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HEALTHCARE CONSUMPTION, EXPERIENCES OF CARE AND TEST OF AN INTERVENTION IN FRAIL OLD PEOPLE

Implications for case management

Jimmie Kristensson



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*To Maj-Britt and Kjell,
my grandparents*

CONTENTS

ABSTRACT.....	7
ABBREVIATIONS AND DEFINITIONS.....	9
ORIGINAL PAPERS.....	10
INTRODUCTION	11
BACKGROUND	12
Becoming older and in need of frequent care and services.....	12
Healthcare and social services for frail older people	15
Organisational aspects.....	15
The consumers' perspective	17
Receiving healthcare and/or social services	17
Power and empowerment	19
The producers' perspective.....	20
Healthcare consumption and healthcare costs	20
Factors related to consumption and costs	22
Preventive interventions.....	24
Case management.....	25
Definitions and development.....	25
Effects of Case management for frail older people.....	26
AIMS.....	28
METHODS AND MATERIALS.....	29
Design.....	29
Sample and settings.....	29
The Swedish health system	29
Sample and sampling procedures.....	30
The case management intervention.....	33
Data collection.....	35
Study I	35
Studies II - III	35
SNAC.....	35
Healthcare consumption registers.....	37
Study IV.....	39
Background data	39
Social aspects	40
Health status.....	40
Health-related quality of life and life satisfaction	41
Healthcare and social services	41
Data Analysis	42
Qualitative analysis	42
Statistical analysis	42
ETHICAL CONSIDERATIONS.....	44
FINDINGS.....	46

Experiences of receiving healthcare and/or social services	46
Having power or being powerless	46
Extrapersonal power or powerlessness	46
Interpersonal power or powerlessness	48
Intrapersonal power or powerlessness	48
Healthcare consumption and costs in men and women	49
Healthcare consumption and cost in relation to age.....	52
Factors influencing healthcare consumption and costs.....	55
Patterns of healthcare consumption and costs.....	56
Results from the intervention	57
Case descriptions	57
An escalating infection	57
Alone and not knowing where to turn	58
DISCUSSION.....	60
Methodological considerations	60
Trustworthiness	60
Internal validity	61
External validity	62
Construct validity	63
Statistical Conclusion validity.....	64
General discussion of the results.....	65
The intrapersonal perspective.....	65
The extrapersonal perspective	66
The interpersonal perspective.....	68
CONCLUSIONS AND CLINICAL IMPLICATIONS.....	70
FURTHER RESEARCH	71
SUMMARY IN SWEDISH.....	72
ACKNOWLEDGEMENTS.....	76
REFERENCES	79
APPENDIX I – II	
PAPER I – IV	

ABSTRACT

The overall aim of thesis was to explore frail older people's experiences of receiving healthcare and/or social services and to investigate healthcare consumption and costs in both men and women and in different age groups in the two years prior to the introduction of long-term municipal care. A second aim was to explore a preventive intervention in a pilot study using case managers to older people with functional dependency and repeated healthcare contacts.

Study I was qualitative in design and comprised 14 people (mean age 81) who were interviewed about their views and experiences of the healthcare and social services delivered to them. The results were analysed using content analysis. A cross-sectional, comparative design was used in Studies II and III, which comprised 362 people who received a decision about the provision of municipal care or/and services during 2002-2003 and the participants were drawn from the Swedish National Study of Aging and Care (SNAC) and the county council register of healthcare consumption and costs. SNAC provided data concerning demographics, functional dependency and informal care at the time decision was made. These data were merged with data from the Skåne County Council patient administrative systems regarding contacts with inpatient and outpatient care, diagnosis (Study II) and costs for these contacts (Study III) during the two years prior to the decision. Study IV was a pilot study with an experimental design and comprised 35 people who were consecutively and randomly assigned to either an intervention (n=19) or a control (n=16) group. Two nurses worked as case managers and carried out the intervention, which had four dimensions. Data were collected at baseline and after the intervention had been in place for about three months. This provided information about demographics, social situation, and health and life satisfaction and also about the healthcare and/or social services used.

Study I showed that the experience of receiving healthcare and/or social services in old age could be interpreted according to the main category: Having power or being powerless, divided into three categories: Autonomous or without control in relation to the healthcare and/or social services system; Confirmed or violated in relation to caregivers and Paradoxes in healthcare or social services. These categories had different subcategories reflecting aspects of having power or being powerless. The results from Study II showed that about 50% of the acute hospital stays occurred within the five months prior to receiving municipal care. The men (n= 115, mean age 80.8) had significantly more bed days in hospital, more diagnoses and contacts with other staff groups besides physicians in outpatient care compared to the women (n=247, mean age 83.8). The results from study III showed that about 13% of the sample had overall higher healthcare costs through out the two years of observation. A majority (58% for the women and 54% for the men) of the costs for acute inpatient care occurred within five months prior to municipal care. The men had higher costs for visits to outpatient physicians and for inpatient care and those aged 85+ had lower costs for outpatient care compared with younger age groups, 12 – 0 months prior to municipal care. The results from Study IV showed no differences between groups at baseline. Those included were frail and reported low life satisfaction, low perceived

health and were also at risk of suffering from depression. The Life Satisfaction Index, Geriatric Depression Scale-20 and the ADL staircase had satisfactory internal consistency. Health care staff must be aware of the risk that older people lose control over their life situation when receiving healthcare and/or social services from various agencies. Preventive interventions and a more empowering approach are seemingly needed. This requires continuity and accessibility on an individual and organisational level. Early detection through a systematic clinical assessment, a more proactive and integrated care and applying preventive interventions to people in a transitional stage of becoming increasingly dependent on continuous care and services seems urgent to prevent escalating acute hospital admissions and thereby costs. The case management intervention had a feasible design. The sampling procedure led to similar groups and the measures were reliable to use. Both groups had a low life satisfaction, a low self reported health and were at risk of having a depression and could benefit from preventive interventions. No effects were found on self perceived health and depressed mood after three months. This might be due to the follow up time being too short. Further investigations about the content of the interventions are needed in the future.

KEY WORDS: Case Management; Content Analysis; Emergency Services, Hospital; Frail Elderly; Health Care Costs; Hospitalizations; Intervention Studies; Long Term Care; Outpatients; Pilot Studies; Primary Health Care; Registries.

ABBREVIATIONS AND DEFINITIONS

ADL	Activities of Daily Living
CM	Case management
DRG	Diagnosis Related Groups
ED	Emergency Department
GAS	Good Ageing in Skåne
GP	General Practitioner
ICD 10	International Classification of Diseases 10 th revision
LOS	Length of Stay
NHS	National Health Services
SNAC	Swedish National Study of Aging and Care
PASiS	Patient Administrative Support in Skåne
SOC	Selective Optimization with Compensations
WHO	World Health Organisation
Case management	Case management is a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources and to promote quality as well as cost-effective outcomes
Health System	The sum of all institutions, organisations and resources whose main purpose is to improve health

ORIGINAL PAPERS

This thesis is based on the following studies referred to in the text by their Roman numerals:

- I Kristensson J, Hallberg I.R & Ekwall A.K. Frail older people's experiences of receiving healthcare and/or social services (*Resubmitted*).
- II Kristensson J, Hallberg I.R & Jakobsson U. (2007) Health care consumption in men and women aged 65 and above the two years preceding decision about long-term municipal care. *Health and social care in the community*, 15: 474-485
- III Kristensson J, Hallberg I.R & Lundborg P. Healthcare costs for people aged 65+ two years prior to them receiving long term-municipal care (*Accepted in Aging Clinical and Experimental Research*).
- IV Kristensson J, Ekwall A.K, Jakobsson U, Midlöv P & Hallberg I.R. Testing the implementation of case managers for frail older people in the home; A randomised controlled pilot study (*Submitted*).

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INTRODUCTION

It is a challenge to organise healthcare and social services in accordance with the complex needs of frail, older people (Åhgren 2005). The risk of fragmentation for those who need care from multiple healthcare agencies has been acknowledged as a side effect of the organisational decentralisation of recent years (Saltman *et al.* 2007). This may be even more of a profound problem for older people (Clarfield *et al.* 2001). The fragmentation between various stakeholders in the geriatric care system has been stated to give rise to a risk that frail older people receive inadequate care (Clarfield *et al.* 2001). Older people are known to consume healthcare from various healthcare agencies (Condellius *et al.* 2008, McCaig & Nawar 2006). In addition there is a small group with particularly high healthcare consumption and costs across various agencies and it is a challenge for the health system to create mechanisms to identify and monitor this frail group and provide them with secondary and tertiary preventive interventions. This requires knowledge about patterns of healthcare consumption and costs during different periods. The time period before an older person starts to receive long- term care at home or in special accommodation may be a vulnerable transition phase characterised by increased healthcare consumption and costs, especially in acute care. More knowledge is needed about this phase in older people's life.

Designing preventive interventions also requires knowledge about the experiences of those receiving care from multiple healthcare agencies. However few studies have investigated this. Preventive interventions may benefit both society and individuals (Hallberg & Kristensson 2004). Case management is one organisational model for a preventive approach that has been evaluated (Allen 1999, Bernabei *et al.* 1998, Lim *et al.* 2003). The effects of case management interventions on older people have been tested in international trials and communities. However, the designs have varied between the studies in terms of target populations, content of interventions and outcome measures. The effects have also differed with some studies reporting reduced healthcare consumption (Bernabei *et al.* 1998) and others reporting no such effects (Gagnon *et al.* 1999). This may partly be explained by the fact that case management is a complex intervention that lacks a clear definition, which makes it hard to establish construct validity and external validity and to replicate the studies. Campbell *et al.* (2007) stated that a rigorous definition and development are important when designing a complex intervention and they suggested a three-phase approach to establish evidence. The first phase includes theory, modelling and exploratory trial. The second and third phases include a definitive, randomised, controlled trial and long-term implementation. Thus before launching such a study it seems important to identify a suitable target population, design the interventions to ensure outcomes that benefit both society and individual and explore it in a pilot trial.

BACKGROUND

Becoming older and in need of frequent care and services

The concept of being old is complex and multi-faceted. One aspect is the ageing process itself which can be described as an individual cumulative multi-dimensional process which starts at birth (Tornstam 1998). It is a process of losses and gains over time (Schumacher *et al.* 1999). Being old is not necessarily congruent with feeling old. Kaufman (1986) stated that even though people know that they are in fact chronologically old, that their health is failing and they have difficulties managing daily life they may consider their lives in terms that reflect their entire lives rather than how old they are (Kaufman 1986). Nilsson *et al.* (2000) interviewed 15 people (aged 85 – 96) and found that the experience of feeling old was characterised by the fear of not being able to manage daily life and being helpless, feeling different from others and not recognising one's former self and also that the date when the person started to feel old often was related to experiencing a physical change for worse.

One way of defining being old is by chronological age i.e. the number of years a person has lived. Sometimes the retirement age (about 65 years of age in Sweden) defines the line between being middle aged and being old. Chronological age according to Given and Given (1989) can be clarified by dividing it into age cohorts in terms of young-old (65 – 74 yrs), mid-old (75 – 84 yrs) and old-old (85 yrs and above). This division may be useful since it is known that the number of diseases and health complaints increases with age (Persson *et al.* 2001) and dividing into age cohorts may be one way of comprehending this process. However, measuring the ageing process only in chronological terms may be too narrow since ageing occurs individually and the numbers of years lived may not reveal anything about functional dependency or about the individual feeling old or being old (Kaufman 1986). There is instead an agreement that the ageing process should be viewed as a multi-dimensional process that includes chronological as well as biological, psychological and social aspects. These processes occur simultaneously and must, with regard to the individual aged person, be viewed together (Bondevik 1994). The biological perspective comprises the ageing process from a biomedical standpoint containing for instance the impact of the natural biological ageing process, genetic dispositions and lifestyle factors. The ageing process from a psychological perspective focuses on aspects of learning, personality and intelligence, sometimes divided into life phases, in terms of personal maturation and adjustments to stressors and environmental demands whilst the social perspective focuses more on the individual entering and leaving various social roles during the life span (Tornstam 1998).

There are several theories about ageing and also about aspects that constitute a good or successful ageing. One of the first major theories was the Activity Theory (Havighurst & Albrecht 1953) stating that ageing well was a result of older people maintaining activities that were important to them when they were middle-aged and thereby continuing to want to take an active part in society throughout their life. This was later challenged by the Disengagement Theory (Cumming *et al.* 1960) which claimed that

the ageing process is characterised by the person continuously disengaging him/herself from the rest of society as a part of genetically determined preparation for functional decline and death (Tornstam 1998). However, both theories have been disputed. Tornstam (1998), for instance, stated that both theories could be interpreted as normative and one-sided and thus a more comprehensive view is to be preferred. Another way of describing the psychological ageing process is Eriksson's developmental theory which claims that the individual goes through eight cumulative phases in the cycle of life. Each phase contains a potential crisis for the individual to deal with and whether or not the person leaves the phase successfully depends on how they managed the crisis. The last phase is old age and is marked by ego integrity versus despair. Ego integrity is a sense of that one's life had meaning even though it can not be relived. Its opposite is despair which means resisting being at the end of life. A successful handling of the crisis leads to wisdom (Erikson *et al.* 1994). Eriksson's theory was further developed in the 1990s to include a ninth phase – very old age (i.e. about 80 – 90 years of age). In this phase the individual loses autonomy despite efforts to maintain strength and control. This may have a negative effect on the person's self esteem but it may also allow them to withdraw and reflect over their situation (Erikson *et al.* 1994).

Another way of describing ageing is to use the concept of successful ageing (Baltes & Baltes 1993, Rowe & Kahn 1998). Baltes and Baltes (1993) point out that successful ageing is affected by biological and mental health and productivity but also by life satisfaction, personal control, social competence and length of life. It is also a matter of the individual ability to adapt to age-related changes that occur preferably in a flexible society and in an age-friendly environment (Baltes and Baltes 1993). Rowe and Kahn (1998) suggested that successful ageing as opposed to ordinary ageing, is defined by engagement in an active life, maximizing physical and mental abilities and minimising risks and disability. Bowling and Dieppe (2005) stated that Rowe and Kahn's theory may be problematic since a disease-free old age may be unrealistic for the majority of older people and thus only a few would be able to experience a successful ageing, from a medical standpoint. They (Bowling & Dieppe 2005) reviewed the literature, including both different theoretical definitions and older people's own views (defined as lay definitions) about successful ageing, and found that life expectancy, life satisfaction, wellbeing, cognitive and physical function and independence, social networks, social participation and also autonomy, control, adaptability, self esteem, coping and having goals were important theoretical aspects. Physical appearance, sense of humour, financial security and spirituality were included in additional lay definitions.

According to Schumacher *et al.* (1999) growing older and maybe needing healthcare and social services can be understood as a series of transitions. A transition can be either unwanted or welcome and is characterised by a turning point, which starts a movement between two relatively stable periods in life. Older people experiences multiple transitions, many of them due to losses, and they may be closely related to the older person coming to need care and services (Schumacher *et al.* 1999). Transitions take time and can be developmental, situational or related to health or illness

(Meleis *et al.* 2000). During this process the person is particularly vulnerable and needs to develop new coping strategies, new relationships and new skills for dealing with life. A transition process can be both healthy and unhealthy. A healthy transition process is marked, for instance, by the individual redefining meaning, modifying expectations, restructuring life routines, developing new knowledge and finding opportunities to grow. Unhealthy transition processes are characterised by the opposite factors. Schumacher *et al.* (1999) stated that there are several indicators that measure how the transition is proceeding for the older person: symptom experiences, senses of empowerment, integrity and connection to a meaningful interpersonal network and functional status. It is important that healthcare supports through assessment, resource mobilisation and creation of healthy environments (Meleis *et al.* 2000). Another way of dealing with difficult changes, according to Baltes and Baltes (1993), is the Selective Optimization with Compensations (SOC) principle. This is one strategy behind successful ageing and concerns the individual's ability to handle losses in function and reduced reserve capacity. Selections refers to the individuals' ability to restrict his/her life to fewer domains of functioning. Optimization refers to behaviours that increase reserve capacity and maximise the quality and quantity caused by the selection. Compensations refer to the ability to adjust and find new ways and involve both cognitive and technical aspects. If these three elements work in harmony it leads to a process resulting in a changed and reduced life but one that still is effective. This in turn may empower the individual when starting the SOC process once again due to new circumstances (Baltes & Baltes 1993).

It is well known that the number of diseases and health complaints increases with age (Persson *et al.* 2001) and thus evolves a phase of transition. Despite this a vast proportion of older people remains able to manage daily life independently (Walker & Maltby 1997). However older people are known to consume healthcare from a variety of healthcare agencies (Condellius *et al.* 2008, Hansagi *et al.* 2001) and a smaller proportion consumes a significant amount of the total healthcare delivered. Some older people may eventually need long-term care or services to manage their daily life and some receive informal care in addition to healthcare and long-term care (Hellström & Hallberg 2004). About 15% of those aged 65 and over receive long term care at home or in nursing homes in Sweden (National Board of Health and Welfare 2007a) and the figures corresponds quite well with those from other western countries (Walker & Maltby 1997). Recently, the municipalities in Sweden have become more restrictive in granting care and services and there has also been a re-arrangement of care in terms of an increase in the homecare sector and a decrease in nursing-home beds (National Board of Health and Welfare 2007a) This may have an impact of older people's patterns of healthcare consumption during different periods, for instance preceding the decision pertaining the provision of long-term care at home and also on how care is experienced by those who receive care from various agencies. More knowledge is needed about these aspects.

It is well known that some older people are particularly frail, although there is no clear definition of the concept of frailty. Various literature reviews have claimed that frailty is related to both individual and environmental factors and includes physical as well as

psychosocial aspects (Lally & Crome 2007, Levers *et al.* 2006, Markle-Reid & Browne 2003). Lally and Crome (2007) argued that frailty was related to biomedical and psychosocial factors that contributed to a reduced capacity to deal with environmental stresses which in turn caused increased dependency. Markle-Reid and Browne (2003) suggested that frailty was independent of age and Levers *et al.* (2006) claimed that frailty was connected with ageing and also with disease.

Coming to need healthcare and social services, especially on a long-term basis in order to manage daily life, constitutes a great change in the life of older people (Janlöv *et al.* 2005) and thus can be considered a major transition. It could be viewed as a formal sign that the person can no longer manage daily life without help from society. This might be a demanding situation for the older person (Janlöv *et al.* 2006, Strandberg *et al.* 2002) and a Swedish report based on an extensive literature review stated that the treatment of the patient should not only correspond with his/her medical need but also with the his/her entire life situation (Ottosson 1999). It is known that the need for help and healthcare consumption may increase during the development of disability (Boyd *et al.* 2005, Ferrucci *et al.* 1997, Gill *et al.* 2004). Ferrucci *et al.* (1997) investigated hospitalisations during the year prior to becoming severely disabled (defined as depending on help in three or more ADL activities) in 6070 people aged 70 years and above. The results showed that about 70% had been admitted to hospital during the year prior to becoming disabled. Investigating healthcare consumption during one year may be too limited and it might be interesting to investigate a longer period to obtain a more comprehensive view. Thus the period before an older person receives long-term care at home or in a nursing home may be marked by declining health and increased healthcare contacts in various settings, especially in acute care. The demand for such care may increase further since the municipalities have become more restrictive in providing care and services. More knowledge is needed about this transitional phase in the healthcare situation of older people since few studies are available.

Healthcare and social services for frail older people

Organisational aspects

As some older people are dependent on a number of different agencies for their health and care, coordination and integration are important. Some studies (Gurner 2001) have indicated that sometimes this is not achieved but such studies are sparse, particularly from the older person's perspective. According to WHO (2007a) a health system is the sum of all institutions, organisations and resources with the main purpose of improving health. A health system needs to be guided and directed in its entirety and requires staff, information, funds, communication, supplies and transport (WHO 2007a). It is a major challenge for most of the developed world to organise a health system and adjust to the needs of an increasing population of older people. This requires not only increased collaboration between various stakeholders in the health system but also an organisational structure that can deal with the complex needs of

older people. One report from Stockholm Gerontology Research Centre (Gurner 2001) investigated 26 frail, older people with inpatient, outpatient and municipal care contacts. The report indicated that there was a lack of continuity in the care and services provided in terms of care coordination and a failure in communication between care providers for those who needed care from various healthcare agents. Even though some patients had several contacts with various agents a number of issues fell between the agencies and thus were not solved.

The number of older people will increase rapidly in the future due to the large number of births after World War II and increased life expectancy (Kinsella & Velkoff 2001). This in turn means there will be increased demands on the health sector. To deal with the increasing demand for healthcare services the health systems in many developed countries have been decentralized in recent decades (Saltman *et al.* 2007). Decentralisation is based on the idea that smaller organisations are more accountable and flexible than larger ones – if they are properly managed and structured (Saltman *et al.* 2007). The World Health Organisation (WHO) has identified a range of decentralisation strategies used in different European countries. For instance, to increase long-term care services available to older people, the responsibility for planning, financing delivering and organising such care has been decentralised to a local level in various countries (Saltman *et al.* 2007). It has also been argued that decentralisation contributes to a severe risk of fragmentation, especially for those who need healthcare and social services from different stakeholders (Åhgren 2007). According to WHO, creating integrated care is a challenge for European health systems (Gröne & Garcia-Barbero 2001). This requires integration between different levels within the system and it has been argued that decentralisation may be one important way to obtain integrated care (Åhgren 2007). On the other hand Gröne & Garcia-Barbero (2001) stated that the integration of primary, secondary and tertiary care is weak in many western countries and this has negative effects on care quality and may cause unnecessary inconvenience for the patients. This may be applicable to several groups but is perhaps a concern especially for frail, older people who are known to consume healthcare on different levels within the health system.

Åhgren (2007) described fragmentation in healthcare as a complex force caused by multifaceted changes in the system. According to the author, fragmentation has its roots in the increasing decentralisation, specialisation and professionalisation (i.e. groups working independently but with extensive responsibility) of healthcare and occurs on three levels; on an organisational level due to decentralisation and specialisation; on a clinical level due to specialisation and professionalism and on a cultural level due to decentralisation and professionalism (Åhgren 2007). This description is supported by Clarfield *et al.* (2001) who argued, from a more clinical point of view focusing on geriatric care, that there are three aspects of discontinuity within geriatric care systems that might cause problems for the delivery of satisfactory care to older people: The split between communities and hospitals, the split between social services and medical care and the split between acute and continuous care. The author's stated that older people are more at risk than others of receiving inadequate care because of these organisational divisions.

Decentralisation and fragmentation is one way of looking at the healthcare system from a macro-perspective, even though this also entails issues on a micro-level. In addition, the healthcare system is a human treating organisation which has been described on a micro level as a so called street-level bureaucracy (Lipsky 1981) and as such may find it difficult to address older people's needs properly. A street-level bureaucracy is characterized by the employment of street-level bureaucrats whose job it is to meet with citizens who come in contact with the organisation. The street-level bureaucrat has a relationship with and a responsibility towards the clients and towards the organisation at the same time. The street-level bureaucrat, therefore, has a substantial influence and at the same time experiences a pressure from society and management to perform in accordance with the job assigned to the organisation. In order for the street-level bureaucrat to deal with people he/she must categorise them and transform them into either clients or patients so that they can be eligible for treatment (Lipsky 1981, Prottas 1979). This requires discretion, which is fundamental for the street-level bureaucrat's profession. Lipsky (1981) stated that such discretion, however, is affected by basic starting points for the organisation i.e. the rules and laws are sometimes vague, the client's needs are complex and individually based and the organisation expect the street-level bureaucrat to make decisions based on professional expertise, which creates space for personal discretion (Dunér & Nordström 2006, Lipsky 1981). These three aspects make the street-level bureaucrats' work difficult and also incorporate a risk for those who seek help from the organisation of being marginalised or inadequately treated. Prottas (1979) stated that humans are too complex to be treated efficiently in a bureaucratic organisation and the street-level bureaucrat may be interested in dealing only with those client-related issues that can be dealt with or are supposed to be dealt with by the organisation. This risk might be even greater for those frail older people who require healthcare and social services from multiple healthcare agencies in order to manage their everyday life. In addition it might also increase the risk that the older person will be caught between different agencies (Gurner 2001). Thus healthcare consumption in old age can be viewed from various perspectives and it seems important to include both the consumers' and the producers' perspectives in order to arrive at a comprehensive view of the situation of frail, older peoples reliant on the health system.

The consumers' perspective

Receiving healthcare and/or social services

Frail, older people are heavily dependent on the health system. This is particular true for those who consume a significant amount of healthcare from a variety of agencies (Condelius *et al.* 2008). The frequency of their contacts demonstrates their dependence on the health system for their health and wellbeing. It demonstrates that their health has failed and they have been forced into a situation where they have to turn to the health system as an emergency. Studies have indicated that the health system can be experienced as inaccessible and complicated, especially for those with chronic diseases (Gott *et al.* 2007). Occasional healthcare contacts may not interfere very

much with the everyday life of older people but repeated visits may in the case of those who are frail.

Repeated contacts with various healthcare deliverers also entails repeated encounters with healthcare staff in different settings. In such encounters a complex relationship is set up and studies have indicated that healthcare staff felt that the relationship was more emotionally based for the caregivers than for the care receivers (Olsson & Ingvad 2001). Various studies have investigated older people's experiences of receiving care in different settings and the results have been both positive and negative. Interpersonal continuity has been found to be one important positive aspect that contributes to feelings of security (Saultz & Albedaiwi 2004, von Bultzingslöwen *et al.* 2006) However, having control, being empowered, and being treated as an individual are also important if the encounter is to be perceived as satisfactory. The studies have mostly explored care provided in specific settings rather than the entire healthcare situation of those receiving repeated care and services from several agencies.

To come to be in need of healthcare and social services also means facing a change in health or new circumstances in life. This might be a demanding situation. Janlöv *et al.* (2005) interviewed 28 people (aged 75 and above) who had recently been needs-assessed for home-care. The results showed that they experienced a discontinuity in their life as a whole and also felt that the countdown to death had begun. Coming to need healthcare and/or social services was very much about losing abilities, worrying about what these losses would signify for the present and the future and also as seeing the situation as a struggle to avoid dependency. This is in line with another study showing that the experience of being needs-assessed could mean standing outside the process and being unprepared but also as introducing a sense of security and being taken seriously (Efraimsson *et al.* 2006). Nevertheless, an empowering approach from the health system may help promote a successful transition (Meleis *et al.* 2000). Hallberg *et al.* (1995) focused on patients with dementia and described the nurse-patient encounter as an interactive process characterised by mutuality or unilateralism. An encounter that focused on sensitivity, attention, seeking contact and focused on relations and tasks contributed to mutuality which led to confirmation and empowerment. On the other hand withdrawal, ill-defined communication, resistance or the use of force or being entirely task-focused caused unilateralism, disconfirmation and finally disempowerment on the part of the patient.

The experience of receiving healthcare and/or social services is seemingly dualistic in that on the one hand the older person has to be confronted with his/her own frailty and on the other hand be put in a situation which can both increase and decrease the feelings of being frail. Hellström and Sarvimäki (2007) explored experiences of self-determination in eleven older people who lived in nursing homes. The overall theme was disempowerment based on feelings of resignation and not being valued, and not having any influence. Themessl-Huber *et al.* (2007) interviewed 18 people (aged 80 and over) who had experienced multiple emergency admissions and were both satisfied and dissatisfied with the care in terms of it failing to meet individual needs or maximise independence. Aronson (2002) investigated experiences of homecare in 20

older women and found that receiving homecare was very much about taking charge but also feelings that things were out of their control and resigning and adapting to the situation when homecare was unsatisfactory. The studies reviewed indicate that those highly dependent on help need to be supported and empowered by the health system in order to retain power over their life situation. However since the studies focused on receiving healthcare and/or social services in specific situations, the overall experience of receiving healthcare and/or social services from a variety of agents was not reflected on.

Power and empowerment

A person is supposed to become powerless mainly when he/she experience loss of control over a situation (Rundqvist 2004). Being dependent on the health system might influence older people to feel that they lost or are loosing control over their life situation (Hellström & Sarvimäki 2007, Janlöv *et al.* 2006). Thus it is related to the distribution of power and this might be even more apparent for those who are frail and highly dependent on help from various agents within the health system.

Power is a complex and multi-dimensional concept that can be viewed from different perspectives. Weber (1964) stated that power is the probability that an actor in a social relationship will be in a position to carry out his/her own will, despite resistance and regardless of the basis for this probability. Power can occur in different contexts and according to Lane (1981) it emanates from three basic structures: individual actors, groups and organisations. All three may interact with each other creating nine different power contexts (Lane 1981). Thus power comprises an interaction-based dynamic between people. This was supported by Kuokkanen and Leino-Kilpi (2000) who suggested that power is something that occurs between people and increasing the power of one person means that another has to surrender parts of his/her power. However power can also be seen as a phenomenon occurring within the person. A concept analysis by Rundqvist (2004) showed that power could be divided into three aspects. Firstly it could be viewed as the individual's inner force and strength. Secondly it could be viewed as the individual's ability to act to benefit other people and thirdly it could be viewed as the individual's ability to act to benefit him/her self. Rundqvist (2004) claimed that power is an inner force revealed as an ability to act freely but also as an ability to refrain from acting. Thus power can be viewed from both extra-, inter- and intra-personal perspectives. This may especially account to be applicable to those frail, older people who interact on a frequent basis with the health system and at the same time undergoes multiple transitions due to declining health. The power of the health system as such and the professionals acting within the system may have a great impact in the older person's experience of either being or not being in power.

Power is considered to be closely linked to empowerment (Kuokkanen & Leino-Kilpi 2000, Rodwell 1996). Empowering involves interactions and can be viewed as a helping process and a partnership in which the self and others are valued, mutual decisions are made and there is freedom to make choices and accept responsibility. But

it can also be viewed as a process in which power is transferred between people or groups (Rodwell 1996). Thus it can also be seen as an important aspect of nursing advocacy (Vaartio *et al.* 2006) and as a tool for reinstating power for the patient to reduce the patient's powerlessness and loss of control (Rundqvist 2004). Empowerment or disempowerment may also be signs of healthy versus unhealthy transitions (Meleis *et al.* 2000). This may be especially applicable to older people who go through several transitions during late life and to those who receive care and/or services from various agents in the health system. However restoring power to the patient requires continuity of care and also close collaboration between agents.

The producers' perspective

Healthcare consumption and healthcare costs

A large body of literature has focused on various aspects of healthcare consumption and costs in older people, focusing mostly on specific diseases (Haentjens *et al.* 2003), specific types of consumption, such as readmissions to hospital (Condelius *et al.* 2008) or admissions to nursing homes (Ahmed *et al.* 2003) or consumption in specific settings (McCusker *et al.* 2003). Since older people are known to have a complex health and social situation a more comprehensive view of their overall healthcare consumption is needed when targeting those at risk of high consumption. Older people are known to consume healthcare from various healthcare agencies (Condelius *et al.* 2008, Hansagi *et al.* 2001) and a large proportion receive informal care in addition to healthcare and long-term care (Hellström & Hallberg 2004) indicating that the interactions between caregivers can not be ignored. This implies a complexity, both when defining high healthcare consumption and when identifying those who have a high level of consumption. Knowledge about different patterns of healthcare use or costs, for example during the period prior to older people entering the public home care system, is therefore important when designing interventions aimed at targeting healthcare consumption.

It is well known that the overall use of healthcare and social services increases with age (National Board of Health and Welfare 2007a, b, Nawar *et al.* 2007). Longevity has been found to have a profound impact on the costs for acute and long-term care (Spillman & Lubitz 2000). Older people are known to have more frequent contacts with the healthcare system than younger people due to declining health and increasing dependency. For instance, in Sweden in 2005 people aged 65 and above accounted for approximately 45% of the hospital admissions and 50% of bed days in hospital (National Board of Health and Welfare 2007b). Similar findings have been obtained in other countries as well. In the USA in 2000 about 40% of those discharged from non-federal short-stay hospitals were aged 65 years or older (DeFrances & Hall 2007) and they accounted for about 14% of the total Emergency Department (ED) visits in 2005 (Nawar *et al.* 2007). The General Household Survey in the UK in 2002 showed that 11% of those aged 65 – 74 and 17% of those aged 75+ had received hospital care during the year prior to the survey (Rickards *et al.* 2004)

More knowledge is needed about different patterns of healthcare consumption in older people as such knowledge is important when developing preventive interventions. There is a certain proportion of older people with a particularly high level of healthcare consumption (Condellius *et al.* 2008). However more studies are needed concerning the characteristics of this group. It is a challenge for the healthcare system to detect and monitor them more closely and provide them with adequate care that accords with their needs. Condellius *et al.* (2008) investigated a Swedish sample of 4907 people aged 65+ over a period of one year and found that about 70% of their hospital stays (n=8040) were classified as acute, and that about 15% of the sample had three or more hospital stays. Those with three or more hospital stays also had significantly more frequent contacts with outpatient physicians (median 15 contacts) than those who had only one hospital stay (median 8 contacts) during the year. Hansagi *et al.* (2001) investigated a sample of 47 349 people who visited an ED in one year (21% were aged 65+). Frequent ED visits were associated with more hospital stays and more contacts with primary care. Thus, there is an apparent interaction between various healthcare providers indicating that a high level of healthcare consumption in one part of the system is associated with high levels of consumption in other parts. However it is a challenge for the health system to develop mechanisms to detect and monitor this group at an early stage.

It is also well known that some of older people in addition to health and medical care, receive healthcare and social services on a long-term basis either at home or in special accommodation (Modin & Furhoff 2004). This may be a particularly vulnerable group. About 9% of older people (aged 65+) in Sweden received healthcare and social services from the municipalities at home and 6% in special accommodations during 2006. The corresponding figures for those aged 80 and above were 20% and 17% respectively (National Board of Health and Welfare 2007c) In the USA about 3% of the older population used home health care and about 4% were nursing home residents in 2000 (Bernstein *et al.* 2003). However there are differences between settings in that those who receive care in special accommodation are more dependent on help (Hellström & Hallberg 2004). Long-term care at home or in special accommodation has been shown to relate to the use of health and medical care. Some studies have indicated that receiving care and services in special accommodation reduced hospital admissions (Ellencweig *et al.* 1990). These findings are supported by the results of a Swedish study showing that those in special accommodation consumed less hospital care than those who received care and services at home (Karlsson *et al.* 2008). However this also indicates that there might be an increase in hospital admissions during the period preceding long-term care, this is so since the trend in the municipalities is towards more homecare and less care in special accommodation (National Board of Health and Welfare 2007c).

Healthcare costs is one aspect of healthcare consumption. However, high levels of healthcare consumption in terms of frequent contacts do not automatically imply high costs since fewer expensive contacts may incur higher costs than several cheaper ones. Thus healthcare costs are an important factor to consider when investigating healthcare consumption in old age. The more frequent contacts that older people have with the

health system leads to expenditure for the society and for the older person. Healthcare expenditure increases with age. In Sweden in 2002 approximately 36% of the total expenditure for public health and medical care was estimated to relate to people aged 65+ (National Board of Health and Welfare 2004). Healthcare expenditure, however, seemingly varies widely among the older population, with a smaller group having higher costs. In 2003, for example, approximately 50% of people 65+ incurred healthcare costs below EUR 550/year and person. About five percent had healthcare costs that exceeded EUR 12 000 per individual per annum (National Board of Health and Welfare 2004). The findings are similar in other western countries. In the USA in 1999, personal healthcare expenditure was approximately USD 2800 per capita for those under 65 years and about USD 11 100 for those aged 65 and above (U.S Department of Health and Human Services 2008). Identifying those who consume extensive healthcare and providing that care in a different way may be more cost effective. To do this also requires knowledge concerning factors related to higher costs

Factors related to consumption and costs

Identifying patterns of healthcare consumption and costs requires knowledge about related factors. Various studies that have investigated aspects related to healthcare consumption in different settings indicate that medical condition, age, gender, previous or ongoing healthcare use of other agencies and functional ability are important aspects to be considered (Ahmed *et al.* 2003, Stoddart *et al.* 2002). Medical diagnoses are one important factor to investigate since they are the major reason for receiving health and medical care. However, since older people often have several diagnoses and health complaints focusing on one specific diagnosis or condition might be too limiting and a more comprehensive view focusing on aspects of comorbidity may be more effective in identifying those at risk of higher consumption.

Bottle *et al.* (2006) investigated all emergency admission patients at NHS hospitals in England 2000 – 2001 (n=2 895 234) with the aim of investigating characteristics of those who became high impact users (defined as three or more admissions) during the survey year. The results showed that about 13% of those aged 65 and above became high impact users. Chronic obstructive pulmonary disease, diabetes with complications and circulatory diseases were common among the high impact users. The authors further stated that almost half had experienced three or more admissions in the year prior to the survey and concluded that routine statistics concerning hospital admissions could be used to identify those at risk of being frequently admitted to hospital as emergency cases. However, a Japanese study found that living alone, low capacity regarding the performance of activities of daily living, and being a woman were related to long-term stays in hospital (Kuroda *et al.* 1992). In addition extensive use of inpatient care may also be associated with high consumption in other agencies as well. Lindström *et al.* (2003a), for instance, found that the number of outpatient visits and high age predicted hospitalisations in a Swedish county.

Various studies have also focused on identifying the determinants for costs. Leon & Neumann (1999) investigated the cost for Alzheimer's disease in managed care

(n=150, mean age 79.4) and found that costs increased in line with cognitive impairment. Haentjens *et al.* (2003) investigated the cost of care over a period of one year after hip fracture in 84 women (aged 50+) in Belgium. High age and living in special accommodation at the time of the injury were associated with increased costs. The results of a Canadian study showed that high levels of functional dependency, heart failure, stroke subtype and neurological impairment were associated with higher costs (n =1341, mean age 70.5) in the three months following stroke (Caro *et al.* 2001). Another study from Australia investigated factors associated with costs for physician outpatient care in a sample of 328 people (mean age 76.1). Sex (woman) and age were associated with greater costs in primary care while physical functioning and mental health were associated with higher costs in specialised care (Pollicino & Saltman 2000). These studies investigated factors associated with costs for specific diseases or conditions. They did not, however, investigate the possible interaction between healthcare costs preceding decision to fund municipal care and services on a long-term basis.

Age, living alone and declining health have also been found to predict long term-care at home or in special accommodation. Stoddart *et al.* (2002) investigated 1540 Swedish people aged 65+. High age, being a widow/er, poor self-reported health, poor physical functioning, problems with cognition and pain were associated with more use of homecare. Rudberg *et al.* (1996) found that high age, living alone, poor functional ability when admitted and reduced functional ability during the hospital stay predicted nursing-home placement after discharge. Ahmed *et al.* (2003) investigated predictors for nursing home admissions after discharge from hospital in an American sample of 986 people with heart failure (mean age 79). High age, previous admission to a nursing home and length of stay in the hospital predicted nursing-home placement. Thus, age, sex, medical conditions and functional ability are important aspects to be considered.

As noted above, several studies have investigated healthcare contacts and costs focusing on gender differences and differences between age groups. This is a reasonable route to follow as old age covers several decades in a person's life and those aged 85+ are known to have more diseases and health complaints than those aged 65- 74, for instance, (Stenzelius *et al.* 2005). In addition women are known to have a longer life expectancy (Kinsella & Velkoff 2001). Thus the patterns of healthcare use may be expected to differ. This was supported by Koziol *et al.* (2002) who investigated all data about hospital charges and discharge for people aged 55 and above in the state of California for the years 1986 – 1995 and found that men had more hospital stays and overall higher charges throughout the ten years. A Swedish study (Linjer *et al.* 2006) investigated predictors for high care costs in a sample (n=6614) with hypertension and reported that male gender and stroke were associated with higher costs for hospital care whilst old age and stroke were associated with higher costs for nursing-home care. On the other hand Redondo-Sendino *et al.* (2006) found in a cross-sectional Spanish study on people aged 60+ that 43% of the women (n=1672) visited a GP at least once a month and 15% received a medical home visit at least once a year compared to 37% and 10% respectively of the men (n=1358). A larger share of the women had a current intake of three or more pharmaceuticals. No

differences were found with regards to hospital admissions. Thus it seems important to consider gender and age related factors when investigating healthcare consumption in old age.

Preventive interventions

Recently, various preventive interventions have been developed targeting both older people in general (Hendriksen *et al.* 1984), those with specific diseases (Poole *et al.* 2001) and those who are generally frail (Bernabei *et al.* 1998). The rationale behind these interventions is often to prevent increasing costs in terms of greater healthcare consumption but also to increase continuity of care, improve quality of life or improve/maintain health (Hallberg & Kristensson 2004). Thus the interventions have targeted aspects benefiting both society and the individual.

According to WHO health promotion is a process that enables people to increase control over their health and improve it. The term disease prevention is sometimes used as a complement to health promotion (WHO 1998) and the concepts overlap. However WHO defines them differently. Disease prevention aims not only to prevent diseases from occurring but also to arrest the progress of diseases and reduce the consequences once they have become established (WHO 1998). Preventive actions could therefore be divided into primary prevention (preventing the diseases before it occurs), secondary prevention (hindering or minimising existing disease) and tertiary prevention (reducing relapses or the establishing of chronic conditions). However prevention does not have to be directed to diseases alone. Neuman (2002) suggests in her nursing theory that preventive interventions can be used when a person experiences some kind of stressor which threatens the individual's system. Thus it comprises a broader perspective. According to Neuman a preventive intervention may start at any point when a stressor is identified or even suspected and she also suggests the division into primary, secondary and tertiary prevention. Here primary prevention comprises actions taken to retain wellness, secondary prevention comprises actions to attain wellness and tertiary preventive actions to maintain wellness (Fawcett 1989, Neuman & Fawcett 2002). Thus with regard to frail older people a secondary and tertiary approach should be regarded as suitable.

One type of intervention focusing on older people has been preventive home visits to older people in general. Hendriksen *et al.* (1984) investigated the effects of preventive home visits on a sample of 285 people aged 75 years and above. The results showed a significant reduction in hospital admissions and telephone calls to EDs. A three-year follow-up study showed that preventive home visits seemed to benefit women more than men in terms of functional ability (Vass *et al.* 2004). The effects of preventive home visits are not undisputed. A systematic review by van Haastregt *et al.* (2000) including 15 trials concluded that no clear evidence had been found in terms of reduced mortality, fewer hospital admissions or increased functional ability. On the other hand Elkan *et al.* (2001) reported in a systematic review and meta analysis that preventive home visits to older people did significantly decrease mortality and

admission to a long-term care institution. The meta-analysis showed no effects on hospital admissions. These results were confirmed in a systematic review by Stuck *et al.* (2002) including 18 trials which concluded that preventive home visits which also involved a comprehensive geriatric assessment and nine or more follow-up visits reduced nursing home admissions and mortality in young-old people. Other preventive interventions have targeted specific diseases such as chronic heart failure (Endicott *et al.* 2003) and stroke (Widen Holmqvist *et al.* 1998). Due to the complexity of the health situation of older people's a model targeting only a specific disease may be too limited and a broader approach might be needed when it comes to preventive health interventions for older people.

Case management

Providing secondary and tertiary prevention for frail older people, who are known to consume healthcare from various agencies, requires continuity, an holistic approach and close collaboration between the various caregivers. Thus it requires assessment, planning, follow up and coordination of the different agents. Case management may meet the requirements of such an approach.

Definitions and development

There is no established definition of the concept of case management. The model was originally developed by American insurance companies in the late 1960s as a care-coordination model for patients with mental disorders, with clerks working as case managers (Lindström 2002). One of the main reasons for using case management was to minimize fragmentation and increase continuity and the goal was to ensure continuity within the health system for both patients and staff. There is no single model of case management and the term is used to define a variety of ways to ensure continuity and care for people with complex health problems (Hutt 2004). Thus various health care professionals can take on the role of case managers and a range of case management models – i.e. with different case manager tasks – has been used to different populations and adopted in hospitals and outpatient care as well as in primary care and homecare settings. It has been suggested that the basic case management functions include finding and outreach, comprehensive individual-based assessment and care planning, coordination of services, direct service provision, monitoring and evaluation and also meeting special needs (Björkman 2000, Powell & Ignatavicius 2001). Many of the case management models originate in psychiatric care. One of the original models was the broker model where the case manager had a large number of clients and the basic tasks was to assess, plan, coordinate, monitor and provide advocacy. Other models, with a more rehabilitational approach, included the strength model which focused more on the individuals' resources and less on the disease. Another of the first more comprehensive case management models was the Assertive Community Treatment (ACT) in which the services were characterised by multidisciplinary team with the team based in the community and not in outpatient settings or offices, low case loads and 24 hour service coverage (Björkman 2000).

According to Young (2003) case management for older people ranges from being a matter of cost control only to a comprehensive approach dealing with both acute and long-term needs across settings and throughout the whole care trajectory. The Case Management society of America have stated that case management is a function within a profession and thus not a profession in itself. It defined case management as “*a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources to promote quality cost-effective outcomes*” (CMSA 2008). Case management for older people can however also include care coordination, clinical care, education and psychosocial support (Sargent *et al.* 2007). The lack of consensus regarding the case management concept increases the complexity of such interventions making it difficult to establish evidence and implement a specific case management model in clinical practise. Nevertheless some concept flexibility might be needed since a too limited case management definition might make it more difficult to transfer it to groups with complex needs and adapt it to their situation.

Effects of Case management for frail older people

The effects of case management for older people have been investigated in international trials mainly in the USA (Allen 1999), the Netherlands (van Achterberg *et al.* 1996), Italy (Bernabei *et al.* 1998), the United Kingdom (Gravelle *et al.* 2007) and Australia (Lim *et al.* 2003) It has been claimed that the evidence concerning effects on healthcare consumption is weak (Hutt *et al.* 2004). One has to take into account, however, that the interventions are complex and the study designs in terms of target population, the content of the interventions, follow-up time, outcome measures and established effects differed among the studies. An Italian, randomised, controlled trial (Bernabei *et al.* 1998) investigated the effects of case management and care planning by general practitioners (GPs) and a geriatric evaluation unit on a sample of 200 people, mean age 80.7 and 81.3, who already received community care services. The results showed significantly fewer hospital admissions and fewer home visits from GPs in the intervention group. Another study (Allen 1999) also investigated the effects of case management in a sample of 456 people mean age 78.0. The results showed significantly shorter hospital stays for the intervention group. Lim *et al.* (2003) investigated the effects of case management on 598 people aged 65+ who had been discharged for hospital and needed social services. The results showed a reduction in used hospital bed days and an increased quality of life for the intervention group (n=311). However no effects were found on unplanned readmissions or mortality.

Nurses have played a key role in case management for older people at home and were often selected as case managers because of their knowledge about the organisations, the care system processes, medical problems among older people and their ability to provide hands on nursing care (Hallberg & Kristensson 2004). A literature review by Hallberg & Kristensson (2004) including 28 case management studies showed that they mainly targeted three outcome areas – although not simultaneously i.e. healthcare consumption, quality of care and patient health and ability. The results showed that case management reduced healthcare consumption in terms of there being fewer

hospital admissions, shorter hospital stays, fewer outpatient visits and nursing home admissions, in some studies. Other studies showed no effect on inpatient, outpatient or ED visits. Some studies reported increased patient satisfaction and others showed no such effects. Some studies reported increased quality of life and increased functional capacity. Other studies found no such effects. The variation in effects may be explained by the different designs used in the studies and by the interventions being performed in different health care settings.

Older people are known to have complex health and social situations with deteriorating health, which may be a confounder when investigating effect on functional ability, healthcare consumption and quality of life. However, the studies in which the case manager was a part of a multidisciplinary team and/or used a comprehensive geriatric assessment tool for outlining interventions seemed to be the most effective (Hallberg & Kristensson 2004). Watt (2001) stated that suitable outcomes for evaluating the effects of case management on older people are that the targeted areas benefit both individuals and the community. According to the author this includes cost effectiveness, healthcare consumption, quality of life, life satisfaction and health status (Watt 2001)

Regardless of outcome measures, interventions using case management raise methodological issues as they are complex. They include several components and are therefore complicated to document and reproduce (Campbell *et al.* 2007). The complexity of the interventions threatens construct validity in that the effects become difficult to evaluate i.e. to actually pin-point the “active ingredient” in the intervention. Campbell *et al.* (2007) stated that thorough definition and development are important when designing a complex intervention and they suggested a three-phase approach to establish evidence: the first phase contains theory, modelling and exploratory trial while the second and third phases include a randomised, controlled trial and long-term implementation. Thus before launching such a study it seems important to identify a suitable target population, design the interventions to ensure outcomes that benefit both the society and the individual and explore the intervention in a pilot trial. In this process it is important to explore the experiences of those who have frequent contacts with the health system, to investigate how the system functions and also to investigate potential areas that might be further developed within the system.

AIMS

The overall aim of thesis was to explore frail older people's experiences of receiving healthcare and/or social services and to investigate healthcare consumption and costs in both men and women and in different age groups in the two years prior to the introduction of long-term municipal care. A second aim was to explore a preventive intervention in a pilot study using case managers to older people with functional dependency and repeated healthcare contacts. The specific aims were:

- To explore older people's experience of receiving healthcare and/or social services (Study I).
- To investigate healthcare consumption in men and women aged 65 and above in the two years preceding decision about long-term municipal care at home or in special accommodation and to investigate determinants for health care consumption (Study II).
- To investigate healthcare consumption with regards to age in people aged 65 and above the two years preceding decision about long-term municipal care at home or in special accommodation (Framework).
- To investigate healthcare costs in men and women (65+) and with regard to age in the two years prior to the start of long term municipal care and services. The aim was also to investigate patterns and determinants of costs (Study III).
- To explore a case management intervention for older people with functional dependency and repeated contact with the healthcare services as well as to investigate the effects of the intervention on perceived health and depressed mood after three months in a pilot study (Study IV).
- The aim was also to illuminate the content of a case management intervention to older people with functional dependency and repeated health care contacts (Framework).

METHODS AND MATERIALS

Design

This thesis used three study designs: a qualitative design (Study I), a cross-sectional, comparative design (Study II – III), and an experimental design (Study IV) (Table 1).

Table 1. Design and sample in Studies I – IV

Study	I	II – III	IV
Design	Qualitative	Cross-sectional Comparative	Randomised Controlled Trial Pilot study
Sample, n	14	362	35
Women%	64	68	57
Age, m, range	81, 74 – 92	83, 65 – 100	83, 71 – 94
Municipal care%	64	100	60
Data collection	Semi structured interview	Questionnaire Registers	Structured interview
Analysis	Content analysis	Student's <i>t</i> -test Mann Whitney <i>U</i> -test χ^2 test One way ANOVA Linear regression Cluster analysis	Mann Whitney <i>U</i> -test χ^2 test Wilcoxon signed ranks test Cronbach's alpha. Case descriptions ¹

1: Only within the framework

Sample and settings

The Swedish health system

Healthcare as well as long-term care for older people in Scandinavia is based on a welfare system mainly funded by taxes (Lagergren 2002), and responsibility is shared by various authorities. There are two laws, the Health and Medical Services Act (Ministry of Health and Social Affairs 1982) and the Social Services Act (Ministry of Health and Social Affairs 2001), which regulate healthcare and social services for people aged 65 years and over. Two authorities, the county councils at regional level and the municipalities at local level, provide care and services. Long-term care and social services are provided by the municipalities either at home or in special accommodation. The county councils provide healthcare, treatment and specialised medical care in outpatient and inpatient facilities and also rehabilitation. The municipalities also provide healthcare, except when provided by physicians, and can also be responsible for home nursing care (Lagergren 2002). People aged 65 and over have the right to ask for and to receive municipal care and/or social services. The decision, however, is based on a needs assessment made by a home-help officer

authorised by the municipality (Janlöv *et al.* 2006). Municipalities has become stricter when it comes to the provision of home care, the number of beds in nursing homes has decreased and more responsibility have been transferred to family members (National Board of Health and Welfare 2007a)

Sample and sampling procedures

This thesis was based on three separate samples (Table 1). In Study I the sample comprised 14 people, nine women and five men, aged 74 – 92 years. The inclusion criteria were that the person should have had at least two hospital stays during the last 12 months and be aged 70 years or older. The person should also be lucid and able to communicate verbally and able to participate in an interview. The participants were recruited either when they were admitted (n=10) to hospital or when visiting an Emergency Department (n=4) at a hospital. Two researchers were involved in the sampling and data collection. Three wards functioned as sources for identification. The staff received information from one of the researchers about the study and when a person who matched the inclusion criteria was admitted, the staff approached them, informed them briefly about the study and asked if they were allowed to give the person's name to the researchers. One of the researchers then approached them, provided oral and written information about the study and scheduled an interview. Those identified at an ED were approached during their visit and informed by one of the researchers. They were then asked if the author could phone them at home a couple of days after the visit to the ED. During the subsequent phone call the potential participant was once again informed about the study and the time for an interview was arranged. Two additional interviews were carried out and later excluded. In one case the tape- recording could not be used due to technical errors. In the other case the results were greatly influenced by the presence of the participant's relative during the interview. Two other interviews had to be cancelled because the participants became too ill.

In Studies II and III the sample comprised 362 people, aged 65 years and above, who received an initial decision concerning long-term municipal care and services during 2002 or 2003. The sample was drawn from a larger longitudinal study, the Swedish National Study of Aging and Care (SNAC) (Lagergren *et al.* 2004). SNAC includes four areas in Sweden (Skåne, Blekinge, Nordanstig and district of Kungsholmen in Stockholm) and has two parts: the care and services part, which focuses on aspects related to older people receiving municipal care and services, and the population part, which focuses on different aspects of the ageing process in older people in general (Lagergren *et al.* 2004). The sample in Studies II-III was drawn from the care and services part, in one of the four areas involved (the region of Skåne in southern Sweden) including five municipalities (Hässleholm, Malmö, Osby, Eslöv and Ystad) representing both rural and urban areas. This particular SNAC sub study is called Good Ageing in Skåne (GAS) (Jakobsson & Hallberg 2006). The criteria for participation were that the person should be aged 65 and above receive long term municipal care either at home or in special accommodation. Those who only had safety alarms, meals-on-wheels or transport services were excluded.

About 1 200 000 people live in the region of Skåne and about 18 percent were 65 years or older in 2006. Approximately eight percent of these received municipal care at home and six percent received it in special accommodation in 2002. The municipalities in GAS were chosen as they reflect the situation in Sweden as a whole with regard to the urban/rural distribution and the number of older people receiving long-term municipal care and services. A drop-out analysis was performed in 2001 on baseline data and official statistics concerning the number of people receiving long-term care and services. The results showed that 39 percent of those receiving long-term municipal care according to official statistics were also included in the GAS study. The main reason for dropping out was that they had not been asked or had refused to participate. The drop out was not systematic concerning age or sex, however a larger number in the GAS study received care in special accommodations compared to the region of Skåne as a whole (46% vs. 40%). Hallberg *et al.* (2002) stated that this might be a reflection of selection bias and also that there is a risk of underestimating healthcare consumption in those included in GAS and overestimating it in those not included.

In Study IV, 35 people were consecutively randomly assigned into a control group (n=16) or an intervention group (n=19) (Figure 2) between October 2006 and May 2007. Inclusion criteria were that they should be aged 65 years and above, live in their ordinary home in the study municipality, have experienced at least two hospital stays, or four contacts with outpatient or primary care, during the last twelve months, need help with at least two activities of daily living such as shopping, cooking or cleaning, were able to communicate verbally and did not suffer from any severe cognitive impairments. Cognition was examined with the Mini Mental Test (Folstein *et al.* 1975) with a cut off level for participation set at 25 points out of a possible 30. The intervention and control group each had two sub groups, one receiving municipal care and services and one without such help.

Sixty-six people were initially assessed as eligible and asked whether they were willing to participate, 25 refused and 6 died before being randomised. The reasons stated for non-participation were being too tired, too ill or not interested. Another 16 people were initially considered to be eligible, but failed to match the inclusion criteria and were therefore not asked. Thus 35 people gave their written informed consent and were randomised through a classic randomisation procedure with sealed envelopes containing information about allocation. Two participants died and one declined to participate before the first follow up. At the time of this study there were 12 people in the control group and 16 in the intervention group who had completed the three-month follow up (Figure 1).

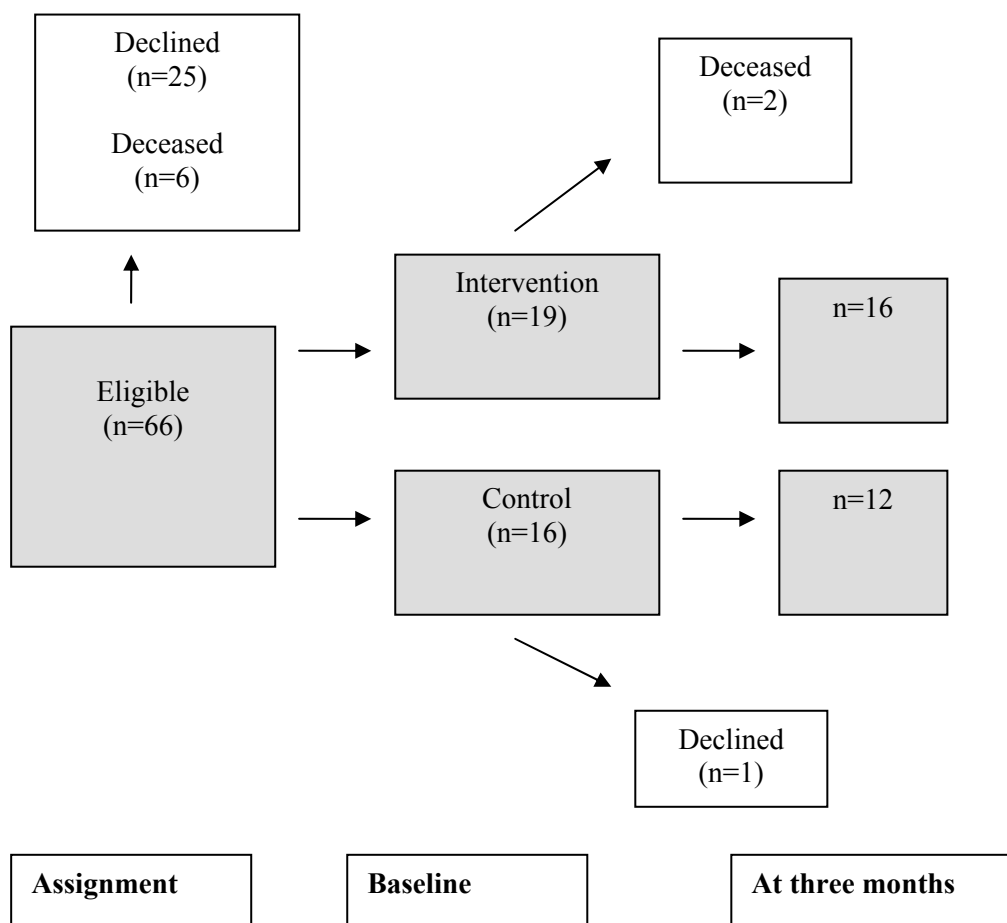


Figure 1: Sample and sample procedure in Study IV.

The sample for Study IV was recruited through referrals from nurses working in the municipality (n=2), through physician/nurse referrals from the primary-care centres (n=12) or by the case managers screening three university hospital clinics (n=20). It was also possible for potential participants to refer themselves (n=1) since information posters and brochures were placed in those setting. Potential participants recruited from hospital were informed about the study by the case managers whilst in primary care and municipal care the participants were briefly informed by staff and then asked if they would allow someone from the research group to contact them with more detailed information.

Study IV was performed in a municipality in southern Sweden and in collaboration with the primary care in the area, the municipality’s health and social care, and a nearby university hospital – which also served as the county hospital in the region. The municipality was of medium size according to Swedish standards and had approximately 30 000 inhabitants. It had one larger city with about 17 000 inhabitants, 11 smaller villages and also people living in the countryside. About 17 percent of the population were aged 65 and above. Of these, about 6% lived in special

accommodation and 8% received long-term care at home. There were three primary-care centres in the area; one in a village and two in the city. The municipality was considered a suitable place to hold the pilot trial since the municipality had also been part of the GAS study and was thus experienced in research. In addition the municipality used a case management model for people with psychiatric illness.

The case management intervention

The intervention in Study IV was initially planned and based on a review of the literature, the results in Studies I – III and experiences within the research group. A collaboration group was then established between the researchers and representatives of the healthcare agents involved. The group developed the intervention further, taking into consideration the specific views of the agents. The group met continuously during the intervention. Two nurses were employed part-time (50% each) as case managers. They were recruited from the university hospital and had several years experience in caring for older people in geriatric wards. They were also experienced in management and had specialised in geriatric nursing. They had also worked in a hospital-based geriatric care-coordination project. Before launching the intervention the case managers received one week’s training in case management in general, the intervention program, common diseases and pharmaceutical-related problems in older people, fall prevention, nutrition in older people and also the health system. The intervention program was launched when the participants were in their own homes, had been randomised and baseline measured. The case managers performed the intervention, which consisted of four parts (Figure 2):

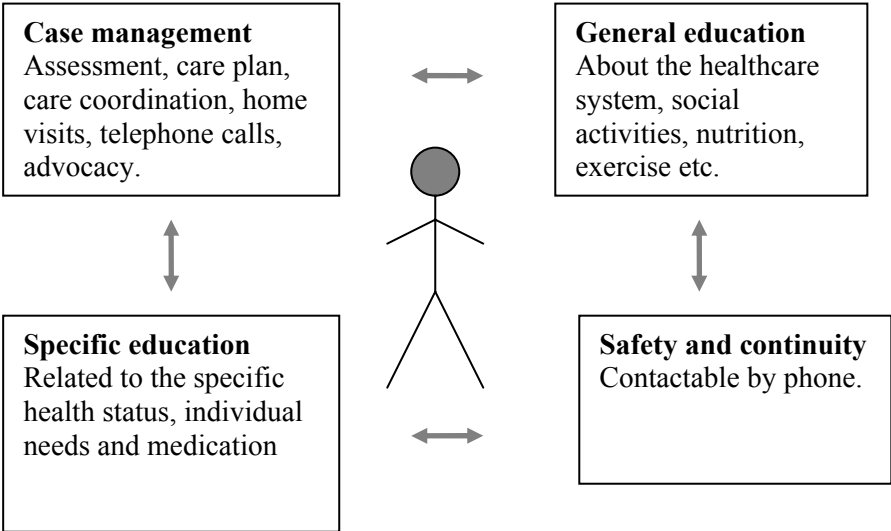


Figure 2: Dimensions of the case management intervention explored in Study IV

The first part concerned traditional case management tasks i.e. assessment, planning, monitoring, care coordination, supervision and evaluation. The case manager made an initial assessment and then one every month using the Mini Data Set for Home Care (MDS-HC), a comprehensive geriatric assessment questionnaire, to outline the interventions needed (Landi *et al.* 2000). A care plan was developed based on the assessment and conversations with the participants. The plan was monitored and followed up continuously. The case manager also made efforts to co-ordinate the participants care and to provide advocacy, in terms of helping the participant to establish contacts with caregivers, by guiding the participants towards an adequate level of care or acting as support in the contact with healthcare agencies This could mean, for example, helping the participant by contacting a physician in primary care or at the hospital to sort out a medical problem, establishing contact with home-help officers to arrange a needs assessment for home care, visiting the participants when they were admitted to the hospital, accompanying them to outpatient visits such as X-ray or vision tests or encouraging participation in various social activities. The case managers made home visits at least once a month but could visit more frequently if the participants needed. The case manager also had frequent telephone contact with the participants and, when needed, with their next of kin's. The mean number of home visits for the case managers was 3.4 during the first three months of the intervention. The case managers also participated in weekly meetings with staff at the primary-care centres and nurses in homecare.

The second part of the intervention contained general education for the participants about the health system and other aspects important to older people in general. This could include various social activities arranged by the municipality, what to eat and how to exercise. It could also include how the actual health system worked and where to turn to in different matters. The third part comprised specific education for the participants about individual based problems and needs. It could be about when to take a certain medicine, taking a walk when having pain or encouraging joining in social activities when feeling isolated. The case manager also made an inventory of the participant's medicines and informed them about their use and side effects. If any problems with medicines were detected, contact could be established with one of the physicians involved in the project. The control group were included in the pharmaceutical inventory and the possibility of establishing contact with a physician. The fourth part of the intervention included aspects of continuity and safety. The case manager was available during office hours if the participants had crisis.

The interventions were individual and based on the needs of the participants. The programme was implemented in a number of phases with the first months being very much about establishing the relationship and outlining needs. Thus the first part of the intervention was launched first followed, by the fourth part. The parts that were about education and information were launched in later stages. The case managers were supported by two primary-care physicians and one hospital-based geriatric specialist and were also part of the project group, collaborating closely with the researchers by telephone contact and attending meetings with the project group. The case managers

documented the interventions for each individual and also kept personal diaries for reflections about the intervention.

Data collection

The data for this thesis were collected through semi-structured interviews (Study I), registers (Study II – III), and a structured interview that was based on a questionnaire covering both single questions and standardised instruments (Study IV). Additional data were collected through interviews with the case managers (n=2) concerning two cases from the interventions. The cases are presented descriptively under the results section in this framework.

Study I

In Study I, 14 people were interviewed: Seven by the first author of the paper and seven by the third. The participants themselves chose the place for the interviews: five took place on a hospital ward and nine in the home environment. The interviews on a ward were carried out in conference rooms except once when the participant was unable to move outside. The interviews lasted in mean 49 minutes (range about 20 – 80), were inspired by Mishler (1986) and based on the view that interviews form a discourse between the participant and the interviewer. The interviews were semi-structured, which means that they were neither entirely structured nor entirely unstructured (Kvale 1996). A thematic interview guide was used. It started with an explanation of the study aim and a clarification of the participant's right to terminate the interview whenever he/she wished. The interview opened with the question: *Could you tell me how your health is at this moment?* The interview guide then covered questions about when the participant started to receive care and services, from whom they received them, how they experienced the care and services that they received, if they received the help they needed and their thoughts about the future (Appendix 1). The interviews were tape recorded and transcribed verbatim.

Studies II - III

The data used in Studies II and III were collected from files from three sources: data from the care and services part of the SNAC study (Lagergren *et al.* 2004) were merged with data from two registers about health care consumption and healthcare costs in the Region of Skåne. The PASiS register covered data from the county council and the PrivaStat register covered data from private agencies (Figure 3).

SNAC

In the care and services part of SNAC since 2001 a longitudinal database has been developed. Data were collected by the responsible staff (nurses, occupational therapists, home-help officers and physiotherapists) using a questionnaire when the person first entered the healthcare and social services system (i.e. received a decision

concerning municipal care and/or services provided for the first time) and then updated if the person's need of care and services changed or if they died. (Lagergren *et al.* 2004).

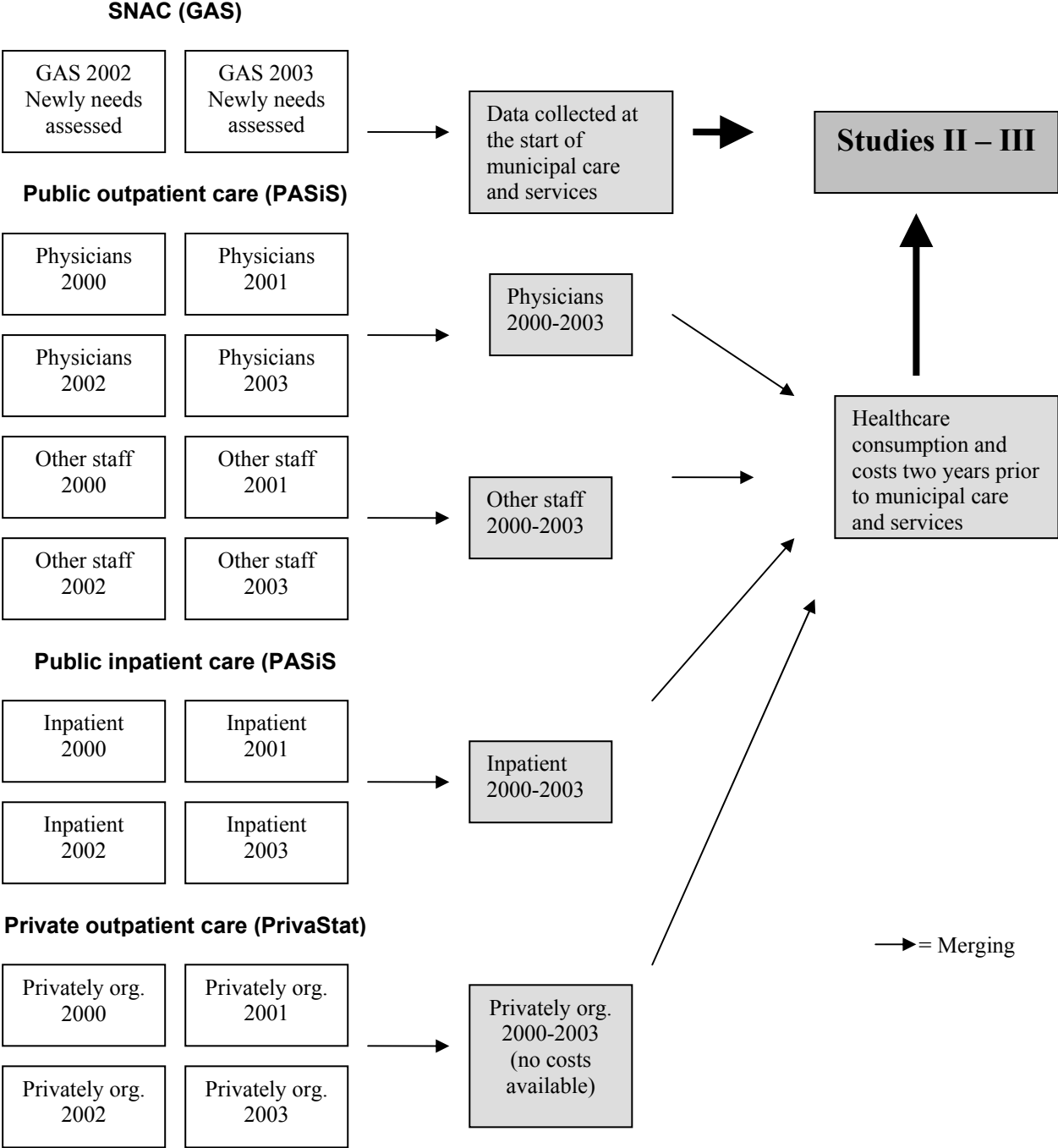


Figure 3: The files with registration year, collected from the registers PASiS, PrivaStat and SNAC, that were checked and merged, resulting in the data file used in Studies II-III.

The questionnaire covered six different areas: demographic data and living conditions, functional status and health complaints, ongoing municipal care and services, special care needs and informal care. The variables used in this thesis were sex, age, marital status, informal care and functional dependency.

Functional dependency was measured in Study III using the ADL staircase (Åsberg & Sonn 1989) which is an extended version of Katz's Activities of Daily Living (ADL) (Katz *et al.* 1963) The index assesses individual performance in six different areas: hygiene, dressing/undressing, ability to go to the toilet, mobility, bowel and bladder control and food intake, usually referred to as Personal Activities in Daily Living (PADL). The level of dependency is graded hierarchically. The ADL staircase also includes the variables cleaning, shopping, transportation and cooking, usually collectively referred to as Instrumental Activities in Daily Living (IADL), giving in all a ten-grade scale (Åsberg & Sonn 1989). A score of zero means independent in all functions, while a score of ten signifies dependence in all ten activities and one to nine dependence in one to nine activities.

In Study II functional dependency was assessed using an earlier developed index (Hallberg *et al.* 2002). This index was based on a factor analysis, including the variables in the ADL staircase (Åsberg & Sonn 1989) the Berger Scale (Berger 1980) and psychosocial variables. The index has three factors: (1) The SNAC-PSN index (psychosocial needs) which contains the variables: Anxiety, Depressed mood, Difficult behaviour, Anything that causes the person to be in need of special care and services or makes the delivery of care and services especially difficult, and/or Need for extra supervision. (2) The SNAC-IADL index (Instrumental Activities of Daily Living) which covers: Washing clothes, Shopping, Cooking, Bathing, Transportation, Cleaning and Going/Being outdoors. (3) The SNAC-PADL index (Personal Activities of Daily Living), which contains the variables: Transfer, Going to the toilet, Faecal continence, Eating, Urinary continence, Mobility, Dressing and Cognitive ability. The levels of dependency regarding IADL and PADL were described on an ordinal scale: No/minimal dependency, Slight dependency, Moderate dependency, Severe dependency and Complete dependency and the levels of psychosocial need were described in terms of: No needs, Minimal needs, Moderate needs, Substantial needs, Extensive needs.

Informal care was measured as the amount of help with the instrumental and personal activities of daily living that the person received from anyone other than the county councils and municipalities.

Healthcare consumption registers

The county council in the region of Skåne has two patient administration systems, PASiS for publicly organised inpatient and outpatient care and PrivaStat for privately organised outpatient care. The systems are similar in structure. In the systems, individually based data about all consumption of publicly organised in- and out-patient care and privately organised outpatient care in the region are registered. Variables in

the systems include contact date, length of stay (LOS) in hospital, acute or planned contact, responsible staff group (physicians, nurses, physiotherapists, occupational therapists, speech therapists, opticians, laboratory staff etc), medical specialty in which the contact occurred and diagnoses. The medical specialties are divided into four groups: somatic care (i.e. specialists outside primary care), psychiatric care, primary care and medical services (i.e. contacts with X-ray units, laboratories, clinical physiology etc.). A registered outpatient contact could be either a visit (face to face) or some other form of contact, e.g. by telephone or mail. A hospital stay has one date for admission and one date for discharge. An individual could have several registrations for one period in hospital due to changing clinic during the in-hospital period. The diagnosis was registered following WHO's ICD-10 (WHO 2007b). The system has 21 chapters representing different organ systems and categories of diseases and is divided into sections of similar diseases. The sections are divided into subcategories that refer to specific stages, conditions or symptoms of the disease. The subcategories are classified using ICD-10 codes (WHO 2007b).

The healthcare costs are calculated in a variety of ways in PASiS. Costs for inpatient care are calculated per clinic/unit mainly by using the international classification system of Diagnosis Related Groups (DRG) (National Board of Health and Welfare 2005) The DRG system is based on the system of the specific hospital for diagnosis classification and provides the individual inpatient contact with a specific DRG group. The various DRG groups are calculated by using information about main and sub-diagnose, sex, age, discharge terms and treatments. Each DRG group is then assigned a specific price. For those clinics which did not use the DRG system, the total cost for the clinic/unit was divided into cost/bed day. The costs for outpatient care were calculated using templates, based on the total costs of the clinics/units and are based on different types of healthcare contacts. Each type of contact is specifically weighted: physician's visits (weight 1.0), day surgery (weight 3.0), day physician healthcare (weight 2.0), team visit physician (weight 1.4), medical treatment (weight 0.4), day healthcare other caregivers (weight 1.4) and team visits other caregivers (weight 0.8) (Region Skåne 2005).

Variables used in Study II were number of acute and planned contacts in inpatient and outpatient care, bed days in hospital, registered diagnosis, specialty responsible for the contact, staff groups contacted and contact date. Contacts with specialist medical services were excluded due to the small number of such contacts. The number of contacts in publicly and privately organised outpatient care was added together due to the low number of private outpatient contacts. The number of hospital stays was processed so that each period represented an admission to, and a discharge from, hospital regardless of which clinic provided care. Variables used in Study III were costs for planned and acute inpatient and outpatient care, medical specialty, responsible staff groups and primary diagnosis groups. The costs were converted from Swedish currency (SEK) into Euros (EUR) using the mean exchange rate value of the Euro for the years 2000 – 2003.

Study IV

In Study IV data was collected from personal interviews using a structured interview protocol covering both single questions and instruments (Appendix II). The questionnaire used in the interview was developed by the research group and covered both single questions and instruments. It consisted of five dimensions: Background data, Social aspects, Health status, Health-related quality of life and life satisfaction and Care and services (Table 2). Data were collected at baseline and then ongoing approximately every third months parallel with the intervention. The first follow up was delayed in some cases (n=11). In four cases it took place four months, in two cases approximately five months, in one case six months and in two cases close to eight months after the baseline measurement. The delay was mostly due to participants being too ill, admitted to hospital or receiving short-term care in special accommodation. In some cases the participant did not have time to meet the researchers (n=3). Three researchers collected the data independently of the intervention. The interview took approximately one hour to complete.

Table 2: Measures and instruments used in the questionnaire in Study IV.

Dimension	Measures and instruments	References
A: Background	<i>Age, gender, marital status</i> <i>Educational level, financial status</i>	
B: Social aspects	<i>Social support</i> <i>Social participation</i> <i>Feelings of loneliness</i>	Lindström <i>et al.</i> (2003) Ekwall <i>et al.</i> (2005)
B: Health status	<i>ADL staircase</i> <i>Self reported diseases</i> <i>Health complaints</i> <i>Geriatric depression scale-20</i> <i>Downton Fall Index</i> <i>Mini Mental State Examination</i> <i>Mini Nutritional Assessment</i>	Åsberg & Sonn (1989) WHO (2007) Stenzelius <i>et al.</i> (2005) Gottfries <i>et al.</i> (1997) Rosendahl <i>et al.</i> (2003) Folstein <i>et al.</i> (1975) Vellas <i>et al.</i> (2006)
C: HQOL and life satisfaction	<i>Life satisfaction index Z</i> <i>EQ-5D</i>	Fagerström <i>et al.</i> (2007) Brooks (1996)
D: Healthcare and social services ¹	<i>Municipal care</i> <i>Informal care</i> <i>Knowledge about pharmaceuticals</i> <i>Beliefs about prescribed medicines</i> <i>Quality from the patients perspective</i>	Hallberg <i>et al.</i> (2002) Hallberg <i>et al.</i> (2002) Horne & Weinman (1998) Wilde Larsson & Larsson (2002)

1: Data about health and medical care will be collected by means of registers.

Background data

Background data were assessed by means of questions about age, sex, marital status, living conditions, educational level and financial status. Financial status was assessed through questions about how well money covered needs, financial status compared

with others and whether the participant could manage to get access to SEK 8 000 (EUR 1 100) within a week if there was an emergency.

Social aspects

Social aspects were investigated by means of questions about feelings of loneliness, participation in social activities and social support. Feelings of loneliness were assessed through four questions: Do you feel lonely now a days? How often have you experienced feelings of loneliness during the last three months? Do you believe that you are lonelier than others of your age? When you feel lonely, how strong is the feeling? The questions had ordinal response alternatives (Ekwall *et al.* 2005). Social participation was investigated using an index containing 13 items representing different social activities (for instance attending a private party or an art exhibition) (Lindström *et al.* 2003) Social support was assessed through a question about how many people the participants felt they could trust and rely on, how they kept in touch and if the participant was satisfied with that contact.

Health status

Health status was investigated through functional and cognitive status, self-reported diseases, health complaints, risk of falling, nutritional status, symptoms of depression and knowledge about pharmaceuticals used and attitude towards them. Attitudes towards pharmaceuticals were assessed using the instrument Beliefs about Prescribed Medicines Questionnaire (BMQ) (Horne & Weinman 1998). Functional status was investigated with the ADL staircase (Åsberg & Sonn 1989) and cognitive status using the Mini Mental Test (Folstein *et al.* 1975) covering six areas of cognition, giving a total score of 30 (higher score indicate a higher cognitive function).

Depression symptoms were investigated using the Swedish version of the Geriatric Depression Scale - 20. This instrument contains 20 questions about symptoms related to depression among older people with the response alternatives Yes/No. The score ranges from 0-20 with a cut off point at six or above indicating a risk of depression (Gottfries *et al.* 1997).

The presence of diseases was investigated by means of self reported diseases suffered during the last three months, dichotomised as Yes/No. The answers were assigned to the different diagnosis groups in the WHO International classification of diseases (ICD-10) (WHO, 2007a). Health complaints were assessed through 30 questions, initially used by Tibblin *et al.* (1990) and further developed by Stenzelius *et al.* (2005) covering common health problems among older people with a four-grade response scale varying from no complaints to much complaint.

The risk of falling was assessed using the Downton Fall Index investigating eleven items related to fall risk. The score ranges from 0-11 with a score off three points or more indicating a high risk of falling (Rosendahl *et al.* 2003). This instrument has been psychometrically evaluated (Rosendahl *et al.* 2003)

Health-related quality of life and life satisfaction

Health-related quality of life (HRQL) was measured using EQ-5D (Brooks 1996). This instrument has five questions covering five dimensions: mobility, hygiene, daily activities, pain/complaints and depression. In addition EQ-5D contains a visual analogue scale (EQ-VAS) from 0-100 on which the person scores his/hers current health status, where 0 represents worst imaginable health and 100 best imaginable health (Brooks 1996). Life satisfaction was investigated using the Life Satisfaction Index Z (LSIZ) (Fagerström *et al.* 2007) a shortened version of Neugarten's Life Satisfaction Index (LSIA) (Neugarten *et al.* 1961) containing 13 statements with which the participant can agree, disagree or not know about. The results are then summed into an index scoring from 0-26, in which higher scores indicate more satisfaction with life. Nutritional status was assessed using the Mini Nutritional Assessment tool (Vellas *et al.* 2006).

Healthcare and social services

Care and services were investigated through questions about formal and informal care and the perceived quality of care. Formal care was investigated by the numbers and length in hours of home visits from different municipal care and/or services professionals, the use of prescribed technical aids and also by the use of special care needs such as injections and dialysis. Informal care was measured by the amount of help received from relatives or friends regarding instrumental or personal activities of daily living. The questionnaire also contained questions about whether the participant was an informal caregiver him/herself and what informal caregiving that they provided. The perceived quality of care was investigated using a short form of the Quality from the Patient's Perspective questionnaire (QPP) (Wilde Larsson & Larsson 2002) containing questions about the care received from physicians, district nurses, home-help staff and informal caregivers. The instrument covers five dimensions concerning whether the participants took part in planning the care, had any influence over decisions had influence over the care performed, received information and whether they received the help they needed from the different caregivers, The responses were given on an ordinal scale varying from very much to not at all and presented on item level. (Wilde Larsson & Larsson 2002) (Table 2).

Questions covering demographics were asked at baseline. Those about life satisfaction and cognitive status were asked at baseline and after six and twelve months. The other questions were asked at all follow ups.

Data Analysis

Qualitative analysis

The text derived from the interviews and underpinning the results presented in Study I was analysed using content analysis influenced by Berg (2004). According to Berg content analysis may cover both latent and manifest levels and the levels can be combined with each other during the analysis process. The latent level of the analysis comprises an interpretable dimension in which the researcher seeks deeper structural meanings in the text. The manifest level concerns the surface of the text, focusing on the more visible and obvious parts. The analysis was inspired by Graneheim and Lundman (2004) and was performed stepwise. In the first step the transcribed interviews and the text as a whole were read repeatedly. All three authors of the paper did the reading independently and then met and discussed their impressions of it. Secondly, meaning units were identified from the text. These were those parts of the text that related to the aim of the study. The third step included condensing the meaning units into codes. The codes could be single words or shorter phrases. The first author of the paper then analysed the meaning units and codes for the whole text. The second and third authors coded specific parts of the text. All three authors met several times to discuss the codes. The fourth step focused more on interpretation and contained movement between the whole text and the codes in order to identify different or similar structures and patterns in the text. During this process categories were identified and later in the process some of these categories were transformed into sub-categories in relation to the categories. All three authors participated in the process of developing categories and sub-categories. In the last phase of the analysis the categories and sub-categories were carefully read by all three authors and a main category was identified. Eleven of the transcribed interviews were included in this part of the analysis. After analysing the text from eleven of the interviews there was a consensus among the authors that saturation had been reached in terms of no new categories emerging that accorded with the aim and had not already appeared in the available text. To confirm the developed structure, the remaining three interviews were analysed and compared with the preliminary results, but produced no change in the structure.

Statistical analysis

The data were analysed using both descriptive and analytical statistics (Studies II – IV). A p-value of 0.05 was set overall to be the upper limit for statistical significance (Altman 1991).

Both parametric and non-parametric methods were used. The χ^2 test was used to compare data on the nominal level (Study II - IV). The Mann Whitney *U*-test was used to compare ordinal data between two groups in Studies II – IV and also when comparing ratio data in Studies II and IV when data was suspected to be skewed or due to small sample sizes. Analysis of Variance (ANOVA) was used to compare ratio data among three groups in Study III and in the framework. When making multiple comparisons, a reduced p-value according to the Bonferroni method was used to

control for type 1 error in the post hoc analysis (Bland & Altman 1995). Wilcoxon's signed rank test was used for comparisons within groups in Study IV (Altman 1991) and internal consistency was tested with Cronbach's alpha in Study IV (Cronbach 1951).

In studies II and III comparisons were made between men and women and in Study III and the framework comparisons were also made between the age groups 65 – 74, 75 – 84 and 85+. In Study IV comparisons were made between intervention group and control group regarding baseline data and between and within groups regarding data from first follow up.

Multiple linear stepwise regression analysis (Altman 1991) were performed to explain the variance in hospital stays, outpatient physician visits (Study II) and total healthcare costs (Study III). The costs were transformed by taking the normal logarithmic so that it followed better the normal distribution (Study III). The following were entered as independent variables: Age; Sex; Marital status; Informal care and the six most common primary inpatient diagnosis groups i.e. Neoplasms, Diseases of the circulatory system, Symptoms, signs and abnormal findings not classified elsewhere, Diseases of the musculoskeletal system, Diseases of the genitourinary system and Injury, poisoning and certain other consequences of external causes. Marital status was coded as a dummy variable with married as a reference. Informal care and the different diagnosis groups were dichotomised as Yes/ No. The Variation Inflation Factor (VIF) and Tolerance were used to test possible multicollinearity, but did not show any high intercorrelations between independent variables in the model (Studies II-III). The residuals were tested visually with histograms and showed an approximately normal distribution (Study II).

In Study III a hierarchical cluster analysis using Ward's method (squared Euclidean distances) (Hair *et al.* 1998) was performed in the total sample and was based on total healthcare costs. Two groups emerged containing 48 and 246 people respectively and they were then used in further analysis. The data were analysed using the software program SPSS 11.0 and 14.0

ETHICAL CONSIDERATIONS

The work in this thesis was performed in accordance with the Swedish law concerning ethical approval for research on humans (Ministry of Education and Research 2003) and the Swedish Data Protection Act (Department of Justice 1998) and followed the ethical principles of autonomy, non-maleficence, beneficence and justice (Beauchamp & Childress 2001).

Autonomy refers to the participant's right to make knowledge-based decisions regarding participation which comprises aspects of informed consent and the possibility to refuse to participate or to withdraw from a study (Beauchamp & Childress 2001). Informed consent was obtained in all four studies and the participants received verbal and written information. In Study I the participants were informed about the study and asked if they wanted to participate on at least two occasions (first when asked about participation and then again before the interview started). The participants themselves chose the venue for the interview and it was emphasised that they could withdraw from the study and terminate the interview at any time without incurring any consequences. In Studies II and III information was provided and written, informed consent was obtained by the data-collecting staff and in those cases where the participant was unable to give his/her consent due to cognitive impairment it was given by their next of kin. In Study IV information was given to eligible participants prior to randomisation and then again before the baseline measure. Written, informed consent was obtained and it was emphasised repeatedly that the participants could withdraw without explanation at any time during the study.

The principles of non-maleficence and beneficence refers to aspects related to the utility of the research or the risks of doing harm (Beauchamp & Childress 2001). Confidentiality was guaranteed by research data being stored separately from personal data. In Studies II and III the participants were assigned coded numbers and thus it was not possible for the researcher to trace back information to any specific individual in the files that were merged. Concerning utility, it was also important to consider that by merging the different registers unique information was obtained.

Data were collected in Studies I and IV during a personal interview and it was taken into consideration that it might be demanding to be interviewed about sensitive topics. Some of the participants were tired or severely ill. The researcher was, therefore, alert during the interview to signals that the participant might be too tired or became sad. This sometimes happened and in those cases the participants were asked if they wanted to terminate the interview and a pause was taken if needed. Performing a randomised controlled trial, like in Study IV, involves one group receiving an intervention whilst the other one does not. Possible benefits to accrue from the intervention were that the participants got access to a person who carried out an individually based intervention. There were also risks that the researchers would discover problems in the control group during the data collection. The participants in the control group had contacts with the health system and if any problem was detected by the researchers in the intervention group the case managers were alerted. In

addition three physicians were involved in the project as consultants and they were also alerted if any problems were found in the control group. This safeguard was, however, not needed. Both groups had a pharmaceutical inventory made by the researcher and if any problems were detected a physician could be contacted regardless of the group in which the participant belonged. There is at this moment no evidence regarding the effects of the intervention. It was, however, decided that the control group will be offered the interventions if it is found to be efficient in the future.

The principle of justice refers to aspects of sampling and that the sampling procedure is performed with fairness (Beauchamp & Childress 2001). This includes aspects of discrimination against certain groups but also to protecting vulnerable groups from being exposed. Participants were selected regardless of age, sex, religion, political belief etc. In Study IV all participants had an equal chance of being randomised in to either the control or intervention group, since the randomisation was done using sealed envelopes. Thus the work in this thesis was performed according to ethical principles and Swedish law.

The Ethics Committee at Lund University approved the studies (nr LU 744-00; LU 650-00 and no 342/2006).

FINDINGS

Experiences of receiving healthcare and/or social services

The experience of receiving healthcare and/or social services in old age (Study I) was represented in the main category “*Having power or being powerless*”. The main category comprised three categories *Autonomous or without control in relation to the healthcare and/or social services system*, *Being confirmed or violated in relation to caregivers* and *Paradoxes in healthcare or social services*. Each category comprised different subcategories representing aspects of having power or being powerless. However, the categories were also interpreted as extra-, inter- and intra-personal aspects of having power or being powerless (Figure 4) and the results from Study I will be further presented under these subheadings

Having power or being powerless

The text revealed situations marked by aspects of both having power and being powerless. The two could occur simultaneously and in the same situation or separately, either having power or being powerless, in a specific situation. The situations could be either single events or, more comprehensively, their current life situation. Having power or being powerless was found in the relationship with the health system, with staff and also in processes within the person (Figure 4). These perspectives seemingly interacted with each other. This was seen for instance when help was needed with the laundry. The one in need realised that ironing and mangling were not included in the municipal services. This caused conflict with the home help-staff and also started a process on an intrapersonal level.

“...with the washing, for example, they can help to do the washing ...//... but they don't mangle and they don't iron...//... It's, it's really a waste of time, they say, it's not necessary...//... I say I've never laid down on a sheet that hasn't been mangled, but now I just have to. Now I sit and iron them by hand, the sheets and stuff because I can't stand downstairs and mangle...//... And they're not allowed to mangle so there's nothing to be done, so it's difficulty twice over.” (12)

Extrapersonal power or powerlessness

Having power or being powerless from an extrapersonal perspective was interpreted as relating to aspects divorced from interpersonal encounters or intrapersonal processes but with the interactions of the individual with aspects related to the health system as an organisation. This was revealed in the main category *Autonomous or without control in relation to the healthcare and/or social services system* (Study I). The system was viewed both as resource and a source of security providing care and services to those in need but also as a complicated bureaucracy that makes decisions without any insight for the individual. Having power in relation to the system was visible in the subcategories

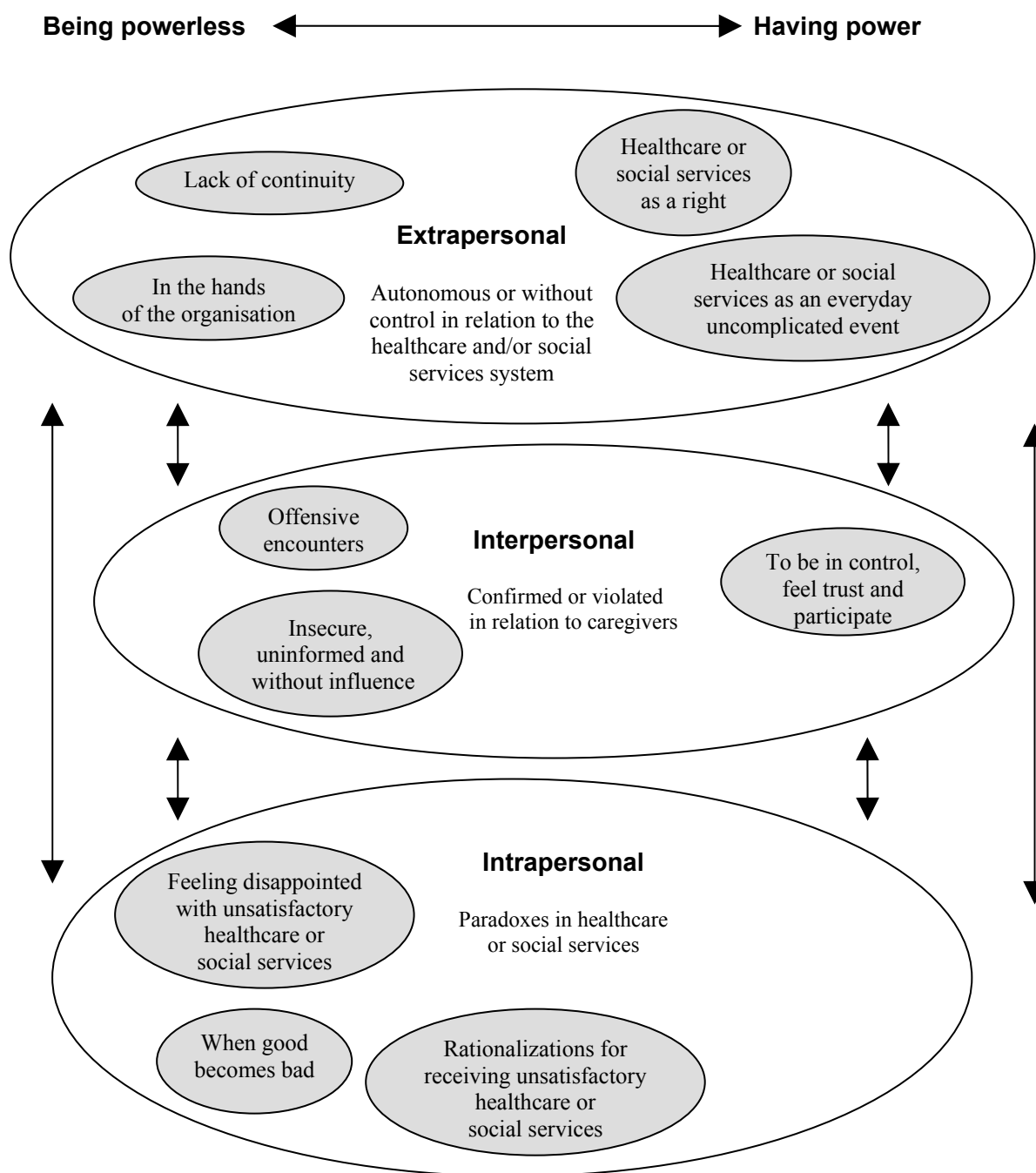


Figure 4: The experience of receiving healthcare and/ or social services in terms of main category, categories and subcategories.

Healthcare or social services as an everyday uncomplicated event and *Healthcare or Social services as a right*. The former included aspects of care and services that were routine and did not contribute to any problems, such as receiving homecare that focused on instrumental activities in daily living. The latter subcategory *Healthcare or Social services as a right* was marked by the awareness of one's right to receive care and services and that this right could be insisted on but also had to be fought for. Being powerless was characterised in the subcategories *In the hands of the organisation* and *Lack of continuity*. Being in the hands of the organisation was revealed for instance in situations when the person knew that he/she was going to move to special accommodation but did not know where or when. Lack of continuity was obvious in situations when care and services were given by several different people.

Interpersonal power or powerlessness

The interpersonal perspective of power or powerlessness was revealed in aspects related to the encounter. Having power in relation to caregivers was shown in being known to the caregiver, experiencing trust influenced the encounters. This was revealed in the subcategories *To be in control, to feel trust and to participate*. Being powerless on the other hand was characterised by the opposite and was also made visible in the experience of *offensive encounters* or feelings of being *insecure, uninformed and without influence*

Intrapersonal power or powerlessness

The intrapersonal perspective of having power or being powerless was interpreted as processes occurring within the individual and personal strategies for handling demanding situations. Powerlessness was revealed *when feeling disappointed with unsatisfactory healthcare or social services* and also *when good became bad*. The latter was mainly concerned with experiencing severe side effects from drugs or when decisions or encounters that started with good intentions resulted in the opposite. This was seen for instance when someone was living in a small apartment and liked playing the piano but also sometimes needed to use an electric wheelchair. The only place to park the wheelchair was in front of the piano, making it impossible to play. Having power was shown in the subcategory *Rationalisation for receiving unsatisfactory healthcare or social services*. This comprised attempts to rationalize and trying to make sense of various aspects of the organisation. Sometimes this was done through expressing solidarity with the staff by blaming their work situation and excusing their actions. Problems associated with organisational aspects was rationalised as being due to politics or poor financing. Rationalisation was also seen on attempt to explain to oneself why the care or services were poor by blaming oneself for being too demanding or simply not worth anything better. Thus the subcategory could also reveal powerlessness. Feeling disappointed, rationalising bad circumstances and also feeling that well-intended actions etc. could turn out badly were interpreted as paradoxical and thus formed the sub-category *Paradoxes in healthcare or social services* (Study I).

Healthcare consumption and costs in men and women

In studies II and III and in the framework comparisons were made between men and women with regard to healthcare use and costs. The men (n=115 mean age 80.7) had significantly (P=0.025) more bed days in hospital (14 vs. 4) than the women (n=247 mean age 83.7) during the two years investigated. The men also had more (P=0.002) visits to physicians (median 6 vs. 5) and other staff groups (median 1 vs. 0) in specialist care and also more (P<0.001) visits in total with other staff groups in outpatient care (median 9 vs. 3). The men, in addition, had more (P<0.001) total contacts (visits and other contacts) with other outpatient staff groups (median 10 vs. 5) (Study II).

The total costs for public healthcare were EUR 1 471 000 (median 9000) for the men and 1 839 000 (median 3 700) for the women during the two years (P <0.001). The costs for acute and planned hospital stays were EUR 1 093 000 for the men and EUR 1 363 000 for the women (P<0.001) (Study III).

With regard to costs for the entire two-year period (only in the framework) the men had significantly higher costs for acute inpatient care (median EUR 4 100 vs. 700), physician visits (1 200 vs 800), other staff group visits (500 vs. 100) and for total healthcare (9 000 vs. 3 700) compared with the women (Table 2).

Table 2: Healthcare costs in men and women during the two years prior to municipal care

Sex	Women (n=247)			Men (n=115)			P-value ^a
	md	(q1 – q3)	range	md	(q1 – q3)	range	
Hospital stays							
Acute	700	(0-6 000)	0-50 300	4 100	(0-8 700)	0-72 000	0.016
Planned	0	(0-0)	0-24 000	0	(0-4 300)	0-40 000	0.007
Outpatient care							
Physicians	800	(200-1 700)	0-10 400	1200	(400-2 500)	0-19 600	0.005
Other staff groups	100	(0-500)	0-37 300	500	(0-1 500)	0-19 900	0.047
Total	3 700	(600-11 000)	0-63 200	9 000	(3 400-18 800)	0-87 200	<0.001

^a Student's t-test; md= median

A cost analysis was also made for two separate periods. During the period 12 – 0 months prior to the provision of long-term municipal care and services the men had higher ($P=0.046$) costs for acute hospital stays (median EUR 3 300 vs. 0) and total ($P=0.003$) hospital stays (median EUR 4 700 vs. 700) than the women. In addition the men had a higher ($P<0.001$) cost for total visits to outpatient physicians compared with the women (median EUR 700 vs. 400) (Study III).

During the two years 45% of the total sample had a cost that varied between EUR 400 – 12 000 for inpatient care whilst 20% had a cost above EUR 12 000 (Figure 5a). Seventy two percent had a cost of EUR 100 – 3 000 whilst 12% had costs exceeding this for visits to outpatient physicians (Figure 5b). Sixty-five percent had a cost for visits to other outpatient staff groups that varied between EUR 50 and 3 000 whilst 7% had a cost above EUR 3 000 (Figure 5c).

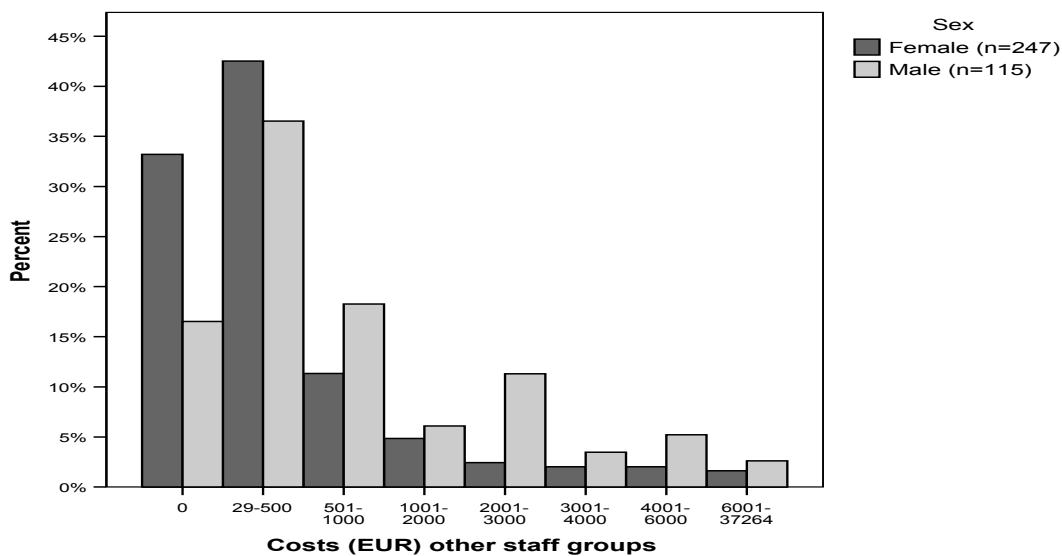
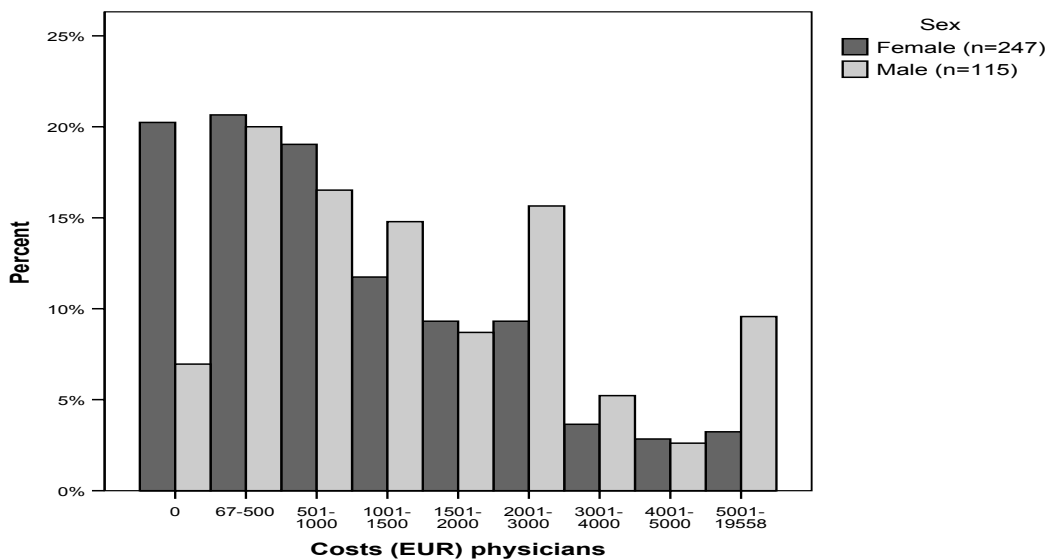
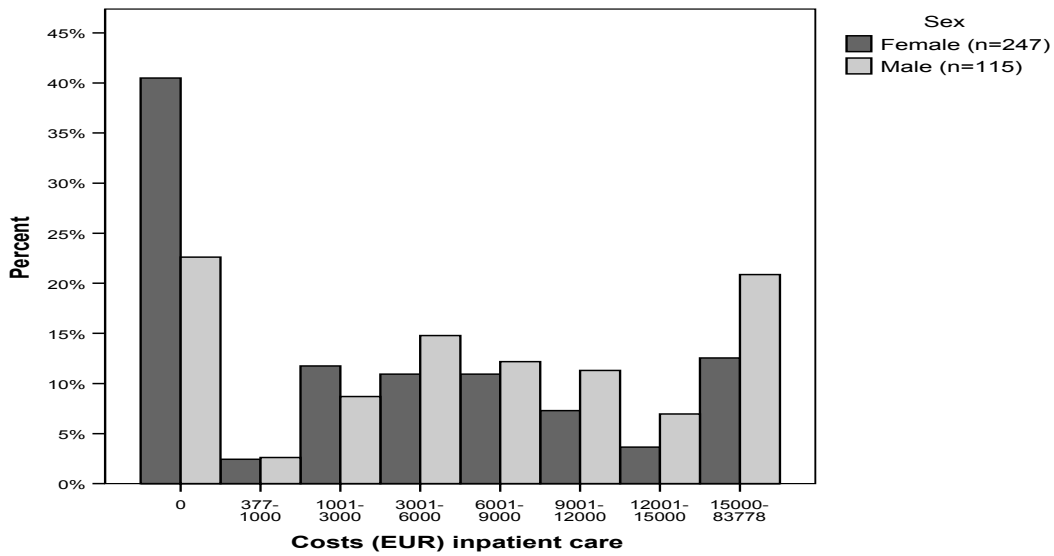


Figure 5a – c: Costs (EUR) for inpatient care (5a) and visits to physicians (5b) and other staff groups (5c) in outpatient care in men and women two years prior to the introduction of municipal care and services.

Healthcare consumption and cost in relation to age

With regard to healthcare contacts during the two years investigated as a whole (framework) (Table 3), the age group 65 – 74 had significantly more (median 11) total contacts (visits and other contacts) with other outpatient staff groups compared with those 75 – 84 (median 6). Those aged 75 – 85 had significantly more visits (median 6) to physicians in specialised outpatient care compared with those aged 85+ (median 4), more total contacts with other outpatient staff groups (median 6) than those aged 85+ (median 4) and more visits to physicians in primary care than those aged 65 – 74 (median 4 vs. 2) (Table 3). Those aged 85+ had more visits to physicians in primary care than those aged 65 – 74 (median 4 vs. 2) (Table 3).

With regard to healthcare costs during the two years investigated as a whole (only in the framework), the age group 85+ had significantly lower costs for visits to outpatient physicians (median EUR 700) than those aged 75 – 85 (median 1000) and those aged 65 – 74 (median 900) (Table 4). Those aged 75 – 84 (median EUR 1000) had significantly higher costs than those aged 65 – 74 (median EUR 900) for visits to physicians. Those aged 65 – 74 had significantly higher costs (median EUR 600) for visits with other staff groups compared with those aged 75 – 85 (median 200) and those aged 85+ (median 100) (Table 4)

Cost analyses were also made for two separate periods (Study III): the three age groups all had median costs of zero in all investigated variables for the period 24 – 13 months prior the provision of long-term municipal care with the exception of costs for visits to physicians in specialised outpatient care. For this variable the age group 75 – 85 had significantly ($P=0.014$) higher median costs (EUR 100) than those aged 65 – 74 (EUR 0) (Study III)

During 12-0 months prior to the introduction of long-term municipal care the age group 65 – 74 had significantly ($P=0.006$) higher costs for visits to physicians in specialised outpatient care (median EUR 400) than those aged 85 + (Median EUR 0). The youngest age group also had higher ($P=0.001$) total costs for outpatient physician visits (median EUR 600) compared to those aged 75 – 84+ (median EUR 500) as well as higher ($P< 0.001$) total costs (median EUR 100) for visits to other outpatient staff groups compared to the other age groups, which both had a median cost of EUR 0 (Study III).

Table 3: Healthcare consumption in three age groups the two years prior to the provision of long-term municipal care and services.

Age groups	65 – 74 (n= 53)			75 – 84 (n= 150)			85+ (n=159)			P-value ^a	Post hoc
	md	(q1 – q3)	range	md	(q1 – q3)	range	md	(q1 – q3)	range		
Hospital stays											
Acute	1	(0 – 2)	0 – 9	1	(0 – 2)	0 – 6	1	(0 – 2)	0 – 7	0.647	
Planned	0	(0 – 1)	0 – 5	0	(0 – 1)	0 – 5	0	(0 – 0)	0 – 3	0.003	A,C
Total	1	(0 – 2)	0 – 11	1	(0 – 2)	0 – 8	1	(0 – 2)	0 – 8	0.123	
Bed days	7	(0 – 21)	0 – 111	8	(0 – 20)	0 – 195	6	(0 – 20)	0 – 83	0.201	
Visits, outpatient care											
Somatic care											
Physicians	6	(1 – 13)	0 – 33	6	(2 – 11)	0 – 41	4	(1 – 8)	0 – 29	0.016	C
Other staff groups	1	(0 – 12)	0 – 77	1	(0 – 4)	0 – 211	1	(0 – 4)	0 – 67	0.049	B
Psychiatric care											
Physicians	0	(0 – 0)	0 – 118	0	(0 – 0)	0 – 17	0	(0 – 0)	0 – 1	0.013	A,B
Other staff groups	0	(0 – 0)	0 – 100	0	(0 – 0)	0 – 3	0	(0 – 0)	0 – 1	<0.001	A,B
Primary care											
Physicians	2	(0 – 5)	0 – 13	4	(2 – 7)	0 – 26	4	(1 – 7)	0 – 54	0.012	A,B
Other staff groups	2	(0 – 12)	0 – 44	2	(0 – 7)	0 – 137	1	(0 – 4)	0 – 47	0.019	C
Total visits											
Physicians	10	(4 – 21)	0 – 125	12	(6 – 19)	0 – 46	9	(4 – 16)	0 – 78	0.109	
Other staff groups	9	(0 – 31)	0 – 100	5	(1 – 18)	0 – 211	3	(0 – 10)	0 – 76	<0.001	A,C
Other contacts											
Physicians	2	(0 – 7)	0 – 69	3	(0 – 6)	0 – 45	2	(0 – 5)	0 – 24	0.524	
Other staff groups	0	(0 – 4)	0 – 21	1	(0 – 3)	0 – 20	0	(0 – 2)	0 – 15	0.002	A,C
Total											
Physicians	15	(5 – 25)	0 – 129	16	(8 – 24)	0 – 61	14	(7 – 21)	0 – 79	0.082	
Other staff groups	11	(0 – 44)	0 – 108	6	(2 – 20)	0 – 230	4	(1 – 12)	0 – 77	<0.001	A,C

^a) Analysis of variance (ANOVA); Significant differences between age groups: A= 65–74 vs 75–84; B= 65–74 vs 85+; C= 75–84 vs 85+; md= median

Table 4: Healthcare costs in three age groups during the two years prior to the provision of long-term municipal care and services

Age groups	65 – 74 (n= 53)		75 – 84 (n= 150)		85+ (n=159)		P-value ^a	Post hoc			
	md	(q1 – q3) range	md	(q1 – q3) range	md	(q1 – q3) range					
Hospital stays											
Acute	1 200	(0-6 000)	0-71 900	2 200	(0-8 000)	0-39 000	2 200	(0-6 400)	0-50 300	0.892	
Planned	0	(0-6 500)	0-24 400	0	(0-3 400)	0-40 000	0	(0-0)	0-18 300	0.006	A,C
Outpatient care											
Physicians	900	(100-2 500)	0-13 200	1 000	(400-2 200)	0-19 600	700	(200-1 600)	0-6 300	0.006	A,C
Other staff groups	600	(0-2 700)	0-19 900	200	(0-800)	0-37 200	100	(0-400)	0-8 000	<0.001	A,B
Total	7 900	(900-18 600)	0-87 200	7 100	(1 000-15 400)	0-63 100	4 300	(900-10 900)	0-63 200	0.007	A,B

^{a)} Analysis of variance (ANOVA); Significant differences between age groups: A= 65–74 vs 75–84; B= 65–74 vs 85+; C= 75–84 vs 85+; md= median

Factors influencing healthcare consumption and costs

Increased number of hospitalisations, visits to outpatient physicians (Study II) and total costs for public healthcare (Study III) were mainly associated with medical diagnosis (Table 5). Circulatory diseases were associated with more acute inpatient care ($\beta=1.15$), planned inpatient care ($\beta=0.45$), visits to outpatient physicians ($\beta=4.36$) and higher costs ($\beta=2.12$). Cancer were associated with more acute ($\beta=0.84$) and planned ($\beta=0.98$) admissions to hospital, visits to physician ($\beta=9.83$) and higher costs ($\beta=2.45$). Musculoskeletal diseases were associated with more planned ($\beta=0.84$) and acute ($\beta=0.72$) inpatient care and also with greater healthcare costs ($\beta=2.15$). External causes (mainly injuries) were associated with more visits to outpatient physician ($\beta=5.66$) and also more acute admissions to hospital ($\beta=1.21$) and greater costs ($\beta=2.15$). Genitourinary diseases were associated with greater costs ($\beta=1.35$) and acute ($\beta=1.06$) and planned ($\beta=0.65$) inpatient care and also visits to outpatient physicians ($\beta=7.06$). Symptoms and clinical findings not classified elsewhere in the ICD10 were associated with more acute inpatient care ($\beta=1.42$), more visits to physicians in outpatient care ($\beta=6.39$) and greater costs ($\beta=1.65$). Being unmarried was associated with more acute inpatient care ($\beta=0.56$). Age was associated with fewer planned hospital admissions ($\beta=-0.01$) and being a woman was associated with fewer visits to outpatient physician visits ($\beta=-2.83$). Being a widow/er was associated with lower healthcare costs ($\beta=-1.06$). Receiving informal care was not associated with any of the variables investigated (Study II-III).

Table 5. Significant ($P<0.05$) β coefficients from the multiple linear regression analysis investigating variables associated with acute and planned inpatient care, visits to physicians in outpatient care and total healthcare costs

Variable	Acute inpatient (Study II)	Planned inpatient (Study II)	Physician visits (Study II)	Total costs (Study III)
Circulatory dis.	1.12	0.45	4.36	2.12
Neoplasms	0.84	0.98	9.83	2.45
Genitourinary dis.	1.06	0.65	7.06	1.35
Injuries etc	1.21	non significant	5.66	2.15
Musculoskeletal dis.	0.72	0.84	non significant	2.15
Unspecified clinic	1.42	non significant	6.39	1.65
Age	non significant	-0.01	non significant	non significant
Woman	0.56	non significant	-2.36	non significant
Unmarried	non significant	non significant	non significant	non significant
Widow/er	non significant	non significant	non significant	-1.06

Receiving informal care, being married or divorced were not significant in any model. Total costs were transformed into normal logarithmics. With an adjusted R² of (0.39) for acute inpatient care, (0.37) for planned inpatient care, (0.17) for physician visits and (0.33) for total costs.

Patterns of healthcare consumption and costs

The total costs of acute hospital stays were EUR 956 000 for all the women and EUR 696 000 for men in the sample. Of these, 58% and 54% respectively for the women and men occurred 5 months or less prior to the introduction of long-term municipal care (Study III). This confirmed the findings in Study II, showing that 52% of the acute hospital stays for men (81 men and 161 stays) and 45% for women (126 women and 231 stays) occurred within five months prior to the provision of long-term municipal care and services. In addition the cluster analysis in Study III identified two groups. Cluster I (n=48) had overall higher healthcare costs for acute (median EUR 15 900 vs. 700) and total inpatient care (median EUR 21 500 vs. 2 300) than Cluster II (n=314). Cluster I also had higher median costs for visits to physicians (EUR 2 500 vs. 700) and visits to other staff groups in outpatient care (EUR 1500 vs. 100) and total healthcare (EUR 25 000 vs. 3 800). Those in Cluster I were significantly more often men (66% vs. 30%) and more often married (38% vs. 22%). Circulatory diseases (48% vs. 18%), cancer (35% vs. 8%) and injuries (29% vs. 15%) as the primary diagnosis in inpatient care was significantly more common in Cluster I than in Cluster II. Cluster I had higher median costs for acute inpatient care than Cluster II throughout the two years. In both clusters the costs for acute inpatient care started to increase approximately one year prior to the provision of long-term municipal care and services. In Cluster I the costs increased faster and to a greater extent. In Cluster two the costs also increased over time but not as much as in Cluster I (Study III). With regards to total costs for inpatient care the trends were similar to that showed in Study III (Figure 6).

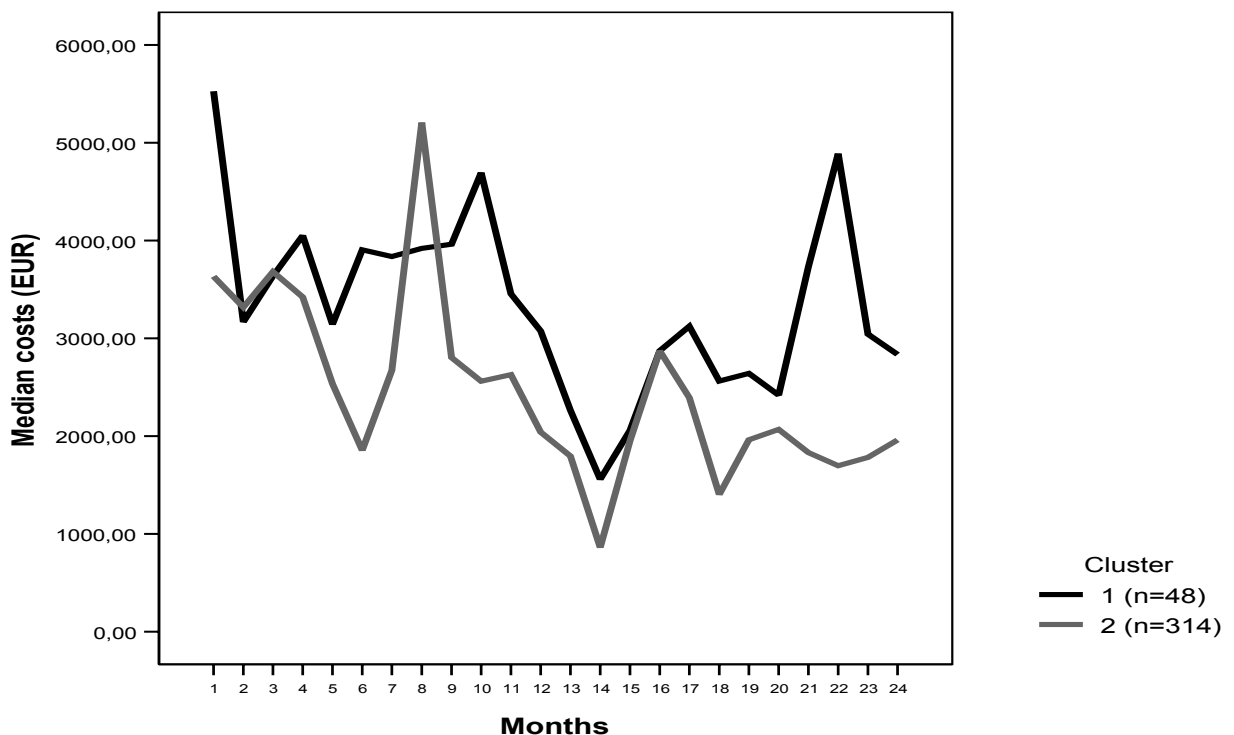


Figure 6: Median costs for total inpatient care (acute and planned) in Cluster I (n=48) and Cluster II (n=314) the two years prior to long-term municipal care and services.

Results from the intervention

No differences were found between the intervention group (n=19) and the control group (n=16) regarding sex, age, marital status, educational level, having someone to trust and rely on, feelings of loneliness, ADL status, number of health complaints and number of reported diagnosis groups according to ICD-10. The intervention group more often reported that they had felt lonely during the preceding year (Study IV).

Both groups reported 10 health complaints in median. The five most common complaints for both groups were pain, dizziness, breathlessness, hearing difficulties and fatigue (all non-significant). The control group significantly more often reported problems with urinary incontinence and the intervention group significantly more often reported difficulties with reading. The control group reported in median 3 different diagnose groups and the intervention group in median 2 (non-significant).

The five most common diagnostic groups for both the intervention and control groups were: circulatory diseases, diseases of the eye and adnexa, certain infectious and parasitic diseases, diseases of the respiratory system and endocrinal, nutritional and metabolic diseases (Study IV).

Cronbach's alpha was 0.80 for the GDS-20, 0.67 for LSIZ, and 0.76 for the ADL staircase (Study IV).

Median LSIZ scores were (non-significant) 12 for the intervention group and 14 for the control group. The median (non-significant) perceived health status was 50 for the intervention group and 55 for the control group and the GDS-20 score was 6 for both groups at baseline. For those who completed the first follow up, the median GDS-20 score was 7 vs. 5 at baseline for the control group (n=12) and the intervention group (n=16) respectively and 6 vs. 5 for the two groups respectively at first follow up (non-significant). The median for perceived health status for those who completed the first follow up was 50 in both groups at baseline and 50 vs. 57 for the intervention and the control group respectively at follow up. No significant differences were found between and within groups regarding GDS-20 or perceived health (Study IV).

Case descriptions

Two cases were selected for closer descriptions based on two interviews with the case managers and they are presented below.

An escalating infection

An 80-year-old woman lived alone in her apartment and did not receive any municipal care or services. Sometimes a relative helped her with some house hold work. Among other conditions she had type II diabetes and a peripheral arterial disease which caused pain in her legs. When the case manager made her initial visit, the woman told her that she had a pain in her foot. Because of this she had been unable to go outside for the past three months and did not get much sleep at night, which made her tired during the

day. The case manager inspected the foot and noticed that it was discoloured, red and swollen and she also noticed a small ulcer. The case manager contacted the woman's GP the same day and the GP then contacted the woman, also that same day.

The case manager also contacted a home-help officer who arranged for a district nurse to make home visits to attend to the ulcer. The GP arranged a time at the hospital's outpatient diabetes clinic. The case manager accompanied the woman on the outpatient visit and also to the department in the hospital that dealt with trying specialised made shoes.

One month later the woman had been to a magnetic resonance but despite painkillers she was experiencing severe pain in her foot. Thus the case manager accompanied her to the outpatient diabetes clinic and later to undergo a revascularisation procedure. However, a couple of weeks later the woman was admitted to hospital for an infection in her foot and she was treated with antibiotics. In the hospital they had noticed a pending blood sugar level and had changed the diabetes treatment to insulin injections. They had contacted the municipality and a discharge conference was planned

After about three months as part of the intervention the woman was on long-term treatment with antibiotics, the pain in her foot was almost gone, the ulcer was much better and it was being attended to by a district nurse three times a week. A district nurse came everyday to help with the insulin injections and the woman also received municipal help with laundry and cleaning. She was waiting for a walking frame and also to have the thresholds in her apartment removed so that she could walk more easily.

Alone and not knowing where to turn

A single 90-year-old woman lived alone in a house, had no close relatives and, with the exception of a safety alarm, she managed without municipal care and services. She had poor vision and a friend sometimes helped her with practical matters. She had undergone hip surgery many years earlier and sometimes the hip ached a little. When the case manager made her initial visits she had difficulty in identifying any needed interventions. However, the woman told her that she had problems seeing and also some hip-related pain and therefore she needed help with some practical matters in the home. The case manager arranged for a municipal janitor to come and change some light bulbs in the house.

A few weeks later the woman called the case manager. She had received several letters from the hospital calling her to various outpatient physicians for examinations. She could not read the letters because of her poor eye sight. The case manager helped her read the letters and sorted out where and when the visits were to take place.

About one month later the case manager tried to call the woman several times to arrange for a home visit, but the woman did not answer the phone. After a couple of days the woman's friend finally answered. She told the case manager that the woman

had severe pain in her hip and was unable to get out of bed. The case manager talked to the woman who told her that she had been in pain for a while. She did not want to use her safety alarm since she was afraid of disturbing people. The case manager immediately contacted a district nurse who made a home visit and arranged for transport to the hospital. There they observed a moving nail in the hip. She was given surgery and could return home about one week later.

A few weeks later the case manager phoned the woman to follow up. The woman told her that her hip was much better but also that she had suffered extreme pain before the operation. A few days before the case manager succeeded in contacting her she became desperate. She did not know where to turn; she could not go to the toilet or prepare any food for herself. She had with much despair and suffering managed to cut an orange into pieces. She took it with her and went to bed to die. She had decided that her life was over and the orange pieces were only used to keep her mouth from getting too dry. She stated that the case manager's phone call had saved her life.

DISCUSSION

Methodological considerations

This thesis was based on three different designs – a qualitative design, a cross-sectional, comparative design and also on an experimental design in a pilot study. The aim of a qualitative design is to explore and achieve a deeper understanding about a certain phenomenon. The goal of a cross-sectional comparative study is mainly to achieve generalisable results that reflect the conditions of the empirical world as faithfully as possible whilst the ambition of an experimental design is to assess change due to manipulation (Polit & Hungler 1999). Using different methods may produce a deeper understanding of the research question. However, it also gives rise to methodological issues since the designs have different quality indicators which may affect the results in various ways. Studies with a qualitative design can be assessed by means of the concept of trustworthiness, which comprises credibility, transferability, conformability and dependability (Lincoln & Guba 1985). Studies with a quantitative design, on the other hand, can be assessed in terms of validity which comprises internal, external, construct and statistical conclusion validity (Kazdin 2003). There are threats to validity in every step of the research process but as Kazdin (2003) has stated, the various threats have to be reasonable and seen in context. The potential threats were considered in this thesis and are discussed under the subheadings: Trustworthiness, internal validity, external validity, construct validity and statistical conclusion validity.

Trustworthiness

Studies that have a qualitative design can be assessed by means of the concept of trustworthiness, which comprises credibility, transferability, conformability and dependability (Lincoln & Guba 1985).

Credibility refers to the truth and the believability of the data (Graneheim & Lundman 2004) and whether the results are based on faithful descriptions and are tenable. (Lincoln & Guba 1985). The conditions for data collection, i.e. the prerequisites for the interviews, sampling, and how well the data are covered in themes and categories are all important aspects to consider (Graneheim & Lundman 2004). One threat to credibility in this thesis was that the participants were interviewed about their overall experiences when in a specific care situation. In addition some of the interviews were short and lasted about 25 minutes and some of the participants were interviewed when in hospital. This might have influenced the depth of the interviews and also posed the risk that some narratives were very much coloured by the participant's current situation. However, efforts were made to collect a variety of experiences and also to create good conditions for the interviews. The inclusion of both men and women, of different ages, with different needs regarding both medical care and long-term municipal care and services, and also people at different stages of an acute-care process contributed to the variation. The participants themselves chose the location for the interview to ensure that they felt that a secure environment should had been

established. Several participants were severely ill and in great need of care and services and thus some interviews became short. This might be expected when interviewing a frail group of people. However the mean length of the interviews were approximately 50 minutes and the content of the texts was judged to be detailed and rich. The interpretation of the data was made visible to the reader through the use of quotations from the transcribed text and also by showing examples of the analytical process in study I. Thus the results can be viewed as credible.

Dependability is concerned with whether the interpretations are stable over time and if they are representative (Lincoln & Guba 1985). Data were collected using a thematic interview guide; it has been suggested that this strengthens dependability (Graneheim & Lundman 2004). The guide ensured that the participants were asked about the same areas. However, it was also considered important that the participants felt free to narrate in their own way both about the areas in the guide and also about any other aspects they chose in order to obtain a rich and detailed material (Mishler 1986).

Confirmability refers to the subjectivity of the researcher (Lincoln & Guba 1985). To deal with these aspects two researchers were involved in the data collection and performed seven interviews each. Another important aspect to consider is the researcher's preunderstanding. To deal with issues linked to this the material was analysed using investigator triangulation (Polit & Hungler 1999) in which three researchers analysed the text both one-on-one and together. In all several steps were taken to establish trustworthiness in Study I and based on these the results can be viewed as trustworthy.

Internal validity

Internal validity refers to the extent to which the results can be explained by the independent variable rather than other factors. There are several threats to internal validity such as history, maturation, instrumentation, testing, statistical regression towards the mean, selection bias and attrition (Kazdin 2003).

Attrition may be a problem in Studies II and III. Even though no internal dropout was found in the county council's register during the merging process it is most probable that more individuals than the 362 included in the study received municipal care and services for the first time in the investigated area during the relevant two years. The external dropout was mainly due to people not being asked to participate. Hallberg *et al.* (2002) performed a dropout analysis in 2001 where the results showed that about 50% of those who received municipal care in the area were included in the data collection at baseline. The stated reason for the dropout was that the staff did not have enough time carry out the data collection. The dropout was not, however, systematic with regard to age and sex (Hallberg *et al.* 2002). There was a large internal dropout in the SNAC-IADL, SNAC-PADL and SNAC-PSN (Study II). The dropout analysis indicated that it was systematic in that those with internal dropout were more dependent in several of the index variables compared with those who were included. This may have affected the results of the indexes, giving a false positive view due to

the exclusion of those who are most frail. This has to be taken into account when interpreting the findings.

Healthcare costs are calculated in PASiS either by using templates or the DRG system. The different methods have one thing in common: identical DRG points or templates in a clinic/unit have the same registered costs, regardless of individual aspects of the healthcare contact. This entails a risk that the costs will be either too high or too low. This situation was the same for the entire sample but nevertheless the costs in terms of exact figures have to be interpreted with caution and also with regard to that economic aspects such as currency, inflation etc. which might change over time. There is also a risk that some individuals received care, and thus had costs, in other county councils outside the region of Skåne and it is also reasonable to believe that the total costs for healthcare might be underestimated since no private or informal caregiving was included in the cost analysis. It was not possible to obtain such data at the time of the data collection. However, through combining the different registers unique information was obtained about that period in the life of older people when they were in the transition from independence to receiving long-term help in order to manage their daily life.

Internal validity was also an issue in Study IV. In an experimental design, internal validity is very much about creating equivalent groups and, with exception of the intervention, treating and measuring the groups in the same way (Kazdin 2003). A large number of those initially asked declined to participate in Study IV, mainly because they felt too ill or weak. The great majority were also recruited from the hospital and thus they were in a process of acute care which might have influenced their willingness to participate. Six people died before randomisation and two died before the first follow up. In addition those included were above 80 years of age and had several health complaints and diseases. Thus the study participants were a frail group which may increase the risk of future drop out. The recruitment seemingly worked in terms of screening the hospital for eligible participants. However, recruitment in primary care and municipal care was less successful and more efforts have to be made in this area in the future to increase the number of participants. Other threats in terms of selection bias, maturation (intrapersonal changes or processes), history (external changes or processes), testing (participants getting used to the questionnaire), instrumentation (altered prerequisites for the measures) and statistical regression (a tendency for measures to regress towards the mean) were all important aspects to take into account for when designing Study IV. Those aspects may also occur in both intervention and control groups and since the randomisation seemed to create equivalent groups, they have to be considered more as processes that may appear in both groups rather than threats affecting future results.

External validity

External validity concerns whether the findings can be generalised to settings and groups outside the study context (Kazdin 2003). Threats that had to be considered included sample characteristics and features of the study context. It was also important

in the experimental design to consider such aspects as novelty effects, the sample being exposed to multiple interventions and the timing of the measurement.

The sample in Studies II-III included people aged 65 years and above who had received a first-time decision regarding the provision of long-term municipal care at home or in special accommodation. All those registered in GAS for the years investigated were included in this study and it is thus fair to assume that they were representative of the population. However, the results have to be interpreted with caution as health systems differ between countries in terms of organisation, funding, needs assessment procedures etc.

External validity was not an issue in Study IV as it was a pilot trial, the results obtained may be used in a future power calculation. It was nevertheless still important to consider external validity when designing the experimental trial so that it would be valid if continued on a larger scale. By randomising the sample into intervention and control groups and establishing equivalent groups many of the threats to external validity was theoretically considered. Novelty effects and also issues related to follow-up procedures may occur to the same extent in both groups. The follow up was sometimes delayed, mainly due to the participants being too ill, readmitted to hospital or did having time to meet the researchers. This should not be unexpected since the design managed to include a frail group, but reducing the number of follow-ups might be worth considering. The intervention group was exposed to multiple interventions. This will be further discussed under construct validity.

Construct validity

Construct validity refers to the content of an intervention and which theoretical assumptions and constructs may explain the causality between an intervention and the results (Kazdin 2003). The intervention programme in Study IV was complex since it contains several dimensions that were launched and developed individually. Thus it is difficult to document and reproduce (Campbell *et al.* 2007). The intervention was based on a personal relationship between case manager and client and needed to be multidimensional since frail, older people are known to have a complex health and social situation. Threats to construct validity in an experimental design may, according to Kazdin (2003), be related to the researcher, influencing participants both by having contact with them and also by acting in a certain way. Another threat is that the researcher might misinterpret important aspects of an intervention as irrelevant ones. The nature of the interventions did not allow for a blind design. Both participants and case manager needed to know that they were part of an intervention, thus placebo effects have to be considered in the future but they may also occur in the control group to some extent. The case managers were experienced nurses and this may also have an impact of the content and replicability of the intervention. On the other hand the intervention needed to be based on the case managers' competence to communicate with clients and outline the interventions needed. The intervention had four dimensions, which were not implemented simultaneously. The parts that were about general and specific education were implemented at a later stage. The experiment was

developed in different phases, as suggested by Campbell *et al.* (2007). The authors also suggest that both quantitative and qualitative methods should be used when evaluating a complex intervention. The case managers documented their work and also kept personal reflective diaries about the intervention. They were also interviewed and additional interviews with participants and their next of kin will be carried out in the future.

Statistical Conclusion validity

Statistical conclusion validity refers to statistical methods and their ability to show or prove causations or differences between variables (Kazdin 2003) This may be viewed from two angles: the risk of type I and of type II error (Altman 1991). Type I error occurs when differences are detected in the material even though they do not exist in the population (Altman 1991). The risk of type I error is determined by the p-value, which in this study was set at 0.05 (5% risk), a commonly used limit. Type II error concerns the opposite which is the risk of not detecting differences in the material even though they exists in the population (Altman 1991). It is related to sample size and power. Power was not calculated for any of the quantitative studies. Study IV was an explorative pilot trial and the results can be used to conduct a power analysis in a future main trial. All available people were used in study II and III and the sample was quite large (n=362). The smallest group compared contained 48 people which was judged to be large enough to avoid type II error. However, the results have to be interpreted with this in mind.

Both non-parametric and parametric tests were used in this thesis and they were chosen based on scale type and data quality (Altman 1991). In Study IV non-parametric tests were used throughout due to small sample sizes and also in Study II it was assumed that it was advantageous to use non-parametric tests on ratio data that were suspected of being skewed. However, in Study III and in the framework healthcare costs were analysed with parametric tests since it was judged that despite the probability that the data were skewed the sample size was large enough for parametric statistics (Norman & Streiner 2000), which are more powerful for detecting differences (Altman 1991). This apparently was a valid decision since the trends were similar in terms of differences regardless of tests.

Statistical conclusion validity is also about using instruments that are valid and reliable and thus includes a psychometric aspect (Streiner & Norman 2003). The instruments used in Study IV had satisfactory internal consistency (Streiner & Norman 2003) and thus it seems feasible to use them.

General discussion of the results

The results of this thesis can be viewed from the perspective of the healthcare providers or the healthcare consumers. The results from Study I were interpreted as the extra-, inter- and intra-personal perspectives of receiving healthcare and/or social services. The extra personal perspective concerned organisational aspects; the interpersonal concerned the older person's encounter with those working in the health system whilst the intrapersonal perspective concerned aspects related to the older person him/herself. This is one way of interpreting healthcare consumption from the consumer's perspective. However this may also be applicable to the results that concerned rather the producer's perspective (Study II-III). It is important to bear in mind that a healthcare contact always comprises an encounter between the health system and the individual and the encounter between individuals may be affected by organisational aspects and processes within individuals and vice versa and thus there is an interaction that cannot be ignored. The results will, therefore, be further discussed under the subheadings: Intrapersonal perspective, Extrapersonal perspective and Interpersonal perspective.

The intrapersonal perspective

The results revealed a smaller group (about 13%) who had more healthcare contacts and higher costs than the rest of the sample (Study II-III). This appears to be an exposed and vulnerable group with several health complaints and low life satisfaction (Study IV) who have to struggle to retain power over their life situation (Study I). Needing repeated interventions from the health system is an indication of deteriorating health and maybe also of new circumstances in life. A transition such as this implies vulnerability and increases the risk of losing control over the situation (Meleis *et al.* 2000). Those who have limited contacts with the health system due to a declining health may experience a smoother transition since their health status sooner becomes stable whilst those who need repeated contacts may stay in a constant transition that further increases their vulnerability. Support from the health system is required to transform this negative process into a healthy transition since the older person may be too vulnerable to deal with it him/herself (Meleis *et al.* 2000). The results from Study I showed that the support from the health system sometimes failed and that the older person felt disappointed or needed to rationalise receiving unsatisfactory care or services. This strongly affected the experience and sometimes also the person's sense of value. This also implied a need for understanding and for the situation to be dealt with. Sometimes the rationalisations restored the person's sense of having power but sometimes it affected the older person's self esteem negatively as they assumed the blame (Study I). Thus it seemingly had a lot to do with coping. It has been suggested that coping strategies can either be problem or emotionally oriented (Lazarus & Folkman 1984) and rationalising receiving unsatisfactory care or services may be an example of the latter. Taking the blame oneself might imply a lack of a coping strategy. Rationalising the reason for the system's failure may play an important role in the older persons feelings of value but it may also hinder a disclosure of failure in the health system that organisational problems being might be wrongly identified as issues

that the older person needs to handle emotionally. Maintaining control over one's life has been found to be important when experiencing failing health (Dunér & Nordström 2005). The results from Study I also showed that the health systems sometimes succeeded in empowering the older person and this was often related to continuity. The intervention program used in Study IV might be one way of creating continuity and, if this can serve as an empowering strategy it might also be one way of restoring power to the individual. However, the low life satisfaction found in Study IV can not be explained by the participant's care or service situation, even though they were frequent users, but it might be related to their health status as frailty and instable health make their life difficult to predict. It has been reported that feeling hampered by health problems (Fagerström *et al.* 2007) and poor self-reported health (Borg *et al.* 2006) may be strong predictors for low life satisfaction. The level of life satisfaction was even lower here than that reported in earlier studies. The results from this thesis imply that interventions aimed at low life satisfaction may have a positive outcome in terms of how frail older people view their situation. However, this requires the support from the health system so the system needs to function properly. This might be even more important for those who are frail and heavily dependent on the health system for their daily life.

The extrapersonal perspective

The results showed that a vast majority of acute hospital admissions and costs occurred within the five months prior to the sample entering the long-term municipal care and service system. One group of 13% had higher overall healthcare costs for the two years investigated. This group was younger, more often male and married and diagnosed as having cancer, circulatory diseases or injuries.

It is known that hospital admissions may increase during the development of disability (Ferrucci *et al.* 1997) and thus the results may not seem surprising, since receiving long-term care or services is a formal mark that the older person can no longer manage without help from society. It is also known that hospital care might decrease when the older person starts to receive long-term care at home or in a nursing home (Ellencweig *et al.* 1990). It is important not only to identify and monitor those with an escalating consumption of healthcare but also to establish tools to identify, assess and monitor those with a higher consumption in general, since early detection of these people may give the health system time to find care on an appropriate level. There are many reasons why older people seek acute care, an acute medical condition may be a major reason, but needs in the home that are not met (Cheek *et al.* 2005) or failing health in the informal caregiver may be others (Sewitch *et al.* 2006). Bearing in mind that the sample in Studies II and III was about to receive long-term municipal care within five months after the acute admissions started to escalate, seeking acute care could also be interpreted as a result of a fragmented health system. It is possible that some of the acute admissions could have been prevented by a more proactive strategy and coordination among the agencies or municipal care and services being set up earlier. The results may be explained by the structure of the health system. During the last decade there has been a change in the way in which care and services are provided for

older people. The county councils have shortened the length of stays in hospital and the municipalities have become more restrictive in providing care and services. There has also been a decrease in the number of nursing home beds and a dislocation in terms of increasing homecare and less nursing home care (National Board of Health and Welfare 2007a). This may have implications for the county councils in terms of an increasing demand for healthcare within their regime and since the days in hospital has become fewer it may lead to readmissions. This change in both county councils and municipalities apparently creates a gap between the agencies and a risk that those with complex needs fall between the stakeholders. This was the case, for instance, for many of those frail older people who were investigated in the report by Gurner (2001). It has been stated that a decentralised health system may be fragmented (Åhgren 2007) and that frail older people are more at risk than others of being mistreated in such an organisation because of their complex needs (Clarfield *et al.* 2001). This may account particularly for those who are in transition between independence and needing long-term care and services in order to manage their daily life. The results of the thesis show that the healthcare costs in general started to increase one year prior to the introduction of municipal care, however, it was more pronounced for some particularly vulnerable people. The results of this thesis show that the health system might benefit from a more proactive approach when providing care and might perhaps adopt a system that alerts the authorities when acute healthcare admissions start to escalate. Preventive interventions aiming at integrating care using case management for instance have been found to reduce the consumption of healthcare in frail, older people (Bernabei *et al.* 1998). Close collaboration between the different agents within the system is crucial in the creation of integrated care for this frail group of older people. Åhgren (2007) stated that clinical integration is the foundation for creating integrated care and that it needs to be prioritised. In Study IV the case manager strove to establish continuity in care by for example co-ordinating caregivers. This was done by means of the case manager accompanying participants on outpatient visits or visiting them when they were in hospital and also by contacting primary-care physicians or municipality when problems were detected. Thus this part of the intervention had aspects both of continuity and advocacy. This was illustrated by the case description in which a woman suffered an escalating infection in a foot ulcer. The case manager contacted her GP and later visited her in hospital and could thus support the woman, gain a picture of her health status and also collect information from and provide adequate information for the caregivers.

A poorly monitored healthcare situation for those who need repeated interventions from various stakeholders may be costly for the health system and also have a profound impact on the individual's daily life. It was found, for example, in Study I that experiencing a lack of continuity and being in the hands of the organisation contributed to feelings of powerlessness. Other studies have also indicated that frail, older people might experience a loss of control in relation to the health system in terms of not having any influence over decisions or experiencing that the organisation is inaccessible (Janlöv *et al.* 2006). Thus the results of this thesis indicate that more empowering strategies could be used on an extrapersonal level perhaps by providing information about the system and its structures and also by confirming that the older

person is a part of the decision-making processes and ensuring that she/he is aware of her/his rights in relation to the system. One way of achieving this might be through information, which was one aspect of the case management intervention used in Study IV.

The interpersonal perspective

The relationship with professionals was an important aspect of having power or being powerless (Study I). This interpersonal perspective was striking in the results and the narratives about it were deeper and more emotionally loaded. People felt they had power when they had control, felt trust and/or participated in the interaction with the staff. In contrast, feelings of being powerless occurred when they experienced offensive encounter or when they felt insecure, uninformed and without influence. Olsson and Ingvad (2001) showed that patients and staff did not experience the emotional climate in homecare in the same way. Staff tended to rate it higher than the patients did. Feelings of powerlessness when receiving care and/or services in old age have also been found in other studies indicating this it is a situation in which the older person is very exposed (Hellström & Sarvimäki 2007). Maintaining control over one's life has found to be an important aspect when experiencing failing health (Dunér & Nordström 2005) and it has been suggested that treatment should not only be performed in accordance with a specific medical need but also in accordance with the individual's entire life situation (Ottosson 1999). According to Meleis *et al.* (2000) interpersonal aspects are important in creating a healthy transition. However, this view is based on a functioning encounter and this places a lot of the responsibility on the individuals involved. That is one important aspect but another is that the prerequisites for the encounter between staff and those who seek help occur in a context that is influenced by organisational aspects. This might influence the content of the encounter.

On a micro-level it has been suggested that the health system could be viewed as a street-level bureaucracy. One of the characteristics of such a system is the street-level bureaucrats themselves who are hired to prioritise and pass on those who seek help to the right level of assistance. It has been argued that people can not be treated efficient in a bureaucracy (Prottas 1979) since they have individual needs that might not be attended to in a specialised organisation. It is possible that such an organisation encourages encounters that are more task-oriented and this might be disempowering for the older person (Hallberg *et al.* 1995). However, it also poses risk on a more clinical level in that the staff might miss important things in the older person's health situation. Lack of continuity and care coordination was also visible in the cases reported from the case management interventions (in the framework). One of the examples was a woman with poor vision who received several letters from different caregivers which she could not read because of her vision problems. Later she suffered so much by her pain that she decided to die. She did not want to bother any one by using her safety alarm. This example shows that it is not only important for the health system to empower older people but also to work preventively and to deliver care, services and information that are individually based. If the structure of the system prevents anyone from obtaining a comprehensive view of the older persons situation it becomes difficult for the system to work in an empowering manner. This is especially

important for those who receive care and services from several agencies. Interpersonal continuity has, on the other hand been shown to be important for satisfaction with care (Saultz & Albedaiwi 2004) but it also increases the chance for staff to detect any problems that need to be dealt with.

The intervention used in Study IV is one suggested model that might be beneficial in terms of integrating caregivers and providing a more comprehensive structure. Case management programs have been found to reduce healthcare consumption and increase quality of life (Hallberg & Kristensson 2004). Those which seemed most effective used a multi-professional approach and were also based on a comprehensive geriatric assessment tool. It might also be beneficial to implement such a tool in the current organisation. Regular assessment may give rise to interventions and also to closer communication between different caregivers. The results from Studies I-III showed both from a provider's and consumer's perspective, that it might be beneficial to have a more proactive standpoint and make efforts to integrate care in the current organisations. This could be advantageous for both the health system and the older people who need repeated interventions from various agencies.

CONCLUSIONS AND CLINICAL IMPLICATIONS

Receiving healthcare and/or social services was characterized by having power or being powerless. This was revealed in processes within the person him/herself, in the relationship with caregivers and also in the relationship with the health system. Thus it could also be interpreted in terms of intra-, inter- and extra personal aspects of having power or being powerless. To be in the hands of the organisation, experience a lack of continuity, being uninformed, insecure and without influence and feeling disappointed contributed to being powerless. To be known and in control, to participate and have influence and be aware of one's rights contributed to having power. Healthcare staff must be aware of the risk that older people will lose control over their life situation when they receive healthcare and/or social services from various agencies. Preventive interventions and a more empowering approach seemingly needed. This requires continuity and accessibility on an individual level but primarily also on an organisational level. This may be particularly important for those frail, older people who are very dependent on the healthcare and/or social services system in order to manage their daily life.

There was a breakpoint in terms of escalating hospital admissions and costs in acute care the five months prior to older people receiving the decision about the provision of long-term municipal care for the first time. A proportion amounting to 13% had overall higher costs throughout the two years prior to the decision and their costs for inpatient care started to increase about a year prior to the provision of long-term municipal care and services. Early detection through systematic clinical assessment, more proactive and integrated care and the application of preventive interventions to these people in the transitional stage of becoming increasingly dependent on continuous care and services seems urgent if escalating acute hospital admissions and thereby costs are to be prevented.

The case management intervention program had a feasible design. The sampling procedure led to similar groups and the measures used to assess depressed mood, life satisfaction and self-reported health in the sample were reliable. Both groups had low life satisfaction, low self reported health and were at risk of suffering from depression and could benefit from preventive interventions. No effects were found on self-perceived health and depressed mood after three months. This might be due to the follow-up time being too short and it is possible be that they occurred later. Further investigations about the content of the interventions are needed in the future.

FURTHER RESEARCH

There was an escalation in acute healthcare consumption and costs prior to the provision of municipal care and services. Other studies have indicated that receiving long-term care might reduce the number of hospitalisations. It might be interesting to investigate patterns of healthcare consumption and costs in the studied sample for the period after receiving long-term care and services to gain a deeper understanding of this transitional phase in older people's lives.

The experience of receiving care and services was very much about having power or being powerless. This was shown in relation to the organisation, to healthcare staff and also in the form of intrapersonal processes. It might be interesting also to interview next of kin about how they experience the older person's healthcare and/or social services in order to explore aspects of power from their perspective. In addition it might be interesting to develop an instrument that attempts to measure power dimensions involved in receiving healthcare and or social services in old age.

The case management intervention seemed feasible. Further research is needed about the content of the intervention. This could be done using a qualitative method and interviewing participants, their next of kin and the case managers. It also seems important to proceed with a main trial to investigate outcome measures such as, quality of life, healthcare consumption, and depressed mood and health status. It also seems important to perform a health economic analysis in the future.

SUMMARY IN SWEDISH

Svensk sammanfattning

Det är vanligt att äldre personer konsumerar hälso- och sjukvård från olika vårdgivare, men det är en mindre grupp som står för en stor del av de sammanlagda sjukhusvistelserna och öppenvårdsbesöken. En del av dessa har även kommunala vård- och omsorgsinsatser i kombination med regional vårdkonsumtion. Hög konsumtion hos en vårdgivare kan dessutom medföra hög konsumtion även hos andra. Det är på så vis är utmaning för samhället att identifiera och följa personer med upprepade vårdkontakter och ge dem adekvat hälso- och sjukvård på rätt nivå utifrån deras behov. Tiden före det att en äldre person beviljas kommunal vård och omsorg för första gången kan innehålla upprepade akuta sjukhusvistelser. Det är troligt att den tiden präglas av gradvis minskande funktionsförmåga och risk för multipla sjukdomar, med risk för ökad sjukvårdskonsumtion och höga kostnader för individ och samhälle som följd. Det innebär att det kan finnas ett behov av förebyggande insatser under den här perioden. Få studier har emellertid undersökt detta. Sådan kunskap är viktig i utvecklandet av förebyggande interventioner. Samtidigt är det viktigt att i den processen också ta hänsyn till den äldre personens upplevelser av att få vård och omsorg från flera olika vårdgivare eftersom vård och omsorg spelar en stor roll i deras dagliga liv.

Tidigare studier som utförts med syfte att förbättra äldres hälsa, förebygga skador och komplikationer till sjukdom samt minska sjukvårdskonsumtion har varit riktade mot äldre oavsett funktionsförmåga. Interventionerna har främst bestått i primär- och sekundärpreventiva åtgärder och bland annat genomförts i form av regelbundna hembesök till äldre. Andra studier har inriktats på specifika sjukdomar som t.ex. stroke. Kunskapen är begränsad kring effekterna av modeller som, förutom primär- och sekundär- även innehåller ett tertiärpreventivt arbete, d v s arbete som avser att minska redan uppkomna skador, förhindra komplikationer, hejda sjukdomsprocesser och vidta rehabiliterande åtgärder och som riktas mot äldre i ordinärt boende. En sådan modell kan vara "case management". Modellen växte fram i USA under 60- och 70-talet inom psykiatrin som ett svar på nedläggningar av de stora psykiatriska institutionerna. En "case manager" kan definieras som en person utsedd att planera, samordna, organisera och utvärdera vården av en patient genom hela vårdprocessen. Effekterna av "case managers" för äldre har undersökts i internationella studier, främst i USA, Australien och Italien. Studierna har haft olika design, urval, visat olika resultat och effekterna blir därför svårvärderade. Några studier har inte visat några effekter, medan andra studier har visat positiva effekter på individens hälsa, funktionsförmåga och sjukvårdskonsumtion. Vad som ingick i "case managers" uppgifter varierade. I några studier hade "case managern" en mer traditionell roll, vilket bland annat innebär: identifiering av klienter, planering, koordinering, övervakning och utvärdering av den äldres vård och omsorg. I andra studier var "case managers" roll mer utvidgad till att bland annat omfatta bedömningar, åtgärder och undervisning. Effekterna av "case management" i vården av äldre med nedsatt funktionsförmåga och multipla sjukdomar kan således minska vårdkonsumtion och förbättra livskvaliteten för den äldre. Det

krävs emellertid studier, förutom om dess effekter, om när ”case management” behövs i den äldre personens vård och omsorgssituation och vad som bör ingå i ”case managers” uppgifter.

Avhandlingen bestod av fyra delstudier med det övergripande syftet: Att undersöka vårdkonsumtion och vårdkostnader bland äldre personer två år före beslut om kommunal vård och omsorg, hur äldre personer med upprepade vårdkontakter upplever den vård och omsorg de får från kommuner och landsting samt att undersöka genomförbarheten av en intervention med ”case manager” till äldre personer med nedsatt funktionsförmåga och upprepade vårdkontakter.

Den första delstudien var en kvalitativ intervjustudie som syftade att belysa hur äldre personer upplever den vård och omsorg de får från kommuner och landsting. Fjorton personer (medelålder 81 år) intervjuades och resultatet som analyserades med innehållsanalys visade tre huvudkategorier och det övergripande temat tolkades som ”att ha makt eller vara maktlös”. Huvudkategorierna var att ha självbestämmande eller vara utan kontroll i relation till vård- och omsorgsorganisationen, att bli bekräftad eller kränkt i relationen till personerna som vårdar samt att uppleva paradoxer i vård och omsorg. Detta kunde också tolkas som extra-, inter-, och intrapersonella aspekter av att ha makt eller vara maktlös. Bristande kontinuitet, att vara i händerna på organisationen, men också att veta sina rättigheter och uppleva vården som en vardaglig oproblematiserad händelse relaterade till de mer organisatoriska aspekterna. Att vara otrygg, oinformerad, inflyttelselös, att uppleva kränkande bemötande men också att vara känd och bekräftad, trygg och ha möjlighet att påverka relaterade till interaktionerna med de vårdande personerna. Paradoxer i vård och omsorg handlade om att uppleva läkemedelsbiverkningar, att känna besvikelse över vården men också att utveckla strategier för att rationalisera varför vården och omsorgen ibland upplevdes som dålig. Detta ledde ibland till sänkt självkänsla

Den andra delstudien var en registerstudie med syftet att undersöka äldre personers sjukvårdskonsumtion två år före beslut om kommunalt bistånd samt faktorer som påverkade vårdkonsumtionen. Studien baserades på befintligt material från studien Gott Åldrande i Skåne (GÅS), som är en del i det nationella SNAC-projektet, insamlat i fem skånska kommuner och Region Skånes patientadministrativa system PASiS (för regional vård) och PrivaStat (för privat öppenvård). Urvalet hämtades från GÅS och bestod av 362 personer, 65 år eller äldre, som under 2002 och 2003 beviljats kommunalt bistånd gällande hemtjänst eller särskilt boende. Från GÅS hämtades variabler som rörde: kön, ålder, civilstånd, funktionsförmåga samt stöd- och vårdinsatser från närstående. Från PASiS och PrivaStat hämtades variabler från år 2000 och framåt och som rörde antalet vårdkontakter, vårdtillfällen, vård dagar och diagnoser i öppen, slutet och privat vård. Resultaten visade att ungefär 50 % av alla akuta sjukhusvistelser ägde rum fem månader före biståndsbeslutet. Männerna (n=115 medelålder 80.7) hade fler vård dagar på sjukhus fler registrerade diagnoser och fler kontakter med övriga personalgrupper (ej läkare) i öppenvård jämfört med kvinnorna (n=247 medelålder 83.7). De sex vanligast förekommande primära diagnosgrupperna i slutenvård (cirkulationssjukdomar, cancer, skador, sjukdomar i urin- och könsorgan,

muskuloskeletala sjukdomar och ospecificerade kliniska fynd) associerade på olika vis med ökande sjukhusvistelser och ökande läkarbesök i öppenvården.

Delstudie III omfattade samma urval och register (förutom PrivaStat) som delstudie I och hade syftet att undersökta vårdkostnader två år före beslut om kommunalt bistånd. Syftet var också att undersöka kostnadsmönster och vad som påverkar kostnader. En klusteranalys visade att 13 % av urvalet hade betydligt högre kostnader än övriga inom både öppen och sluten vård under båda åren (totala kostnader 26 000 Euro jämfört med 4000 Euro). Giftna personer, män, hjärt- kärl sjukdomar, cancer och skador var signifikant mer vanligt förekommande i den gruppen. Resultaten visade också att närmare 60 % av kostnaderna för akut slutenvård ägde rum inom fem månader före biståndsbeslutet. Männerna hade högre kostnader för besök hos öppenvårdsläkare i jämförelse med kvinnorna (700 Euro versus 400 Euro) året före biståndsbeslutet.

Den fjärde delstudien ägde rum i en skånsk kommun och var en randomiserad kontrollerad pilotstudie med syftet: Att undersöka genomförbarheten av en intervention med "case managers" till personer, 65 år eller äldre, med hög vårdkonsumtion och minskad funktionsförmåga.

Urvalet (n=35) bestod av slumpmässigt randomiserade personer som var minst 65 år, behövde hjälp med minst två aktiviteter i dagligt liv och hade minst två sjukhusvistelser eller fyra öppenvårdsbesök under de senaste tolv månaderna. Personerna randomiserades till antingen interventionsgrupp (n=19) eller kontrollgrupp (n=16) och rekryterades via ett universitetssjukhus, via primärvården eller den kommunala vården och omsorgen på studieorten. Två sjuksköterskor anlätades som närjsjuksköterskor ("case managers") och de utförde interventionen som kunde delas upp i fyra typer av insatser: Den första bestod av regelbundna hembesök och en systematisk bedömning, planering och uppföljning av behov och problem. Vidare skulle närjsjuksköterskorna sträva efter att samordna och skapa kontinuitet i undersökningspersonens kontakt med olika vårdgivare. Den andra och tredje typen bestod av allmän (t.ex. om egenvård och utbud av sociala aktiviteter) och specifik (relaterat till individens sjukdomar och läkemedel) information och undervisning. Den fjärde typen av insats omfattade en trygghetsaspekt och innebar att närjsjuksköterskan var tillgänglig under kontorstid vid frågor, problemlösning eller akuta situationer. Studien avsåg att undersöka bland annat livskvalitet, livstillfredsställelse: funktionellt hälsostatus och depressionssymptom. De olika frågorna och instrumenten ställdes samman i ett intervjuformulär och materialet samlas in under en personlig intervju vid baslinjen (studiens start) samt efter tre, sex, nio och tolv månader med interventionen. Intervjuerna genomfördes av personer, oberoende av närjsjuksköterskan.

Resultaten visade inga skillnader mellan grupperna med avseende på ålder, kön, civilstånd, boendeform, diagnosgrupper eller hälsoproblem. Interventionsgruppen rapporterade oftare att de hade känts sig ensamma under det gångna året och att de hade problem med synen. Kontrollgruppen rapporterade oftare inkontinensproblem. Interventionsgruppen rapporterade i median två diagnosgrupper (enligt ICD-10) i jämförelse med tre i kontrollgruppen. Båda grupperna rapporterade i median 10

hälsoproblem. De fem vanligaste diagnosgrupperna var cirkulationssjukdomar, ögonsjukdomar, endokrinologiska sjukdomar, infektioner och sjukdomar i andningsorganen. De vanligaste hälsoproblemen var smärtor, svårigheter att höra, trötthet, yrsel och andfåddhet. Båda grupperna rapporterade låg självupplevd hälsa och anmärkningsvärt låg livstillfredsställelse och var i riskzonen för att ha en depression. Det fanns dock inga skillnader mellan grupperna med avseende på detta. Inte heller upptäcktes några skillnader mellan eller inom grupperna efter tre månader med avseende på depression och självupplevd hälsa

Sammanfattningsvis visade resultaten en eskalerande akutuårdskonsumtion som startade fem månader före beslut om kommunalt bistånd. Det indikerar att det finns ett behov av förebyggande åtgärder riktade mot äldre personer som gradvis håller på att bli beroende av hjälp från samhället för att klara sitt dagliga liv. Äldre personer som löper risk för upprepade akuta sjukhusvistelser kan eventuellt gynnas av ett mer proaktivt förhållningssätt inom den akuta slutenvården. Män hade fler vård dagar på sjukhus, fler läkarkontakter och även högre kostnader för slutenvård och läkarbesök i jämförelse med kvinnor. En liten grupp bland äldre hade generellt sett högre vårdkostnader tiden före biståndsbeslut. Det är möjligt att både hälso- och sjukvårdssystemet och individen hade gynnats av att implementera en systematisk samordnad bedömning för att identifiera dem som ligger i riskzonen för höga kostnader. Det kräver emellertid ett nära samarbete mellan olika vårdgivare.

Resultaten skildrade också vårdkonsumtion utifrån ett individperspektiv och upplevelsen av att få vård och/eller omsorg handlade i hög grad om att ha makt eller vara maktlös. Detta var synligt både i relationen till hälso- och sjukvården som organisation, till dem som vårdar och även i processer inom individen. Resultaten indikerade att hälso- och sjukvårdspersonal på alla nivåer måste vara medvetna om risken att äldre personer förlorar kontrollen över sitt liv när de har instabil hälsa och får vård och omsorg från olika vårdgivare, vilket troligen kan leda till låg livstillfredsställelse och risk för att bli deprimerad. Vård och omsorg bör utformas i överensstämmelse med individens livssituation. Det kräver informationskanaler, tillgänglighet och kontinuitet både på system- och på individnivå, vilket kanske är ännu viktigare för dem som i hög grad är beroende av vård och omsorg för att klara sitt dagliga liv. Resultaten visade också att en preventiv intervention med sjuksköterskor anställda som "case managers" verkar genomförbar bland annat i den meningen att studiens design ger upphov till jämförbara grupper. Deltagarna hade flera sjukdomar, hälsobesvär, låg livstillfredsställelse, låg självupplevd hälsa och var i riskzonen för att vara deprimerade. Det indikerar ytterligare behovet av förebyggande åtgärder. Inga skillnader upptäcktes efter tre månader med avseende på självupplevd hälsa och depressiva symptom. Det kan emellertid bero på den korta uppföljningstiden och att interventionen inte implementerats tillfullo. Det krävs dock en djupare undersökning av interventionens innehåll i framtiden.

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