that this instrument fulfilled the quality criteria when using the MMSE to quality assess the severity of cognitive impairment and cognitive changes occurring over time (*ibid.*).

The MMSE has demonstrated validity and reliability in different populations. A low MMSE-score ( $\leq 23$ ) does not automatically indicate dementia according to Grut et al. (1993). A low score can be explained by other factors, such as somatic diseases or psychiatric disorders. In studies of older hip fracture patients with multiple diseases (**II-IV**) we included two patients in the cognitively intact group, despite low MMSE scores (one was blind and the other had recently been prescribed pain-killers).

Delirium is common in hip fracture populations, especially among patients with dementia (Edlund et al. 1999, Lundström et al. 2003). When grouping the patients according to the MMSE-score, information regarding the patients' pre fracture cognitive state helped us to distinguish delirium from dementia. Some of the patients were confused to some extent and Swedish was not the native language of one person. Therefore, this particular patient did not participate in the MMSE. Factors such as these were observed and taken into consideration, when sorting the patients into cognitively impaired or cognitively intact groups.

One way of ensuring reliability regarding the classification of the two cognitive groups would have been to test them repeatedly with the MMSE. Patients with scores slightly higher than the turning point of  $\leq 23$  would probably have scored more points, while patients with scores slightly lower than the turning point, would probably have remained on the same low level (*cf.* Helkala et al. 2002).

### **7.2.2 Validity and reliability**

Study **I** is a retrospective total investigation of secondary diagnoses in a hip fracture population. All patients were included in the study for a six-year period, following their first stay in hospital for a hip fracture. The results of the study were validated, by comparing them with other studies that describe the prevalence of cognitive impairment in hip fracture populations of similar ages.

There was no special designed questionnaire found at the time of the project start. Thus, a specific questionnaire was developed for this particular purpose, even though a standardised questionnaire might have saved time, resources and had made it easier to compare findings from other studies. Despite pre-testing the questionnaire (content validity), some of the questions were not valid, for example, one follow-up question and retrospective questions regarding time-estimation and were excluded from the analysis (**IV**).

Having a choice of alternatives when answering a survey, i.e. either open-ended or closed-question formats, might produce different kind of answers (Schwarz 1999). Breaking continuity during the answering process can cause bias. Without being aware of this, the informants might emphasise earlier responses and provide similar answers to previously answered questions. In addition, the answer frequency can be reduced if participants are expected to answer a difficult/challenging question. However, a questionnaire can be more reliable than an interview because the respondents are anonymous. Therefore, questions that focused on assessments of the rehabilitation period, (as being very good, good, bad or unacceptable) might have resulted in answers that were more honest than in case of interviewing.

When sending a questionnaire to a respondent it is impossible to know whether the person that the letter is addressed to, will complete the questionnaire. In the present study, we found that one daughter completed the questionnaire instead of her father (IV).

### 7.2.3 Sample size

The study that focused on Stockholm County Council's ICR cannot be seen as an incidence study on co-morbid conditions in a hip fracture population (I) since only a limited number of co-morbid conditions were available in the register.

The initial sample size of 40 consecutive patients and their relatives and significant others, was considered to be an appropriate number for comparing the results with other studies. Recruiting these older persons and their relatives was a time consuming process, since hip fractures cause stressful situations for both the patients and their families. Considering this fact, the size of the sample, which included thirty-two relatives/significant others to patients with a hip fracture (IV) was quite substantial (*cf.* Ahlbom & Norell 2006). Sneeuw et al. (2002) however observed that lower levels of agreement were predominantly found in studies with a small sample size. Recruiting more participants and focusing on either spouses and children *or* staff only, would have strengthened the results, as the sample would have been more homogeneous.

In comparative studies, it is important to eliminate the risk of other aspects than those in focus affecting the results. In a descriptive study design, the associations between variables are established, but a large sample size is needed to get reliable results. Therefore, the results of Study IV should be interpreted with caution. Furthermore, patients *with* cognitive impairment were older than patients *without* cognitive impairment. This might have influenced some of the results. Despite this, no significant differences were found between the groups as far as the number of new falls was concerned, which could be an effect of the limited sample size.

### 7.2.4 Activities of daily living

Assessing a person's ability to perform daily activities can be observed by using very structured methods (*cf.* Yasuda 2004), which give more exact results compared to an ADL estimation.

The first estimation of the patients' ADL abilities depended on how well the relatives were able to remember the patient's real level of ability pre-fracture, which implies the risk of overestimating or underestimating their actual ability. The retrospective estimation of ADL performance is, however, in line with other hip fracture studies (*cf.* Hagsten, Svensson & Gardulf 2006). This is also a common way of gaining information about the person's status before the hip fracture occurred, since the probability of actually gaining this type of information is limited.

Two different data collection methods were used (interview and questionnaire) to collect information about the patients' pre and post physical function and this might have affected the quality of the results. During interview sessions, the researcher can explain the question when the patient has difficulty in understanding and obviously, this is not possible while completing a questionnaire. However, the relatives can observe how the

patient reacts, while completing the questionnaire six months after the fracture. The same sources (relatives and significant others) and the same instrument (Katz-ADL) were used in the interviews and the questionnaires.

To report the patients physical function, proxy information was used instead of self-reporting (II and IV), which can influence the truth-value of the findings. Sneeuw, Sprangers & Aaronson (2002) described in one review, that patient-proxy agreements regarding life quality evaluation of patients with chronic disease were moderate to good. These patient-proxy agreements were compared between spouses, parents, relatives, and friends. Sneeuw and co-workers found that health care providers and relatives tended to minimise the patients' resources and to overestimate problems (*ibid*). This can explain the results from Study III, where the relatives'/significant others' were significantly dissatisfied with the patients' care.

### 7.2.5 Generalisation of the findings

External validity is linked to the question of generalisation (Polit & Beck 2004). A total investigation makes it possible to generalise the results to similar types of registers (I) in other contexts.

The measurements and quantifications performed in Study IV are limited, due to the sample size and the data quality. Hence, the results should be interpreted with caution when generalised to a new population. However, the consecutive recruiting technique (of relatives from two different hospitals) in different catchment areas strengthens the possibility of generalising the findings beyond the group in this setting (external validity).

## 7.3 DISCUSSION OF THE METHODS

One surprising sub-finding, which has not been found in other studies, was the fact that the largest group of relatives participating in the study were elderly husbands (II). In another study focusing on the difficulties and rewards of care giving to older post-rehabilitation patients (Riedel, Fredman & Langenberg 1998), the sample consisted of 71% females compared to 59% in our study (IV). In the above-mentioned study, 72% were spouses and daughters, which was approximately the same scale as in our study.

Other participants in their study were other relatives than spouses and daughters to the patients. These relatives represented 28% of the sample. This is approximately the same size as in study IV, although three staff members also took part in our study. However, in study III the majority of the diary writers were women (eight of eleven participants).

In study (III) the expectations of relatives'/significant others' and their personal motives may have affected their diary writing (in an emotional sense) since in some cases, the information was fragmentary. It was difficult to recruit diary writers in this study. Therefore, in-depth interviews with a limited number of relatives or health workers might be another suitable method for collecting data on cognitively impaired patients, post hip fracture

Study **III** might have achieved better results if the diary writers had been provided with more detailed instructions about topics to focus on. However, this would not have led to a higher number of participants, since the probable reason for non-participation, and the quality of the diary writing, was related to the relatives'/significant others' life situation. Despite this, the contents of the diaries, clarified some relevant differences between the two cognitive groups. Further studies are necessary, which focus on the relatives'/significant others' experiences.

The informants (relatives and significant others) were from different parts of Stockholm and they varied in age, gender and relation to patients. Variation such as this is desirable in qualitative research, in order to obtain as much information as possible on the study phenomenon, i.e. how cognitive impairment affects the care and rehabilitation of hip fracture patients. In quantitative research, the sample representative, i.e. consecutive sampling, is important since it allows a statistical generalisation of data (Maxwell 2005).

Some changes have occurred since the onset of this study, regarding recommendations on hip fracture treatment of displaced femoral neck fractures. Arthroplasty has replaced internal fixation to some extent, which reduces complications and pain (Rogmark 2006). However, Blomfeldt et al's findings (2005) do not entirely support Rogmark's recommendations in patients with severe cognitive dysfunction.

In the present thesis, many relatives and significant others complained about patients suffering from complications and pain (**III, IV**). This new approach to surgical treatment may result in fewer complaints. Furthermore, the relatives' may nowadays experience less distress and strain, which was primarily caused by complications and an unsuccessful recovery.

The number of available studies on 'hip fracture and cognitive impairment' has increased greatly since this project started. A possible reason for this might be that there has been an increase in political awareness and concern for the ageing population, regarding appropriate care provision for older persons with cognitive impairment.



## 8 DISCUSSION

The essential question of this thesis deals with the impact of cognitive impairment on care and rehabilitation after hip fracture. Both a registered study and the experiences of relatives and significant others were examined, in order to answer this question systematically. The main findings indicated unequal opportunities after a hip fracture when comparing patients *with* and *without* cognitive impairment. These findings are discussed below.

### 8.1 LACK OF PAIN RELIEF AND COGNITIVELY IMPAIRED HIP FRACTURE PATIENTS' REACTIONS

Studies (II-IV) found that patients with hip fractures, with and without cognitive impairment, suffered from troublesome pain. However, other studies have pointed out that unidentified and untreated pain is more common in patients *with* cognitive impairment (Feldt et al. 1998, Blomqvist & Hallberg 1999, Morrison & Siu 2000, Miller et al. 2000).

According to the relatives and significant others of patients with cognitive impairment, these patients reacted to pain in an unusual way. Behavioural symptoms such as this can be difficult for both the patient and the staff (III). The patient's reactions affected the staff's responses. Furthermore, the patients' behavioural symptoms sometimes meant that they were sent back to the nursing homes earlier than planned, because staff in the acute care context experienced the patients as 'difficult' (III). Miller et al. (2000) shows that assessing pain and providing pain relief to individuals with dementia, are two effective strategies for avoiding 'aggressiveness' and offering the patients comfort. However, our findings indicate that relatives and significant others of cognitively impaired patients were not taken seriously when requesting pain relief for these patients (III). This is not a satisfactory solution. Thus, further intervention studies are recommended which investigate the nurses' level of knowledge about pain treatment and their willingness to support the cognitively impaired patients' needs. This area of research has, to some extent, been verified by Miller et al's (2000) and Blomqvist et al's (2003) earlier work. According to Miller et al. (2000) barriers still exist in relation to effective pain relief, and one of these is linked to health care personnel's lack of knowledge about pain assessment and treatment of individuals with dementia (*ibid*). Furthermore, Blomqvist et al. (2003) found in a Swedish study, that staff used different pain relief strategies when dealing with older patients. Blomqvist's findings showed that staff can deal with this in different ways. Three examples are 1) taking no measures at all, 2) distracting patients and 3) administering medication. The staff's decisions were based on an assessment of the patient's pain. In addition to pain relief, it is important to improve the patients' physical function by for example, gait training (Blomqvist & Hallberg 1999).

In Study II, the cognitively impaired patients were unwilling to participate in training programmes when the physiotherapist offered the patient this type of service. The patients were scared of falling, felt unprepared and did not understand why they were supposed to participate in the training programme. Thus, in clinical practice, staff must

become more aware of how cognitively impaired patients interpret and experience the attempts to encourage patients to participate in physical training programmes. Some studies have focused on the interaction between persons with dementia and their care providers (*cf.* Hallberg et al. 1990, Graneheim et al. 2001, Skovdahl et al. 2003, Skovdahl et al. 2004). However, more specific studies are needed which focus on the interaction between dementia patients and their care providers, in the context of care and rehabilitation after hip fracture.

## **8.2 PHYSIOTHERAPIST-LED REHABILITATION SUPPORT**

A significant difference was found between the two cognitive groups, concerning access to physiotherapist-led rehabilitation (**IV**). We found that only twenty percent of the cognitively impaired patients received physiotherapist-led rehabilitation, which is a discouraging finding, as several studies have shown that cognitively impaired patients improve physical function after physiotherapy (Goldstein et al. 1997, Resnick 1997, Heruti et al. 1999, Ruchinskas, Singer, & Repetz 2000, Huusko et al. 2000, Naglie et al. 2002). Therefore, it is vital that patients with cognitive impairment have access to physiotherapy to improve their physical function. Moreover, physiotherapists need more knowledge of dementia disease and other relevant skills, since this is extremely important for the rehabilitation process. It would be extremely valuable for clinical practice, if specific guidelines were developed to facilitate the staff's work with cognitively impaired patients after a hip fracture. Above all, by focusing on having compassion and sensitivity for these patients and understanding the environmental pressures, as shown in Study **II**.

In the studies included in this thesis (**II** and **IV**), some crucial factors were described which influenced the success of rehabilitation care for hip fracture patients with cognitive impairment: loss of memory, support with physical functions, and supervision and encouragement. These factors should be taken into account and included in the above-mentioned guidelines.

Providing care and rehabilitation to cognitively impaired patients with a hip fracture, requires support from staff. In order to reduce the health care staff's workload, the author propose that measures for pain relief, environmental interventions, and attitudes, are three important components when attempting to deal with this problem. This combination of behavioural and environmental approaches will probably be the best way to reduce the patients' feelings of discomfort.

## **8.3 IMPLICATION OF REHABILITATION ENVIRONMENT**

Study **II** indicates that habitual environment for cognitive impaired patients, such as nursing homes, group dwellings or blocks of service flats were 'the best places' for rehabilitation. However, relatives said that an increase in staff was needed, especially persons with specific knowledge of hip fracture rehabilitation care. The staff's level of knowledge about dementia disease and rehabilitation after hip fracture, were the two most important aspects linked to secure and good care (**II**). This is in line with Borbasi's study (2006), which shows that treatment in acute hospitals can adversely affect

people with dementia and their health outcomes, regarding functional independence and quality of life.

According to relatives and significant others, when patients were living in nursing homes pre-fracture a practical solution was to provide his/her rehabilitation care at the same place (II). They also pointed out the cost aspect when cognitively impaired patients were living in nursing homes, since extra resources were needed for supervision and rehabilitation. For example, one of the effects of having a cognitive impairment or dementia disease was that patients often became confused due to changes in the environment and this required extra staff. These extra costs were charged to a separate account, and not to the group dwelling (II). These findings allowed us a brief look into the allocation of resources for rehabilitation of cognitively impaired patients with a hip fracture.

Hasson & Arnetz (2006), who studied two groups of staff from different care settings (home care staff and staff in nursing homes), found that staff in both study groups had limited opportunities to develop their skills, especially in areas that were related to dementia care, psychiatric illnesses, threats and violence (*ibid*).

The County Councils are responsible for the acute phase of care and the municipalities are responsible for the care and rehabilitation of elderly people post hip fracture. According to Thorngren et al. (2005), patients with cognitive impairment, who lived in municipal group-dwellings, nursing homes, or other sheltered living accommodation before the hip fracture, were rapidly transferred back to the same living accommodation, post hip fracture (*ibid*). Thorngren suggests that individual planning of the rehabilitation procedure can be used as an alternative strategy for all patients.

The relatives/significant others complained of a shortage of staff and that physical restraints were used to confine patients. They also spoke of how difficult it was to motivate cognitively impaired patients to take part in care and rehabilitation post fracture (IV). An ethical dilemma arises when there is a shortage of nurses (or other staff) and staff are unable to take the appropriate ethical actions (Erlen 2001, Erlen 2004). The nurses feel moral distress (knowing the right ethical actions, but unable to use them because of constraints in the system). Experiencing moral distress has an effect on the nurses' lives and influences the way they view their profession (*ibid*). This type of moral distress can be lessened, by providing nurses with adequate tools and resources, which will enable them to provide good care and rehabilitation. This is especially important for the most vulnerable groups of hip fracture patients with numerous co morbid conditions and specific needs, as for the patients with cognitive impairment.

#### **8.4 PHYSICAL FUNCTION OUTCOMES AFTER A HIP FRACTURE**

Maintaining physical function is of genuine importance for all individuals when trying to sustain independence. The findings in Study IV show that there is a significant difference in the ADL-Index score when comparing the two cognitive groups, six months after the hip fracture. The cognitively impaired patients' level of locomotion decreased significantly, when compared to the cognitively intact patients. Almost all of the cognitively impaired patients had a lower score of at least one ADL-grade six months post

fracture when compared to pre fracture (*cf.* Blomfeldt et al. 2005). In contrast, in the cognitively intact group, only one-third lost one or more degrees of independence on the ADL-grade scale. These outcomes are in line with Eastwood et al's (2002) and Gruber-Baldini et al's (2003) studies, who found poor functional outcomes after a hip fracture in persons with cognitive impairment. Eastwood et al. (2002) showed that all patients showed poorer physical function post fracture, but in a dementia sub group, almost all patients became completely dependent.

In Study **III**, relatives and significant others of cognitively impaired patients reported poor follow up of the patient after surgery and inadequate rehabilitation activities, such as physical exercise and mobility assistance. Furthermore, they complained about poor medical treatment. This indicates that cognitively impaired patients are at risk of becoming wheelchair-bound and bedridden, as found in studies (**III-IV**). Siu et al. (2006) examined the relationship between inpatients' bed rest and functional outcomes. The findings showed that there was an improvement of functional outcomes after a hip fracture, when patients were encouraged to leave their beds.

## **8.5 ATTITUDES TOWARDS THE REHABILITATION OF COGNITIVELY IMPAIRED PATIENTS**

A person's value system tends to influence their attitudes (general opinions and beliefs), and in turn, this influences how people behave and act (*cf.* Nâden & Eriksson 2004).

In Study **III**, the relatives/significant others complained about the staff in acute care settings, who talked about patients in a disrespectful manner, displaying negative attitudes towards both patients and relatives. It also emerged that one rehabilitation hospital had refused to accept one particular patient, whom they considered unsuitable for rehabilitation. The relatives/significant others of cognitively impaired patients also complained that evaluations of the patient's individual ability was based only on the acute hospital staff's opinions. The patient's physical status *before* the hip fracture was not taken into account (**III**). Our findings show that health professionals judged the cognitively impaired patients as being incapable of managing rehabilitation (**II**). In this thesis, the negative attitudes of staff in acute care settings, when dealing with cognitively impaired patients and their relatives, correspond to a study conducted by Jones et al. (2006). Jones found that unpredictable behaviour in acute care settings created tension.

A review by Courtney, Tong & Walsh (2000) showed that negative attitudes toward the elderly in clinical settings reflected registered nurses knowledge deficits and ageist stereotypes, which also affected the patients' quality of care. Study **II** found that cognitively impaired patients suffer from communication and language difficulties, which can cause problems when patients meet new staff in different care settings. Lawton's ecological model (1982) of behaviour refers to interaction between the individual and the environment, and he emphasises that hip fracture patients with cognitive impairment are sensitive to environmental pressure (**II**).

## 8.6 ATTITUDES TOWARDS DEMENTIA AND DELIRIUM DIAGNOSES

The outcomes of Study I are based on the Inpatient Care Register database of Stockholm County Council, which in previous studies has been found to be reliable for hip fracture diagnoses (*cf.* Strömberg et al. 1997b). The medical records contain all main and secondary diagnosis codes. The register plays a very important role in the field of health care, something that is also stated in the government bill (Prop 1997/98:108, on Health data and Care register). This register is used for planning purposes, for assessing care consumption, for the assessment of quality assurance, etc. but also for public health work and many different research projects. This obviously requires a very high level of correctness and reliability of the register.

In the light of the description above, the most surprising finding in Study I was the fact that no specific pattern was used for coding secondary diagnoses in the register. Furthermore, the number of delirium diagnoses was very low. These findings suggest that traditions, attitudes and local policies, contribute to an unreliable and inconsistent register. Therefore, if the doctors become more aware of this, the reliability of the register can be improved.

If the care register is consistent, with respect to co morbid conditions, it could provide a better base for community care planning. More studies are needed to validate the secondary diagnoses of hip fracture patients included in the register. However, some studies found a shortage of documentation (from doctors and nurses) in hip fracture patients' medical records, concerning the patients' mental state (Gustafson et al. 1991, Söderqvist 2006a). One shortcoming of the present study is the lack of comparison between the registered data and actual state of the patients. This limitation is however, counterbalanced by the huge number of diagnoses, distributed at many different hospitals. In addition, the findings can be compared to other prevalence studies on dementia and delirium in hip fracture patients of various age groups, in order to investigate whether the register is reliable.

## 9 CONCLUSIONS

In conclusion, this thesis indicates unequal opportunities for rehabilitation, when comparing cognitively impaired patients with cognitively intact hip fracture patients. This is supported by the following facts:

- Although Stockholm's in-patient care register seems to be suitable when planning hip fracture care, it may not be appropriate for the care of patients with comorbid diagnoses of dementia and delirium.
- Cognition was found to be decisive for pain relief, physiotherapist-led rehabilitation support, and support in improving physical function.
- Health personnel lack knowledge and strategies that can control and prevent the cognitively impaired patients' behaviour and support them during rehabilitation.
- The cognitively impaired patients' locomotion and dependency scores, compared pre- and 6 months post fracture, were found to be significantly different than the cognitively intact group. The cognitively impaired group had lower locomotion scores and higher dependency when compared to the cognitively intact patients, although only slight differences were found before the hip fracture.
- Hip fracture patients *with* cognitive impairment experience problems related to their cognitive condition, for example, in taking the initiative to participate in rehabilitation activities. However, the care of individuals with impaired autonomy, such as patients with dementia disease, is an area that is prioritised in the Swedish public health care ranking system. Thus, the cognitively impaired patients' specific needs for care and support from staff must be guaranteed, since this can lead to better rehabilitation care and outcomes.

Based on the results of the four studies in this thesis, it can be concluded that patients with cognitive impairment, i.e. dementia and confusion, are not given the care and attention they need after a hip fracture. This is based on the relatives' views and assertions, which point out that rehabilitation outcomes for cognitively impaired patients are less successful and that their rehabilitation care is less carefully prepared and/or supported by physiotherapists, when compared to cognitively intact patients. This leads to greater dissatisfaction among relatives to hip fracture patients with cognitive impairment. The findings indicate that the cognitively impaired patients' individual preconditions for recovery, are not seriously considered when planning care after a hip fracture, since this group has specific needs in regard to support.

These conclusions indicate unequal opportunities for rehabilitation of hip fracture patients *with* and *without* cognitive impairment.

## 10 ACKNOWLEDGEMENTS

I would like to express my sincere gratitude to all the people that have supported me in different ways and contributed to the accomplishment of this work.

I especially want to thank:

All participating patients and their relatives and significant others, who took part in the study and let me share their experience and perceptions.

The gatekeepers who took the time to escort me around the hospital wards.

The project group at The Dementia Association of Stockholm, Inga Lindmark, Dagny Hellqvist and Elisabeth Monsén who identified the research issue and for your pioneer work in planning the project.

My main supervisor Kristiina Heikkilä, you guided me in the right direction with your support and quick and wise responses. Thank you for sharing your scientific way of thinking with me.

Professor emerita Margareta Grafström who first inspired me to begin the research and convinced me that it was possible. Thank you for being so positive and encouraging right from the beginning of the project.

Lars Strömberg for your support and excellent supervision, particularly during the register study and for all the time you used to help and encourage me.

Professor Bengt Winblad for making it possible for me to undertake my doctoral studies and for your sensible advice throughout the studies.

Sirkka-Liisa Ekman, for providing high quality research courses and doctoral seminars in the network for nurses CECAR. Thank you also to my colleagues and your constructive criticism of my work during our seminars.

My colleagues at The Red Cross University College of Nursing, for sharing my daily life and supporting and encouraging me through difficult times. Special thanks to Ann Langius, Christina Forsberg and Eva Henriksen for reading and commenting on my work. Mats Samuelsson, thank you for your assistance and for facilitating my working conditions.

I also wish to express special thanks to:

Andrejs Leimanis and Torsten Siegel, at Stockholm County Council, for helping me download data from the ICR database. Ove Almqvist for looking at the categories through the eyes of a neuropsychologist. Benny Brännström and Matti Viitanen for reading the manuscript and to my co-author Gunnar Ljunggren for your interest in and knowledge of register studies.

Julie Hammarwall for your kind and quick assistance with the language revision.

Last, but not least, many thanks to my family for always being there. I would especially like to express my gratitude and love to Klas, my husband, for his endless support and encouragement. Fredrik, Martin and Jenny, thank you for filling my life with happiness and pleasure.

This thesis and all the work included in the research project, was made possible by grants from:

Insamlingsstiftelsen för Alzheimer och demensforskning, SADF  
The Dementia Association, Stockholm  
The Dementia Association - The National Association for the Rights of the Demented, Stockholm  
The Foundation of the Red Cross Home, Lori Lindahl's scholarship, Stockholm  
Gustaf V and Queen Victoria's foundation, Stockholm  
The Swedish Foundation for Health and Caring Sciences and Allergy Research, Stockholm  
Maja Johanssons och Maria Brantefors stipendiefond, Hälsovetenskapliga institutionen, Örebro universitet  
Stockholm County Council  
The Red Cross University College of Nursing, Stockholm



## 11 POPULÄRVETENSKAPLIG SAMMANFATTNING

### Olika möjligheter för patienter med och utan kognitiv nedsättning – Närståendes och andra betydelsefulla personers syn på vård och rehabilitering efter höftfraktur

I Sverige får omkring 18 000 personer per år en höftfraktur. Medelåldern är omkring 80 år. Initialt krävs kirurgisk behandling och sjukhusvård. Därefter behöver patienterna stöd och vård utanför akutsjukhuset i varierande omfattning.

Många höftfrakturpatienter lider även av annan sjuklighet, som inom sjukvården benämns bidiagnoser. Forskning visar att risken för fallolyckor ökar vid demenssjukdom (kognitiv nedsättning). Det betyder att en avsevärd andel av dem som faller och får en höftfraktur också är drabbade av en demenssjukdom. Det har från anhörigföreningar också framförts misstankar om att personer med demenssjukdom inte får likvärdig vård och rehabilitering som icke-dementa personer.

Det övergripande syftet med denna avhandling var att undersöka hur kognitiv nedsättning inverkar på vård och rehabilitering efter höftfraktur. Fyra delarbeten ingår vars specifika syften var:

- att undersöka i vilken utsträckning demens, förvirring och annan samsjuklighet hos patienter med höftfraktur var diagnostiserade och kodade i patienternas journaler och införda i Stockholms läns landstings databas för inläggande patienter **(I)**
- att beskriva villkoren för rehabilitering av äldre patienter med demenssjukdom och höftfraktur utifrån ett närståendeperspektiv **(II)**
- att belysa hur närstående till höftfrakturpatienter, med och utan kognitiv störning, upplever de första sex månaderna efter frakturen, för att fastställa om den kognitiva nedsättningen var av betydelse för hur rehabiliteringsperioden upplevdes **(III)**
- att undersöka och jämföra två grupper av höftfrakturpatienters utfall och närståendes uppfattning av en sex månaders rehabiliteringsperiod. Den ena gruppen var kognitivt intakta och den andra utgjordes av kognitivt nedsatta äldre personer **(IV)**

I avhandlingsarbetet ingår en registerstudie med 14 993 patienter, som var 65 år och äldre, med en höftfraktur och ett första vårdtillfälle inom Stockholms läns landsting **(I)**.

Tre av delarbetena utgår från närståendes upplevelser och erfarenheter av perioden efter höftfraktur för äldre konsekutiva patienter med och utan kognitiv nedsättning **(II, III, IV)**.

Intervjuer genomfördes med 20 närstående till kognitivt nedsatta och med 20 närstående till kognitivt intakta patienter **(II)**. Närstående till 11 patienter skrev dagböcker under 6 månader **(III)** och 32 svarade på en enkät 6 månader efter frakturen **(IV)**. Dessutom analyserades data om patienternas fysiska funktion (Katz-ADL-Index) före frak-

turen (intervjudata) och 6 månader efter frakturen (enkätsvar). Med närstående avses den person som stod patienten närmast, baserat på patientens egen bedömning, hämtat från personal eller från vårdanteckningar. Makar, barn och övriga släktingar (i de fall inga släktingar fanns att tillgå har vänner och vårdpersonal deltagit) i åldrarna 37 till 88 år har medverkat.

Patienter med höftfraktur deltog i ett minnestest och gav information om närmaste anhörig. Det var ingen skillnad i frakturtyp mellan de båda patientgrupperna *med* och *utan* kognitiv nedsättning. Deskriptiv statistik, Pearson Chi-två test och innehållsanalys, har använts för analys av data.

Nedan följer en kort redovisning av resultat av de fyra delarbetena, som bygger på data från Stockholms läns landstings vårdregister, intervjuer, dagböcker och enkäter med närstående till höftfrakturpatienter med och utan kognitiv nedsättning.

Det förekom stor variation mellan de tio olika enheternas registrering av bi-diagnoserna demens och förvirring (6 till 17 %) inom höftfrakturpopulationen (I). Den totala andelen registrerade demens- och förvirringsdiagnoser i hela materialet var elva procent av vilka 1 % (153) var förvirringsdiagnoser.

De kognitivt nedsatta patienters förmågor beskrivs med de fem områden enligt Lawtons modell om åldrandet och anpassning. I avhandlingsarbetet beskrivs följande områden: patientens kognitiva förmåga, biologisk hälsa, sinnes- och förmåga, motorisk färdighet och patientens jag-styrka (II). Trötthet, viktnedgång, smärta, förstoppning och feber var några aspekter som identifierades postoperativt inom området biologisk hälsa.

De motoriska färdigheterna beskrevs som *före* och *efter* höftfrakturoperationen. Patienterna med kognitiv nedsättning hanterade situationen efter höftfrakturen på två sätt, antingen tog patienten inte något initiativ till rehabilitering alls eller så började patienten gå omkring helt ovetande om frakturen. I båda fallen behövde patienterna stöd för att hantera situationen (II-III).

Närståendes syn på rehabilitering av äldre patienter med höftfraktur och kognitiv nedsättning visade sig vara nära relaterad till demenssjukdomen (II). Patientens kompetens, behov av specifikt stöd utifrån egen förmåga, miljöfaktorer och rehabiliteringsaktiviteter var områden som relaterades till rehabiliteringen.

Speciella behov för patienter med kognitiv nedsättning beskrevs som behov av hjälp med exempelvis träning, med påminnelse om aktiviteter, att endast ta en sak i taget vid utförande, behov av hjälp med instruktioner och stöd av personal som är positiv och villig att hjälpa till (II).

Utifrån Lawtons modell har miljön kategoriserats inom personliga, fysiska och sociala områden (II). Den personliga miljön beskrevs ur två perspektiv – personalens kunskaper om demenssjukdomar och om rehabiliteringen efter höftfraktur. Bra miljö beskrevs som en invand miljö för de kognitivt nedsatta patienterna, det vill säga sjukhem, gruppboende och servicehus. Dessa miljöer ansågs som bästa platsen för rehabilitering.

Emellertid betonades att det behövdes mer personal med särskild kunskap om rehabilitering efter höftfraktur. Rehabiliteringsaktiviteter för kognitivt nedsatta patienter beskrivs ske i förhållande till de dagliga aktiviteterna. Tre aspekter för deltagande i rehabiliteringen var i fokus: gå-träning, ett allmänt träningsprogram och att ge uppmärksamhet till patienterna. Inom området social miljö beskrivs tre aspekter: lämplig för närstående, kostnadsaspekter och omflyttning till annat boende (II).

De kognitivt nedsatta patienterna fick vanligtvis rehabiliteringen inom skyddat boende (IV). Det huvudsakliga stödet gavs av vårdpersonal i allmänhet medan de kognitivt intakta patienterna huvudsakligen fick hjälp av en sjukgymnast. Det förekom klagomål om brist på personal och om att patienterna i den kognitivt nedsatta gruppen blev sittande med bälte i rullstol. Enligt närstående gjordes i några fall bedömningar inom akutsjukvården att några patienter med kognitiv nedsättning inte var rehabiliteringsbara.

Närstående till patienter med kognitiv nedsättning visade sig ibland vara missbelåtna med relationen till vårdpersonalen (III). De upplevde att personalen visade negativa attityder mot patienten, att rehabiliteringsinsatser, fysisk träning och smärtlindring uteblev. De beskrev också hur konflikter uppstod i samband med utskrivning från akutsjukhuset (III). Patienterna sändes tillbaka till sjukhemmet utan planering av åtgärder för rehabilitering. Beslutet att skriva ut en patient motsvarade inte patientens rehabiliteringsbehov, t.ex. skickades en patient tillbaka till sjukhemmet tidigare än planerat eftersom akutsjukvårdspersonalen uppfattade patienten som svår att vårda (III).

De närstående till patienter *med* och *utan* kognitiv nedsättning beskrev rehabiliteringsperioden på olika sätt (III). Känslor av "tillfredställelse", "missbelåtenhet", "ansträngning" och "sorg" var de teman som framkom i analysen av dagböckerna. Bland närstående till kognitivt intakta patienter var många nöjda med patientens tillfrisknande. Närstående till patienter med bibehållen kognition kände ansträngning när komplikationer uppstod under en utdragen period med vårdande, medan närstående till patienter i den kognitivt nedsatta gruppen kände oro och sorg för patienternas lidande (III).

Närstående till personer med kognitiv nedsättning skattade rehabiliteringsperioden lägre än de närstående till de kognitivt intakta patienterna (IV). Läkningsskomplikationer efter kirurgi förekom i båda grupperna. När komplikationer uppträdde, när förflyttningsförmågan sänktes och när omvårdnadspersonal huvudsakligen medverkade i rehabiliteringen skattades rehabiliteringsperioden lägre.

Alla patienter kunde förflytta sig själva före frakturen. I gruppen med kognitiv nedsättning var sex av tjugo patienter oberoende i alla sex aktiviteterna före frakturen medan vissa andra inte följde mönstret för ADL-Index (den hierarkiska uppbyggnaden enligt Katz ADL-Index). Det innebar att en patient kunde vara oberoende vid förflyttning men beroende i aktiviteter som till exempel att äta (II).

Sex månader efter frakturen var 50 % sängliggande och totalt beroende i den kognitivt nedsatta gruppen medan 80 % av patienterna i den kognitivt intakta gruppen var oberoende i alla aktiviteter (III). Beroende i det dagliga livet ökade och förflyttningsförmågan

efter höftfrakturen minskade i större utsträckning hos personerna med kognitiv nedsättning (IV).

Utifrån resultatet av ovanstående fyra delstudier kan konkluderas att det kognitiva tillståndet (demens och förvirring), inte speciellt betonas i vården av patienter med höftfraktur – ett tillstånd av särskild betydelse för planering, vård och behandling. Patientens egna förutsättningar för återhämtning – behov av specifikt stöd utifrån demenssjukdomen – är inte grunden för vårdandet. Risk finns att patienter med demenssjukdom sätts åt sidan i osynliga prioriteringar av vårdinsatser efter höftfraktur på grund av sitt kognitiva tillstånd.

Resultaten av dessa studier indikerar ojämlika möjligheter för patienter med och utan kognitiv nedsättning att återta sina förmågor efter höftfrakturen.

## 12 REFERENCES

Aguero-Torres H, Kivipelto M & von Strauss E (2006) Rethinking the dementia diagnoses in a population-based study: what is Alzheimer's disease and what is vascular dementia?. A study from the Kungsholmen project. *Dementia and Geriatric Cognitive Disorders* 22, 244-249.

Aguero-Torres H, von Strauss E, Viitanen M, Winblad B & Fratiglioni L (2001) Institutionalization in the elderly: the role of chronic diseases and dementia. Cross-sectional and longitudinal data from a population-based study. *Journal of Clinical Epidemiology* 54, 795-801.

Ahlbom A & Norell S (2006) Grunderna i epidemiologi. Stockholm: Studentlitteratur.

American Psychiatric Association (2000) *Diagnostic and statistical manual of mental disorders (4<sup>th</sup> ed.)*. Text revised. Washington, DC: APA: American Psychiatric Association.

American Psychiatric Association (2006) Ethical principles and practices for research involving human participants with mental illness. *Psychiatric Services* 57, 552-557.

Atchison, T. B., Massman, P. J., & Doody, R. S. (2006) Baseline cognitive function predicts rate of decline in basic-care abilities of individuals with dementia of the Alzheimer's type. *Archives of Clinical Neuropsychology (Epub ahead of print)*.

Beauchamp T & Childress JF (2001) *Principles of biomedical ethics* (5<sup>th</sup> ed.). New York: Oxford University Press.

Beloosesky Y, Grinblat J, Epelboym B & Hendel D (2001) Dementia does not significantly affect complications and functional gain in elderly patients operated on for intracapsular hip fracture. *Archives of Orthopaedic and Trauma Surgery* 121, 257-260.

Beloosesky Y, Grinblat J, Epelboym B, Weiss A, Grosman B & Hendel D (2002) Functional gain of hip fracture patients in different cognitive and functional groups. *Clinical Rehabilitation* 16, 321-328.

Berg B (1995) *Qualitative Research Methods for the Social Sciences*, (4<sup>th</sup> ed.). Thousand Oaks, CA: Sage.

Bland M (1995) Clinical measurement. *An introduction to medical statistics* (2<sup>th</sup> ed.). Oxford: Oxford University Press.

Blomfeldt R, Törnkvist H, Ponzer S, Söderqvist A & Tidermark J (2005) Internal fixation versus hemiarthroplasty for displaced fractures of the femoral neck in elderly patients with severe cognitive impairment. *Journal of Bone and Joint Surgery British* 87, 523-529.

- Blomqvist K & Hallberg IR (1999) Pain in older adults living in sheltered accommodation – agreement between assessments by older adults and staff. *Journal of Clinical Nursing* 8, 159-169.
- Blomqvist K (2003) Older people in persistent pain: nursing and paramedical staff perceptions and pain management. *Journal of Advanced Nursing* 41, 575-584.
- Borbasi S, Jones J, Lockwood, C & Emden C (2006) Health professionals' perspectives of providing care to people with dementia in the acute setting: Toward better practice. *Geriatric Nursing* 27, 300-308.
- Burns A, Gallagley A & Byrne J (2004) Delirium. *Journal of Neurology, Neurosurgery, and Psychiatry* 75, 362-367.
- Cameron ID (2005a) Coordinated multidisciplinary rehabilitation after hip fracture. *Disability and Rehabilitation Suppl* 2, 1-10.
- Cameron ID (2005b) Coordinated multidisciplinary rehabilitation after hip fracture. *Disability and Rehabilitation* 27, 1081-1090.
- Colón-Emeric CS, Pieper CF & Artz MB (2002) Can historical and functional risk factors be used to predict fractures in community-dwelling older adults? development and validation of a clinical tool. *Osteoporosis International* 13, 955-961.
- Courtney M, Tong S & Walsh A (2000) Acute-care nurses' attitudes towards older patients: a literature review. *International Journal of Nursing Practice* 6, 62-6
- Crotty M, Whitehead C, Miller M & Gray S (2003) Patient and caregiver outcomes 12 months after home-based therapy for hip fracture: a randomized controlled trial. *Archives of Physical Medicine and Rehabilitation* 84, 1237-1239.
- Cserháti P, Fekete K, Berglund-Rödén M, Wingstrand H & Thorngren KG (2002) Hip fractures in Hungary and Sweden - differences in treatment and rehabilitation. *International Orthopaedics* 26, 222-228.
- Downe-Wamboldt B (1992) Content analysis: Method, applications, and issues. *Health Care for Women International* 13, 313-321.
- Eastwood EA, Magaziner J, Wang J, Silberzweig SB, Hannan EL, Strauss E & Siu AL (2002) Patients with hip fracture: subgroups and their outcomes. *Journal of the American Geriatrics Society* 50, 1240-1249.
- Edlund A, Lundström M, Lundström G, Hedqvist B & Gustafson Y (1999) Clinical profile of delirium in patients treated for femoral neck fractures. *Dementia and Geriatric Cognitive Disorders* 10, 325-329.

- Erlen JA (2001) Moral distress: a pervasive problem. *Orthopedic Nursing* 20, 76-80.
- Erlen JA (2004) Wanted-nurses. Ethical issues and the nursing shortage. *Orthopedic Nursing* 23, 289-292.
- Faden RR & Beauchamp TL (1986) *A history and theory of informed consent*. New York: Oxford University Press.
- Feldt KS, Ryden MB & Miles S (1998) Treatment of pain in cognitively impaired compared with cognitively intact older patients with hip-fracture. *Journal of the American Geriatrics Society* 46, 1079-1085.
- Folstein MF, Folstein SE & McHugh PR (1975) Mini-mental state. A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research* 12, 189-198.
- Frankfort-Nachmias C and Nachmias D (1992) *Content analysis*. In *Research Methods in Social Sciences (4<sup>th</sup> ed.)*, London: Edward Arnold. A division of Hodder & Stoughton 311-8.
- Goldstein FC, Strasser DC, Woodard JL & Roberts VJ (1997) Functional outcome of cognitively impaired hip fracture patients on a geriatric rehabilitation unit. *Journal of the American Geriatrics Society* 45, 35-42.
- Graneheim UH & Jansson L (2006) The meaning of living with dementia and disturbing behaviour as narrated by three persons admitted to a residential home. *Journal of Clinical Nursing* 15, 1397-1403.
- Graneheim UH & Lundman B (2004) Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today* 24, 105-112.
- Graneheim UH, Isaksson U, Ljung IM & Jansson L (2005) Balancing between contradictions: the meaning of interaction with people suffering from dementia and "behavioral disturbances". *International Journal of Aging & Human Development* 60, 145-157.
- Graneheim UH, Norberg A & Jansson L (2001) Interaction relating to privacy, identity, autonomy and security. An observational study focusing on a woman with dementia and "behavioral disturbances", and on her care providers. *Journal of Advanced Nursing* 36, 256-265.
- Gruber-Baldini AL, Zimmerman S, Morrison RS, Grattan LM, Hebel JR, Dolan MM, Hawkes W & Magaziner J (2003) Cognitive impairment in hip fracture patients: timing of detection and longitudinal follow-up. *Journal of the American Geriatrics Society* 51, 1227-1236.

- Grut M, Fratiglioni L, Viitanen M & Winblad B (1993) Accuracy of the Mini-Mental Status Examination as a screening test for dementia in a Swedish elderly population. *Acta Neurologica Scandinavica* 87, 312-317.
- Gustafson Y, Brännström B, Norberg A, Bucht G & Winblad B (1991) Underdiagnosis and Poor Documentation of Acute Confusional States in Elderly Hip Fracture Patients. *Journal of the American Geriatrics Society* 39, 760-765.
- Gustafsson B, Hermerén G & Petersson B (2006) *Good research practice - what is it?: views, guidelines and examples*. Stockholm: Vetenskapsrådet [Swedish Research Council].
- Hagsten B, Svensson O & Gardulf A (2006) Health-related quality of life and self-reported ability concerning ADL and IADL after hip fracture: a randomized trial. *Acta Orthopaedica Scandinavica* 77, 114-119.
- Hallberg IR, Luker KA, Norberg A, Johnsson K & Eriksson S (1990) Staff interaction with vocally disruptive demented patients compared with demented controls. *Aging (Milano)* 2, 163-171.
- Handoll HH, Sherrington C & Parker MJ (2004) Mobilisation strategies after hip fracture surgery in adults. *Cochrane Database of Systematic Reviews* 4, CD001704.
- Hasson H & Arnetz JE (2006) The impact of an educational intervention for elderly care nurses on care recipients' and family relatives' ratings of quality of care: A prospective, controlled intervention study. *International Journal of Nursing Studies* (In Press).
- Heikkinen T & Jalovaara P (2005) Four or twelve months' follow-up in the evaluation of functional outcome after hip fracture surgery? *Scandinavian Journal of Surgery* 94, 59-66.
- Heinonen M, Karppi P, Huusko T, Kautiainen H & Sulkava R (2004) Post-operative degree of mobilization at two weeks predicts one-year mortality after hip fracture. *Aging Clinical and Experimental Research* 16, 476-480.
- Helkala EL, Kivipelto M, Hallikainen M, Alhainen K, Heinonen H, Tuomilehto J, Soininen H & Nissinen A (2002) Usefulness of repeated presentation of Mini-Mental State Examination as a diagnostic procedure--a population-based study. *Acta Neurologica Scandinavica* 106, 341-346.
- Helman C (2000) *Culture, health and illness*. Oxford: Butterworth-Heinemann.
- Herrick C, Steger-May K, Sinacore DR, Brown M, Schechtman KB & Binder EF (2004) Persistent pain in frail older adults after hip fracture repair. *Journal of the American Geriatrics Society* 52, 2062-2068.



- Heruti RJ, Lusky A, Barell V, Ohry A & Adunsky A (1999) Cognitive status at admission: does it affect the rehabilitation outcome of elderly patients with hip fracture? *Archives of Physical Medicine and Rehabilitation* 80, 432-436.
- Hoenig H, Nusbaum N & Brummel-Smith K (1997) Geriatric rehabilitation: state of the art. *Journal of the American Geriatrics Society* 45, 1371-1381.
- Holmes J & House A (2000a) Psychiatric illness predicts poor outcome after surgery for hip fracture: a prospective cohort study. *Psychological Medicine* 30, 921-929.
- Holmes JD & House AO (2000b) Psychiatric illness in hip fracture. *Age and Ageing* 29, 537-546.
- Huusko TM, Karppi P, Avikainen V, Kautiainen H & Sulkava R (2000) Randomised, clinically controlled trial of intensive geriatric rehabilitation in patients with hip fracture: subgroup analysis of patients with dementia. *BMJ: British medical journal* 321, 1107-1111.
- Hägström TM, Jansson L & Norberg A (1998) Skilled carers' ways of understanding people with Alzheimer's disease. *Scholarly Inquiry for Nursing Practice* 12, 239-266.
- Iwarsson S (2005) A long-term perspective on person-environment fit and ADL dependence among older Swedish adults. *Gerontologist* 45, 327-336.
- Izal M, Montorio I, Márquez M & Losada A (2005) Caregivers' expectations and care receivers' competence Lawton's ecological model of adaptation and aging revisited. *Archives of Gerontology and Geriatrics* 41, 129-140.
- Johnell O & Kanis JA (2006) An estimate of the worldwide prevalence and disability associated with osteoporotic fractures. *Osteoporosis International* 17, 1726-1733.
- Johnell O, Kanis JA, Odén A, Sernbo I, Redlund-Johnell I, Petterson C, De Laet C & Jönsson B (2004) Mortality after osteoporotic fractures. *Osteoporosis International* 15, 38-42.
- Jones J, Borbasi S, Nankivell A & Lockwood C (2006) Dementia related aggression in the acute sector: is a Code Black really the answer? *Contemporary Nurse* 21, 103-115.
- Kallin K, Gustafson Y, Sandman PO & Karlsson S (2005) Factors associated with falls among older, cognitively impaired people in geriatric care settings: a population-based study. *American Journal of Geriatric Psychiatry* 13, 501-509.
- Kallin K, Jensen J, Olsson LL, Nyberg L & Gustafson Y (2004) Why the elderly fall in residential care facilities, and suggested remedies. *Journal of Family Practice* 53, 41-52.

- Kallin K, Lundin-Olsson L, Jensen J, Nyberg L & Gustafson Y (2002) Predisposing and precipitating factors for falls among older people in residential care. *Public Health* 116, 263-271.
- Kane R, Reinardy J, Penrod J & Huck S (1999) After the hospitalization is over. *Journal of Gerontological Social Work* 31, 119-140.
- Kanis JA, Johnell O, De Laet C, Jonsson B, Oden A & Ogelsby AK (2002) International variations in hip fracture probabilities: implications for risk assessment. *Journal of Bone and Mineral Research* 17, 1237-1244.
- Katz S, Ford AB, Moskowitz RW, Jackson BA & Jaffe MW (1963) Studies of Illness In The Aged. The Index of Adl: A Standardized Measure of Biological And Psychosocial Function. *JAMA: The Journal of the American Medical Association* 185, 914-919.
- Kim SY, Cox C & Caine ED (2002) Impaired decision-making ability in subjects with Alzheimer's disease and willingness to participate in research. *American Journal of Psychiatry* 159, 797-802.
- Kivipelto M & Solomon A (2006) Cholesterol as a risk factor for Alzheimer's disease - epidemiological evidence. *Acta Neurologica Scandinavica Supplementum* 185, 50-57.
- Kivipelto M, Helkala EL, Laakso MP, Hänninen T, Hallikainen M, Alhainen K, Soininen H, Tuomilehto J & Nissinen A (2001) Midlife vascular risk factors and Alzheimer's disease in later life: longitudinal, population based study. *BMJ: British medical journal* 322, 1447-1451.
- Kivipelto M, Ngandu T, Fratiglioni L, Viitanen M, Kåreholt I, Winblad B, Helkala EL, Tuomilehto J, Soininen H & Nissinen A (2005) Obesity and vascular risk factors at midlife and the risk of dementia and Alzheimer disease. *Archives of Neurology* 62, 1556-1560.
- Koval KJ, Friend KD, Aharonoff GB & Zukerman JD (1996) Weight bearing after hip fracture: a prospective series of 596 geriatric hip fracture patients. *Journal of Orthopaedic Trauma* 10, 526-530.
- Landi F, Bernabei R, Russo A, Zuccalà G, Onder G, Carosella L, Cesari M & Cocchi A (2002) Predictors of rehabilitation outcomes in frail patients treated in a geriatric hospital. *Journal of the American Geriatrics Society* 50, 679-684.
- Lawton MP & Nahemow L (1973) Ecology and the aging process. In *The psychology of adult development and aging*. Eisdorfer C & Lawton MP (Eds.) Washington DC: American Psychological Association.
- Lawton MP (1982) Competence, Environmental Press, and the Adaptation of Older People. In *Aging and the Environment. Theoretical Approaches*. Lawton MP, Windley PG & Byerts TO (Eds.) New York: Springer Publishing Company.

- Lin PC & Chang SY (2004) Functional recovery among elderly people one year after hip fracture surgery. *Journal of Nursing Research* 12, 72-82.
- Lin PC & Lu CM (2005) Hip fracture: family caregivers' burden and related factors for older people in Taiwan. *Journal of Clinical Nursing* 14, 719-726.
- Lincoln YS & Guba EG (1985) *Naturalistic Inquiry*. Beverly Hills CA: Sage.
- Lindskog DM & Baumgaertner MR (2004) Unstable intertrochanteric hip fractures in the elderly. *Journal of the American Academy of Orthopaedic Surgeons* 12, 179-190.
- Lum TY, Lin WC & Kane RL (2005) Use of proxy respondents and accuracy of minimum data set assessments of activities of daily living. *Journals of Gerontology Series A, Biological Sciences and Medical Sciences* 60, 654-659.
- Lundström M, Edlund A, Bucht G, Karlsson S & Gustafson Y (2003) Dementia after delirium in patients with femoral neck fractures. *Journal of the American Geriatrics Society* 51, 1002-1006.
- Lyons AR (1997) Clinical outcomes and treatment of hip fractures. *American Journal of Medicine* 103, S63-S64.
- Löfman O, Berglund K, Larsson L & Toss G (2002) Changes in hip fracture epidemiology: redistribution between ages, genders and fracture types. *Osteoporosis International* 13, 18-25.
- Macleod M, Chesson RA, Blackledge P, Hutchison JD & Ruta N (2005) To what extent are carers involved in the care and rehabilitation of patients with hip fracture? *Disability and Rehabilitation* 27, 1117-1122.
- Maxwell J A (2005) *Qualitative research design. An Interceptive Approach. 2nd ed.* London: Sage Publications Ltd.
- Miller LL, Nelson LL & Mezey M (2000) Comfort and pain relief in dementia: awakening a new beneficence. *Journal of Gerontological Nursing* 26, 32-40.
- Morrison RS & Siu AL (2000) A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip fracture. *Journal of Pain and Symptom Management* 19, 240-248.
- Naglie G, Tansey C, Kirkland JL, Ogilvie-Harris DJ, Detsky AS, Etchells E, Tomlinson G, O'Rourke K & Goldlist B (2002) Interdisciplinary inpatient care for elderly people with hip fracture: a randomized controlled trial. *CMAJ: Canadian Medical Association Journal* 167, 25-32.
- Nightingale S, Holmes J, Mason J & House A (2001) Psychiatric illness and mortality after hip fracture. *Lancet* 357, 1264-1265.

- Nissinen A & Kivipelto M (2005) Leisure-time physical activity at midlife and the risk of dementia and Alzheimer's disease. *Lancet Neurology* 4, 705-711.
- Nåden D & Eriksson K (2004) Understanding the importance of values and moral attitudes in nursing care in preserving human dignity. *Nursing Science Quarterly* 17, 86-91.
- Nolan M & Nolan J (1997) Rehabilitation: realizing the potential nursing contribution. *British Journal of Nursing* 6, 1176-1180.
- Oldmeadow LB, Edwards ER, Kimmel LA, Kipen E, Robertson VJ & Bailey MJ (2006) No rest for the wounded: early ambulation after hip surgery accelerates recovery. *ANZ Journal of Surgery* 76, 607-611.
- Olofsson B, Lundström M, Borssén B, Nyberg L & Gustafson Y (2005) Delirium is associated with poor rehabilitation outcome in elderly patients treated for femoral neck fractures. *Scandinavian Journal of Caring Sciences* 19, 119-127.
- Parliamentary auditors of Sweden. Report 2001/02:15 (2002). *National objectives in municipal elderly care (Nationella mål i kommunernas äldreomsorg)*. Stockholm: Parliamentary auditors of Sweden.
- Patton MQ (2004) *Qualitative research & evaluation methods*. London: Sage.
- Polit DF & Beck C (2004) *Nursing research: principles and methods*. Philadelphia: Lippincott Williams & Wilkins, cop.
- Quine S, Helby L, Cameron I & Lyle D (1994) Carer burden after proximal femoral fracture. *Disability and Rehabilitation* 16, 191-197.
- Ragneskog H, Gerdner LA, Josefsson K & Kihlgren M (1998) Probable reasons for expressed agitation in persons with dementia. *Clinical Nursing Research* 7, 189-206.
- Ranstam J, Elffors L & Kanis JA (1996) A mental-functional risk score for prediction of hip fracture. *Age and Ageing* 25, 439-442.
- Resnick B & Daly MP (1997) The effect of cognitive status on outcomes following rehabilitation. *Family Medicine* 29, 400-405.
- Riedel SE, Fredman L & Langenberg P (1998) Associations among caregiving difficulties, burden, and rewards in caregivers to older post-rehabilitation patients. *Journals of Gerontology Series B, Psychological Sciences and Social Sciences* 53, P165-P174.
- Rikkert MG, van den Bercken JH, ten Have HA & Hoefnagels WH (1997) Experienced consent in geriatrics research: a new method to optimize the capacity to consent in frail elderly subjects. *Journal of Medical Ethics* 23, 271-276.

- Roberto KA & Bartmann J (1993) Factors related to older women's recovery from hip fractures: physical ability, locus of control, and social support. *Health Care for Women International* 14, 457-468.
- Roche JJ, Wenn RT, Sahota O & Moran CG (2005) Effect of comorbidities and post-operative complications on mortality after hip fracture in elderly people: prospective observational cohort study. *BMJ: British medical journal* 331, 1374.
- Rogmark C & Johnell O (2005) Orthopaedic treatment of displaced femoral neck fractures in elderly patients. *Disability and Rehabilitation* 27, 1143-1149.
- Rogmark C & Johnell O (2006) Primary arthroplasty is better than internal fixation of displaced femoral neck fractures: a meta-analysis of 14 randomized studies with 2,289 patients. *Acta Orthopaedica Scandinavica* 77, 359-367.
- Rogmark C, Carlsson A, Johnell O & Sernbo I (2002) Primary hemiarthroplasty in old patients with displaced femoral neck fracture: a 1-year follow-up of 103 patients aged 80 years or more. *Acta Orthopaedica Scandinavica* 73, 605-610.
- Rovio S, Kåreholt I, Helkala EL, Viitanen M, Winblad B, Tuomilehto J, Soininen H, Nissinen A & Kivipelto M (2005) Leisure-time physical activity at midlife and the risk of dementia and Alzheimer's disease. *Lancet Neurology* 4, 705-711.
- Ruchinkas RA, Singer HK & Repetz NK (2000) Cognitive status and ambulation in geriatric rehabilitation: walking without thinking? *Archives of Physical Medicine and Rehabilitation* 81, 1224-1228.
- Rydholm Hedman A, Ljunggren G, Grafström M & Strömberg L (2005) Dementia, delirium and other comorbid conditions in acute hip fracture care. Traditions, attitude and local policies rather than actual state guide diagnose making? *Nursing Science and Research in the Nordic Countries [Vård i Norden]* 25, 25-29.
- Rydholm Hedman A-M, & Grafström M (2001) Conditions for rehabilitation of older patients with dementia and hip fracture – the perspective of their next of kin. *Scandinavian Journal of Caring Sciences* 15, 151-158.
- Sadigh S, Reimers A, Andersson R & Laflamme L (2004) Falls and fall-related injuries among the elderly: a survey of residential-care facilities in a Swedish municipality. *Journal of Community Health* 29, 129-140.
- Sandelowski M (1994) The use of quotes in qualitative research. *Research in Nursing & Health* 17, 479-482.
- SBU- report (2003) The Swedish Council on Technology Assessment in Health Care. Osteoporos - prevention, diagnostik och behandling: en systematisk litteraturöversikt Vol. 1. Stockholm: Statens beredning för medicinsk utvärdering (in Swedish).

Schwarz B (2003) M. Powell Lawton's three dilemmas in the field of environment and aging. In *Physical environments and aging: Critical contributions of M. Powell Lawton to theory and practice*. Scheidt RJ & Windley PG, Eds. New York: Haworth Press, pp 5-22.

Schwarz N (1999) Self-reports. How the questions shape the answers. *American Psychologist* 54, 93-105.

Scheiner AS (2001) Aggressive behaviours among nursing home residents in Japan. *International journal of geriatric psychiatry* 16, 209-15.

SFS 1982:763 (1982) The Health and Medical Services Act (Hälso- och sjukvårdslagen). Stockholm: Ministry of Health and Social Affairs (Socialdepartementet).

SFS 1997:142 (1997) The Health and Medical Services Act. Om ändring i hälso- och sjukvårdslagen (1982:763) Stockholm: Ministry of Health and Social Affairs (Socialdepartementet).

Shaw FE & Kenny RA (1998) Can falls in patients with dementia be prevented? *Age and Ageing* 27, 7-9.

Shaw FE, Bond J, Richardson DA, Dawson P, Steen IN, McKeith IG & Kenny RA (2003) Multifactorial intervention after a fall in older people with cognitive impairment and dementia presenting to the accident and emergency department: randomised controlled trial. *BMJ: British medical journal* 326, 73.

Sherrington C, Lord SR & Herbert RD (2004) A randomized controlled trial of weight-bearing versus non-weight-bearing exercise for improving physical ability after usual care for hip fracture. *Archives of Physical Medicine and Rehabilitation* 85, 710-716.

Siu AL, Penrod JD, Boockvar KS, Koval K, Strauss E & Morrison RS (2006) Early ambulation after hip fracture: effects on function and mortality. *Archives of Internal Medicine* 166, 766-771.

Skovdahl K, Kihlgren AL & Kihlgren M (2003) Dementia and aggressiveness: video recorded morning care from different care units. *Journal of Clinical Nursing* 12, 888-898.

Skovdahl K, Kihlgren AL & Kihlgren M (2004) Dementia and aggressiveness: stimulated recall interviews with caregivers after video-recorded interactions. *Journal of Clinical Nursing* 13, 515-525.

Slauenwhite CA & Simpson P (1998) Patient and family perspectives on early discharge and care of the older adult undergoing fractured hip rehabilitation. *Orthopedic Nursing* 17, 30-36.

- Sneeuw KC, Sprangers MA & Aaronson NK (2002) The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease. *Journal of Clinical Epidemiology* 55, 1130-1143.
- Stenvall M, Elinge E, von Heideken Wågert P, Lundström M, Gustafson Y & Nyberg L (2005) Having had a hip fracture – association with dependency among the oldest old. *Age and Ageing* 34, 294-297.
- Stevens JA, Powell KE, Smith SM, Wingo PA & Sattin RW (1997) Physical activity, functional limitations, and the risk of fall-related fractures in community-dwelling elderly. *Annals of Epidemiology* 7, 54-61.
- Strömberg L, Lindgren U, Nordin C, Öhlén G & Svensson O (1997a) The appearance and disappearance of cognitive impairment in elderly patients during treatment for hip fracture. *Scandinavian Journal of Caring Sciences* 11, 167-175.
- Strömberg L, Öhlén G & Svensson O (1997b) Prospective payment systems and hip fracture treatment costs. *Acta Orthopaedica Scandinavica* 68, 6-12.
- Svensson O, Strömberg L, Öhlén G & Lindgren U (1996) Prediction of the outcome after hip fracture in elderly patients. *Journal of Bone and Joint Surgery British Volume* 78, 115-118.
- Swedish Government Offices (2006) Health and medical care in Sweden (Fact sheets). Stockholm, Sweden: Ministry of Health and Social Affairs.
- Söderqvist A, Miedel R, Ponzer S & Tidermark J (2006a) The influence of cognitive function on outcome after a hip fracture. *Journal of Bone and Joint Surgery American* 88, 2115-2123.
- Söderqvist A, Strömberg L, Ponzer S & Tidermark J (2006b) Documenting the cognitive status of hip fracture patients using the Short Portable Mental Status Questionnaire. *Journal of Clinical Nursing* 15, 308-314.
- Thorngren KG, Hommel A, Norrman PO, Thorngren J & Wingstrand H (2002) Epidemiology of femoral neck fractures. *Injury* 33 Suppl 3, C1-C7.
- Thorngren KG, Norrman PO, Hommel A, Cedervall M, Thorngren J & Wingstrand H (2005) Influence of age, sex, fracture type and pre-fracture living on rehabilitation pattern after hip fracture in the elderly. *Disability and Rehabilitation* 27, 1091-1097.
- Tinetti M E, Speechley M & Ginter SF (1988) Risk factors for falls among elderly persons living in the community. *New England Journal of Medicine* 319, 1701-1707.
- Tombaugh TN & McIntyre NJ (1992) The mini-mental state examination: a comprehensive review. *Journal of the American Geriatrics Society* 40, 922-935.

Toussant EM & Kohia M (2005) A critical review of literature regarding the effectiveness of physical therapy management of hip fracture in elderly persons. *Journals of Gerontology Series A, Biological Sciences and Medical Sciences* 60, 1285-1291.

von Heideken Wågert P, Gustavsson JM, Lundin-Olsson L, Kallin K, Nygren B, Lundman B, Norberg A & Gustafson Y (2006) Health status in the oldest old. Age and sex differences in the Umeå 85+ Study. *Aging Clinical and Experimental Research* 18, 116-126.

von Strauss E, Viitanen M, De Ronchi, D, Winblad B & Fratiglioni L (1999) Aging and the occurrence of dementia: findings from a population-based cohort with a large sample of nonagenarians. *Archives of Neurology* 56, 587-592.

Williams MA, Oberst MT, Bjorklund BC & Hughes SH (1996) Family caregiving in cases of hip fracture. *Rehabilitation Nursing* 21, 124-31 138.

World Health Organization (2004) International statistical classification of diseases and related health problems: ICD-10. Geneva: World Health Organization.

Yasuda N, Zimmerman S, Hawkes WG, Gruber-Baldini AL, Hebel JR & Magaziner J (2004) Concordance of proxy-perceived change and measured change in multiple domains of function in older persons. *Journal of the American Geriatrics Society* 52, 1157-1162.

Zeisel J, Silverstein NM, Hyde J, Levkoff S, Lawton MP & Holmes W (2003) Environmental correlates to behavioral health outcomes in Alzheimer's special care units. *Gerontologist* 43, 697-711.

Zuckerman JD (1996) Hip Fracture. Review Article. *New England Journal of Medicine* 334, 1519-1525.

Zuidema SU, Derksen E, Verhey FR, & Koopmans RT (2006) Prevalence of neuropsychiatric symptoms in a large sample of Dutch nursing home patients with dementia. *International Journal of Geriatric Psychiatry (Epub ahead of print)*.



**13 ORIGINAL PAPERS I-IV**