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Case management for frail older people

Effects on healthcare utilisation, cost in relation to utility,
and experiences of the intervention

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Abstract

The overall aim of this thesis was to investigate healthcare utilisation patterns and to explore the effects of a case management intervention for frail older people on healthcare utilisation and costs in relation to utility. A further aim was to explore the older people's and the case managers' experiences of the intervention.

Study I was a quantitative study comprising ten age cohorts aged between 60 and 96 years (n=1402) drawn from the Swedish National Study on Aging and Care (SNAC). Baseline data were collected between 2001 and 2003 and data on number and length of hospital stays were collected for the six years after the baseline year. The sample was divided into two pairs of groups; those who were dependent/independent in activities of daily living (ADL), and those at risk/not at risk of depression. The six years period of healthcare utilisation was also divided into utilisation 1-2, 3-4, and 5-6 years after baseline. **Studies II and III** had an experimental design where 153 people were consecutively and randomly allocated to either a control group (n=73) or a group that received a case management intervention (n=80). Included were those aged 65+ years who lived in their ordinary homes, were dependent in two or more ADL, and had had at least two hospital stays, or four physician visits, in the previous year. Data concerning inpatient (hospital stays and length of stay) and outpatient healthcare utilisation (contacts with physician or other healthcare professionals, and emergency department visits) (**Study II**) and costs (**Study III**) for the year before baseline and for the one year study were collected from registers. Data concerning health-related quality of life (HRQoL) used for calculations of Quality-adjusted life-years (QALY), informal care, municipal home care and municipal home services (**Study III**) were collected through structured interviews at baseline and 3, 6, 9 and 12 months after baseline. **Study IV** had a qualitative design and interviews were made with 14 participants who had received the case management intervention in **Studies II and III**, and six case managers who had performed the intervention. The case managers were interviewed about a total of 15 different participants, whom they had met in the intervention. The interviews were analysed with content analysis.

Study I revealed a significant increase in hospital stays in all groups over time. ADL-dependent persons and those at risk of depression had significantly more hospital stays, except for those at/not at risk of depression in years 2, 4 and 5. Main predictors for healthcare utilisation 5-6 years after baseline were age, previous healthcare utilisation and various symptoms; and at 1-2 and 3-4 years after baseline, age, various

diagnostic groups and various physical variables. Thus healthcare utilisation patterns seem to be similar for the different groups over the six years, but it is difficult to find universal predictors.

In **Studies II and III** there were no differences between the interventions and control groups were found at baseline (in demographics, baseline characteristics, in or outpatient healthcare utilisation, utilisation in informal care, municipal home care, municipal home services or costs). The results showed that, compared to the control group, the intervention group had significantly lower mean number and proportion of emergency department visits not leading to hospitalisation 6-12 months after baseline (0.08 vs. 0.37, $p=0.041$ and 16.7 vs. 46.9%, $p=0.012$, respectively). The intervention group also had a significantly lower mean number of visits to physicians in outpatient care 6-12 months after baseline (4.09 vs. 5.29, $p=0.047$). The intervention group had significantly less help with self-reported informal care in terms of provided hours and cost for help with Instrumental ADL (IADL) during the one-year study (200 vs. 333 hours per year, $p=0.037$; €3927 vs. €6550, $p=0.037$). There were no significant differences between the intervention group and control group in terms of total cost of the one-year study, or QALY.

Study IV showed that the experience of the case management intervention could be interpreted according to two content areas: providing/receiving case management as a model and working as, or interacting with, a case manager as a professional. The findings in **Study IV** constituted four categories: case management as entering a new professional role and the case manager as a coaching guard, as seen from the provider's perspective; and case management as a possible additional resource and the case manager as a helping hand, as seen from the receiver's perspective. Each category constituted different subcategories, all reflecting aspects of the respective category.

The results indicate that the population of older people are heterogeneous which may be one reason for the difficulties to find universal predictors for healthcare utilisation. This may also be the reason for the lack of effects on hospital stays, length of stay, and HRQoL in the case management studies. However, the case management intervention appears to have effects in emergency department visits not leading to hospitalisation, visits to physician in outpatient care, in informal care, and is cost neutral. This indicates that the case management intervention seems to have impact on the situation; not only for the older person, but also their informal caregivers. Possible features of the case management intervention that may explain these effects may be interpersonal continuity, coordination of care, someone that discovers problems and potential problems, support in a long term strong relationship and the case managers' ability to work in close collaboration with primary care. Further investigations about the process and delivery of the intervention are needed in the future to determine the efficacy of the intervention. Also long-term follow-ups are needed since 12 months may be too short to see effects on for HRQoL.

Original papers included the thesis

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

- I: Sandberg, M.**, Kristensson, J., Midlöv, P., Fagerström, C. & Jakobsson, U. (2012). Prevalence and predictors of healthcare utilization among older people (60+); focusing on ADL dependency and risk of depression, *Archives of Gerontology and Geriatrics*, 54 (3): e349-63.
- II: Sandberg, M.**, Kristensson, J., Midlöv, P. & Jakobsson, U. Effects on healthcare utilisation of case management for frail older people: a randomized controlled trial. *Submitted*.
- III: Sandberg, M.**, Kristensson, J., Steen Carlsson, K., Midlöv, P. & Jakobsson, U. Cost utility analysis of case management to frail older people (+65) – Effects of an RCT. *In manuscript*.
- IV: Sandberg, M.**, Jakobsson, U., Midlöv, P. & Kristensson, J. Case management for frail older people – receivers' and providers' experiences of a complex intervention. *Submitted*.

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List of abbreviations

ADL	Activities of daily living
CM	Case manager
DRG	Diagnosis-related groups
ED	Emergency department
ES	Effect size
HRQoL	Health-related quality of life
IADL	Instrumental activities of daily living
LOS	Length of stay
MRC	Medical Research Council
PADL	Personal activities of daily living
PASIS	Patient Administrative Supports in Skåne
QALY	Quality-adjusted life-years
RCT	Randomised controlled trial
SNAC-B	Swedish National Study on Aging and Care: Blekinge

Introduction

The health systems of today are in a near future going to face many challenges. Many of them are related to the complex needs of frail older people. It is well-known that the proportion of older people, and thus also frail older, will increase in the next decades and this at a time where many health systems are under pressure to reduce costs. These frail older people may suffer from multimorbidity (1), and they are usually in contact with various health agencies at various levels in the system (2). In addition, a small group of older people stands for a great proportion of the total utilisation of healthcare (2, 3). Disabilities, the number of diseases and health complaints increase with high age (4, 5) as well as other problems such as impaired hearing (6) and reduced cognitive function (7). This could make it difficult for older people to manage their contacts with multiple healthcare agencies at various levels. The risk of fragmentation imminent has attracted the attention of researchers as this may cause inadequate and poorer care (8, 9).

This group of frail older people with future high healthcare utilisation is interesting to identify in an early stage. If so, it may then be possible to intervene in order to improve the situation for the older person, and thereby reduce healthcare utilisation. Various interventions have been launched targeting this group. The interventions have had different approaches where some focused on the coordination of care and the reduction of fragmentation, some at preventive actions for instance with preventive home visits in combination with geriatric assessments, and some to provide information in order to make it possible for the older person to improve their situation by them self. One approach that combines many of these approaches is case management. There are no agreed definition of case management, but is described as a process of assessment, planning, implementation, evaluation, care coordination and advocacy to meet an individual's and family's comprehensive health needs (10-12).

The research on case management are contradictory, with for instance studies showing reductions in healthcare utilisation (13) and increase in health-related quality of life (14) and others reporting no such effects (15). This may partly be explained by the complexity of the intervention with many components acting independently and interdependently (16) and the impact of context and the design of the health system in which the case management intervention is investigated. Up to this point little research has been conducted on case management for frail older people in Sweden (17, 18). Another reason may be the lack of a clear case management definition and

the multitude of different case management models, many of them poorly described in the studies. Few studies also report experiences of the interventions, and what parts that had been important in from the older people's, and the case managers' perspective. This is particularly important as they provide greater understanding of the intervention's content and construction. They could also provide insights in different barriers and facilitators that could be underlying reasons for an intervention being successful or not (19). Many studies also only focus on healthcare utilisation at one level, or at one agency. This is problematic because that there might be a shift of resources where there could be reduction in one agency/level by a corresponding increase in another. Comprehensive economic evaluations are therefore crucial to determine the efficacy of the intervention. However, economic evaluations of case management interventions are sparse and they rarely take evaluate cost in relation to any utility outcome that may reflect effects on the participant.

Thus, there is a need to investigate and evaluate case management for older people in a Swedish context, both in terms of healthcare utilisation and cost, but also from the older person's perspective, to investigate effects on health-related quality of life as well as experiences of the intervention. There is also a need to deal with the problems of the complexity of such intervention. The British Medical Research Council (16) has developed a framework for complex interventions with suggestions how to deal with issues related to development, feasibility/piloting, evaluating, and implementing a complex intervention. One case management intervention for frail older people has been launched in the southern of Sweden. So far, the result of the pilot study has been published (17). It is highly important to make a comprehensive evaluation of the full effects of this intervention, both on healthcare utilisation, costs, cost in relation to utility, and how the intervention has been experienced. This is necessary to be able to determine the efficacy of case management for frail older people in Sweden.

Background

As people get older the number of diseases and health complaints will increase (4). Greater age also implies a risk of having acute and chronic medical conditions and functional disabilities simultaneously (20). A study reported that over 80% of people older than 70 years in Sweden (n=414) visited a general practitioner or specialist, every year, and that every fifth person was hospitalised (21). This is consistent with another Swedish study (22) of people 85 years or older (n=496): a quarter (25%) reported in-patient care and 77% had visited a primary care general practitioner in the preceding 12 months. They also reported that 30% had an emergency department (ED) visit, and that only 4% that had visited neither a hospital nor primary care. Chronic conditions or the number of diagnoses have been reported to signify hospital stays (1, 23), physician visits (24, 25), home care (26) and municipal home care and services (2). It is also well known that older people's need for help and healthcare utilisation increases with age and during the development of disabilities (27, 28). In addition a small proportion of older people utilise a great proportion of the total utilised healthcare (2). The study by Condelius, Edberg, Jakobsson and Hallberg (2) showed that 15 per cent of the sample (aged 65+) (n=4907) had three or more hospital stays, but accounted for 35 per cent of all admissions. In another study looking at healthcare costs it was reported that 19.6% of those who had stable functional dependence or who declined dependence in at least one Activity of Daily Living (ADL) accounted for almost half (46.3%) of total expenditures (29). Older people also utilise healthcare from different providers. A study by Modin and Furhoff (30) showed that a large number of people in different professions were involved in the care of older people. They also reported that older people receiving home nursing care often also received specialist care in hospital and outpatient settings, and were in contact with other healthcare staff such as physiotherapists or occupational therapists. This is in line with the study by Condelius, Edberg, Jakobsson and Hallberg (2). They showed that those with three or more hospital stays had significantly more contacts with physicians in outpatient care compared with those with fewer than three hospital stays. This means that there is a group of older persons with disabilities and comorbidity who is more likely to be high healthcare users. This group also utilises healthcare from several care providers and that it accounts for a substantial part of the total amount of healthcare utilised. Thus, if this group of older people was better monitored and nursing action actions could be initiated earlier, this may lead

to a reduction in healthcare utilisation. This is something that would be valuable, both for this group of older people but also for the healthcare agencies.

Frailty

Older people with multiple diseases often have complex health needs. They may also be vulnerable and could therefore be considered as frail. Studies have estimated that between a quarter and a half of people older than 85 years are frail (31, 32). However, there is no clear definition of the concept of frailty (33, 34). In 1988 Woodhouse, Wynne, Baillie, James and Rawlins (35) defined frail older people as those 65 years or older who were dependent in ADL and that were often under institutional care. However, it has recently been suggested that frailty is a state of increased vulnerability changes after a stressor event, which increases the risk of adverse outcomes, such as falls and disability (36). It is also suggested that frail people undergo a larger deterioration than the non-frail, leading to dependency to a higher extent, and that they do not return to homeostasis (36) (see Figure 1).

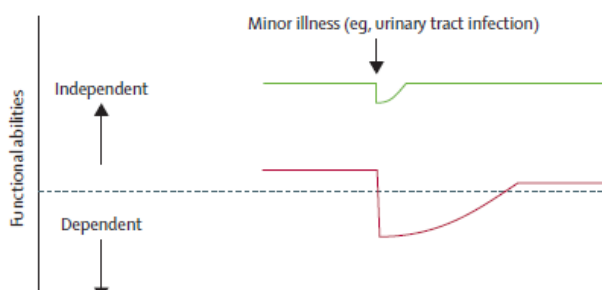


Figure 1: Vulnerability of frail older people to a sudden change in health status after a minor stressor. © The Lancet

The non-frail individual (green line) and a frail individual (red line) exposed to a minor stressor event. The non-frail has a small deterioration and returns to homeostasis. The non-frail has a larger deterioration, which may be manifested as functional dependency, and does not return to the same level of functional ability as before the stressor event. Source Clegg, Young (36).

Abellan van Kan, *et al.* (37) suggested that if frailty would be a useful clinical condition, it should be considered a predisability state. They stated that conceptually, frailty should exclude persons with disability. The reason is because when a frail individual is exposed to a stressor, it is postulated that they are at increased risk of developing disability or suffering other adverse outcomes (such as death, hospitalisation, or institutionalisation) and that that frailty is part of a continuum between normal physiological changes and the final states of disability and death (38).

There are two emerging models of frailty: the phenotype model and the cumulative deficit model. The phenotype of physical frailty has been proposed as the

combination of unintentional weight loss, self-reported exhaustion, low energy expenditure, slow gait speed, and weak grip strength (31). The cumulative deficit model forms the basis of the Canadian Study of Health and Aging (CSHA) frailty index, an index calculated from 92 variables comprising symptoms (e.g. low mood), signs (e.g. tremor), and abnormal laboratory values, disease states, and disabilities (collectively referred to as deficits) (39). This means that frailty is defined as a cumulative effect of individual deficits, with each of the 92 deficits contributing equally to the index (39).

Although the phenotype model contains five components, additional components have also been suggested. Ferrucci, *et al.* (40) presented fourteen different studies that reported components of the frailty syndrome. The studies had different combinations of mobility, strength, balance, motor processing, cognition, nutrition, endurance, and physical activity. The different approaches to defining frailty also have consequences for determination of the group of frail individuals. A study by Cigolle, Ofstedal, Tian and Blaum (41) examined the prevalence of frailty using three different frailty definitions. They found that 30% were frail according to at least one of the definitions, but only 3% were frail according all three definitions (41). It therefore seems important to be clear in defining frailty. In addition, there are proposals to operationalise the definition of frailty as a clinical measure and include not only physical components as mentioned above, but also, for instance, social circumstances and also other consequences of frailty, for instance healthcare utilisation (42). In this study, the authors reported the development of the instrument Clinical Global Impression of Change in Physical Frailty (CGIC-PF), which contains six intrinsic domains of physical frailty (mobility, balance, strength, endurance, nutrition, and neuromotor performance) and seven consequence domains (medical complexity, healthcare utilisation, appearance, self-perceived health, activities of daily living, emotional status, and social status) (42).

Thus, frailty could be seen as a combination of factors that influence a person's physiologic state and make the person vulnerable to external stressors (43). This vulnerability can in turn result in, for instance, disability or hospital stays. From a clinical point of view it could be useful to be able to define frailty without face-to-face examinations, which demands time and resources. One way of defining frailty could therefore be through physical dependency, as an assessment of physical domains, and through healthcare utilisation, as a form of consequence. It is important to try to identify frail older people as they may utilise a large proportion of healthcare, but also because they are at risk of severe deterioration and therefore unnecessary suffering. In addition, it could be valuable to try to reduce or prevent sudden changes in health status by removing or minimising stressors.

To be older and dependent on a fragmented health system

For a frail older person, contacts with multiple health agencies could be experienced as challenging. One aspect is problems that may occur when interacting with multiple health agencies, and navigating through the health system. According to the World Health Organization (WHO) (44) a health system can be defined as the sum of all institutions, organisations and resources with the main purpose of improving health. A health system needs an overall guidance and also requires staff, funds, information, supplies, transport, and communications. In addition the health system needs to provide services that are responsive and financially fair (44). In Sweden, as in many other western countries, healthcare is provided by a variety of healthcare agencies (9) and it has during the last decades been decentralised due to an increasing number of older people and an increasing demand for healthcare and social services (45). The need for interaction between different caregivers cannot be ignored and there is a challenge for the health system to provide coordinated care for older people with complex needs (8). But it has been found that health systems often contain parallel organisations with little or no collaboration or communication and with no one taking overall responsibility for the care. Williams (46) reported that people with chronic and co-morbid conditions experienced their care as discontinued and fragmented due to the involvement of various care providers, both at various levels in the health system, but also various staff groups within a specific clinic. It has been shown that older people are admitted to acute medical wards because of unmet social as well as physical needs (47, 48), perhaps due to difficulties in seeking care from the right agency and at right the level. One important source of poor continuity in the care of those with comorbidities is a lack of communication, including between different specialists and between different healthcare and service providers (46). Older people have also experienced the health system as being complicated and inaccessible because they did not know what they were entitled to or how to access information (49). It has also been reported that dependent older people experience the health system as insecure, due to reduced autonomy and limited possibilities for negotiation (50). Other studies found that older people fear that they will be abandoned by their carer and will not receive any care if they criticise their care (51, 52).

Another important aspect is that repeated encounters with different healthcare staff could affect the older person in various ways. A complex relationship is set up between the caregiver and care receiver. A good relationship has been reported to improve health outcomes (53). However, it is not always easy to achieve a solid relationship. Trust and confidence are two important factors for building and maintaining a relationship (54-56) and can be achieved through interpersonal continuity and patient-/person-centred care (54, 57). However, studies have reported that this is not always achieved in the health system (58-60). The experience could also be associated with being neglected or not listened to by healthcare staff. In a

study by Kristensson, Hallberg and Ekwall (61) it was reported that receiving healthcare and/or social services in Sweden in old age entailed a range of power positions, from having power to being powerless. Frail older people have particular difficulties to be taken seriously. Efforts must be made to improve care coordination and the focus needs to be on the older person rather than the organisation.

Transition in old age

Thus, there are several reasons why older people, especially those with multiple healthcare contacts, may face various challenges and therefore need support. It could be both because of the contacts with the health system, but also because of the transition(s) that the older person may be in. To go from being independent to dependent could be a challenge for frail older people, as they may, for instance, have a larger deterioration as reaction to minor stressors (36). Furthermore, going from independent to being dependent on the health system could also be experienced by older people as a great change in life (62) and could be one of the reasons for the difficulties older people experience in their contacts with the health system. This process could be described as a transition. A transition has by some been defined as a passage between two relatively stable periods in a person's life and is characterised by a turning point that starts the movement (63). Another characteristic of transitions is that they are processes that take time (64). A transition could, for instance, be a change in health status, role relationships, or a person's abilities or expectations, and denotes a change in needs of all human systems (65). There is often a sense of loss or of alienation from something that had been valued and familiar, and strategies in terms of new skills, new coping mechanisms, and new relationships need to be developed during transitions (63). These strategies are needed to deal with a significant marker event that cannot be dealt with in a usual way. This could be strategies to handle, for instance familiar, daily life experiences, such as maintaining one's health, or performing daily activities (63). Transitions on an individual level could be developmental, situational, or related to health/illness, and older people can experience several of these transitions simultaneously (63). Examples of transitions are illness experiences, such as diagnosis, rehabilitation and recovery; lifespan transitions, such as aging and death; and social and cultural transitions, such as role loss or retirement (64). During such transitions people tend to be more vulnerable to risks that may in turn affect their health (64). A transition could be facilitated and thereby, a healthy transition could be achieved. There are several nursing therapeutics that could be used as support to facilitate the transition, for example: assessment of the transition process (to determine which way the transition progresses), reminiscence (to facilitate integration of the transition into the life course), role supplementation (to facilitate the process of developing new knowledge and skills), creation of a healthy environment, and mobilisation of resources (enhancement of both personal

and environmental resources) (63). However, Schumacher, Jones and Meleis (63) state that there is some evidence that older people and their family members do not always receive the professional support they need during the transition. It is therefore important that different kinds of support are provided to older people, especially frail older people, to facilitate healthy transitions that enable a well-functioning life.

Predictors of healthcare utilisation and frailty

Knowing that there are frail older people that are in various kinds of transitions and at risk of deterioration, it could be valuable to identify these people. But as has been shown above, the concept of frailty is a combination of variables rather than a single variable. As a result, predictors of one of these associated variables or consequences of frailty could be investigated, rather than frailty itself. Studies have, for instance, identified predictors of falls (66) and reduction in activities of daily living (67). One particularly interesting variable associated with frailty is healthcare utilisation. This is interesting from an organisational point of view as frail people's healthcare utilisation has a great impact on the health system, but also from an individual point of view as healthcare utilisation has to be assumed to be undesirable for most people. Several studies have tried to identify predictors of healthcare utilisation. Known predictors for different kinds of healthcare utilisation include functional dependency (68), number of diseases (69), depression (70), and living at home rather than in special accommodation (i.e. a nursing home) (71). In addition, healthcare utilisation has been associated with living alone, economic hardship (72), medical diagnoses (73), problems with cognition, foot problems, number of falls (74), and comorbidity (75). Some studies showed that hospital stays itself could be a risk factor for subsequent utilisation and becoming a high-impact user (76-78). However, in a study by Roland, Dusheiko, Gravelle and Parker (79) it was shown that older people with two or more ED visits accounted for 38% of the admissions in the index year, but less than 10% the next year and just over 3% five years later (79). Therefore, more studies investigating predictors of healthcare utilisation are needed as this could be one way to identify frail older people and thus potential high healthcare users. Research on long-term predictors is sparse and focus should therefore particularly be given to longitudinal studies with long-term perspectives.

The knowledge base also shows that there is a variety of variables that could affect healthcare utilisation and it is thus important to include variables that have been found to predict healthcare utilisation. Much literature focuses on physical components, but few studies have investigated psychosocial variables' impact on healthcare utilisation. There are also little research on healthcare utilisations patterns and the impact of psychosocial variables compared to physical components. To obtain a comprehensive picture of predictors of health utilisation, social factors,

physical, psychosocial components, and previous healthcare utilisation must be included. These predictors could be used to identify those who may benefit from different forms of preventive interventions.

Case management

Various preventive interventions for older people have been developed during recent decades. The aims of these have been to reduce the risk of care fragmentation (80), prevent healthcare utilisation and increases in healthcare costs, improve quality of life (QoL), or maintain/improve functional ability or health (81). For frail older people with complex health needs and various contacts within the health system, often with multiple diseases, such interventions (e.g. preventive home visits targeting those of a certain age or single disease management programmes targeting those with a specific disease) may not be sufficient. A broader more holistic approach such as a case management programme may be necessary. This could improve care coordination and minimise the risk of fragmentation, as well as improving older people's overall situation by making them seek care at the right level and at the right time. Case management could maybe improve or maintain older people's health or overall situation and at the same time help them to take control of their healthcare situation and other kinds of support.

Case management has developed during a long period and has been used in different areas and with different aims. This had led to misunderstandings and the use of different concepts in the case management literature, which has made different case management interventions difficult to understand and compare. It is therefore important to understand the history of case management, its different origins, and the development to understand how separate models emerged.

Case management can be traced back to the late 19th century as the early public health nurses practiced a form of case management (82). But it was not until the 1960s and the early 1970s that case management got its big resurgence because of a rapid expansion of human service programmes (83). These programs were often developed to provide extremely specialised services or to serve narrowly defined target groups. As a result highly complex, fragmented, and duplicated and countless individual programs emerged. This was particularly troublesome for those with complex health needs that required them to have contact with multiple uncoordinated programmes (83, 84). Therefore, in the 1970s, the United States Department of Health, Education, and Welfare introduced special grants to test various service integration techniques (83). One feature that was common to most launched projects was the role of a "systems agent," operationally a case manager. Another important reason for an upsurge in case management in the 1970s was the deinstitutionalisation of the

mentally disabled. Persons who had previously been living in various institutions were now forced to depend on community service networks for support (82). Case management was here identified as a key function in navigating through and integrating a complex and uncoordinated system (82). Many different labels have been used for case managers over the years: integrator, expeditor, ombudsman, patient representative, personal programme coordinator, and continuity agent, to mention a few. It was early recognised that even if case management has its roots in psychiatry and social work, nurses have played important parts in these studies. Lamb (85) highlights that nurses have served both as principal investigators in many studies conducted in this area, and also as case managers delivering the intervention. Case management expanded into other healthcare areas during the 1980s due to escalating healthcare costs (82). Hospitals in the USA restructured in an effort to standardise plans and reduce costs (86), mainly because of prospective payment systems and the implementation of diagnosis-related groups (DRGs) in 1984 (82). The DRG system created reimbursement incentives for decreased lengths of stay (LOS) by paying for care for the specific case rather than the actual care provided (82). Thus, case management has its base in psychiatry and social services, but has strong connections to nursing, and has many areas of application (86). This may be one reason for the function/concept partly developing in parallel and partly differently.

The use and development of case management in various areas may be one reason for the lack of a common classification and definition of case management. Because, even though the case management concept has been used in the health system for at least 40 years, there is still no agreed definition of case management in the literature (87, 88). This is important to acknowledge because if it is not clear which assumptions and functions are included in each case management model it will be difficult to compare them. This problem has also been put forward by different researchers over a long period (11, 89, 90). To be able to distinguish between different case management models it is important to know something about the different ways of classifying case management models. In the following sections, definitions and a model that describe the case management process are presented, followed by two different ways of classification: one based on the amount of functions, and the other based more on the origin and objectives of case management.

Lee, Mackenzie, Dudley-Brown and Chin (88) reported that some authors define case management as primarily a matter of matching, distributing, and coordinating services, where other, for instance Young (91), argues that case management for older people ranges from being a matter of cost control to being more complex, including both acute and long-term needs across various settings and throughout the whole care trajectory. Many of the leading professional organisations, especially in the USA, have adopted definitions of case management. The National Association of Social Workers (NASW), the American Board for Occupational Health Nurses (ABOHN), and the Association of Rehabilitation Nurses (ARN) all have their own definitions, each

slightly different from the others, but all similar in context. The Case Management Society of America (CMSA) supports a multidisciplinary approach to case management, as a function within a profession rather than as a function of one specific discipline. The definition of case management in CMSA's *Standards of Practice for Case Management* (10):

Case management is a collaborative process of assessment, planning, facilitation, care coordination, evaluation and advocacy for options and services to meet an individual's and family's comprehensive health needs through communication and available resources to promote quality cost-effective outcomes. (p. 8)

The American Nurses Credentialing Center (ANCC), a subsidiary of the American Nurses Association (ANA) has according to Leonard and Miller (12) defined nursing case management as:

Nursing Case Management is a dynamic and systematic collaborative approach to providing and coordinating healthcare services to a defined population. It is a participative process to identify and facilitate options and services for meeting individuals' health needs, while decreasing fragmentation and duplication of care, and enhancing quality, cost-effective clinical outcomes. The framework for nursing case management includes five components: assessment, planning, implementation, evaluation, and interaction. (p. 23)

Both definitions, but especially the ANCC definition, make it clear that one way of defining and classifying case management is to clearly identify the functions or components that are included. In the definition above, the ANCC states that assessment, planning, implementation, evaluation, and interaction are the essential components of case management. Several case management functions have been suggested to be included in basic case management. According to Björkman (92) and the CMSA (10), this should include identification and outreach, comprehensive individual-based assessment, care planning, care coordination, service provision, monitoring, evaluation, and meeting individual needs. There seems to be some consensus about these main components. These are similar to the functions presented by the ANCC, Hutt, Rosen and McCauley (11) who present six functions: screening or case finding, assessment, care planning, implementation (or action), monitoring, and back to assessment (or reassessment or review). Freund, Kayling, Miksch, Szecsenyi and Wensing (93) have arranged these functions in a figure demonstrating the cyclic nature of the case management process (Figure 2). This figure also makes it clear why nurses are well suited to the role, as the functions of case management closely follow the framework of the nursing process (assessment, planning, implementation, and evaluation) (12, 86). Others have suggested that nurses are well suited because their broad scope of practice, mix of clinical skills, and experience in coordination (94).

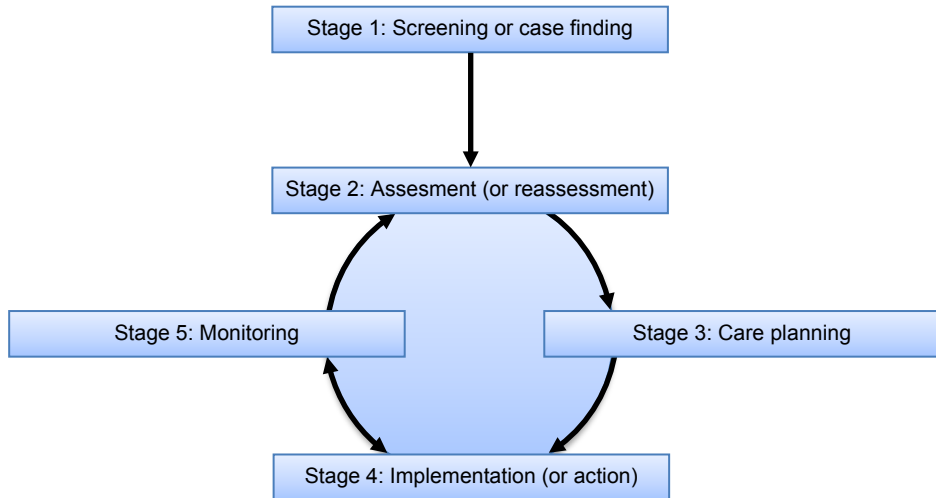


Figure 2: The case management process

A schematic view of the essential elements of the case management process. Adopted from Freund, Kayling (93).

Even if there are similarities with the traditional nursing role and nursing process, there are several things that are unique to the case manager. Compared to chronic illness management interventions, that are usually includes nurses, case manager can be seen conceptually as an agent of the patient, taking a “whole person” and the patients “whole” situation and potential areas problems, rather than solely focusing on problems related to disease(s) or problems that were the causes of the care (95). There are no sharp boarder between the roles and responsibilities, but should be seen an overall general differences. There are several functions that case management have in common with nursing care and other interventions. Based on the case management interventions included in the review by Hickam, *et al.* (95) features shared with other chronic illness management interventions was clinical assessment, care planning, health education, self-care instructions, monitoring clinical parameters, adjusting medications and communicating with practice team. Hickam, *et al.* (95) also provided distinctive features of the case management programmes in their review, where these differed from chronic illness management interventions:

- Prominent supervisory role in coordinating multiple aspects of care
- High-intensity, longitudinal engagement with patient, families and other caregivers
- Functioning as a patient advocate/agent
- Comprehensively assessing, monitoring, and addressing patients’ needs
- Facilitating access to community resources, including social services

- Mainly for patients with complex care needs

These listed features may also occur in other chronic illness management, but the case manager performs these functions to a higher extent. For example could there be coordination of activities in chronic illness management, but in contrast to case management this is usually the responsibility of a team or larger group rather than a single case manager. The role of the case manager is often also to coordinate a wide range of health agencies or services, while other chronic illness management is not as extensive (95). There are many various forms of case management, with similarities and differences between the models. Intagliata (83) refers to Ross who offers three different models for case management designed for older people based on functions (Table 1), where those features presented in the work by Hutt, Rosen and McCauley (11) and those included in Figure 2, have some features in common with the minimal model being and some with the coordination model.

Table 1: Three models for case management programmes. From Ross, in Intagliata (83).

	Minimal model	Coordination model	Comprehensive model
Outreach	X	X	X
Client assessment	X	X	X
Case planning	X	X	X
Referral to service providers	X	X	X
Advocacy for client		X	X
Direct casework		X	X
Developing natural support systems		X	X
Reassessment		X	X
Advocacy for resource development			X
Monitoring quality			X
Public education			X
Crisis intervention			X

Another way to classify case management models was proposed by Mueser, Bond, Drake and Resnick (96). Their approach in their review of care for severe mental illness was more built on the objectives of the models. They also suggested that models involving provision of case management services should be named “community care models” in order to reduce confusion when using the case management concept. They identified three broad types of case management: 1) standard case management (including broker service models and clinical case management models), 2) rehabilitation-oriented community care (including strengths and rehabilitation models), and 3) intensive comprehensive care (including assertive community treatment models and intensive case management models) (96). These groups of case management models are in line with, for example, those presented in

the review of the care for substance-abusing populations by Vanderplasschen, Wolf, Rapp and Broekaert (97). They presented four broad groups including the same subgroups of case management models, but they suggest a somewhat different grouping. Here below follows a brief description of the different types of case management according to the three-group classification suggested by Mueser, Bond, Drake and Resnick (96).

Standard case management models

In the **broker or expander-broker model** the case manager's primary task is to connect the patient to the services needed and to coordinate the services between the different service providers. The model emerged early in the deinstitutionalisation process to address many patients' problem with navigating through the complex and confusing community mental health system (98). The specific tasks of the case manager in this model included assessment, planning, linking to services, monitoring and advocacy (83). Emphasis in this model is on assessing patient needs, referring to, as well as coordinating, services, and monitoring ongoing treatment (96). The brokered case manager has little patient contact (just one or two contacts in total) (97) and it is assumed that the services needed could be identified without the case managers themselves acting as clinicians (96). In this model clinical skills are not necessary to be able to perform effective case management.

The **clinical case management model** was developed as it was recognised that case managers most often provide direct services and therefore act as clinicians (99, 100). Clinical case management includes providing services in four broad areas: (1) the initial phase (including engagement, assessment, and planning), (2) environmental interventions (for example, consultation with families, maintenance and expansion of social network, collaboration with physicians and hospitals, and advocacy), (3) patient interventions (such as psychotherapy, training in living skills, and psychoeducation), and (4) patient-environmental interventions (such as crisis interventions and monitoring) (101).

Rehabilitation-oriented community care

As a reaction to standard case management models, which tend to overemphasise the limits and impairments associated with mental illness, **the strengths models** focus on the relationship between the client and the case manager and the individual's abilities to identify their strengths. The goals in the care plan are identified by the individual rather than the case manager (102). The model is guided by the following six principles: (1) people with psychiatric disabilities can recover, continue to learn, grow, and change; (2) the focus is on individual strengths rather than deficits; (3) the community is viewed as an oasis of resources, not as an obstacle; (4) interventions are based on client self-determination; (5) the case manager-patient relationship is

primary and essential; and (6) the primary setting for contacts is in the community (102).

The **rehabilitation models** have many similarities with the strengths models when it comes to emphasising the provision of case management based on the goals and desires of the individual client. In contrast to the strengths model which may have focus on overall goals of the formal health system the rehabilitation model focus more on the individual's unique goals and needs. What makes this model unique is its focus on assessing and improving instrumental and social skills that may promote functional living in the community and the attainment of personal goals (96).

Intensive comprehensive care models

The **assertive community treatment (ACT) model** was developed as a community treatment and rehabilitation programme by Stein and Test during the 1970s (103). This model was designed as an alternative to hospital for people with mental illness and as a comprehensive model that went beyond the limits of either the broker or the clinical case management model (103). ACT is usually delivered by multidisciplinary teams consisting of a nurse, a psychiatrist, and at least two case managers (96). The model is based on six different principles: (1) a low patient ratio (1:10 rather than 1:30 or higher); (2) most services being provided in the community (for instance at patients' homes) rather than in an office; (3) the caseloads being shared across clinicians (rather than having individual caseloads); (4) 24-h coverage; (5) most services being provided by the ACT team and not being brokered out; and (6) time-unlimited services (103). The model's key principles of a low patient ratio, direct service provision, and service provision in the patient's natural environment are reflections of the ACT model's prioritisation of providing practical support in daily living, such as laundry and shopping (96).

The **intensive case management model** was developed as a reaction of growing recognition that not all patients with severe mental disorders could take part in traditional case management practices. However, they still utilised a substantial proportion of costly healthcare and service treatments, such as emergency room and new initiatives had to be taken to try to reduce the needs of these high service users (104). Intensive case management is characterised by low caseloads and provides assertive outreach and services in patients' natural environments, as well as practical assistance in daily living skills (96). One distinction between the intensive case management model and the ACT model is that the caseloads are not shared in the intensive case management model.

Similarities between the models

The three different types of case management presented by Mueser, Bond, Drake and Resnick (96) share many similarities. This is a result of constant adoption and modification to meet the unique needs of specific patient populations in various

contexts. For instance, the ACT model has successfully been replicated but with various degrees of fidelity (96). Furthermore, the original six principles of the ACT have changed, both in content and in number. Kent and Burns (105) presented an adapted version of the ACT model that contains nine elements, where, for example, the principle of 24-hour coverage stated by Stein and Test (103) is no longer included. The broker services and the clinical case management models may appear similar because case managers rarely act purely as service brokers without employing clinical skills (96). One way to explain the similarities is not to see the models as different approaches but as a continuum with multiple factors. Each of these factors has endpoints lying at opposite ends of the continuum, for instance high or low intensity, or shared or individual caseloads. Kanter (101) stated that assertive community treatment is a pure form of clinical case management and lies at the opposite end of the case management continuum to the earlier 'brokerage' model. Depending on the context and patient population, the model may need to be adapted to suit specific objectives. Many of the ACT models' underlying concepts have also become emblematic of good clinical practice (105), and the key principles of the models may therefore not be suitable to distinguish models. Instead, it seems more useful and important to present a comprehensive description of the case management model used.

Research on case management

A substantial number of studies investigating case management for older people have been published. Most studies have been conducted in the USA, but an increasing number of studies are being conducted around the world, including in Europe. There are examples of studies investigating case management for older, or frail older, people, carried out in, besides the USA (106, 107), Canada (15), Hong Kong (108), Australia (109), New Zealand (110), the United Kingdom (111), the Netherlands (112), Finland (113), and Italy (13). There is also an increasing interest in case management for older people in Sweden. One study by Reinius, *et al.* (18) investigated the effects of telephone-based case management on healthcare utilisation in frequent ED visitors. This study, however, focused on the population in general and not only on older people. There seems to be only one Swedish study so far investigating case management for frail older people in a Swedish context. For this study, of which the majority of this thesis is a part of, the pilot study has been published by Kristensson, Ekwall, Jakobsson, Midlov and Hallberg (17).

The effects on different outcome measures have been investigated, for instance different healthcare utilisation measures such as LOS, hospital stays, and ED admissions, but also physical or cognitive functioning, quality of life (QoL), psychological health or well-being, mortality, and costs. Several reviews have,

however, concluded that there are inconclusive results and weak evidence for the effects of case management for frail older people in these areas (11, 90, 95, 114). Some case management interventions are also telephone based, while other are performed face to face. Thus, more research is needed to understand whether, and under what circumstances, case management can be effective (114-116). It could also be difficult to draw conclusions about an entire intervention based a single outcome measure, especially when the interventions contain many different parts that could act dependently or interdependently. For example, when using healthcare utilisation as an outcome measure, a case management intervention could result in a significant reduction in utilisation at one level and a simultaneous increase at other level. This means that case management may lead to shifts in resources between different levels or agencies (117) and that any evaluation has to be comprehensive, including different health agencies at different levels. This is particularly true when it comes to costs. However, comprehensive cost evaluations of case management interventions combining costs of in- and outpatient care, municipal care and services, and informal care are sparse. Thus, differences in outcome measure may be one reason for the inconclusive results. However, one must bear in mind that case management studies also often have differences when it comes to study design, sample, content of the intervention, provider of the intervention, setting (hospital or home), intensity, and follow-up time, which may all be reasons for the inconclusive results (90, 118). In addition, the interventions and study designs are not always described in enough detail (90, 118, 119). Moreover, there is also a need for studies of how the interventions have been performed and experienced, as in-depth investigations can give deeper understanding of the interventions.

Another aspect of case management evaluation is that it often has organisational focus. For frail older people it could be experienced as something positive that a case manager is able to meet an unmet healthcare need (90), even if this means an increase in healthcare utilisation. Therefore, it is important to conduct qualitative studies that may contribute to comprehensive descriptions of the interventions and experiences of the intervention, and provide insight as to why an intervention does or does not work. However, reported qualitative studies of case management interventions for older people, experienced by the participants, the case managers, or both, are still rather few (120-129). Nonetheless, it was shown that the relationship was highly valued and it contributed to clients' experiences of security, safety, comfort (127), and improved quality of life (124). There are studies that have reported that their participants were satisfied with the case managers' different skills and ability to arrange services (124, 129). The study by Sargent, Pickard, Sheaff and Boaden (129) investigated these skills more closely. Their aim was to describe case management from the perspective of the patients and carers. Five categories of case management tasks emerged; clinical care, co-ordination of care, education, advocacy, and psychosocial support. The importance of psychosocial support was emphasised by

both the patients and the carers and was viewed as equally important as clinical care. These outcomes, which illuminate the benefits and advantages of case management from the participants' point of view, should not be ignored. Thus, to determine whether an intervention is effective, a combination of effects on the participants, the participants' experiences, and effects at an organisational level must be investigated.

A change in an individual's status in relation to costs is one way of evaluating this combination of organisational and individual levels. In studies of case management for older people there are examples where costs have been related to death rates (130), and successful treatment (prevented functional decline accompanied by improved well-being) (131). There are also examples of studies with comprehensive home-visiting programs, that are not explicitly defined as case management, but that share many of the features, where costs are related to preventing one day of a permanent stay in a nursing home, disability-free years gained by the intervention (132), self-reported health (133). Studies with costs in relation to any patient-oriented outcome are however lacking. It is also difficult to compare these studies. They are all examples of cost-effectiveness analysis (CEA), where a health effect is presented as a single outcome, unvalued, and in natural units related to the objectives of the programme (134). Cost-utility analysis (CUA) on the other hand is a method that allows comparisons between different studies. In this analysis the outcome is measured as some utility that may be single or multiple, that is generic as opposed to programme specific, and that incorporates the notion of values. A common utility outcome in CUA is quality-adjusted life years (QALY) gained. This outcome simultaneously incorporates both changes in quantity of life (mortality) and changes in quality of life (morbidity) (134). QALY could be described as a quality adjustment weight for a health state multiplied by the time in the state (134). There are several advantages of using QALY and CUA compared to CEA. One is that when health-related quality of life (HRQoL) is measured with, for instance, SF-12 or EQ-5D, it can be converted to QALY. Another advantage is that the wide use of QALY allows broad applicability and makes it possible to compare different interventions in different areas. This is not only true for interventions in one specific area, but also completely different areas. CUA is therefore more useful for decision-makers than CEA (134). However, for case management for frail older people there seem to be no studies using a CUA.

The Neuman Systems Model - A framework for prevention as intervention

Chronic conditions are common among older people. The prevalence of multimorbidity (having two or more concurrent diseases) among older people has in a review by Marengoni, *et al.* (1) been suggested to vary from 55 to 98%. The

healthcare of today has a predominantly biomedical approach to older people with chronic conditions, which is one reason for the fragmented service provision, which could be described as reactive, unplanned, and episodic (135). The traditional biomedical model of client assessment, based upon examinations of the body, is incapable of capturing all aspects that may be the reason for reduced health and to make a holistic care plan with actions making it possible for the individual to perceive health and wellbeing (135). One way to describe older people's struggles that takes this into account is The Neuman Systems Model (136). This model provides a comprehensive, flexible, "wholistic", and system-based perspective for nursing (137). It could be used to describe how and why people feel illness and what mechanism and factors are involved, as well as why frail people are at greater risk of illness and what could be done to prevent bad health.

The Neuman Systems Model itself is complex but is, according to the authors, not complicated (136). The client system, where the client may be an individual, family or community, illustrates the relationship among four different nursing metaparadigm concepts: human beings, environment, health, and nursing (136). These four constructs interact with each other and are interdependent (136, 138).

Human beings are viewed as clients or client systems and consist of five interacting variable areas that are uniquely blended for each system: physiological, psychological, sociocultural, developmental, and spiritual (136). These five client system variables interact with a set of defence lines that together serves as protection for the client. The client system is defined in terms of a series of concentric circles surrounding a core, or the basic structure. These lines—the lines of resistance, the normal line of defence, and the flexible line of defence (see Figure 3)—are basically what protect the basic structure. The client system variables interact with defence system and ideally, these variables are in harmonious balance for the individual and are stable (136, 138). In the defence system elements, such as, coping patterns, lifestyle factors, and belief system influences, are found that are similar but that are specific functionally, related to the client system variables (136). According to Neuman and Fawcett (136) the outer boundary, the flexible line of defence, surrounds the normal line of defence and acts like a protective buffer system for the normal or stable state and prevents stressors from invading the system (Figure 3). As it is flexible, it could expand away from the normal line of defence, giving more protection, or it could draw closer giving less protection. The line is dynamic and can change rapidly, for instance in a state of sleep loss or dehydration. That is, individual or multiple stressors have the potential to reduce the effectiveness of this buffer system. The normal line of defence is marked as a solid line and represents what the client has become and the "normal state", or usual wellness level. This is determined by the adjustment of the five client variables to environmental stressors.

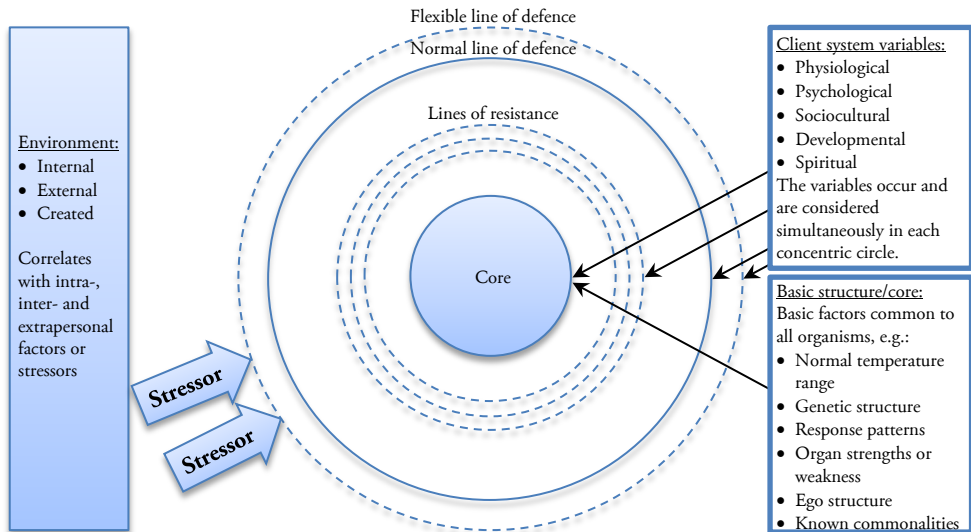


Figure 3: Human beings as clients/client systems

Human beings are viewed as clients or client systems with the core, the lines of resistance, the normal line of defence, and the flexible line of defence. Adapted from Neuman and Fawcett (136).

When the normal line of defence is penetrated by stressors, a reaction within the client system will occur. The client will react with symptoms of instability or illness. Lines of resistance contain both known and unknown factors, internal and external resource factors that contribute to the support of the basic structure and the normal line of defence. Neuman and Fawcett (136) give the example of the body's activation of the immune system mechanisms. If these lines are effective, the system is allowed to reconstitute; if not, the stressor will deplete the system of energy, causing illness and death. The central structure, the core, is the source of the five client system variables. These represent the human processes of living and dying within the context of the interacting and interrelated client system variables. Basic survival factors, such as innate and genetic features, are also located in the core. Each client system variable in the core will also have its own unique characteristics. For the physiological variable, they include physical and physiological intactness of the body cells, and the preservation of tissues and organs. Sense of self and cognition are included in the psychological variable. The sociocultural variable includes extent of integration into a culture and the larger society. The feature of the developmental variable is the extent of accomplishment of developmental tasks, and the spiritual variable includes the extent of understanding of meaning of life and faith (136).

The environment can, according to Neuman and Fawcett (136), both be internal (inside the client), external (outside the client), or created. The created environment represents an open system exchanging energy with both the internal and external

environments. It is created unconsciously by the client and is symbolic expression of the system's wholeness. Various kinds of stressors can be found within these three environments. The stressors are defined as tension-producing stimuli that have the potential to cause instability (136). The stressors may be interpreted by the client as positive or negative and depends on the client's ability to handle them. The Neuman Systems Model's environmental stressors are classified as intrapersonal stressors, internal environmental forces that occur within the internal and external environmental boundaries of the client system, for example conditioned or autoimmune responses; interpersonal stressors, external environmental interaction forces that occur outside the boundaries of the client system in the proximal range, such as between one or more role expectations or communication patterns; and extrapersonal stressors, which are external environmental interaction forces that occur outside the boundaries of the client system in the distal range, for instance between one or more financial concerns. The reaction to the stressors is determined by the strength of the stressors, the strength of the defence system within the client, and whether or not the client has experiences of the particular stressor (136).

Health is the third concept and is viewed in the model as a continuum with wellness and illness at opposite ends (136). The health of the client changes throughout the life course, falling or rising to various levels depending on basic structure factors and satisfactory and unsatisfactory adjustment of the client system to environmental stressors. The model implies that there is a continuous energy flow between the client system and the environment and that the state moves towards wellness if more energy is generated than is used; and if more energy is used than is generated, the health state moves towards illness and death. Changes in wellness or in the stability of the system are caused by stressor invasion of the normal line of defence (136).

According to Neuman and Fawcett (136) the major concern for the last concept, **nursing**, is to keep the client system stable and equilibrated. This is achieved by accurate assessment of the effects and possible effects of the environmental stressors, as well as by assisting client adjustments to attain an optimal level of wellness. This is done by three "prevention-as-interventions": primary prevention, secondary prevention, and tertiary prevention. Primary prevention is used as wellness retention to strengthen the client's flexible line of defence and thus protects the normal line of defence. It also reduces the possibility of encounters with stressors. The goal is to promote client wellness by stress prevention and reducing of risk factors. This also includes different forms of health promotion (see Figure 4). Secondary prevention is used as wellness attainment to protect the basic structure by strengthening the lines of resistance. The goal here is to identify pre-existing stressors at an early stage and to provide appropriate treatment of symptoms to attain optimal client wellness (Figure 4).

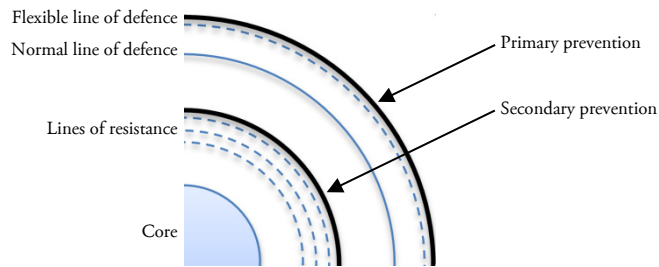


Figure 4: Primary and secondary prevention

Format of primary and secondary prevention as intervention modes. Adapted from Neuman and Fawcett (136).

Tertiary prevention is used to maintain wellness to protect the client system's reconstitution. This could be during the return to wellness after treatment. The goal is to maintain an optimal wellness level by supporting existing strengths and conserving client system energy (136).

The Neuman Systems Model is appealing as it gives a theory to understand frailty as a condition of unbalance and being frail as temporarily. That is, stability can be achieved again. The five client system variables in the Neuman Systems Model (physiological, psychological, sociocultural, developmental, and spiritual) seem to have similarities to the domains of physical frailty suggested by Studenski, *et al.* (42). Even though they suggested six intrinsic domains, for instance strength and balance, and seven consequences domains including, among others, appearance, self-perceived health, emotional status, and social status, many of them could be fitted into the Neuman System Model's five client system variables. It also gives a logical approach to interventions, used as prevention on different levels. Another advantage is the model helps the understanding of how prevention could help the client to strengthen the defence lines and thus achieve stability (136). Another advantage is the view of the client as a part in an open interacting system in constant interface with internal and external environmental stressors and factors. The environment is put forward as critically important because nursing in, for instance, community care cannot control the client's environment as nurses can in inpatient settings. This could for example be about hygiene and safety which are difficult to influence in a home environment. It is therefore necessary to view the client as a part of other systems such as the family or the community (136). In addition, the link between unbalanced systems with unbalance in the system variables will lead to poor health and by extension healthcare utilisation. However, it is unclear whether all client system variables are equally important for a balanced system or how they affect the system. It is therefore important to investigate what impact stressors related to the different client system variables have on healthcare utilisation.

Case management and the Neuman Systems Model

Theoretical backgrounds for case management are sparse (89), even though classification on a more theoretical approach has been presented. Conti (139) classified the various case management models as grand, middle-range and practice-based models. Grand theories include abstract conceptual systems and theories and focus on central phenomena in a certain discipline or paradigm (140). The grand models are based on systems theory and mainly focus on integrating and coordination (139), like the broker model. The middle-range models could be divided into purchaser-/client-based models, such as hospitals-based, and provider-based models (139). Middle-range theories are more circumscribed and elaborate more concrete relationships and concepts. These theories could be connected and relate to grand theories, on the higher theoretical level, or directly to the discipline/paradigm on the lower theoretical level (140). Practice-based models are models targeting and tailored to a specific population (139). They can be considered practice traditions and are related to grand and middle-range theories (140).

The reason for the limited theoretical foundations for case management could be that most case management interventions are based on middle-range theories or are practice based. However, case management could easily fit into the Neuman Systems Model (136). The preventive case management approach is recognised in “prevention-as-intervention” (136). Case management works on both on primary, secondary, and tertiary levels of prevention. A major part of case management is to assess and detect needs. This is done through regular visits, which give the case managers knowledge about the client and how the client reacts in certain situations. This is clearly a vital part of the Neuman Systems Model, where it is stated that unmet needs reduce the client’s wellness. It is also stated that it is possible to predict client reactions to stressors based on similar situations with similar stressors, thus, acknowledging the advantage of knowing the client. The model also emphasises the uniqueness of each individual or client. This is also in line with case management, which is a person-centred approach where each intervention is tailored to the needs of each client. The strong connection to environmental factors is another aspect that enables application of the Neuman Systems Model to case management. Another advantage of using the Neuman Systems Model when evaluating case management is that according to Neuman and Fawcett (136) the result of successful “prevention-as-interventions” increased wellbeing. This could therefore be used as an outcome measure when evaluating the effects of various interventions. Other concepts, e.g. HRQoL and QoL, are closely related to wellbeing (141).

Complex interventions

As a case management intervention involves interpersonal relationships between the case manager and the frail older person, and could comprise several components, it could be considered as complex (16). There is a wide possible range of complexity, with several dimensions, for instance: the number and difficulty of behaviours required by those delivering or receiving the intervention; the number of groups or organisational levels targeted by the intervention; number and variability of outcomes; and the degree of flexibility or tailoring of the intervention permitted (16). The complexity, with different parts interacting with each other, is also highlighted in the Neuman Systems Model (136). This complexity makes interventions difficult to develop, document, deliver, and replicate because it could be hard to know what will be, or what, the active and effective component in the intervention was. In 2000 the British Medical Research Council (MRC) developed a framework (142), revised in 2008 (16), that in a structured way tries to deal with some of these difficulties, but also raises special demands on research of complex interventions. The first version of the MRC framework suggested a three-phased approach when studying complex interventions. The first phase comprises theory, modelling, and an exploratory trial; the second a randomised controlled trial (RCT) and third long term implementation. The revised version now comprises four stages: development, feasibility/piloting, evaluation, and implementation. In addition to these stages there are different key functions and activities at each stage. Even though they are presented as stages, they often do not follow a linear or even a cyclical sequence (See Figure 5) (16). According to this framework, a complex intervention not only has to be developed and conducted in a certain way, but also has to be properly evaluated for conclusions to be

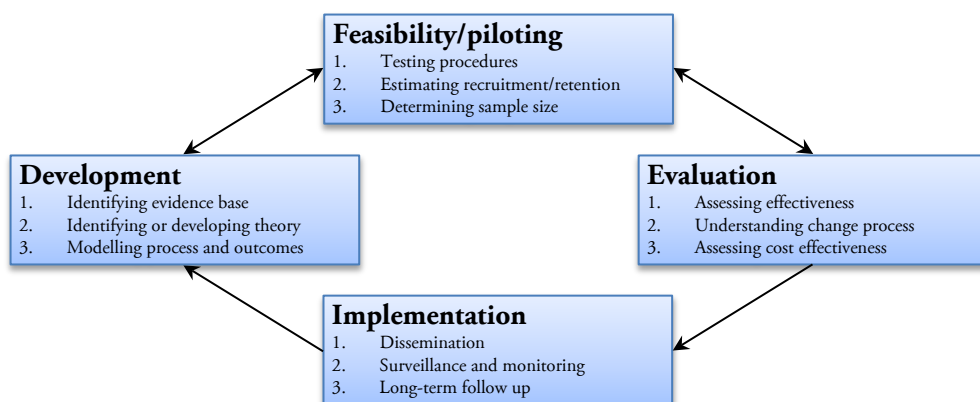


Figure 5: Key elements of the development and evaluation process

The main stages and key activities at each stage in the MRC framework for complex interventions. Reporting is not shown as a separate activity but should be an important element of each stage. Source The Medical Research Council (16).

drawn about effectiveness and to enable replication. The evaluation step includes quantitative, qualitative, and economic evaluation (16).

Focus when evaluating a complex intervention should also be given to cost-effectiveness and impact on healthcare utilisation. Economic evaluation could be valuable because it will make the results of the evaluation much more useful for decision-makers (16). In an organisational intervention, such as a case management programme, outcomes such as healthcare utilisation are also of interest. This could be looked on both as an outcome at the individual level, something that may affect the situation for the participant, but also as an economic outcome, where, for example, LOS and hospital stays are directly linked to healthcare costs and health system dimensioning. A mix of evaluation methods is therefore necessary to capture the perspectives of the individual and the organisation. This is also true when it comes to outcome measures in complex interventions. Even if the MRC suggests a single primary outcome and a few secondary outcomes as the most straightforward way to analyse, they also state that this may not represent the best use of data or capture the success of the intervention in more unexpected areas. A key message is that the choice of outcome variables needs to be theoretically underpinned and carefully selected (16). In addition, the MRC framework also suggests performing a process evaluation, which could be highly valuable and could give insight into why an intervention fails or how it works and can be optimised (16). Thus, conducting different studies using different methodology and/or different outcomes is crucial when evaluating complex interventions.

Aims

The overall aim was to investigate healthcare utilisation patterns and to explore the effects of a case management intervention for frail older people on healthcare utilisation and costs in relation to utility. A further aim was to explore the older people's and case managers' experiences of the intervention.

The specific aims of the different studies were:

- To investigate healthcare utilisation patterns, in terms of hospital stays and length of stays over a six-year period, among older people (aged 60 years and older) classified as dependent/independent in activities of daily living (ADL), and/or at/not at risk of depression. The aim was also to identify predictors of healthcare utilisation (**Study I**).
- To investigate the effects of a case management intervention for frail older people (aged 65+ years) on healthcare utilisation (**Study II**).
- To evaluate the effects of a case management intervention for frail older people (aged 65+ years) on costs in relation to utility (**Study III**).
- To explore frail older people's and case managers' experiences of a complex case management intervention (**Study IV, Framework**).

Methods

Design

This thesis consists of four studies with three designs: a longitudinal cohort design (**Study I**), an experimental design (**Study II-III**), and a qualitative design (**Study IV**). In addition semi structured interviews were used for three case reports (**framework**). A schematic overview of the design and sample of **Studies I-IV** are shown in Table 2.

Table 2: Design and sample in Studies I-IV

Study	I	II-III	IV
Design	Longitudinal cohort study	RCT	Qualitative
Sample, n	1 402	153	20 (6 CM and 14 elderly)
Age (years), mean (range)	76.7 (60-96)	81.5 (66-94)	CM: 41.3 (31-51) Elderly: 83.7 (75-95)
Female (%)	58	67%	71%
Data collection	Questionnaire Registers	Questionnaire Registers	Semi structured interviews
Analysis	Student's t-test Mann-Whitney U-test Chi-square test Linear regression Friedman's test Cox regression Wilcoxon signed-rank test	Student's t-test Mann-Whitney U-test Chi-square test Cost-utility analysis	Content analysis

CM = Case manager

In **Study I** the Neuman Systems model is used to understand the different variables that could affect a person's healthcare utilisation. The five client system variables presented by Neuman (physiological, psychological, sociocultural, developmental, and spiritual) could be used as a map of what dimensions need to be investigated and could be the reason for having an unbalanced system according to Neuman Systems model (136).

Studies II-IV are parts of a larger intervention study. The study was designed as an experimental two-armed RCT with repeated follow-up that in addition has a quasi-experimental cross-over design (143) where participants in the control group after 12 months received 12 months of intervention. The study was a collaborative study and involved municipal home care and municipal home services, primary care and a nearby university hospital, and the university. This interventions study was developed according to the first version of the MRC's framework for developing and evaluating RCTs for complex interventions to improve health (142). The study underwent pilot testing, the results of which, together with descriptions of the development and content of the intervention, have been published (17). The intervention described in this thesis differed from the pilot study in that there were also additional home visits from case managers educated as physiotherapists. The main reason for adding this to the intervention was that falls and a low degree of physical activity were in the research group seen as big problems among older people living at home. Both healthcare utilisation measured in different areas, and cost are used primary outcomes, as recommended by the MRC (16). In addition, it points out the need for qualitative evaluation and economic evaluation.

In this thesis, the effect on one of the primary outcomes, healthcare utilisation (**Study II**), is evaluated, together with cost-effectiveness (**Study III**). The qualitative study (**Study IV**) gives insight into the process of the intervention's delivery. To get an even deeper understanding of the intervention and how it was actually performed, three case reports of different levels of success of the case management intervention are presented (**framework**). Traditionally there have been arguments against combining both qualitative and quantitative methods within a single study because each of them belongs to distinctively different paradigms (144). However, there are reasons in favour of a mixed method approach that should not be ignored. In a review of 57 mixed methods studies Greene, Caracelli and Graham (145) identified five purposes of mixing methods; triangulation, where different methods are used to measure the same phenomenon, increasing confidence in the conclusions reached; complementarity, where methods are used to investigate different aspects to deepen and broaden understanding of the phenomenon; development, where the results from one method are used to develop, for example, instruments, sampling methods, or implementation methods; initiation, similar to complementarity but where the divergence is used to generate new understanding; and expansion, where different methods are used to assess different phenomena to expand the scope of the study. Also (144) have identified five advantages of a mixed methods approach; practicality, complementarity, incrementality, enhanced validity, collaboration. A mixed methods approach is also suggested by the MRC (16).

Sample and settings

Sample and sampling procedures

The sample in **Study I** was drawn from one of four centres in a longitudinal multi-centre cohort study, the Swedish National Study on Aging and Care, Blekinge (SNAC-B) (146). In this study, performed in the county of Blekinge in the south-eastern part of Sweden, the sample comprised one municipality with approximately 60,600 inhabitants, and included both urban and rural areas. The sample comprised 1 402 participants in ten different age cohorts; 60, 66, 72, 78, 81, 84, 87, 90, 93 and 96 years. The participants in the four youngest age cohorts were randomly selected and the six oldest cohorts included all inhabitants in those age groups (147). This was done since the older persons are fewer. In addition they are more likely to have poorer health and are therefore more likely to decline participation. The response rate varied between 55% and 75% in the different age cohorts. The response rate was higher in the younger cohorts than the older ones, but oversampling in the oldest cohorts resulted in a distribution of responders of 28.3% for those aged 60–69 years, 24.5% for those aged 70–79 years, 36.0% for those aged 80–89 years, and 11.2% for those aged 90–96 years (148). In total 2 312 people were invited to participate and 61% consented to do so (149). Of those who did not participate 39% were men and 61% were women. Reasons for not participating were unwillingness (83%), prospective participants considering themselves too sick to participate (10%), and failure to contact prospective participants (7%) (149). No statistical differences were found in gender between the dropouts and the participants (150).

Studies II and III were carried out in the municipality of Eslöv in southern Sweden and comprised 153 people who were randomly allocated to an intervention (n=80) or a control group (n=73) (Figure 6). Participants were consecutively recruited between October 2006 and April 2010 from three clinics at the university hospital (n=20) and three primary care centres in the municipality (n=117); through municipal home care organisations (n=13); or by the participants contacting the research group themselves (n=3). Inclusion criteria were: (1) age at least 65 years, (2) residence in an ordinary home in the studied municipality, (3) need for help with two or more ADL, and (4) admission to hospital at least twice, or at least four visits to outpatient care, in the 12 months prior to entering the intervention study. In addition, participants had to be able to communicate verbally and not suffer from any severe cognitive impairment. Cognitive impairment was examined by using the Mini Mental State Examination (MMSE) (151) with a cut-off of 25 points or higher out of a maximum of 30 as the requirement for participation in **Studies II and III**. At the hospital the recruitment process were carried out by the nurses in the case management intervention. They screened three of the clinics and informed potential participants about the study and

asked them whether they would allow someone from the research team to contact them to determine whether they met the inclusion criteria and to provide more information about the study. In primary care and municipal care, the staff simply asked people that they thought met the inclusion criteria whether they would allow someone from the research team to contact them, again to determine whether they met the inclusion criteria and to provide more information about the study. In addition to these recruitment procedures at two times in two public primary care centres all those aged 65 years or older with four or more registered visits in primary care the previous year were contacted by the research team. They were contacted by telephone or by mail with information about the study. Those contacted by mail also got a reply form and a prepaid envelope, and were asked to send in consent that they allowed the research team to contact them by telephone in order to give additional information and to investigate whether or not they met the inclusion criteria. A total of 1,079 people were approached (862 through mail or telephone in the primary care register recruitment procedures). Of those approached, 926 were excluded, of whom seven died before randomisation, 231 did not meet the inclusion criteria, and 688 could not be randomised. The main reason for them not being randomised was failure to respond to the letter in the primary care register recruitment procedure (n=571). Other reasons were unwillingness to participate (n=71), inability to contact prospective participants (n=28), or prospective participants feeling too tired or too ill (n=18) (Figure 6). The randomisation procedure included sealed identical envelopes containing information about the group to which the participants had been assigned. All participants had an equal chance of being allocated to each group. The simple randomisation procedure was performed by the research team. At the time of baseline measurements, information about the project was repeated once more, together with information about which group the participant had been assigned to. After this, all participants provided written informed consent. A total of 153 participants underwent baseline measurements, of whom 45 died or declined further participation during the 12-month study, leaving 108 who completed the study (Figure 6). A power calculation was made a priori with mean change in hospital stays as the primary outcome. A mean difference of 1.0 hospital stays over 12 months was regarded as clinically relevant and for 80 per cent power the power calculation showed that a total sample of 140 participants was needed.

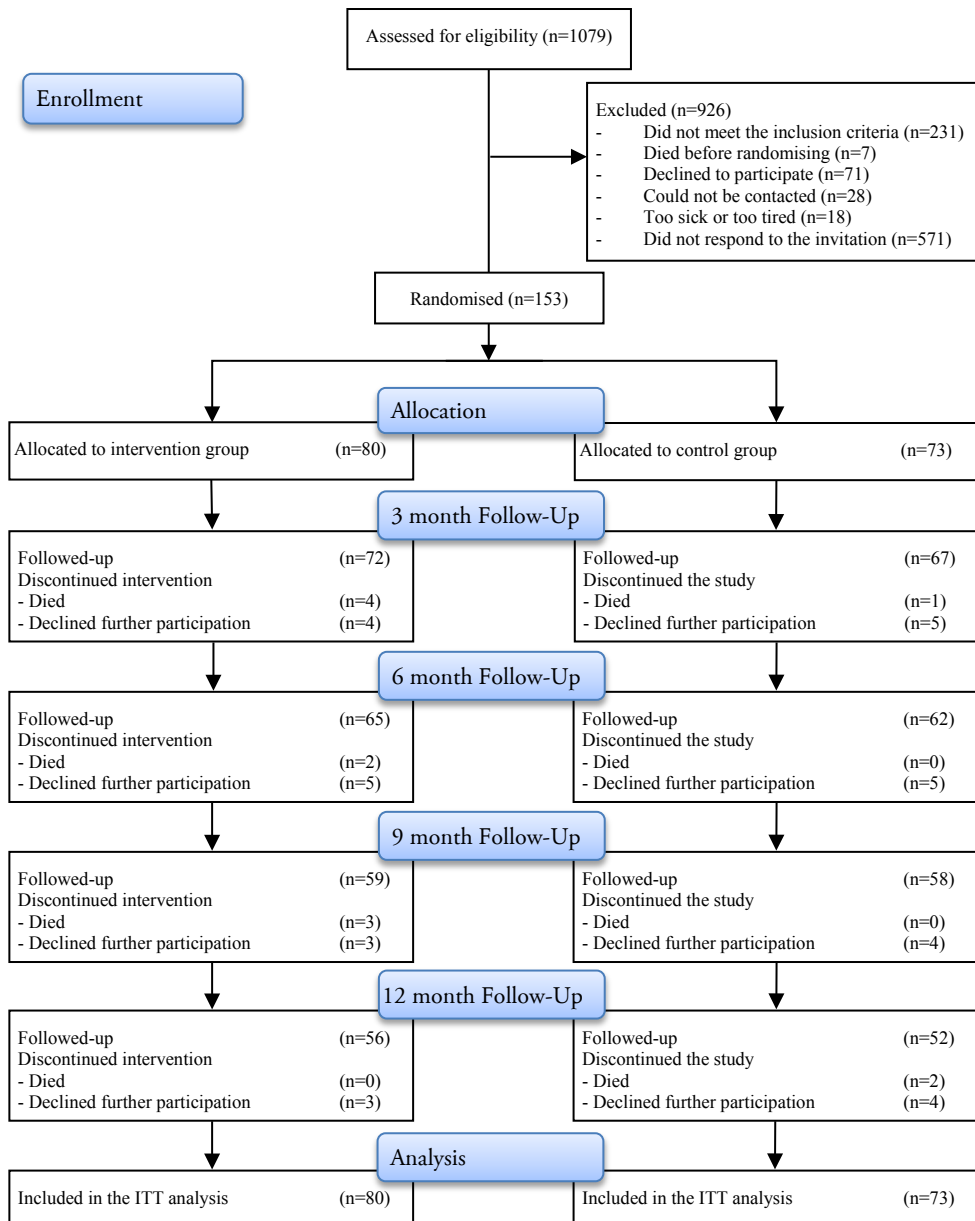


Figure 6: CONSORT flow diagram for Studies II and III

Flow chart of participants in the studies. The participants were followed-up at 6- and 12 months after baseline in Study II, and at 3-, 6-, 9-, and 12 months after baseline in Study III. For some of the followed-up it was not possible to collect questionnaires used for data collection (e.g. if they were hospitalised or feeling too sick) and was therefore only followed-up in terms of register data.

The sample in **Study IV** comprised 20 people, of whom 14 were older people who had received the case management intervention and six were case managers who had performed the intervention. The older persons were recruited face-to-face by the research team during their participation in the case management intervention study. They had all met the inclusion criteria for the intervention study. In total 29 interviews with participants were conducted from which 14 was selected. Purposeful selection (144) was used to obtain variation in gender, age, use of municipal home care or municipal home services, and which case manager they had met. Of the older persons were four men and 10 women and they were aged 75-95 years (median age 83). Six of them had municipal home care or municipal home services, and eight of them were widow/er, two married, three were divorced or lived apart, and one was unmarried. Before entering the case management intervention study, the older persons were informed, both in writing and verbally, that they might be asked about being interviewed with open-ended questions. This information was then repeated after nine months of the 12-month intervention, when they were asked to participate in an interview.

Six case managers were included in the sample, of whom two had education as physiotherapists and four as nurses (age 31-51 years, median age 44). The case managers were interviewed about every individual that they had met as a case manager, and in total 162 interviews were conducted. Of these fifteen interviews was chosen for analysis. Purposeful selection was used to obtain variation in case managers. Variation was also sought for gender, age, and use of municipal home care or municipal home services of the older persons that the interviews were about. Seven of the final 15 case manager interviews used in the analysis was with nurse case managers and eight with physiotherapist case manager. Eight of the interviews were about female receivers of case management and five of the interviews were about participants with municipal home care or municipal home services.

In addition, three case manager interviews were used as case reports in this framework. The interviews were selected to illuminate different levels of success of the intervention, with one case where the intervention was performed in a good or very good way, one case with a standard performance of the intervention, and one case where the intervention did not go as planned.

The case management intervention

The intervention was performed by six case managers. Depending on the caseload, one or two nurses and one or two physiotherapists were employed on a part-time basis. All employed case managers worked in the intervention for between two and five years and all had experiences of caring for, or rehabilitating, older people, either in a municipal home care/community setting or in geriatric wards at a university

hospital. Each participant in the intervention group received visits from a nurse case manager, and all participants entering the study after the pilot phase also received visits from a physiotherapist case manager, i.e. these participants received visits from two case managers. The home visits took place in the participants' own homes and the case manager made at least one visit a month during the 12-month intervention. If the participant was hospitalised, visits could also take place at the hospital. The first visit was made when the case managers was informed by the research group that the participant had undergone baseline measurements.

The case management intervention was designed to comprise four different parts: "traditional" case management, general information, specific information, and safety (17). The traditional case management included assessment, care planning and coordination, implementation, monitoring, and reassessment, i.e. the case manager tasks suggested by Hutt, Rosen and McCauley (11), except for case finding. The case managers made efforts to coordinate participants' in terms of helping the participants to contact healthcare agencies at an adequate level in the health system or helping them to establish a contact at the care facility. Also included in this part were home visits, telephone calls, and advocacy. Advocacy could, for example, be supporting the participant's contacts with different healthcare agencies. The second part contained general information about the health system, aging, or other aspects that could be important for older people in general, for example nutrition and older people's changed metabolism. It also included general information about different activities arranged in the community, such as social arrangements. Specific information comprised issues related to the participant's specific health status, individual needs, and medication. This could, for example, be information about a certain medication, how to deal with pain, or encouragement to join social activities when feeling lonely. The last part was aspects of safety, but also continuity. This included case managers being contactable by cell phone during working hours if the participant had a crisis. It was also intended that the participant should meet the same case managers throughout the intervention period. This was, however, not always achieved due to changes of staff. All case managers worked according to these four intervention parts, but for the first part the nurse case managers were more focused on nursing care (participant's health, making and evaluating a care plan), while the physiotherapist case managers focused more on the prevention of falls (balance training, home adaption, home and living aids, bathing and toileting aids etc.), and on increasing physical function. The nurse case managers evaluated the participant's prescribed medication. A physician in the project also reviewed medications for both the intervention and control groups.

At the first home visit the nurse case manager made an initial assessment using the Minimum Data Set for Home Care (MDS-HC) (152, 153). This is a comprehensive geriatric assessment tool that has showed good validity in terms of correspondence to research quality instruments for cognition, activities of daily living, and diagnoses (152, 154). The reliability has been investigated with for instance high interrater

reliability and considerable evidence for the consistency of clinical data in the instrument (154). The first assessment was followed by re-assessments at each visit in order to identify problems or possible intervention areas. An individual care plan, consisting of goals that the case manager and the participant decided on jointly, was developed for each participant. The care plan was monitored and followed up at the later visits (17). The physiotherapist case manager evaluated the participant's functional status through anamnesis (questions about diseases, activities/activity levels, and what aids they used), and assessments using the General Motor Function assessment scale (GMF) (155). To evaluate the participant's physical function, the physiotherapist case manager also used the Berg Balance Scale (BBS) (156) and Fukuda Stepping Test (157). Assessments of vibration sensations in the lower limbs were also performed (158). The physiotherapist case manager developed an individual physical training programme based on information from the nurse case manager about disabilities and diagnoses. Thus, the training programme was based on each of participant's physical ability and risk of falling. The participants performed the programme on their own and during subsequent visits the physiotherapist gave support and adjusted the programme if necessary.

If severe medical problems were detected, the case managers had the possibility to contact one of the physicians in the project. This option was also available for the control group if the researchers discovered any medical problems. Particularly difficult and complex cases and possible solutions were regularly discussed in meetings between the case managers and the research group (17). The case managers documented the intervention for each participant and also wrote diaries containing their reflections on the intervention.

The goals of the case management intervention are similar to those presented as primary and secondary "prevention-as-intervention", according to Neuman and Fawcett (136). The goals in the model are prevention by reduction of stressors and risk factors (primary "prevention-as-intervention") and providing appropriate treatment of symptoms (secondary "prevention-as-intervention"). Primary "interventions-as-prevention" corresponds with the second and third part of the case management intervention (general and specific information), and the first part (traditional case management) corresponds with both primary and secondary "prevention as intervention", as it is both about discovering various symptoms and trying to make sure that right treatment is provided, and discovering and removal of various risk factors. A natural part of the intervention was also tertiary "prevention-as-intervention" as this follows secondary prevention strategies. The goal is here to allow the system to reconstitute after a stressor attack. This is done by supporting existing strengths, conserving or add energy to the system, or reduce the energy needed in order to facilitate reconstitution (136).

During the 12-month intervention, each nurse case manager made an average of 11.1 home visits and 1.9 telephone calls, and each physiotherapist case manager made 10.4 visits and 0.8 telephone calls, for those completing the intervention period. For dropouts (Figure 6), the mean intervention time was 5 months, and there were an average of 3.7 visits and 1.0 telephone calls from the nurse case manager and 2.5 visits and 1.0 telephone calls from the physiotherapist case manager.

Data collection

The data for this thesis were collected in different ways. Healthcare utilisation data for **Study I** were collected from the SysTeam Cross register (previously named Pasorigo). Information about demographics, physical dependency, risk of depression, HRQoL, self-reported health complaints, sense of coherence, and cognitive impairment was derived from the health and service part of SNAC-B (146). For the case management study data on in- and outpatient healthcare utilisation and costs were collected via the registers: Patient Administrative Support in Skåne (PASiS), and PrivaStat (**Studies II and III**). Data were also collected through structured interviews based on a questionnaire covering single-item questions, and using standardised instruments. The case management study also used data collected through semi-structured interviews (**Study IV, framework**).

The SNAC-B study

Baseline data collection for **Study I** was carried out between 2001 and 2003. Participants were invited by mail to come to the research centre to participate in the study (75). Those who did not respond were contacted again by telephone. If they then declined participation, reasons for not participating were registered. The data collection process consisted of two sessions, each about three hours long. During these sessions, the participants were examined medically and cognitively by the research staff (i.e. physicians and nurses) and had to respond survey questions in structured interviews. During the first session, the participants provided informed written consent and were asked to sign a release form for their medical records. After the first session, a second session at the research centre was booked, and the participants were given a questionnaire to complete during the time between the sessions. Participants unable to come to the research centre were offered the option of being examined in their own homes (75).

The case management study

For **Studies II and III**, researchers, working independently of the case managers, performed structured interviews at baseline and every third month during the 12-month intervention, i.e. on five occasions. They collected data for the larger case management study and the structured interviews were based on a study questionnaire covering single-item questions, standardised instruments, and physical tests. The questionnaire consisted of five dimensions: background data, social aspects, health status, HRQoL and life satisfaction, and healthcare and social services (17) and after the pilot study (17), additional questions about functional ability and balance. In **Studies II and III**, baseline data from these interviews were used to assess baseline characteristics. In **Study III**, data concerning HRQoL, informal care, municipal home care and municipal home services collected at the structured interviews at all measurement points were used. Some flexibility was allowed for these interviews as it was not always possible to conduct the interview exactly three months after the last one. The interview was not allowed to be delayed by more than six weeks (in cases of longer delays the interview was not conducted at all, which happened in 27 cases). The main reasons for delayed interviews or interviews not being conducted at all were participants being too ill, being admitted to hospital, or receiving short-term care. The interview took an average of about 75 minutes to complete.

Healthcare utilisation

Data collected in **Studies I and II** included healthcare utilisation data. In **Study I**, data concerning inpatient healthcare and treatment provided by the County Council of Blekinge were collected from SysTeam Cross/Pas-origo. For **Study II**, data concerning healthcare utilisation provided in the County of Skåne were collected from two administrative patient registers: PASiS for all publicly organised inpatient and outpatient healthcare in Skåne, and PrivaStat for all privately organised care. These registers are administrative registers for care and treatment in which individual data concerning healthcare utilisation are registered. Inpatient data used in **Study I** comprised hospital stays and LOS, and those used in **Study II** comprised number of acute and planned hospital stays, LOS, inpatient diagnoses. Outpatient care data used in **Study II** comprised number of contacts with physicians and other healthcare staff (nurses, physiotherapists, occupational therapists, etc.), medical specialty, and whether or not the visit was at an ED. Inpatient care was registered either as somatic admission or psychiatric admission. In both studies each admission or visit caused a new registration in the systems, and an individual could have several registrations for one hospitalisation period due to a change of clinic during the hospital stay. In this thesis a hospital stay was considered as a continuous stay with one date for admission and one date for discharge, regardless of the number of registrations. LOS is therefore

the number of days from admission to discharge. In **Study II**, an acute admission was registered as inpatient care and could occur at any ward. ED visits were registered as outpatient care, and may or may not have led to a hospital stays.

Data regarding inpatient medical diagnoses used in **Studies I and II** were also collected from the registers. The diagnoses that were registered followed WHO's International Classification of Diseases 10th Revision (ICD-10) (159). Up to fifteen diagnoses could be registered for each contact. The primary code is assumed to be the main reason for the registration. As each hospital visit could also yield several registrations, an individual could have several primary diagnoses for each hospital stay. The first registered primary diagnosis was assumed to be the one that led to the hospitalisation and was therefore used in the analysis. The data were entered by administrative and/or healthcare staff.

Outpatient data in **Study II** comprised contacts with physicians in somatic care (i.e. outpatient specialist care outside primary care), primary care, medical services (i.e. contacts with X-ray departments, laboratories etc.), specialist dental care, and psychiatric care. For other healthcare staff providing outpatient care, the data comprised somatic care (i.e. outpatient specialist care outside primary care), primary care, medical services, rehabilitation, and psychiatric care. Privately organised care included both primary care and out-patient specialist care. In this study, contacts with physicians in outpatient care included private and public somatic/specialist care and primary care. An outpatient contact could either be a face-to-face visit, a telephone call, or another form of contact (e.g. a letter or e-mail).

In **Study I**, data on LOS and number of hospital stays were collected for the 6 years following baseline. Data concerning diagnoses were only collected at baseline. Annual hospital stays and LOS stays were calculated. Hospital stays and LOS were also calculated for years one and two, three and four, and five and six. Data for the variables in **Study II** were collected for one year before and one year after the baseline interview.

Measurements

The healthcare utilisation data from SysTeam Cross/Pas-origo were combined data from the SNAC-B study, and data from PASiS/PrivaStat were combined with the data from the case management study. In **Studies I-III**, several single-item questions and instruments were used to collect baseline data. In **Study III**, HRQoL data were collected at baseline and at 3, 6, 9, and 12 months. Some measurements were used to derive healthcare costs and are therefore presented in the healthcare cost section. The measurements could be presented according to the Neuman Systems Model (136) using the five client system variables. Some measurements are multifaceted and could fit under more than one client system variable. For example, marital status,

educational level, and financial status are listed under both the sociocultural and developmental variables as they could be about social history and roles, as well as the possibility to develop, where marital status, finances, and education could make it easier or more difficult to develop or make a transition. The variables used in **Studies I-III** are listed as shown in Table 3 and are described more comprehensively below. If a measurement is present under more than one heading, it is described at its first appearance. The variables about care and services and informal help are more about consequences of imbalance in the five client system variables and reduced wellbeing, and are therefore presented under a separate heading.

Table 3: Measures and instruments used in Studies I-III according to Neuman Systems Model (136)

Measures	Study I	Study II	Study III
A. Physiological			
HRQoL	SF-12		EQ-5D, EQ-VAS
Functional ability	ADL staircase	ADL staircase	ADL staircase
Health complaints	Self-reported ¹	Self-reported ¹	Self-reported ¹
Diagnosis	From PAS-origo ²	Self-reported and from PASiS ²	Self-reported
B. Sociocultural			
Background data	Age	Age	Age
	Gender	Gender	Gender
	Marital status	Marital status	Marital status
	Educational level	Educational level	Educational level
	Financial status	Financial status	Financial status
	Living conditions		
		Having children	Having children
HRQoL	SF-12		EQ-5D, EQ-VAS
C. Spiritual			
Risk of depression	MADRS ³	GDS-20	GDS-20
D. Developmental			
Background data	Marital status	Marital status	Marital status
	Educational level	Educational level	Educational level
	Financial status	Financial status	Financial status
Sense of coherence	SOC		
E. Psychological			
HRQoL	SF-12		EQ-5D, EQ-VAS
Risk of depression	MADRS	GDS-20	GDS-20
Cognitive impairment	MMSE	MMSE	MMSE

¹⁾ 31 items in Study I and 32 items in Studies II and III

²⁾ Only inpatient care

³⁾ Nine-item version

A. Physiological

Health Related Quality of Life (HRQoL)

To measure HRQoL SF-12 was used in **Study I** and EQ-5D and EQ-VAS in **Study III**.

SF-12 is a short version of the SF-36 health survey, which was designed for use in clinical practice and research, health policy evaluations, and general population surveys (160). The shorter version contains a Physical Component Summary Scale (PCS), which includes questions about physical functioning, physical role, bodily pain, and general health, and a Mental Component Summary Scale (MCS) including questions about vitality, social functioning, emotional role, and mental health (161). A score between 0 (poorest wellbeing) and 100 (highest wellbeing) is obtained for each subscale. Two-week test-retest in a general population showed correlations of 0.86 and 0.77 for the PCS and MCS respectively, and the SF-12 score explains over 90% of the variance in PCS-36 and MCS-36 (161). Another study with an older population (age 75-105 years) showed good reliability in terms of Cronbach's alpha (0.73-0.86) and convergent and divergent validity, where SF-12 had moderate correlations with physical functioning (ADL) and different symptoms (162). However, despite a good explanation rate (63%) for a factor analysis with a two-factor solution, some items didn't follow the theoretical structure of the scale, i.e. the instruments construct validity could be questioned (162).

EQ-5D, developed by The EuroQol Group (163), is a non-disease-specific instrument with five three-level questions covering five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression (164). This means that there are 243 possible health states (i.e. five questions with three alternative responses = $3^5=243$). One of the aims with EQ-5D was that it should be possible to use it to calculate QALY. A QALY could be described as the life quality weight during one year, with a value of 1 representing the best possible health and a value of zero representing the worst imaginable health, i.e. death (134). Each health state in EQ-5D can be graded through different methods to obtain a numeric value on a 0-1.00 scale (134). In this thesis the values, or weights, for all health states were obtained using a tariff based on a British general community sample (n=3395) using a time-trade-off technique for direct valuation of 42 of the health states (165). Some health states can have values below zero (in the British tariff as low as -0.59), with the interpretation that the health state is worse than death (165). Together with the five-dimensional scale there is also a visual analogue scale (EQ-VAS). On the scale, the respondents are asked to mark their own perceived health state on a 20 cm vertical 100-step scale, where the endpoints are zero and one hundred and are labelled "worst imaginable health state" (zero) and "best imaginable health state" (one hundred) (164). The instrument is widely used and has been tested for validity and reliability. Strong correlations have been shown between EQ-5D and SF-36 sub-scale scores and

total score, indicating high criterion validity (166, 167). Intraclass correlation (ICC) has showed moderate results (ICC=0.70; 95% confidence interval [CI] 0.58–0.80) when patients with osteoarthritis of the knee were examined on two occasions separated by one week (168).

Functional ability

In **Studies I-III** functional ability was assessed using a modified ADL staircase (169). The ADL staircase is a further development of Katz's ADL-index (170). The scale assesses physical performance in terms of dependency, or independency, in ten different activities. Four activities are related to household, referred to as Instrumental Activities of Daily Living (IADL): cleaning, shopping transportation, and cooking; and six questions are related to personal care and are referred to as Personal Activities of Daily Living (PADL): bathing, dressing, toileting, transfer, continence, and feeding. The level of dependency is graded hierarchically on a ten-grade scale, where each question is scored 0 or 1, where zero denotes independence and one denotes dependence, yielding a total score of 0-10. In this thesis the number of activities was summarised in each section, i.e. PADL and IADL, and as a total, with subscale ranges of 0-6 and 0-4 and a total range of 0-10. The ADL staircase is widely used and has shown an internal consistency of 0.84 (IADL), 0.86 (PADL), and 0.90 (total) (5). The instrument has showed a varying degree of acceptable construct validity and reliability but seems to be suitable for older people (171).

Health complaints

In **Studies I-III**, health complaints were assessed with dichotomous questions about various symptoms and whether the participant had suffered from any of these symptoms in the last three months. The questions were inspired by the 30 four-response questions presented by Tibblin, Bengtsson, Furunes and Lapidus (6) and further developed by Stenzelius, Westergren, Thorneman and Hallberg (172). In **Study I**, the measurement consisted of 31 questions, and in **Studies II and III** it consisted of 32 questions. The ten most common health complaints in the sample were used in the analyses in **Study I**, and the five most common in **Studies II and III**.

Self-reported diagnoses

In **Studies II and III**, data concerning the number of self-reported diagnosis groups were collected using questions about diseases during the last three months (Yes/No). These were documented according to WHO's ICD-10 diagnosis groups (159). The number of diagnoses was summed, yielding a score of 0-15.

B. Sociocultural

Background data

Background data, which according to the Neuman Systems Model (136) could be referred to as sociocultural variables, were used and presented in various ways in **Studies I-III**. These studies used different combinations of background questions. Background data were assessed by means of questions about age, gender, marital status, living conditions, educational level, and financial status. Financial status was assessed in **Study I** with the questions “Can you obtain 14 000 SEK (approx. €1500) within a week to cover any unforeseen expenditure?” (Yes/No) and “Have you had difficulties covering daily expenses, rent, bills etcetera during the last 12 months?” (Yes/No). In **Studies II and III** it was assessed with the question “How do you think your financial situation looks?” (Better than others/Same as others/Worse than others).

C. Spiritual

Risk of depression

In **Study I**, risk of depression was measured with the Montgomery-Åsberg Depression Rating Scale, MADRS (173). This instrument is based on the 65-item Comprehensive Psychopathological Rating Scale (CPRS) (174). MADRS is a 10-item scale with items concerning, for instance, apparent sadness, inner tension, and pessimistic thoughts. Each item can be scored from 0 to 6, yielding a total score of 0-60. In this thesis, item six (difficulties concentrating) was excluded due to low inter-item correlation, and thus a nine-item version of the scale was used (175), with a possible score of 0-54. The cut-off for the MADRS score was based on previously suggested cut-off criteria (176), where 0-6 represents absence of risk of depression; 7-19 mild risk of depression; 20-34 moderate risk of depression; and 35+ severe risk of depression. Montgomery and Åsberg (173) demonstrated satisfactory inter-rater reliability (0.89–0.97) when comparisons between two English raters, two Swedish raters, and one English and one Swedish rater were made. The instrument has also been showed to have a sufficient degree of reliability (177) and concurrent validity to the sum score (178). The content validity and the construct validity have been questioned as all depression symptoms are not included in the instrument (177, 178). The insufficient connection to depression was shown in a study where patients with severe depression had the same MADRS score as patients who fulfilled the criteria for bulimia nervosa (179). However, the criterion validity, i.e. the extent to which two measures that are stated to measure the same thing correlate, was also demonstrated to be high, with correlations of 0.92 between MADRS and the 17-item Hamilton Depression Rating Scale, and of 0.77 between MADRS and the Beck Depression Inventory (180).

In **Studies II and III**, the risk of depression was assessed using the 20-item version of the Geriatric Depression Scale (GDS-20) (181). The GDS is a rating tool for symptoms of depression developed for older people and originally contained 30 statements answered with yes/no (182) and has been translated, validated and modified in a Swedish context (181). The modified version contains 20 questions where each question gives a score of 0 or 1, yielding a maximum total score of 20. A score of six or above was considered to indicate risk of depression (181).

D. Developmental

Sense of coherence

People's ability to manage and adapt their situation was measured in **Study I** with the Sense of Coherence (SOC) short form (183). The short form contains 13 items, each with seven alternatives (1-7), and gives a summary score of 13-91, where a higher score indicates a higher sense of coherence and a high SOC score indicates an individual's possibility to find the best way to deal with a given situation (183). Cronbach's alpha was reported to be 0.74-0.91 in 16 different studies (183) and test-retest reliability has been tested on several occasions with acceptable results (183, 184). However, it has been found to increase with age with highest scores for the oldest population compared to young (college students and people under 30 years of age) (184, 185). Questions have also been raised about the numbers of factors the items should be divided into (one, three, or another number) (186). Nonetheless, the instrument has been found to be a reliable, valid, and cross culturally applicable instrument (185).

E. Psychological

Cognitive impairment

In **Studies I-III**, the MMSE (151) was used to measure cognitive impairment. The instrument covers cognitive areas of orientation, memory, attention, the ability to name, the ability to follow verbal and written commands, write a sentence spontaneously, and copy a complex polygon. The test has a maximum score of 30, where a lower value indicates a greater cognitive impairment (151). Different cut-offs have been suggested (187). One reason is that the MMSE performance has been shown to vary by population, age, culture, and education (7, 188). The different cut-offs also depend on the instrument's failure to discriminate between people with mild dementia and those not demented (188). But generally accepted cut-off points are; 25-30 for normal cognition; 21-24 for mild cognitive impairment; 14 or below for moderate or severe cognitive impairment (189) which have been used by for instance Iliffe, *et al.* (190) and Włodarczyk, Brodaty and Hawthorne (191). Based on this the inclusion criterion in the case management study (**Studies II and III**) were set to a score of 25 or higher. Tombaugh and McIntyre (188) investigated MMSE's psychometric properties and found that MMSE showed moderate to high reliability

coefficients. The instrument also showed high sensitivity for detecting cognitive deficits in patients suffering from moderate to severe Alzheimer's disease, and was able to reflect the cognitive decline typical of dementia patients.

Care and services

In **Study I**, data concerning formal care were recorded and covered by two dichotomous (yes/no) single-item questions “Do you get any help with home care, other activities of daily life, nursing or medical home care from the municipality or county” and “Do you get any help with personal care from the municipality?”.

In **Study III**, questions about formal care covering municipal home services and related to decisions according to the Social Services Act (192) (for instance cleaning, shopping and transportation) were collected through the structural interviews at baseline and at 3, 6, 9, and 12 months. The interview comprised dichotomous questions concerning whether participants received any municipal home services for help with IADL, PADL, or municipal home services in the evening/at night, and if so, how many hours each week. The questions also covered numbers of grocery deliveries each week, number of accompaniment hours each week with (to doctors, out-patient visits etc.), if they had personal safety alarm, and how many days they had spent in short-term accommodation since the last time of measurement.

Data concerning municipal home care provided by the municipality according to the Health and Medical Services Act (193) used in **Study III** were also collected through the structured interviews. The participants were asked to estimate the number of hours of municipal home care they received each week, and to specify the number of visits each month and the number of visits from each of the following professionals: physician, nurse, nurse assistant, physiotherapist, and “other”. It was only possible to specify the total number of hours per week, regardless of whether they received municipal home care from more than one type of professional. This meant that time was evenly distributed between specified types of professionals. Values for hours per week <1 but >0 were rounded up to 1. Values >1 were rounded to the nearest integer.

In **Study I**, data concerning informal care were also covered by two dichotomous (yes/no) single-item questions “Do you get help with home care, other activities of daily life, nursing or personal care from relatives or friends, due to reduced health?” and “Have you, during the last month received help from relatives or friends with home care or other activities of daily life, due to reduced health?”. The questions asked at the structured interviews in **Study III** also covered informal care. The participants were asked about the number of hours of informal care for IADL and PADL. They were asked to estimate how many hours of help they received each week and to indicate who provided it. Responses with values <1 but >0 were rounded up to 1. Values >1 were rounded to the nearest integer.

Healthcare costs

The calculated costs in **Study III** are presented in the four categories suggested by Drummond, Schulpher, Torrance, O'Brien and Stoddart (134): health sector, other sectors, patient/family, and productivity losses. Because all participants are senior citizens it was assumed that there were no losses in the "productivity losses" category. All costs are presented in 2011 prices and transformed from Swedish Kronor (SEK) to Euros (€) using the mean exchange rate for 2012.

Health sector resource use and prices

Information about costs for in- and outpatient healthcare used in **Study III** was collected from the PASis and PrivaStat registers. The registrations formed the basis for cost calculations, but are made in a variety of ways. For publicly organised healthcare in the of southern region of Sweden, six different principles are used to derive healthcare costs: (1) price per DRG per visit or care event, (2) price per product, (3) price per patient for special or extreme care events (4), price per; admission, care event, physician visits, or medical treatment (5) price per bed day, and (6) price per subscription or a fixed price for all patients that are attached to a health centre (194). The principles could be used alone or in combination, but the main principle has been DRG and the Nordic classification agreement in NordDRG (195). DRG is a system for classifying cases into categories with similar resource uses. Grouping is based on diagnoses, procedures performed, age, sex, and status at discharge (196). Each DRG obtains a specific price that is used for reimbursement. Costs for privately organised care, registered in PrivatStat, are calculated in similar ways to that for public care. However, each private healthcare clinic entering into a contract with the county council and is according to the number and characteristics of registered patients at the healthcare clinic. Thus, this reimbursement depends on each clinic's specific contract with the county and is not solely based on the resources used. The actual costs for privately organised healthcare are therefore difficult to calculate, but the calculated reimbursement for each contact can be used as an estimate of the costs, even if they are somewhat underestimated.

Other sectors resource use and prices

Self-reported data concerning hours of municipal home services help each week for IADL and PADL, municipal home services in the evening/at night, numbers of grocery deliveries each week, number of accompaniment hours each week with (to doctors, out-patient visits etc.), personal safety alarms, and number of days spent in short-term accommodation since the last time of measurement were used to calculate costs for municipal home services. The costs for help with IADL in the studied municipality were reported to be approximate €30 per hour (SEK 257) and the costs for help with PADL were about €42 per hour (SEK 367). These figures were used as

estimates in **Study III**. The hourly costs of accompaniment (accompaniment to doctors, out-patient visits etc.) in the municipality were €30 per hour. The municipality differentiates between those that living in rural areas and those living in the main town of the municipality. If the person lived in a rural area an additional cost of €4 (SEK 35) was added to the IADL, PADL, and accompaniment costs. According to the studied municipality, these costs included all costs for the provision of the services, including education of staff, transport, and administration. In the studied municipality, people with grocery deliveries were assigned 30 min extra of IADL municipal home service if they lived in an urban area and 60 min extra if they lived in a rural area. The costs for safety alarms were calculated using information about the total number of alarms in the studied municipality in 2011 and the municipality's total costs for the alarms during this year. The cost per safety alarm was estimated to about €36 per month (SEK 313). Information on total costs and utilisation of short-term accommodation in the studied municipality for 2011 was used to calculate cost per day in short-term accommodation (€207/SEK 1802 per day), which was used in this study.

Data concerning municipal home care provided by the municipality were used to estimate the municipal home care costs. Average hourly salaries in the studied municipality for each specific type of professional, including payroll surcharges, were multiplied by the self-reported amount of municipal home care. The hourly salary for nurse assistants/other, registered nurses, physicians, and physiotherapists were estimated to about €25, €33, €64, and €30, respectively (SEK 218, 287, 557 and 261 respectively) (197).

Participants and families resource use and prices

Costs associated with the participants and their families comprised patient fees for in- and outpatient care and estimated costs for informal help provided by family and friends and any other privately organised help. Data for patient fees were collected from the PASiS and PrivaStat registers, where fees were registered on an individual level. The costs of informal care were estimated from data for self-reported amount of informal care by the opportunity cost method (198). The opportunity cost is what you would have earned if you had worked instead of providing help. The reported number of hours of informal help calculated for each month was multiplied by the average hourly salary in the studied municipality (€20/SEK 174, including payroll surcharges) (199). The same amount was used regardless of who provided the informal care, even if they were retired and unlikely to be able to work.

Intervention resource use and prices

The costs of the intervention were calculated using the case managers' salaries (including payroll surcharge). In general each case manager was employed to work 50% of full time. However, the numbers of case managers varied during the study

period and due to the variation in case load the amount that they worked also differed somewhat. In **Study III** it was estimated that each case manager was employed and had worked 50% of full time during the whole study period. In addition, the case managers also performed the intervention to a cross-over group, not included in **Study III**. The proportion of time used for **Study III** was estimated based on the proportion of participants in the study sample in relation to the cross-over population for each month during the study period. The cost for each month during the study period, from September 2006 to April 2011, was used to calculate a mean cost for the 80 participants in the intervention group. The cost for each participant for a three months interventions period was estimated to €879 (SEK 7652).

Interviews

In **Study IV** and for the three case reports in this **framework**, data were collected by means of personal interviews. In **Study IV**, a total of 29 interviews used: 14 with older persons who had taken part in the case management intervention, and 15 with the six case managers who performed the intervention. The interviews were carried out between 2007 and 2012. Due to a change in staff during the study period, the interviews were conducted by four different persons. The author of this thesis conducted eleven of the interviews, and the other three persons conducted eight, eight, and two interviews. An additional seven case manager interviews were selected for the three case reports.

The interviews with the older persons were carried out in a place chosen by the participant. All participants chose their own home as the place for the interview. Interviews were conducted both with participants who had been directly allocated to the intervention group and with those who had received intervention in the cross-over part of the study. The interviews took place at least 9 months after the person had been included in the intervention in order that the participants had undergone the majority of the intervention. Time from start of the 12-month intervention to interview was on average 14 months (range 12-18 months). The interviews were semi-structured, which meant that they were neither fully structured nor fully unstructured and that the participants were free to talk about any subject, but the interviewer guided the interview (200). A thematic interview guide was used to ensure that all interviews covered the same areas of content. This guide did not only cover questions about the intervention. The interview guide comprised four main themes: (1) help and support (including questions about the case manager); (2) health; (3) contacts with the healthcare system; and (4) the future and concerns. The interview guide was changed slightly during the study, mainly in terms of the order of the four themes. Thus, the interview covered the same topics but the first seven interviews, conducted before mid-2008, started with the question *Could you tell me how your*

health is at this moment?, and the seven conducted subsequently started with the question *Could you tell me how an ordinary day looks for you?* The reason for the change was that not everyone had given a lot of thought concerning their health, and they sometimes started to talk about their health, their contacts with healthcare professionals, and how they managed their everyday life at the same time. The interviews were between 40 minutes and 2 hours 51 minutes long and during the interviews, no-one besides the participant and the interviewer was present. However, in one interview the sister was in an adjacent room and the participant asked her some questions.

A thematic interview guide was also used in the interviews with the case managers. The case manager interviews covered two themes: (1) the person they met and how the contact started, what they had done, and what effects they thought this might have had; and (2) how they perceived the intervention, and whether there was something that they considered successful or unsuccessful. The case manager interview started with a request to talk about the person whom they met in their role as a case manager. The case manager interviews were also conducted after the participant they were interviewed about had received the intervention for at least 9 months. The case manager interviews in **Study IV** were conducted an average of 17 months after the participant had been included in the case management intervention. All case manager interviews took place at the department of the researchers and lasted between 9 and 24 minutes. In addition to the 15 case manager interviews used in **Study IV**, seven interviews were used for the three case reports (**framework**). This means that two interviews were used for two of the case reports, and three for one of them. All but one were conducted between 15 and 19 months after the participant the interview was about had been included in the intervention. One interview was conducted after 3 months of the intervention due to a change in staff, with the interview being conducted with the case manager before she left the project. The interviews lasted between 6 and 13 minutes, with the shortest interview being the one conducted after three months of the intervention.

All interview guides were pilot tested. No changes in the interview guides were. Each interview started with clarification of the aim of the interview and the interviewee's right to terminate the interview whenever he/she wanted, and all interviews were recorded and transcribed verbatim.

Data analysis

Statistical analysis

In **Studies I-III**, data were analysed using both descriptive and analytic statistics. A p-value <0.05 was regarded as statistically significant, except for in post hoc analysis in **Study I**, where a reduced p-value ($p=0.003$) was used according to the Bonferroni method to avoid mass significance (201).

The sample in **Study I** was divided into two pairs of groups: those who were dependent in ADL ($ADL > 0$) and those who were not dependent ($ADL = 0$), and those at risk of depression (MADRS score > 6) and those not at risk (MADRS score 0-6). In **Studies II and III**, the sample consisted of an intervention group and a control group. Comparisons of baseline data between groups in **Studies I-III** were performed using the chi-square test for nominal data, the Mann-Whitney U-test for ordinal data and numeric data that were not normally distributed, and Student's t-test for interval and ratio data.

Multiple linear regression analyses (forward method) were performed to explore predictors of healthcare utilisation (**Study I**). Healthcare utilisation in terms of LOS and hospital stays for 1-2, 3-4, and 5-6 years after baseline were used as dependent variables. This resulted in six regression analyses and therefore six separate final models. In all models, all of the following were entered as independent variables: gender, age, living conditions, marital status, total SOC score, total IADL score, total PADL score, SF12 Mental Component Summary Scale (MCS), SF12 Physical Component Summary Scale (PCS), total MMSE score, total MADRS score (9-item version), the ten most common self-reported health complaints (fatigue, pain in the legs, back pain, joint pain, impaired hearing, impaired vision, walking problems, sleeping problems, breathlessness, and cough), finances ("Can you obtain 14 000 SEK (approx. €1500) within a week to cover any unforeseen expenditure?" [yes/no]), formal help ("Do you get any help with home care, other activities of daily life, nursing, or medical home care from the municipality or county?" [yes/no]), informal help ("Do you get help with home care, other activities of daily life, nursing, or personal care from relatives or friends due to reduced health?" [yes/no]), and main diagnosis groups for the baseline year. For marital status, a dummy variable was constructed with "married" as the reference. In addition, when LOS and hospital stays for 5-6 years after baseline were used as dependent variables, LOS and hospital stays for 1-2 and 3-4 years after baseline were entered as independent variable. When LOS and hospital stays for 3-4 years after baseline were analysed, LOS and hospital stays for 1-2 years after baseline were entered as independent variables. The data in **Study I** were analysed to determine whether there was any threat to the assumptions of normality, and homoscedasticity, or if there were any problems with

multicollinearity. Total IADL score and formal care showed a correlation of 0.743, which was higher than the recommended cut-off of 0.7 (201). The latter was therefore removed from the analyses. Bivariate correlation and correlation tests (variation inflation factor (VIF) and tolerance tests) revealed no other problems with multicollinearity. Some problems with the assumptions of normality and homoscedasticity were found when investigating a normal probability plot of the regression standardised residuals, a normal P-P plot, and the standardised residuals histogram (201). Therefore, to exclude all outliers, only data within one standard deviation (SD) from the mean value for the dependent variable were used. After this adjustment, no other threats to the assumptions of normality and homoscedasticity were found.

In **Study I**, the Friedman test was used to investigate the changes in mean LOS and mean hospital stays during the 6 years following baseline among those dependent/independent in ADL and those at risk/not at risk of depression. Only those with valid data for all six years were included in the analyses; those with missing data (those who died during the 6-year period) were automatically excluded. In the analyses with LOS as the dependent variable, only those with at least one hospital stay during the 6 years were included. The Wilcoxon signed-rank test was used as a post hoc test with correction of the p-values by the Bonferroni method (201). To compare those included in the Friedman test for hospital stays and those who were excluded, a survival analysis using Cox regression (forward LR) was performed. Independent variables entered in the Cox regression were: age, gender, living conditions (ordinary housing/special accommodation), total IADL and PADL scores, total MADRS score, SF-12 MCS and PCS scores, number of self-reported health complaints at baseline, and the questions “Do you get any help with home care, other activities of daily life, nursing, or medical home care from the municipality or county?” (yes/no) and “Do you get help with home care, other activities of daily life, nursing, or personal care from relatives or friends due to reduced health?” (yes/no).

In **Study II**, hospital stays were not divided into somatic and psychiatric care because all but one four-day hospital stay was in somatic care. The numbers of contacts in outpatient care are presented as visits and telephone contacts, and as totals, where all other kinds of contacts (for instance contact by mail) are included. Health utilisation data for the year preceding baseline and inclusion in the study and the whole study year were analysed. The data were divided into four time periods: 6-12 months, and 0-6 months before baseline, and 0-6 and 6-12 months after baseline. In **Study III**, data concerning in- and outpatient costs were also collected for the year preceding baseline and inclusion in the study and the whole study year, but the data the year preceding baseline were used to calculate a 3-month average which was used as baseline data. All costs were calculated for the whole one-year study period (**Study III**). Total numbers of inpatient primary diagnoses were calculated for the baseline

year (**Study I**) and for the year before baseline and the year after baseline (**Study II**). In **Study II**, the numbers of all registered diagnoses were also calculated.

Studies II and III adopted the intention-to-treat (ITT) principle (201). In **Study II**, dropouts during the first 6 months after baseline were given their actual registration for this period and for the subsequent period (6-12 months after baseline) their last known value in accordance with the Last-Observation-Carried-Forward technique (LOCF) (202). Attritions during 6-12 months after baseline were given their actual registration for this period. In **Study III**, missing values for in- and outpatient care costs were replaced using the mean healthcare cost for the time from the year preceding inclusion in the study to the time of dropout, i.e. case mean substitution (203). Imputations of costs for home safety alarms were made by LOCF. If no known value existed it was assumed that they did not have an alarm. For individuals that had one or more missing values between baseline and a later known value, linear interpolation was used for imputation. For all other imputations in municipal home care, municipal home services, and informal care, case mean substitution was used (203). In **Study III**, costs for the one-year intervention were also calculated. QALY were also calculated for the one-year study using the area under the curve (AUC) technique (201). The differences in QALY and total costs between baseline and 12 months were calculated. The differences between baseline and 6 months, and between 6 months and 12 months, were also calculated for QALY and total costs as it was considered unlikely for the intervention to be successful directly from baseline. In addition, the incremental cost-effectiveness ratio (ICER) was calculated as:

$$ICER = \frac{(C_{CM} - C_C)}{(QALY_{CM} - QALY_C)} = \frac{\Delta C}{\Delta QALY}$$

Where C_{CM} and C_C are costs in the intervention and control groups, respectively, and $QALY_{CM}$ and $QALY_C$ are the corresponding values for the one-year study. In **Study II**, effect sizes (ESs) were calculated for all significant results as:

$$ES = \frac{(m_1 - m_2)}{s_1}$$

Where m_1 is the pre-treatment mean, m_2 the post-treatment mean, and s_1 the pre-treatment SD (204). As **Study II** had two pre-baseline values and two post-baseline values, two ESs were calculated for each significant difference, using the significant value as m_2 and the two pre-treatment values as m_1 . ESs were calculated for both the intervention and control groups. ES interpretation was based on the nomenclature suggested by Cohen (205), where 0.2 represents a small, 0.5 a medium, and 0.8 a large effect. In the present study, a positive ES represents a reduction in healthcare utilisation. A complete case analysis was also conducted in **Studies II and III** (206). The statistical analyses in **Studies I-III** were performed using SPSS 18.0, PASW 20.0, and IBM SPSS Statistics 21.0.

Qualitative analysis

The texts obtained from the interviews in **Study IV** were analysed using content analysis influenced by Berg (207). Berg (207) suggests that content analysis may comprise a combination of both manifest and latent parts and that these parts could be combined during the analysis process. The manifest part concerns what is said and is visible in the text, while the latent part concerns finding an interpretable structure, a deeper underlying meaning (207). The analysis was carried out using different steps that were inspired by Graneheim and Lundman (208). As a first step, all the 29 transcribed interviews in **Study IV** (15 interviews with intervention participants and 14 interviews with case managers) were read several times to obtain a sense of the whole. In the second step meaning units related to the aim of the study were identified in the text and highlighted. In the next step the meaning units were condensed into codes. The codes could be single words or shorter phrases capturing the essence of the text. The fourth step included a movement between the codes, its parts, and the text as a whole and simultaneously during this process subcategories and categories were identified. The first author and last author of **Study IV** independently analysed three interviews. They then met and discussed the subcategories and changes were made until a consensus was reached. After that, the first author analysed an additional 12 interviews and the subcategories were once more discussed by the first and last author. At this time, subcategories sharing similar content were arranged into tentative categories. The remaining interviews were divided between the two authors, who analysed them independently and thereafter met to discuss the subcategories and make adjustments to the categories. It was agreed that no new categories emerged when analysing these last interviews, and that no further interviews needed to be analysed. The final categories were read carefully by all four authors of **Study IV** and then discussed. Small adjustments were made to the categories until a consensus was reached.

Ethical considerations

The studies in this thesis were performed in accordance with the Swedish Act concerning the Ethical Review of Research Involving Humans (209) and the Swedish Data Protection Act (210). The work also followed the ethical principles of respect for autonomy, non-maleficence, beneficence, and justice (211), and the Helsinki declaration (212).

Both the SNAC-B study (**Study I**) and the case management studies (**Studies II-IV**) have been reviewed and approved by the Ethics Committee at Lund University (**Study I**: Nos. LU 650-00, and LU 744-00; **Studies II-IV**: Nos. 342/2006, and 499/2008).

The principle of respect for autonomy

Autonomy refers to the participant's right to make independent decisions regarding participation in a study. This decision must be based on understanding, i.e. it must be knowledge-based, and it must be voluntary (211). Because of the unequal levels of knowledge between the participants and the researchers it is the researchers who have an obligation to allow the participants to act autonomously and to disclose information (211). This comprises the possibility to participate, to refuse participation, or to withdraw from a study at any time, and the right to information about the study. In **Study I**, written informed consent was obtained from all participants during the first session at their first interview by data-collecting staff. At this time, they were also asked to sign a release form for their medical records. For participants who were unable to give their consent due to cognitive impairments, written informed consent was obtained from their next of kin. All participants in **Study II-IV** received both written and verbal information on several occasions, both when they were first approached, when the time for the baseline interview was decided and, also, before the baseline interview. The information also comprised information about the participants being considered for personal interviews at the end of the intervention period and that data concerning their healthcare utilisation was going to be collected from PASiS and PrivaStat registers. Before this data was retrieved, during the autumn of 2012, information about this and the possibility of withdrawing was advertised in the two major newspapers in the municipality where the study took place. In addition, participants received contact information for the research team, which they could contact if they had questions regarding the study. Informed consent was obtained from all participants in all studies (**Study I-IV**). It was emphasised repeatedly that the participants could withdraw from the study (**Studies II and III**) or interview (**Study IV**) at any time without giving any explanation. In addition, before the personal interview (**Study IV**) it was repeated that participation was voluntary and the participants themselves could choose the venue for the interview.

The principle of non-maleficence

This principle refers to the risk of doing harm to those participating (211). This risk was reduced as no one but the research staff in these respective studies had access to the research data. In **Study I** the participants were assigned coded numbers and thus, it was not possible for the researchers to track back information to any specific individual. As this study did not attempt to have any impact on the participants' lives, health or received care, the risk of doing harm can be assumed to be small. In **Studies II and III** confidentiality was guaranteed as the research data and personal data were stored separately in locked cabinets, and data for these studies were presented on a group level. Data for **Studies II-IV** was collected through personal interviews. These interviews could take time and could be experienced as demanding, especially since some of the topics could be experienced as sensitive; also, some participants were tired or severely ill. This was taken into account and the researchers were alerted during the interviews if this was the case. They would then ask the participants if they wished to terminate the interview or to take a break. As these studies constituted parts of an intervention study, the risk of doing harm in **Studies II-IV** must have been greater than in **Study I**. In **Studies II and III** there was a risk that participants would experience the case managers as being bothersome and fearing that they would initiate interventions that would do them harm. The case managers emphasised that all parts of the intervention were voluntary and there was also a possibility for the participant of changing case manager if things did not work out between them.

The principle of beneficence

The principle of beneficence refers to the value and benefits of the study. There are no sharp breaks on the continuum from the one end, doing no harm to the other end, providing benefit, but the principle of benefits requires positive steps to help others (211). There was a risk that the researchers would discover problems in the control group during the interviews (**Studies II-III**). If any problems were detected the researchers contacted the participant's next of kin, the physician in primary care, or any of the physicians involved in the study as consultants. This was needed once, when a person in the control group became severely ill and was unable to contact next of kin, healthcare providers or relatives. The person had a severe infection and had to go by ambulance to hospital and was also admitted. If the researchers discovered problems in the interventions group the case manager was alerted. Furthermore, both groups had a pharmaceutical review made by a physician. If any problems were detected, in any of the groups, the participants' primary care physician could be contacted.

The principle of justice

The principle of justice refers to the fairness and desert, as well as allocation of resources (211). In **Studies II and III** this was an issue in terms of that the sampling and sampling procedure was made with fairness among participants. It also refers to the possibility to participate in the study, that inclusion and exclusion criteria are fair and that no discrimination against certain groups occurs. This also implies that vulnerable groups should be protected from being exposed. Participants in **Studies II and III** participants were selected regardless of age, gender, religion, race, political beliefs etc. Participants in these studies had equal of being randomised into either the intervention group or the control group. Those randomised to the control group was also were also offered to participate in the cross-over part of the study, and thus, they had also the opportunity to take part of intervention.

Results

The results are divided into three parts, which are permeated by the Neuman Systems Model (136). In the first part, results from **Study I** and the stressors according to the client system variables affecting and predicting healthcare utilisation are presented. The second part is about prevention as intervention and the effects of case management for frail older people on healthcare utilisation and healthcare costs. The last part is about how this intervention was experienced by the older people and the case managers.

Stressors associated with and/or predicting healthcare utilisation and death

Physiological, sociocultural, spiritual, and psychological client system variables were all found to be associated with and/or predict healthcare utilisation in **Study I**. The sample in **Study I** (n=1402) had a mean age of 77 years, and comprised 58% women. Forty-two per cent were classified as dependent (n=581) and 20% (n=228) being at risk of depression. Of those being classified as at risk of depression 58% (n=132) were also classified as dependent in ADL. When investigating those classified as dependent or independent in ADL, i.e. a physiological client system variable, there were significantly more with at least one hospital stay in all six years after baseline among those dependent in ADL (n=581), i.e. dependent in one or more ADL, than in those independent in all ADL (n=792) (18.2 vs. 32.5%; 16.2 vs. 36.4%; 16.7 vs. 32.7%; 16.9 vs. 33.0%; 16.9 vs. 29.2%; and 18.1 vs. 37.2%, for years 1-6 respectively; $p < 0.001$ for all comparisons). This was also seen when looking at mean hospital stays at all six years for each year separately, i.e. including all participants with valid data, with significant differences for all six years (Figure 7a). Friedman's test (including those with valid data for all six years) showed non-significant differences for year one and year five after baseline (Figure 7b). The Friedman's test also revealed that hospital stays for the sixth year after baseline in Figure 7b was significant higher compared with years 1-5 in both groups. The fifth year after baseline was also significant higher than years 1-3 in the independent group, and years one and two in the dependent group. When comparing the psychological client system variable and those with a

MADRS score >6 ($n=228$) and those with a score of ≤ 6 ($n=934$), similar patterns were noted. However, there were only significant values for the first, third and sixth years when looking at the proportion with at least one hospital stay (22.4 vs. 32.9%, $p=0.001$; 21.7 vs. 29.3%, $p=0.022$; 21.9 vs. 32.4%, $p=0.006$) and mean number of hospital stays (Figure 7c). The differences only reached statistical significance for year 6 after baseline when using Student's t-test, but also for year one ($p=0.002$) and year three ($p=0.003$) when using non-parametric statistics (Mann-Whitney U-test). The sixth year were significant higher than years 1-5 in both groups, and the fifth year was significant higher than years 1-4 in the no risk of depression group (Figure 7d).

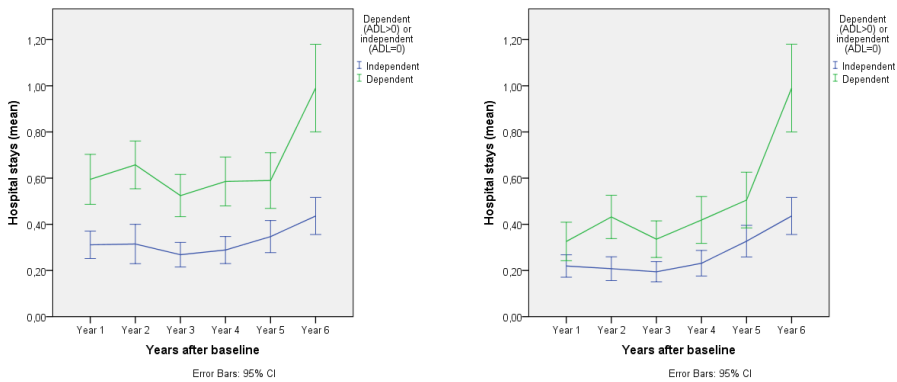


Figure 7a and 7b: Hospital stays between independent (ADL=0) and dependent (ADL>0) 1-6 years after baseline

Mean number of hospital stays for all valid data (7a, left) ($n=998-1373$) and for individuals with valid data for all six years (7b, right) ($n=980$).

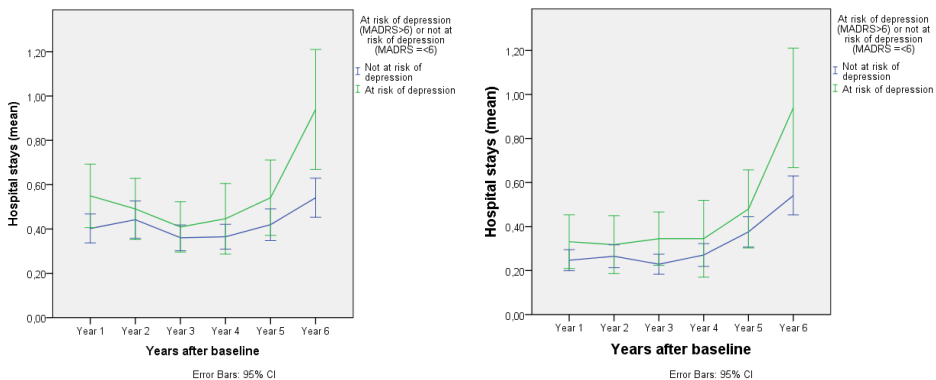


Figure 7c and 7d: Hospital stays between those not at risk of depression (MADRS ≤ 6) and those who are at risk (MADRS >6) 1-6 years after baseline

Mean number of hospital stays for all valid data (7c, left) ($n=998-1373$) and for individuals with valid data for all six years (7d, right) ($n=869$).

The increase is also larger among those dependent in ADL and those with MADRS scores >6 compared to those classified as independent and not at risk of depression when looking at the mean number of hospital stays over the six years, suggesting that the stressors also affect healthcare utilisation after six years (Figure 7a-d). These stressors are also associated with LOS. Those dependent in ADL had significantly higher mean LOS values for the second (13.5 vs. 15.0, $p=0.030$) and sixth years (15.0 vs. 22.3, $p=0.004$) than those independent in ADL. Those with a MADRS score >6 had a significantly higher mean LOS in the sixth year compared with those with a score of ≤ 6 (16.8 vs. 23.1, $p=0.024$).

When conducting regression analysis, the exclusion of outliers, participants with incomplete answers in some questionnaires, and those with a lack of valid health utilisation data (i.e. those who had died), meant that between 688 and 847 participants were included in the final regression analyses (49-60% of the complete sample). The six multiple linear regression analyses revealed that sociocultural variables such as age (in all six models), being a widow/er (model 2, LOS 5-6 years after baseline), and gender (model 5, hospital stays 1-2 years after baseline) were predictors of hospital stays and/or LOS (Table 4). In addition, physiological variables such as pain, difficulties in moving, and breathlessness were significant predictors of healthcare utilisation 3-4 years and 5-6 years after baseline, but not 1-2 years after baseline (Table 4). Other physiological predictors in the short term were ADL and SF-12 (hospital stays and LOS 1-2 years after baseline, models 5 and 6) and various diagnosis groups (hospital stays and LOS 1-2 years and 3-4 years after baseline, models 3-6) (Table 4).

Further effects of physiological and sociocultural variables on the client system were seen when looking at those who died during the six-year period. Those who died were significant older (84 vs. 74 years, $p<0.001$), higher number of self-reported health complaints (8.2 vs. 6.8, $p<0.001$), higher ADL score (3.4 vs. 0.6, $p<0.001$), higher MADRS score (4.5 vs. 3.5, $p=0.001$), and lower SF12 PCS and MCS (36.3 vs. 44.1; 52.1 vs. 54.7 respectively, $p<0.001$ for both comparisons) (**framework**). Those who died during the six years following baseline had significant higher number of hospital stays for all years (years 1-5 following baseline), compared to those who survived (0.9 vs. 0.3; 1.0 vs. 0.3; 0.9 vs. 0.2; 1.1 vs. 0.3; and 1.2 vs. 0.4 for years 1-5 respectively, $p<0.001$ for all comparisons). The dropouts were further investigated in a Cox regression. For variables entered in the Cox regression model, significant values were obtained for age ($p<0.001$, HR=1.075, 95% CI 1.053-1.098), gender ($p<0.001$, HR=2.237, 95% CI 1.611-3.105), total IADL score ($p<0.001$, HR=1.344, 95% CI 1.182-1.528), and total PADL score ($p=0.049$, HR=1.194, 95% CI 1.001-1.425), suggesting that old age, being male, and dependence in terms of both IADL and PADL increase the risk of dying (**Study I**).

Table 4: Variables associated with the total number of hospital stays and LOS (days) 1-2, 3-4, and 5-6 years after baseline

	Dependent variable	Independent variable	B	95% CI	p-value
Regression 1, final model n=690 Adj. R ² for model=0.140	Hospital stays for years 5-6 after baseline ^{a, b}	Age	0.031	0.020 to 0.041	<0.001
		Hospital stays for years 3 & 4	0.316	0.221 to 0.410	<0.001
		Walking problems	0.362	0.138 to 0.586	0.002
Regression 2, final model n=688 Adj. R ² for model=0.146	LOS for years 5-6 after baseline ^{c, d}	Age	0.345	0.254 to 0.436	<0.001
		Widow/widower	-1.929	-3.802 to -0.057	0.043
		LOS for years 1 & 2	0.091	0.010 to 0.173	0.028
		LOS for years 3 & 4	0.126	0.058 to 0.193	<0.001
		Back pain	2.549	0.953 to 4.145	0.002
		Pain in the legs	-2.302	-4.086 to -0.517	0.012
Regression 3, final model n=767 Adj. R ² for model=0.110	Hospital stays for years 3-4 after baseline ^a	Age	0.018	0.011 to 0.025	<0.001
		Hospital stays for years 1 & 2	0.217	0.163 to 0.272	<0.001
		Diseases of the genitourinary system (N00-N99)	0.612	0.048 to 1.177	0.034
		Back pain	0.181	0.052 to 0.311	0.006
Regression 4, final model n=764 Adj. R ² for model=0.114	LOS for years 3-4 after baseline ^c	Age	0.172	0.112 to 0.231	<0.001
		LOS for years 1 & 2	0.147	0.092 to 0.202	<0.001
		Diseases of the genitourinary system (N00-N99)	6.269	1.529 to 11.009	0.010
		Breathlessness	1.658	0.326 to 2.990	0.015
Regression 5, final model n=847 Adj. R ² for model=0.110	Hospital stays for years 1-2 after baseline	Age	0.019	0.010 to 0.027	<0.001
		Gender	0.166	0.009 to 0.323	0.036
		Diseases of the respiratory system (J00-J99)	0.828	0.244 to 1.412	0.006
		SF-12 PCS	-0.014	-0.022 to -0.007	<0.001
		Total IADL Score	0.159	0.073 to 0.246	<0.001
		Total PADL Score	-0.186	-0.277 to -0.095	<0.001
Regression 6, final model n=843 Adj. R ² for model=0.131	LOS for years 1-2 after baseline	Age	0.131	0.067 to 0.195	<0.001
		Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism (D50-D89)	26.067	12.473 to 39.661	<0.001
		Diseases of the respiratory system (J00-J99)	6.833	2.676 to 10.990	0.001
		SF-12 PCS	-0.110	-0.163 to -0.057	<0.001
		Total PADL Score	-1.182	-1.822 to -0.543	<0.001
		MMSE Score	-0.190	-0.347 to -0.032	0.019
		Informal help	2.463	0.787 to 4.140	0.004

^{a)} Hospital stays for years 1 & 2 after baseline entered as an additional independent variable

^{b)} Hospital stays for years 3 & 4 after baseline entered as an additional independent variable

^{c)} LOS for years 1 & 2 after baseline entered as an additional independent variable

^{d)} LOS for years 3 & 4 after baseline entered as an additional independent variable

A case management intervention as prevention

Sample characteristics

No significant differences were found between the intervention and control groups in terms of demographics or socioeconomics at baseline (Table 5).

Table 5: Demographics and socioeconomic status at baseline in Studies II-III

Group	CM (n=80)	Control (n=73)	p-value
Demographics			
Age (years), mean (SD)	81.4 (5.9)	81.6 (6.8)	0.795 ^a
Women, n (%)	52 (65.0)	50 (68.5)	0.648 ^b
Municipal care at baseline, n (%)	30 (37.5)	24 (32.9)	0.550 ^b
Marital status, n (%)			0.338 ^b
- Married or living together	23 (28.8)	29 (39.7)	
- Widow/er	41 (51.3)	34 (46.6)	
- Divorced or living apart	8 (10.0)	7 (9.6)	
- Other	8 (10.0)	3 (4.1)	
Having children, n (%)	67 ¹ (84.8)	67 (91.8)	0.184 ^b
Socioeconomics			
Educational level, n (%)			0.437 ^c
- Primary <8 years	40 (50.0)	31 (42.5)	
- Secondary >8 years	32 (40.0)	35 (47.9)	
- Tertiary/university	8 (10.0)	7 (9.6)	
Financial status, n (%) ²			0.477 ^c
- Better than others	16 (21.1)	10 (14.7)	
- Same as others	51 (67.1)	50 (73.5)	
- Worse than others	9 (11.8)	8 (11.8)	

¹⁾ Missing=1 ²⁾ Missing: Intervention group=4, Control group=5

^{a)} Student's t-test ^{b)} Chi-square test ^{c)} Mann-Whitney U-test

CM=Case management

There were no significant differences between the intervention and control groups in terms of other baseline characteristics controlled for at baseline (number of self-reported diagnosis groups, number of self-reported health complaints, the five most common self-reported health complaints, functional dependency, risk of depression, and cognitive impairment) (Table 6).

Table 6: Self-reported diagnosis groups, self-reported health complaints, ADL, risk of depression, and cognitive impairment at baseline

Group	CM (n=80)	Control (n=73)	p-value
Self-reported diagnosis groups			
Number of diagnosis groups, median (q1-q3)	3 (2-4)	4 (3-5)	0.163 ^a
Range	1-8	1-7	
Self-reported health complaints			
Number of complaints, median (q1-q3)	11 (7-15)	11 (8-15)	0.655 ^a
Range	2-22	2-23	
Five most common complaints, n (%)			
- Walking problems	55 (68.8)	55 (75.3)	0.365 ^b
- Pain in the musculoskeletal system	55 (68.8)	52 (71.2)	0.738 ^b
- Breathlessness	47 (58.8)	40 (54.8)	0.622 ^b
- Fatigue	45 (56.3)	41 (56.2)	0.991 ^b
- Memory impairment	41 (51.3)	42 (57.5)	0.436 ^b
Activities of daily living			
Dependency in no. of ADL, median (q1-q3)			
- IADL	2 (1-3)	2 (1-3)	0.651 ^a
- PADL	0 (0-0.8)	0 (0-0.5)	0.881 ^a
- Total ADL	2 (1-3)	2 (1-3)	0.831 ^a
Range	0-8	0-7	
Risk of depression			
GDS-20, median (q1-q3)	6.0 ¹ (3.0-8.0)	6.0 (4.0-8.0)	0.824 ^a
Cognitive impairment			
MMSE, median (q1-q3)	28.0 (27.0-29.0)	28.0 ² (27.0-29.0)	0.571 ^a

¹) Missing=2 ²) Missing=1 ^a) Mann-Whitney U-test ^b) Chi-square test

CM=Case management

The organisational perspective - effects on utilisation and costs

There were no significant differences between groups regarding inpatient care in terms of hospital stays or LOS during any of the four time periods (6-12 and 0-6 months before, and 0-6 and 6-12 months after baseline) (**Study II**, Table 7). The most common primary diagnosis (in ICD-10 codes) the year before baseline were in the intervention group: atrial fibrillation and flutter (I48) (n=7), acute myocardial infarction (I21) (n=5), and pain in throat and chest (R07) (n=5) and, in the control group, heart failure (I50) (n=5), I21 (n=4) and other chronic obstructive pulmonary disease (J44) (n=4). For the study year the most common primary diagnosis were in the intervention group: atrial fibrillation and flutter (I48) (n=9), and heart failure (I50) (n=6) and, in the control group, cerebral infarction (I63) (n=4), pneumonia, organism unspecified (J18) (n=3), and other chronic obstructive pulmonary disease

(J44) (n=3) (**Study II**). There were no significant differences regarding mean total number of ED visits or mean number of ED visits leading to hospitalisation (**Study II**) (Table 7). However, for ED visits not leading to hospitalisation there was a significantly lower mean number in the intervention group 6-12 months after baseline compared to the control group (0.08 vs. 0.37, $p=0.041$) (**Study II**, Table 7), indicating that the control group participants were more frequently sent home compared to the intervention group participants. This reduction was also seen when investigating the proportion of ED visits not leading to hospitalisation, with a significantly lower proportion in the intervention group 6-12 months after baseline (17% vs. 47%, $p=0.016$) (Table 7). The corresponding ESs on the effects on ED visits not leading to hospitalisation were 0.28 and 0.19 for the intervention group for 6-12 months before baseline compared to 6-12 months after baseline and for 0-6 months before baseline compared to 6-12 months after baseline, respectively, while negative effects (-0.42 and -0.23, respectively) were found in the control group (**Study II**). There was no difference between intervention and control group regarding the proportion with at least one hospital stay, or acute hospital stay, the year before inclusion in the case management study (52 vs. 51%, $p=0.921$, and 41 vs. 44%, $p=0.747$) or the study year (44 vs. 44%, $p=0.991$, and 35 vs. 38%, $p=0.667$). When looking at all outpatient care, there was a significant difference between the intervention and control groups 6-12 months after baseline in terms of mean number of physician visits (4.09 vs. 5.29, $p=0.047$) (**Study II**, Table 7). The corresponding ES for 6-12 months before baseline compared to 6-12 months after baseline were 0.33 for the intervention group and 0.05 for the control group; the ES values for 0-6 months before baseline compared to 6-12 months after baseline were 0.31 and 0.19 for the intervention and control groups, respectively. There were no significant mean differences in contacts with other professionals in outpatient care.

There were no significant differences between the intervention and the control group in utilisation or costs of municipal home care, municipal home services, or informal care at baseline (data not shown). In addition there were no significant differences in inpatient or outpatient care costs at baseline (data not shown). In **Study III**, there were no significant differences between the groups in utilisation of care in other sectors (municipal home care and municipal home services) for the one year study (Table 8). There were no effects on healthcare costs for outpatient care, with only non-significant values when comparing one-year costs for the intervention and control groups (**Study III**, Table 8). However, a significant reduction of informal care in hours of help with IADL for the whole intervention year, with significant lower mean number in the intervention group compared to the control group (200 vs. 333 hours, $p=0.037$) (Table 8). There was no significant differences between the intervention and the control group in health sector costs (inpatient and outpatient care), costs in other sectors (municipal care and municipal home services), in patient fees, or total costs when looking at the whole one-year study (**Study III**) (Table 8).

Table 7: Inpatient care, ED visits, and contacts with physicians in outpatient care for the intervention and control groups

Group	6 to 12 months before baseline			0 to 6 months before baseline			0 to 6 months after baseline			6 to 12 months after baseline		
	CM	Control	p-value	CM	Control	p-value	CM	Control	p-value	CM	Control	p-value
Health sector – Inpatient care												
No. of hospital stays, mean (SD)												
- Total	0.38 (0.64)	0.45 (0.91)	0.545 ^a	0.48 (0.84)	0.62 (1.14)	0.381 ^a	0.40 (0.69)	0.40 (0.91)	0.983 ^a	0.49 (0.81)	0.48 (0.84)	0.952 ^a
- Acute	0.29 (0.60)	0.37 (0.83)	0.478 ^a	0.40 (0.79)	0.45 (0.85)	0.695 ^a	0.30 (0.62)	0.30 (0.70)	0.990 ^a	0.39 (0.72)	0.42 (0.71)	0.748 ^a
- Planned	0.09 (0.28)	0.08 (0.28)	0.907 ^a	0.08 (0.31)	0.16 (0.65)	0.285 ^a	0.10 (0.34)	0.10 (0.45)	0.949 ^a	0.10 (0.34)	0.05 (0.28)	0.377 ^a
Length of stay (days), mean (SD)												
- Total	2.14 (6.15)	2.79 (6.83)	0.532 ^a	5.05 (12.74)	3.90 (7.26)	0.501 ^a	2.38 (5.34)	1.78 (4.63)	0.466 ^a	4.60 (15.42)	4.05 (11.71)	0.807 ^a
- Acute	1.31 (3.95)	2.21 (5.61)	0.261 ^a	4.49 (12.56)	3.29 (6.92)	0.471 ^a	1.71 (4.26)	1.63 (4.59)	0.909 ^a	3.80 (15.01)	3.90 (11.54)	0.962 ^a
- Planned	0.83 (4.34)	0.59 (2.47)	0.684 ^a	0.56 (2.53)	0.62 (2.28)	0.890 ^a	0.66 (3.46)	0.15 (0.78)	0.202 ^a	0.80 (3.65)	0.15 (0.81)	0.125 ^a
Health sector – Outpatient care												
ED visits												
No. of ED visits, mean (SD)												
- Leading to hospitalisation	0.25 (0.56)	0.32 (0.72)	0.534 ^a	0.39 (0.79)	0.36 (0.71)	0.798 ^a	0.24 (0.58)	0.25 (0.64)	0.927 ^a	0.34 (0.69)	0.42 (0.71)	0.672 ^a
- Not leading to hospitalisation	0.23 (0.53)	0.18 (0.45)	0.557 ^a	0.15 (0.36)	0.22 (0.65)	0.412 ^a	0.15 (0.51)	0.15 (0.54)	0.994 ^a	0.08 (0.27)	0.37 (1.18)	0.041a
- Total	0.48 (0.76)	0.49 (0.88)	0.892 ^a	0.54 (0.93)	0.58 (1.13)	0.820 ^a	0.39 (0.80)	0.40 (0.91)	0.944 ^a	0.41 (0.77)	0.79 (1.59)	0.066 ^a
Number ED of visits, n (%)												
- Total	38	36		43	42		31	29		23	49	
- Not leading to hospitalisation	18 (47.4)	13 (36.1)	0.327 ^b	12 (27.9)	16 (38.1)	0.318 ^b	12 (38.7)	11 (37.9)	0.951 ^b	4 (17.4)	23 (46.7)	0.016b
Contacts with physicians												
No. of contacts, mean (SD)												
Visits	5.49 (4.22)	5.45 (3.51)	0.955 ^a	5.30 (3.94)	6.10 (4.20)	0.229 ^a	4.55 (2.98)	4.78 (3.63)	0.667 ^a	4.09 (2.63)	5.29 (4.45)	0.047a
Telephone calls	3.14 (3.47)	3.12 (4.07)	0.981 ^a	2.96 (4.09)	3.34 (3.93)	0.560 ^a	2.55 (3.20)	2.82 (3.88)	0.545 ^a	2.10 (2.60)	2.84 (3.88)	0.167 ^a
Total	10.79 (6.67)	10.12 (7.54)	0.564 ^a	10.73 (7.49)	11.49 (6.83)	0.518 ^a	9.68 (6.03)	9.36 (6.84)	0.760 ^a	8.81 (5.99)	10.18 (8.18)	0.245 ^a

^{a)} Student's t-test ^{b)} Chi-square test. Significant differences are highlighted in bold.

CM=Case management

Table 8: Costs and use of care during the 12-month study for the intervention and control groups

Group	CM (n=80)		Control (n=73)		p-value ^a
Health sector					
- Inpatient care costs in €, mean (SD)	9319	(26408)	4196	(6738)	0.097
- Outpatient care costs in €, mean (SD)	2560	(2388)	2656	(2280)	0.800
- Total costs in €, mean (SD)	11880	(27832)	6853	(7585)	0.124
Other sectors					
Use of municipal home services, mean (SD)					
- Hours of help with IADL	20.9	(48.7)	14.9	(29.2)	0.363
- Hours of help with PADL	13.7	(36.3)	15.0	(52.7)	0.866
- Hours of help at night	2.7	(14.6)	1.9	(7.9)	0.660
- No. of grocery deliveries	4.9	(18.1)	12.7	(38.0)	0.114
- Accompaniment hours	0.2	(2.2)	0.3	(2.3)	0.940
- No. of months of safety alarms	5.6	(5.3)	5.9	(5.1)	0.731
- Days of short-term stays	0.0	(0.0)	0.2	(1.2)	0.159
Costs (in €) of municipal home services, mean (SD)					
- Help with IADL	633	(1450)	462	(915)	0.389
- Help with PADL	593	(1551)	666	(2414)	0.822
- Help at night	114	(615)	82	(346)	0.693
- Grocery deliveries	94	(417)	200	(570)	0.196
- Accompaniment	7	(65)	8	(68)	0.939
- Safety alarms	204	(192)	214	(186)	0.731
- Short-term stays	0	(0)	40	(238)	0.159
- Total for municipal care	1645	(3473)	1671	(3310)	0.961
Use of municipal home care, mean (SD)					
- Hours of municipal home care: daytime	15.3	(55.8)	10.4	(34.4)	0.512
- Hours of municipal home care: evening	1.1	(6.8)	3.1	(11.0)	0.194
- Hours of municipal home care: at night	0.3	(2.9)	0.0	(0.0)	0.339
Costs (in €) of municipal home care, mean (SD)					
- Municipal home care: daytime	355	(1318)	241	(796)	0.523
- Municipal home care: evening	24	(143)	67	(237)	0.182
- Municipal home care: night	7	(61)	0	(1)	0.340
- Total for municipal home care	385	(1375)	307	(906)	0.683
Participant and family					
Use of informal care, mean (SD)					
- Hours of help with IADL	200	(324)	333	(445)	0.037
- Hours of help with PADL	23	(128)	64	(390)	0.374
Costs (in €) of informal care, mean (SD)					
- Help with IADL	3927	(6361)	6550	(8754)	0.037
- Help with PADL	457	(2506)	1265	(7676)	0.374
- Total for informal care	4383	(8311)	7815	(14486)	0.079
Patient fees, mean (SD)	111	(62)	115	(57)	0.651
Intervention costs (in €), mean (SD)	3516	(0)	-		
Total costs (in €), mean (SD)	21920	(32936)	16762	(17064)	0.235

^{a)} Student's t-test, CM=Case management

A complete case analysis in **Studies II and III** revealed no major differences compared with the ITT analysis. However, some results changed and reached significance. In contrast to the ITT analysis in **Study II**, there was in the complete case analysis (intervention group n=65, control group n=62) a significant difference between the intervention and control groups in telephone contacts with physicians in outpatient care 6-12 months after baseline, with a higher number for the control group compared with the intervention group (3.03 vs. 1.08, p=0.037). For ED visits not leading to hospitalisation 6-12 months after baseline, the difference was non-significant in the complete case analysis (intervention group 0.06, control group 0.37, p=0.056). For internal dropout, and thus where imputation was needed, was in **Study III** was at baseline and at 3, 6, 9, and 12 months between 1 and 34% for EQ-5D and EQ-VAS, between 1 and 35% for municipal care, and between 0 and 31% for informal care. The highest dropout rate was obtained for the 12 months measurement. The complete case analysis in **Study III** showed that the difference in number of grocery deliveries was non non-significant (0.7 vs. 3.5, p=0.102). In addition the complete case analysis showed that informal care costs were significantly lower in the case management group compared to the control group at 3, 6, and 12 months after baseline (761 vs. 1453, p=0.024; 790 vs. 1583, p=0.045; and 705 vs. 2113, p=0.022, respectively) as well as for the entire one-year study (2712 vs. 5774, p=0.021). The corresponding results in the ITT analysis were non-significant.

When looking at dropouts in **Studies II and III**, they did not differ between the two groups in either **Study II** (p=0.546) or **Study III** (p=0.673). In **Study II**, dropouts and those who completed the study did not differ significantly regarding age (p=0.460), sex (p=0.128), municipal care (p=0.711), marital status (p=0.503), having children (p=0.313), or economic status (p=0.316) at baseline. There were no significant differences in the number of self-reported diagnosis groups (p=0.941), number of self-reported health complaints (p=0.491), functional dependency (p=0.276), risk of depression (0.461), or cognitive impairment (p=0.198) at baseline. However, the dropouts had a significantly higher educational level at baseline (p=0.028) (**Study II**). In **Study III**, the dropouts did not differ significantly from non- dropouts regarding age (p=0.466), municipal care (p=0.161), marital status (p=0.562), having children (p=0.386), educational level (p=0.562), or economic status (p=0.346) at baseline. There were no significant differences in the number of self-reported diagnosis groups (p=0.944), number of self-reported health complaints (p=0.293), functional dependency (p=0.095), risk of depression (0.495), or cognitive impairment (p=0.215) at baseline. In **Study III** there were significantly more men among dropouts than among those who completed the study (47.4% vs. 28.7%, p=0.034).

The participant's perspective - effects on HRQoL and experiences of the intervention

There were no significant differences between the two groups in the participants' EQ-5 D and EQ-VAS scores (i.e. QALY) at baseline, at 3, 6, 9, and 12 months after baseline, or for the one-year study (**Study III**, Table 9). The baseline and 12-month measurements showed no significant differences in total costs, EQ-5D, or EQ-VAS. However, after division into 6-month sections, EQ-VAS-based QALY were significantly higher in the case management group, with an increase of 0.03 between 6 months and 12 months after baseline, compared to the control group, which showed a decrease of 0.02 in this period ($p=0.029$). No other significant differences were found in total costs or QALY for this period or for the time from baseline to 6 months after baseline.

Table 9: Differences between the intervention and control groups in HRQoL

Group		CM (n=80)	Control (n=73)	p-value ^a
HRQoL				
QALY EQ-5D	Baseline	0.61 (0.29)	0.57 (0.26)	0.478
	3 months	0.60 (0.30)	0.61 (0.25)	0.781
	6 months	0.63 (0.28)	0.59 (0.28)	0.391
	9 months	0.60 (0.30)	0.61 (0.27)	0.831
	12 months	0.63 (0.28)	0.61 (0.25)	0.779
	One year mean	0.61 (0.25)	0.60 (0.23)	0.801
	Diff. 0-6 months	0.02 (0.28)	0.01 (0.23)	0.859
	Diff. 6-12 months	0.00 (0.22)	0.03 (0.20)	0.421
QALY EQ-VAS	Baseline	0.59 (0.19)	0.62 (0.16)	0.384
	3 months	0.62 (0.18)	0.64 (0.17)	0.487
	6 months	0.60 (0.19)	0.64 (0.13)	0.141
	9 months	0.61 (0.20)	0.63 (0.16)	0.693
	12 months	0.63 (0.18)	0.62 (0.15)	0.764
	One year mean	0.61 (0.17)	0.63 (0.12)	0.401
	Diff. 0-6 months	0.01 (0.16)	0.02 (0.16)	0.594
	Diff. 6-12 months	0.03 (0.13)	-0.02 (0.13)	0.029

^a) Student's t-test

CM=Case management

The impact of the intervention on the participants was not only evaluated with HRQoL instruments. The participants' experiences of the case management intervention were also investigated through interviews in **Study IV**. The results gave two content areas: (1) receiving case management as a model and (2) interacting with a case manager as a professional. The findings constituted two categories: case

management as a possible additional resource and the case manager as a helping hand. Each category comprised different subcategories representing aspects of the two categories.

Case management as a possible additional resource comprised four subcategories: “*Something unknown*” “*Reliable competence*”, “*Limited resource*”, and “*Gaining a safety net*”. For the participants the category reflected the fact that this service was something new. They did not know what to expect and how or when to use this resource or why someone (i.e. the case manager) wanted them to do certain things. When the participants received the help or information that they needed most, they eventually understood what case management comprised and that case management included a competence that one could depend on. They expressed that they knew that they could receive help from the intervention, which was there for them and could help them if needed. This made them feel secure and contributed to the experience of case management as safety net. This, together with, for instance, interpersonal aspects such as personal chemistry, could contribute to a strong relationship, and some participants expressed that they felt that they had become friends with the case manager. In addition, the participants knew that the case management intervention was a limited resource, in terms of both intensity and time. They understood that the intervention had to end and that there were other participants that needed attention. But to be a part of an intervention that provided contact and visits on a regular basis made the participants feel secure. Many participants expressed that they had benefited from the advice or the actions they had received during their time in the case management intervention. Case management was experienced as a resource that sometimes could replace usual care, and a resource not only for practical matters, but also emotional ones.

The second category was about the participants experiencing the contact and interaction with the case manager *as a helping hand* (**Study IV**). This helping hand could lead them and point the direction in times of confusion. A helping hand could also be supportive when, for some reason, one is unbalanced and falters. It could also give confidence to have a hand to hold tight when you are worried and need emotional support. This category covered four subcategories: “*The one who has information*”, “*The one who supports*”, “*The one who keeps an eye on things*”, and “*The one who knows what to do or where to turn*”. The case manager was experienced as someone they could turn to if they had questions and who had information that could be used to solve various problems. They also experienced the case manager as someone who actually solved problems on specific occasions. This could be fixing a specific problem, but it could also be things that the participant had not experienced as problems. One example was that it was expressed that participants got advice from the case manager as to where to turn to in the health system, for instance when they felt ill or if they had a problem. The participants also experienced that they received support from the case manager. The support could be practical

support, when, for instance, they had an appointment at the hospital; social support, which could be just having someone to talk to; and emotional support, having someone around when they, for instance, felt sad. The case manager was also experienced as someone who kept an eye on things and who performed examinations and asked questions. It was also experienced that this and the regular contact contributed to the case managers' ability to react if they noticed any deterioration or change.

The case managers' perspective - Experiences of the intervention and three different cases

Study IV also assessed the case managers' experiences of the intervention. The experiences of the case managers' were classified into in two categories: "*case management as entering a new professional role*" and "*the case manager as a coaching guard*". These categories corresponded with the participants' experiences and two content areas (providing case management as a model, and working as a case manager as a professional, from the case managers' perspective).

The first category, "*case management as entering a new professional role*" included four subcategories: "*The solver*", "*The supporter*", "*The standing guard*", and "*The navigator*". This category was very much about the experiences of working in new ways. This new role entailed both possibilities and barriers. The barriers could be lack of acknowledgement by healthcare agencies or difficulties in contacting with them. The barriers included sometimes failing to reach the participant and therefore failing to help them to perform the intervention, for various reasons. Sometimes the participants simply did not follow their advice and in some cases it was experienced as difficult to find any problems to solve at all. A possibility in the new role concerned building a good strong relationship. This – often expressed as mutual confidence – was seen as an important part of the intervention and was highly valued, enabling the case managers to make a difference by helping the participants. In their new role, the case managers had to work in new ways, interact with participants, and tackle problems other than those they had faced in their professions, and thus needed to set new limits. The strong relationships with the participants could also be challenging as the case managers sometimes felt personally involved and therefore had to define and set limits for the relationships. They also experienced difficulty in ending the intervention and experienced feelings of guilt as they were worried about what would happen to the participant when their contact cased. The analysed text also revealed experiences of various emotions connected to the intervention or the participant, including frustration when the participant did not do what was agreed, guilt and anguish when they had given some advice that did not turn out to be right, and anxiety if the participant for some reason became upset.

The second category of the case managers' experiences, "*The case manager as a coaching guard*", also entailed four subcategories: "*The solver*", "*The supporter*", "*The standing guard*" and "*The navigator*" (**Study IV**). This category concerned the providers' view of themselves as coaching guards in their roles as case managers. To be a coaching guard included solving various problems, including problems related to the participant's health, both also other practical matters such as setting up shelves. The case managers used various strategies to identify problems. The case managers also expressed how they tried to solve the identified problems, for example, encouraging a participant they identified as being lonely to take part in social events or arranging contact with a voluntary organisation. Problems could also be solved by giving information, answering questions, introducing a pain diary so that the participant would get better pain control, or introducing individualised training programs. One special form of problem was related to contact with the health system, and the case managers expressed that they informed the participants about the health system and gave advice as to where to go or whom to contact when they needed help. To be a coaching guard also comprises various forms of support. As in the experiences of the participants, this could be social, practical, or emotional support. One special form of support the case managers experienced was pushing the participant in the right direction, convincing or coaching the participant. The case managers described themselves as offering defence or security and being someone who monitored and had an overview of the participant's situation. This guarding function was seen as important and included being responsive to the participant's interests, advocacy, and having an active role in keeping track and reacting if anything happened.

Case descriptions

Three cases were selected to illustrate differences in the success of the intervention (**framework**). Case 1 is a case where the case managers recognised problems but was unable to fully reach the participant. The second case is a case where the case managers were able to detect and solve some problems. The third case is an example of the intervention having a huge impact on the participant and making a significant difference, even if the intervention was not always performed in the intended way. All cases are derived from interviews with case managers. This means that the text reflects the case managers' perspective and experiences.

Case 1: A woman with chronic pain that did not do what she was asked to do

An 80-year-old woman lived in an apartment with her husband and had no municipal home care or municipal home services. She had numerous of conditions, among other she suffered from chronic pain in her back and her neck, and chronic headache since her youth. Her pain problems had been investigated several times without the cause of her pain being identified. She has had various treatments and her pain had periodically improved, but not completely.

They experienced her as nice and social and they had no problems during their meetings. They recognised that she used to take walks but was now, due to her pain, largely housebound and had become very inactive. She only left the apartment once a week to buy groceries and spent most of the day watching TV. The case managers also recognised that the pain made her incapable of cleaning the apartment and that she had some problems with incontinence.

To increase the mobility in the neck and the back, and to reduce the pain, the case managers provided a training programme. The woman only followed the programme occasionally. Nonetheless, it improved her mobility somewhat, but had no effect on her pain. The case managers suggested that she could contact a physiotherapist in the municipality, but she had already tried once and was therefore not interested. The case managers also suggested other physical activities but she put them off, replying that she might try them later, next month perhaps. To get an insight into what activities she actually performed, they asked her to complete a schedule of her activities, which she did partly. They proposed numerous things and activities that they thought might reduce her pain, but she ignored all of them. They also suggested that they could take a walk together or help her to get to the activity centre, but she did not want that either. The case managers also provided telephone numbers for cleaning companies that could clean the apartment, but she did not call them. Instead the husband, who was quite healthy, took over responsibility for cleaning the apartment. The nurse case manager was nevertheless able to help her with aids for her incontinence.

During the intervention both case managers experienced the participant as hard to motivate and that she did not perform the activities or tasks that she was asked to do. They thought that she might see the pain as a barrier for performing physical activities instead of physical activities as something that could reduce her pain, and that she maybe had accepted her pain as chronic and that there was nothing to do about it. They also experienced that she had high expectations that the case managers would solve her pain problems – which according to the case managers were unrealistic for them to do. They were only able to provide small advices that she followed, such as to brush her teeth after medication to avoid getting cavities in her teeth.

Case 2: The forgotten knee

A 78-year-old woman lived in a ground-level apartment. She was married but her husband suffered from dementia and lived in a nursing home. She visited him regularly, although he did not recognise her. She managed the household work by herself and walked with a walker. Among other conditions, she had diabetes, and problems with her knees and shoulders. She had knee prosthesis in one of her knees and received cortisone injections in the shoulders, which had a good effect. The knee problems, together with a weight problem, meant that she had problems walking up

stairs and getting up from the floor. She also had impaired hearing and a hearing aid, but she only used it occasionally.

In addition to the pain, the case managers identified that the woman had problems with incontinence, and that she felt unsteady and sometimes a bit dizzy. They also discovered that she had little knowledge about her prescribed medications.

One of the case managers examined the woman's knee and provided her with a movement training programme. Her knee deteriorated during the intervention and the case managers encouraged her to contact a physiotherapist in the municipality, which she did. They also encouraged her to contact an orthopaedic specialist. Both case managers accompanied her to this appointment. The specialist explained the injury but the participant did not understand all the information provided by the specialist, so the case managers had to explain this later. The case managers also advocate for the participant when the specialist did not take into account her other conditions, such as diabetes, when prescribing painkillers. The case managers also thought that the woman's knee should be subjected to an MRI scan and the specialist agreed to send a referral. After the meeting, the woman continued to meet the municipality physiotherapist and received additional exercises from the case managers, but with no improvements in the knee. They had not heard from the MRI department. They once more encouraged her to talk to the specialist, who had in fact not sent a referral. After doing so, she finally got the referral and underwent an MRI scan. At the end of the intervention period she also received a referral for knee surgery and a new knee prosthesis. The case managers experienced that she was very pleased that they had helped her with this and very satisfied that something was finally going to be done with her knee.

The case managers also helped her with her incontinence and provided samples of incontinence aids so that she was able to try them out and order the right one from the district nurse. She was very pleased with this help, as well as the result.

The participant also received a balance training programme from the case managers. The programme was continually followed up and the degree of difficulty was gradually increased. The woman performed the exercises to some extent. At the end of the intervention period, she told the case managers that she felt that her balance had improved. The case managers discovered that she was less dizzy when she used her hearing aid. They therefore encouraged her to use her hearing aid as much as possible.

The case managers conducted a pharmaceutical review together with the participant and informed her about her medications. During this review they also found out that she had acid reflux and arranged for her to receive a prescription for it. They also gave advice about different laxatives as she also suffered from constipation. Another problem that they discovered during the intervention year was that she became sadder

about her husband's situation, visited him less, and had another very sick relative. She confided to the case managers and they provided support and someone to talk to about these matters. The case managers experienced that she had great confidence in them. They also talked about the need to use her compression stockings (she used them only occasionally) and her diet, as she was a bit overweight and diabetic.

Case 3: The undiscovered tumour

An 85-year-old woman lived alone in a large house. She had been a widow for 15 years and had been a housewife all her life. She had little or no contact with her two children. She had municipal home services which provided cleaning services and help with help compression stockings every morning, and she had also privately hired help with her garden. She suffered from low blood pressure, had undergone hip surgery about five years earlier and she had broken her arm the previous year after a fall. She felt dizzy and used a cane when she walked outdoors.

Together with the participant, the case managers decided that they should come alone every second week. The participant had a great need and made lists with things that she wanted the case managers to perform. They were usually practical things, such as shopping, visits to the cemetery, and changing light bulbs. They spent a lot of time on this participant – as much as 3 hours for a single visit. The case managers also experienced that she had some cognitive impairment, but that she tried to hide it.

After a month in the intervention one of the case managers was asked to examine a lump in one of her breasts. The case manager judged that this should be investigated by a physician. The participant gave her permission for the case manager to call the primary care centre and the very next day they sent a referral for an X-ray of her breast. The case manager went with the participant to the physician as support when they had received the results of the examinations. The tumour was malignant and she underwent surgery and radiology.

During her hospitalisation the case manager visited her several times at the hospital ward. There she also talked to the staff and pointed out that the participant should not be sent home without assistance assessments. However, it was never performed and she was sent home without any arrangements. When the case manager arrived she found her in her bed, unable to do anything. She had to contact the municipality and the home-help officer to make an acute assistance assessment. It was then decided that she would receive home rehabilitation, with five visits a day. Both before and after the surgery the participant needed to talk about her disease and her situation, and the case managers acted as support for her.

During the rehabilitation period the case managers also tried to activate her. They encouraged her to contact a physiotherapist and at the end of the intervention period she regularly visited a physiotherapist. To help the participant with her dizziness the case manager suggested that she could start to use a walker, but she did not want to.

The case manager also conducted various examinations, but these only showed a minor reduction in balance. She put together a balance programme, but when the participant was followed up it seemed that she did not adhere to the programme, probably because of her impaired memory. The case managers also tried to inform her about her medications, but her memory problems also caused difficulties here. The case managers also contacted volunteer organisations that could help her in various ways, for example with shopping and as company, after the intervention ended.

Discussion

Methodological considerations

There is a risk of methodological threats related to any chosen study design and every methodology has its pros and cons that may also affect the result in various ways. This thesis was based on three different designs – a longitudinal cohort design (**Study I**), an experimental design (**Studies II and III**), and a qualitative design (**Study IV**). One goal of a cohort design is to establish the relation between antecedent events and outcomes (213). Likewise, the goal of the experimental design is to draw conclusions about causal effects by using manipulation. These two designs (**Studies I-III**), and other quantitative designs, can be assessed by means of validity, which comprises internal, external, construct, and statistical conclusion validity (213). Studies with qualitative designs (**Study IV**), on the other hand, can be assessed by their trustworthiness, including credibility, transferability, confirmability, and dependability (214).

Internal validity

Internal validity refers to the extent to which conclusions can be drawn that the independent variable has accounted for the results, and the extent to which other alternative factors or explanations affected the outcome (213). There are several types of threats to internal validity, such as history, maturation, testing, instrumentation, statistical regression, and selection bias (213).

Healthcare utilisations in terms of out and inpatient care and the corresponding healthcare costs were, in this thesis, derived from different registers (SysTeam Cross, earlier Pas-origo in **Study I**, and PASiS and PrivaStat in **Studies II and III**). The validity of the Swedish national inpatient register (IPR), of which these registers are parts, has been investigated in a review of 132 papers (215). Diagnoses according to ICD-10 (159) registered in IPR were compared to diagnoses registered in medical records. Predictive values of 85-95% were found for most diagnoses. Furthermore, for patients dying in hospital, the agreement was good (approx. 90%) between their IPR primary discharge diagnoses and the underlying cause of death (215). All these registers are also well-known and well-established among staff members and form the

basis for reimbursement for the health agencies. The registers for inpatient data are also used on an everyday basis with regards to accounting for the number of occupied beds at each hospital. These are all factors that increase the validity and reliability of these registers, at least in terms of hospital stays, LOS and contacts with a physician in outpatient care. One limiting factor of these registers is that only healthcare provided in each specific county is registered. This means that there is a chance that participants in **Studies I-III** have utilised healthcare in another county council. This threat to internal validity must be considered as small. Data for the **Studies I-III** were also collected by means of a form filled in by the staff working in the different studies. Many people were involved in the collection of data, which may constitute a threat to internal validity since different people may perform the assessments differently. However, the staff members were educated in how to perform the different assessments, and received both oral and written instructions, and the measurements were also standardised. Established methods for the medical examination, instruments, and questions have been reported to be used in SNAC-B (**Study I**) (150). The form and the data collection procedures in the case management study (**Studies II and III**) has been tested by Kristensson, Ekwall, Jakobsson, Midlov and Hallberg (17).

For the self-reported utilisation of municipal home care and municipal home services in **Studies II and III** there is a risk of both over and underestimation as the utilisation may be difficult for the older person to estimate. However, as the experimental design and randomisation in **Studies II and III** seemed to create equivalent groups these errors are therefore equally likely to occur in both groups. Sensitivity analyses for estimated costs for municipal home care, municipal home services and informal care were made with twice and half the cost. No changes regarding significances were seen. Thus, this may not be considered as threats to the internal validity.

Also EQ-5D and EQ-VAS, used as outcome measures in **Study III** may have resulted in threats to internal validity. The values in both groups were relatively stable over time, something that was not expected for such a frail group. There are studies that question whether or not these measures are sensitive enough to discover changes and if they are appropriate to use in QALY calculations, especially among frail older people. Brazier, Walters, Nicholl and Kohler (216) conclude that EQ-5D may be used if large changes in health status are expected. This is because EQ-5D only contains three response alternatives for each item, compared with, for example, SF-36 (160) with seven response alternatives for most items, thus it is possible that it is a more sensitive instrument. Also the derivation to QALY could be questioned. QALY calculations derived from SF-6D (217), which is another HRQoL instrument, were two to three times higher than those of EQ-5D. This means that the choice of preference-based utility instrument may have a significant impact on study outcomes and conclusions (218). Also EQ-VAS proved to be somewhat troublesome as there was a trend that the participants seemed to judge their health in even sets of ten,

especially around fifty, as this is in between the best and the worst imaginable health state. This could also have threatened the internal validity. In addition, Whynes (219) reported that the EQ-VAS score was predicted by variables other than the EQ-5D health states, and that, for instance, psychological disposition, socio-demographic factors such as age and education, and clinically-important distress systematically contributed to the EQ-VAS score. When looking at other case management studies investigating HRQoL none seem to have used EQ-5D. Instead it seems that SF-36 (160) and the shorter SF-12 (161) are preferred (14, 15, 115, 220-222). On the other hand, both EQ-5D and EQ-VAS are well-known measures that are short and easy to use. They are also well tested; there are studies showing high validity and reliability, and it is appropriate to use in an older population (223). However, the threats to internal validity concerning EQ-5D and EQ-VAS should not be ignored and have to be taken into account when interpreting the results.

Attrition may also have contributed to the threat towards internal validity. This is highly important in **Studies I-III**, as they are all longitudinal studies, but for different reasons. In **Study I** this is more important because the absence of a control group affects the abilities to draw conclusions about causalities. The reason is that when persons drop out, the remaining sample may no longer be representative. In addition, changes in outcome may depend on dropouts scoring in a particular way that differed from the remaining sample. The mortality rate in the six years following baseline in **Study I** was 29% (404 of 1402). Dropout analysis showed that these participants had worse health and utilised more healthcare than those surviving all six years following baseline. This is in line with other studies where healthcare utilisation has been found to increase the time prior to death (224). Due to these differences in healthcare utilisation rates, the data were presented both numerically and graphically and covered the entire sample (Figure 7a and 7c; **Study I**, Tables 3 and 4) and those that remained alive throughout the study period (Figure 7b and 7d; **Study I**, Tables 3 and 4). This makes it possible to evaluate the impact on healthcare utilisation of those who died. Even if the utilisation rates are generally lower for those that survived the whole study period, suggesting an underestimation of healthcare utilisation in **Study I**, the same patterns are seen in all four figures (Figure 7a-d). In **Studies II and III** the randomisation makes it possible to draw conclusions about effects, but dropouts could affect the characteristics of the group, and also causal relationships. **Studies II and III** adopted the intention-to-treat (ITT) principle which means that imputations were made for dropouts. This could also be a threat to internal validity, as this may lead to various forms of bias. One assumption for conducting imputations is that the dropouts are missing completely at random (MCAR) (225). Therefore also dropout analyses were conducted in **Studies II and III**. According to Polit and Beck (144) dropouts can be regarded as MCAR when patient characteristics are similar between participants with and without missing, meaning that underlying reasons for values being missing are independent of participant characteristics. Significant differences

between dropouts and those completing the one-year study were only found for two variables; higher educational level among dropouts at baseline in **Study II**, and more men among dropouts at baseline in **Study III**, suggesting the dropouts to be MCAR. Different imputation techniques were used in **Studies II and III** depending on the different types of data. According to Musil, Warner, Yobas and Jones (225) MCAR data are less likely to introduce bias to imputed data, regardless of which imputation technique is used. Complete analyses were also made to investigate the potential impact of the imputations. Also here, only a few differences regarding significances were found between the ITT and complete cases analysis. This most probably increases the internal validity in **Studies II and III** and the likelihood of the ITT-analysis to be unbiased.

History and maturation are threats to **Study I** as this study lasted for six years and changes related to this could affect the participants, and thus the outcome. Healthcare utilisation could be expected to be affected by changes in how this healthcare is provided. One way of reducing the likelihood of being affected by history is to select people within the same general location (143). The sample in **Study I** came from the county of Blekinge, which implies that changes in the county government, by which inpatient care is governed, affect the whole sample equally. In addition, data for each cohort was collected for three years with new participants in the cohort each year. These circumstances are likely to reduce threats of history and maturation and increase the validity.

Other potential threats to internal validity were those of testing (people getting used to the questionnaire) and instrumentation (changes in the measurement procedures, or changes among the staff in the way the data is collected); statistical regression (that scores tend to regress to the mean if a measurement is re-administrated) could also have affected the results. The questionnaire in **Study I** was only used for baseline data; the longitudinal data only comprised data from healthcare utilisation registers and therefore did not pose threats in this study. However, these threats were present in **Studies II and III**. As mentioned above, much about internal validity in experimental designs is about creating equivalent groups with the assumption that factors other than the intervention will affect both of the groups to the same extent (143). Thus, effects of history and maturation, testing, instrumentation, and statistical regression were equally likely to occur in any of the groups. As the intervention and control group in **Studies II and III** did not show any significant differences in demographics, socioeconomics, or other baseline data the assumption of equivalent groups seems to be fulfilled and these threats to internal validity reduced.

External validity

Whether or not a result of an investigation or a study could be generalised to other conditions, settings or populations is a question of external validity (213). All dimensions of generality of interest are included in external validity and all characteristics of the experiment that may limit the generalisability are considered to be threats to the external validity (213). The threats to external validity could, for example, concern representativeness and systems, sample characteristics (and characteristics among non-attenders), settings, timing of measurement, and novelty effects (213).

Generalisability of the results in this thesis (**Studies I-III**) may be limited to health systems in which the healthcare, and care and services delivery systems are similar to those of the health system in Sweden. This system is mainly based on taxes and does not rely on private insurances. In addition, individuals are protected from high costs, both regarding healthcare costs, care and services, and medication. This reduces the impact of income level on the access and utilisation of the system. In **Studies II and III** the seen effect of case management on healthcare utilisation and informal care may not be possible to achieve where the health system is organised in different ways.

One threat to external validity is whether or not the sample is representative for the population intended to be studied (213). The sample was, according to Rennemark, Lindwall, Halling and Berglund (149), representative for the population from which it was drawn, with the exception that the participants had a slightly higher functional status and better health. The SNAC in **Study I** was designed as a national study and, ideally, the study should encompass a representative sample of the total Swedish population of older people (146). The aim of SNAC was also to include different areas of Sweden in order to investigate the availability of resources and local support (146). Thus, a compromise had to be reached, resulting in that the sample in SNAC-B may differ somewhat from the Swedish population of older people and some caution must be taken when interpreting the results in **Study I** in comparison to other settings. However, in the sample in **Study I**, aged 60 or older, there were 6.6% who lived in special accommodation (i.e. nursing homes) compared to 7-8% for the whole Swedish population of those 65 years or older for 2001-2003 (226). Also, when comparing the sample in **Study I** with Swedish official statistics (227) of people 60 years or older there were no major differences in gender (58 vs. 55%) respectively for the years 2001-2003. There were also only small differences when comparing the sample in **Study I** and the Swedish population of 60 years or older in the proportion of married (52 vs. 54%), and unmarried (7 vs. 8%), but there were bigger differences in the proportion of widow/er (36 vs. 24%), and divorced (6 vs. 14%) (227). Nonetheless, it is therefore fair to assume that the sample in **Study I** does not differ on any major points and it may be representative of the population.

Another aspect of representativeness concerns the response rate and those who declined participation. In **Study I** the response rate was 61% leaving 910 people not participating in the study. No analysis of those declining participation has been made and, furthermore, it has been concluded that there were no significant differences in gender among non-attenders and the participants (150). Despite an oversampling in the oldest age cohorts, the older the age, the lower the response rate. It is reasonable to believe that dropouts have skewed the sample to be younger and healthier than the population and may therefore be a threat to the external validity.

In **Studies II and III** dropouts are of interest since, if they differ from the studied sample, the result could be different in other settings even if the same inclusion criteria were to be used. In the case of those who were contacted in **Studies II and III** and who fulfilled all inclusion criteria but did not want, or were too sick, to participate (n=83), valid data concerning age and gender showed that they were slightly younger than the sample (79.8 vs. 81.5 years) and were to a lesser extent females (57% vs. 67%). As females are expected to live longer and also have less chronic conditions in general (228) this indicates that the sample probably has slightly poorer health than frail older people in general in the municipality. However, a great proportion of people invited to the study through mail did not respond, which makes it unclear if they met the inclusion criteria and if they differed in any way from those included in the **Studies II and III**. The setting may also be a threat to external validity. **Studies II and III** were conducted in one municipality with one town and with both urban and rural areas. The municipality was not far away from a university hospital (approximately 20 km) and the result may be different in different settings, for instance in larger cities, or in municipalities that are further away from hospitals. More studies in different Swedish settings are needed to increase external validity in this respect. One aspect that could be a threat to external validity is the timing of measurement, where the result of an instrument may depend on the point in time that data are collected (213). The follow-up time in **Studies II and III** was one year, and almost every significant difference between the intervention and control groups was seen in 9 to 12 months after baseline, which was the last follow-up period. This time period may be too short to detect changes of such a complex intervention as case management. Longer follow-up time has been suggested, by for example, Unutzer, *et al.* (229), who had a 10-month follow-up in their case management study. In the case descriptions (**framework**) there were examples of actions taken by the case managers that will not have immediate effect, for example, that they ensured that case three (**framework**) received treatment for breast cancer. It is therefore possible that full effects of the intervention will not be seen until after the treatment and rehabilitation of the breast cancer, which probably takes longer time than the one year study period. This might underestimate the effect of the intervention and therefore be a threat to the external validity. Nonetheless, the experimental design and the establishment of equivalent groups made it equally likely for many of the threats to external validity,

such as novelty effects and other aspects related to measures or assessments, to occur in both groups, and thus have the same impact in both groups.

Construct validity

Construct validity refers to the intervention, its content and theoretical foundations, and the presumed causal relation between the intervention and the outcomes (213). In **Studies II and III** this is a crucial issue. Was it the intervention itself (case management) that was responsible for the result or was it constructs linked to the intervention, for instance that those in the intervention group were recognised by primary health physicians and therefore given extra attention? The intervention in **Studies II and III** was complex as it contained several components that may have acted independently or interdependently (MRC). The different parts were developed and launched independently. The various components were, however, performed integrated and it is therefore difficult to know which part(s) of the intervention that was successful and which part(s) was not. In addition, the intervention was person-centred and based on a personal relationship between the older person and the case managers. It may therefore be possible that the result was affected by researchers' expectations or by the fact that the participants received some sort of attention, i.e. by different forms of expectancy or placebo effects. The nature of the intervention did not allow a blinded experiment, because both the case managers and the participants needed to know that they were a part of the intervention. MRC suggests that the intervention is developed in different phases using different designs when developing and evaluating complex interventions. This to get a more solid evidence and theoretical base and underpinning of the intervention, as well as to receive a more comprehensive evaluation that may provide insights into if and how the intervention worked. The use of this framework in the development and evaluation of the case management intervention strengthens the construct validity. Although the Neman Systems Model (136) was not used in the development of the intervention, this model contributed to the theoretical understanding of case management and to how and why preventive interventions may work. Furthermore, in this thesis both quantitative (**Studies II and III**) and qualitative (**Study IV**) studies were used to evaluate the case management intervention. The interviews and results in **Study IV** and the case reports in the **framework** indicated that the intervention was mostly performed as intended, but that there were also examples of when it was not. For example, there was one participant who did not receive any visits one month, but instead was contacted by telephone. This constitutes a threat to construct validity. The aim of **Study IV** was not to explore the process of the intervention; thus a process evaluation of the intervention analysing, for instance, the case managers' documentation, may be necessary in order to increase construct validity.

Statistical conclusion validity

Statistical conclusion validity refers to statistical methods and their ability to detect differences between variables when this is the actual state of affairs in the world, and not detect differences when it is not (213). This form of validity is often referred to as a Type I (alpha, α) or a Type II (beta, β) error. A Type I error involves the risk of rejecting the null hypothesis (that there are no differences) when in fact it is actually true, i.e. to say that there is a difference when there is none (213). Doing statistical analysis always involves a risk of Type I errors and a common way of dealing with the risk of a Type I error is to determine the probability value (p-value) and thus the size of the risk. A commonly used threshold is a p-value of 0.05 meaning a 5% risk of making a Type I error. This threshold was used throughout this thesis, except when multiple comparisons were made in **Study I**. In these cases there was a risk of mass significance and a reduced p-value according to the Bonferroni method (201) was used in the post hoc analyses. A Type II error is the opposite, i.e. it involves running the risk of accepting the null hypothesis when it is false (213), i.e. of saying that there are no differences when there actually is a difference. A Type II error is related to the concept of power, which is the probability of rejecting the null hypothesis when it is false or the likelihood of finding differences between groups when, in fact, the groups are truly different (213). Thus, low power increases the risk of Type II errors. Power is a function of the ES (the differences in a measure between the groups that should be detected, and the standard deviation of these values), the p-value (alpha value), and sample size. According to Kazdin (213) (p. 441) Cohen suggested, which is now generally accepted, that the power of a study ought to be at least 80%. In **Studies II and III** a power calculation showed that a sample size of 70 in each group was needed to be able to show a medium ES according to Cohen (230). This decreases the risk of Type II errors and increases the statistical conclusion validity in **Studies II and III**. On the other hand, power was not calculated for costs which mean that this threatens statistical conclusion validity and the conclusions concerning costs. The sample size in **Study I** was large ($n=1402$), with the smallest subgroups containing 104 people (**Study I, Table 5**). This was considered to be a large sample size and thus increases the power, as well as decrease the risk of Type II errors. High power makes it easier to detect small differences which should be in mind when interpreting the results in **Study I**. No effects were seen regarding costs in **Study III**. This may depend on that the power analysis was based on effects in healthcare utilisation and not costs. This means that **Study III** may have been underpowered to detect clinically relevant differences in costs. According to Briggs (231) this is a common problem in economic evaluations as cost data are typically heavily skewed and with wide confidence intervals very large differences or study samples are needed to achieve significant results.

As seen above, the standard deviation is one of the components in the power calculation. If a standard deviation obtained is larger than the one used in the power calculation this could lead to low power. One source of variation (the variance is the square root of the standard deviation) is that the intervention is carried out in different ways. As the intervention in **Studies II and III** was complex some flexibility was allowed, and it was also carried out by a total of six case managers. The intervention was, however, standardised in some ways – the minimum number of visits every month, the general information package, the assessment with MDS-HC, balance assessments, and the prescribed medication review – to increase the statistical conclusion validity.

Linked to the question about variance is subject heterogeneity. According to Kazdin (213) participants within a study could vary along multiple dimensions and conditions. The greater the heterogeneity among the participants the less likelihood of detecting differences. The range of self-reported diagnosis (1-8), self-reported health complaints (2-23) and ADL (0-8) (**Framework**, Table 6) suggests that the sample was rather heterogeneous and could be a threat to the statistical conclusion validity. It was surprising that there were those (n=12) who were independent in ADL, as dependence on ADL was one of the inclusion criteria, indicating that all participants may not have been frail. The problem with a heterogeneous sample in case management studies has also been discussed by Lamb (85). However, when including participants, ADL was self-reported and also included other areas than those in ADL Staircase (169), and, in addition, the participants themselves had the possibility of determining whether they were dependent or not. Even with the aim of the inclusion criteria, with previous healthcare utilisation and help with two or more ADL as two of the inclusion criteria, only about 44%, in both the intervention group and the control group had at least one hospital stays during the study year (n=35 and n=32 respectively). The numbers for the year preceding inclusion were 51 and 52% respectively. This means that they utilised a greater proportion compared to **Study I** (between 16.2 and 36.4% with at least one hospital stays for any of the six investigated years). This could, however, be expected since the sample in **Studies II and III** would be frail, in contrast to the sample in **Study I**. Rockwood, Fox, Stolee, Robertson and Beattie (232) also stated that older people are not homogenous in their need for utilisation of healthcare services. However, the standard deviation of hospital stays used in the power calculation (2.1) was higher than those obtained for hospital stays in **Study II** (between 0.64 and 1.14). This, together with a standardised recruitment and inclusion process, increased the statistical inclusion validity.

Trustworthiness

Studies with qualitative design could methodologically be assessed by the means of trustworthiness. This is referred to as arguments to persuade that the findings are worth paying attention to and worth taking account of (214) and every study must be evaluated in relation to procedures used for derivation of the findings (208). Lincoln and Guba (214) developed a framework for qualitative research and suggested four criteria for developing trustworthiness of a qualitative inquiry – credibility, transferability, confirmability, and dependability. The criteria are sometimes difficult to separate as they are closely related to each other (208).

Credibility

Credibility, which has been viewed as the most important goal of the qualitative inquiry, is about the truth and believability of the data (214) and the interpretations of them (144). Lincoln and Guba (214) stated that there were two important aspects of credibility that needed to be taken into account: Firstly, carrying out the study in a way that improved the believability, and secondly, to demonstrate the credibility when reporting the results. One aspect of credibility put forward by Lincoln and Guba (214) as a prerequisite for a qualitative interview is prolonged engagement. This is about getting to know the context in which the study is conducted, but also about getting to know your study informants in order to build trust. Building confidence is not only about the informants feeling comfortable to reveal their inner thoughts and feelings, but also a developmental process with the aim of, for instance, being able to demonstrate that the interview will not be held against them and that the interest of the respondents will be honoured (214). This was achieved, and hence credibility was increased as the interviewers also collected other kinds of data and thus met many older persons in the study, including those who would later be considered for a qualitative interview. In this way, the interviewers got to know the situation of older people and also had the opportunity to build this vital confidence. In order to increase credibility it is also important to choose participants with different experiences (208). Therefore, in **Study IV**, two types of sources of data were used, the older people, and the case managers. There was also a striving to include older people of different gender, age and marital status, as well as those who had had municipal home care or municipal home services, as this could contribute to different experiences and hence increase the credibility of the study (**Study IV**). For the same reason, all six case managers were included and interviews where they talked about older persons with differences in gender and if they had municipal home care or municipal home services (**Study IV**). One potential threat to credibility was the length and, thus, the depth and the believability of the interviews. The interviews with the case managers were in general short (between 9 and 24 minutes), but as the case managers knew the aim of the interview, what they were supposed to talk about, and because several interviews were conducted after one another, the interviews

became very focused and rich. The interviews with the participants included parts other than the one about the case management intervention. Even though these interviews were longer (between 40 minutes and 2 hours and 51 minutes), this issue, could be a threat to credibility. The amount of data necessary to answer the research question in a credible way varies with the complexity of the investigated phenomena and also the data quality (208). One common approach, with its roots in grounded theory, is to talk about saturation (233). This usually means sampling until no new information is obtained and until redundancy is achieved (233), and could be used, not only in grounded theory, but in qualitative designs in general (144). In **Study IV** no new subcategories emerged during the interviews or when analysing the last interviews (comprising interviews with both case manager and older persons), which led to the conclusion that saturation was reached and no further interviews needed to be analysed. This is also related to credibility in another aspect, namely that of how well the categories and themes cover the data. This includes the fact that no relevant data have unintentionally or systematically been excluded, or the opposite that no irrelevant data have been included (208). Two ways of increasing this aspect of credibility is to present representative quotations from the transcribed text (208), and to seek agreement among, for instance, other researchers and participants (214). Quotations from the interviews are presented in **Study IV** to make the interpretation visible for the reader, and investigator triangulation was used in analysis procedure. Two researchers analysed about half of the interviews independently and the findings were then discussed on several points. In the final stages of the analysis agreement the findings were discussed, and consensus reached, with an additional two researchers (**Study IV**). It was not possible to seek confirmation of participants as they in many cases had deceased or were too ill. Thus, several actions have been taken to increase credibility and the findings could therefore be regarded as credible.

Transferability

The concept of transferability refers to which extent the findings can be transferred to other settings or applicable in other conditions (144). Lincoln and Guba (214) argued that it is the responsibility of the reader to determine if the findings are transferable. The responsibility of the researcher lays in providing sufficient descriptive information about context and the participants included in the study (214). In addition, Graneheim and Lundman (208) stated transferability is enhanced if a clear and distinct descriptions of culture, selection and characteristics of participants, data collection, process of analysis, and a vigorous presentation of the findings is provided. In **Study IV** it has been sought to give as comprehensive descriptions as possible, to make it possible to others to evaluate the applicability to other contexts. The case reports presented in the **framework** could give additional information valuable when determining transferability.

Confirmability

Confirmability refers to the objectivity of the researcher and the data analysis (214). This has been enhanced as the interviews in **Study IV** were conducted by four different persons. Another aspect of confirmability is the researcher's pre-understanding that is, the allowance of the researcher's previous experiences in the subject to influence the analysis. The researcher triangulation was particularly important in relation to the prolonged engagement, and to the interviewers working in the study for a long time and getting to know both the context and the participants. To deal with the issue of pre-understanding, and to make sure that the findings truly were the "voices of the participants", researcher triangulation was used. Also here, quotations from the transcribed interviews are important to give the reader a possibility of linking the findings to the "true text". In addition, the analysts were made aware of the risk of researcher bias related to pre-understanding so that this would not affect the analysis. The fact that the findings included both positive and negative experiences of the intervention could be seen as an indication that the data had not been interpreted in any specific direction. The researchers have been involved in developing the intervention, but not the provision of the same which is one important aspect in the strengthening of confirmability.

Dependability

Dependability is related to the question of the stability of data over time and under different conditions (214). According to Graneheim and Lundman (208) it is important to question the same areas for all the participants. One threat to dependability is that the interviewer acquires new insights and new knowledge during the study period. In order to reduce this risk, thematic interview guides were used in **Study IV** to ensure that all topics of interest were covered. The orders of the topics in the guides were slightly changed during the study period as well as the initial question. The interview guides still covered the same areas and were also pilot tested. Even though interview guides were used, the participants (both the older persons and the case managers) were encouraged to narrate freely about the areas covered in the interview guide, but also about other topics that they considered to be important.

General discussion of the results

It seems that the case management intervention had some effects on healthcare utilisation in terms of visits to a physician in outpatient care (**Study II**), and a reduction in hours of care provided by informal caregivers (**Study III**). It also appears to have had an effect on ED visits, by reducing visits not leading to hospitalisation (**Study II**). The result also indicates that the case managers played an important part

in the participants' lives, with a strong, continuous relationship whereby the case managers were able to detect and remedy problems, coordinate care and provide advice (**Study IV, framework**). In addition, these effects and favourable experiences were possible without an increase in costs (**Study III**). The qualitative data provided examples of case managers reducing risks and preventing diseases (primary prevention), reducing symptoms and ensuring treatment of illness and diseases (secondary prevention), and rehabilitating and helping the participants to adapt and cope with their situation after illness (tertiary prevention) (136) (**Study IV, framework**).

Effects on outpatient care and informal care

There was a reduction in the mean number of ED visits not leading to hospitalisation and in the proportion of ED visits not leading to hospitalisation. This means that participants in the control group were sent home from the ED to a greater extent than those in the intervention group. The complexity of the intervention, with many possible components interacting and contributing to the effects (16), provides a number of potential explanations for these findings. Firstly, the preventive parts of the intervention could have contributed to the reduction, and secondly, according to **Study IV**, important aspects of the interventions appear to be the strong mutual relationship between the case manager and the participant, interpersonal continuity, and the case managers' ability to react if anything happened. The effects of the primary, secondary and tertiary prevention parts in **Studies II and III** are difficult to isolate due to the complexity of the intervention. There are other studies investigating only these preventive parts that have been found to reduce ED visits. In a study with frail older people by Tinetti, *et al.* (234) the intervention group received restorative care provided by a home care agency that drew up individual treatment plans. These plans included various combinations of training, behavioural changes, environmental adjustments, adaptive equipment, counselling and support, medication adjustments, as well as education of participants and their families and friends. The study had a prospective individual matching design and the participants in the intervention group were half as likely to have an ED visit during the home care episode (adjusted odds ratio, 0.44; 95% CI, 0.32-0.61) (234). Interpersonal continuity in healthcare has been found to be strongly related to a solid relationship between staff and patients, care coordination and person-centred care. Haggerty, *et al.* (235) stated that interpersonal continuity is characterized by personal trust and responsibility, and that this is particularly important in the care of chronic and complex diseases where care is provided by several health agencies. Not having a primary care physician or having a low degree of care continuity have been found to be independently associated with higher rates of ED use, regardless of age and comorbidity (236). Better care coordination has been found to be associated with more continuous care relationships

(112, 237) and effective care coordination is predicted on person-centred care (shared goals, shared knowledge, and a respectful mutual relationship) (238). Person-centred care has also been found to be associated with a reduced number of ED visits (239). The person-centeredness in terms of a mutual solid relationship and interpersonal continuity were also revealed as important findings in **Study IV**. The results from **Study IV** also showed that it was experienced as important that the case managers were able to “solve” problems, “stand guard” and “keep an eye” – that they could intervene if any problems were detected. The “standing guard” also included that the participant could contact the case manager in urgent times and thus get help in situations for which they would otherwise have sought the ED. The ability of the case managers to detect problems could be a result of the geriatric assessments made at each visit (**Studies II and III**). Also, this single component is difficult to evaluate in this complex intervention. However, a review by Victor and Higginson (240) has found that the potential of multidimensional assessments of older people to detect various problems, especially if combined with follow-ups, has led to improvements in, for instance, functional status and admissions to nursing homes. In addition Hallberg and Kristensson (87) point out that comprehensive geriatric assessments were seemingly essential for outlining successful case management interventions. The category “the one who keeps an eye” (**Study IV**) is clearly connected to these assessments as the participants expressed that the case manager followed up and checked things, asked and made sure that everything was proceeding as planned. There are, overall, few RCTs with case management for older people that have been able to show significant effects in ED visits (13, 14, 241), but all three of these have included repeated geriatric assessments. Other reasons for the effects that have been shown could be a strong focus on integrated care whereby geriatrics interdisciplinary geriatric teams provide case management in support of, as well as integrated/coordinated with, primary care physicians (13, 14, 241). The study by Counsell, *et al.* (14) also commented that the intervention required time for the development of a trusting and working relationships with both the patient and the primary care physician in order to attain a reduction in ED visits. This need for a relationship again connects to the findings in **Study IV**. The close collaboration with primary care is also similar to how the case managers in **Studies II and III** worked. This may be an indication of coordinated care having been achieved in these studies to a somewhat greater extent. There are also those demonstrating no effects (106, 222, 242-244) and higher rates in the case management group (15, 245). In contrast to the successful ones and **Studies II and III** they seem to have a poorer collaboration with primary care and with a primary care physician (106, 222, 245). Thus, a case management intervention in close collaboration with the primary care, that allows the case managers to have a close continuing relationship, appears to reduce ED visits not leading to hospitalisation. The comprehensive geriatric assessment, interpersonal continuity, and a person-centred approach also appear to be important features of case management for reducing ED visits.

A reduction was also seen in visits to physicians in outpatient care (**Study II**). Similar to the reduction in ED visits, the reasons for this may have been an increase of coordinated care and the case managers' ability to detect potential problems and to meet previously unmet needs. However, there also seems to be little research on the effects of continuity of care and coordinated care on outpatient care. A study by Raddish, Horn and Sharkey (246) found that continuity was associated with a reduction in outpatient visits ($p < 0.001$) and a study by Hjortdahl and Borchgrevink (247) found that it saved time and, as the physician knew the patient and his/her normal state, fewer tests needed to be taken. As has already been mentioned, comprehensive geriatric assessments could detect various problems, such as problems with vision, hearing, chewing, locomotion, and iatrogenic disease (240). These are not severe health problems, which means that not only severe problems could be taken care of and detected by the case managers in **Studies II and III**, but also less severe conditions could otherwise have resulted in visits to a physician in outpatient care. Thus, this may be one explanation for the reduction in visits to physicians in outpatient care (**Study II**).

Another reason could be the ability to meet unmet needs. This has been found in other case management studies (90, 248). Several categories in **Study IV** addressed these issues. In "the solver" the case managers expressed that they identified and solved different forms of the participants' problems and in "The one who knows what to do or where to turn" the text revealed that the participants received advice and or help with problems or when they felt ill. The reason for the reduction in visits to outpatient physicians in **Study II** may be that the case managers were able to solve problems by themselves or were able to coordinate the care and refer them to, or contact, another professional, for instance a physiotherapist, without first referring them to the outpatient physician. This has been found in other studies (220, 241), where, for instance, Rubenstein, *et al.* (241) investigated both unmet needs and the amount of referrals and reported that 83% of the participants in the intervention group had unmet needs or symptoms that were sub-optimally treated, and that 81% were offered a specific referral during the intervention year (in mean 3.1). The referrals were to a wide range of health agencies, such as a geriatric assessment clinic, geriatric psychiatry and outpatient mental health clinics, rehabilitation services, primary care clinics, audiology, prosthetics, and social services (241).

There are few case management studies that have found significant reductions in outpatient care. Only two studies were found with significant reductions in the case management group (13, 115). Latour, *et al.* (115) found significant differences in visits to the practice of a general practitioner (mean 3.0 vs. 1.6, $p = 0.05$), and in the study by Bernabei, *et al.* (13) the control group needed home visits by the general practitioner to a greater extent (13.1 SD. 0.8 vs. 10.2 SD. 1.1, $p = 0.04$). The reasons may, also here, be that the collaboration and contact with primary care physicians was successful. Most other studies have reported increased outpatient care utilisation (241,

242), or no effects (106, 107, 222, 243, 248). The reason for the lack of effects could be that the intervention was mainly telephone-based (222, 241, 242), there was a high work-load (242), it was less intensive (241, 243), or there was a lack of primary care collaboration (106, 222). The ability to monitor the participant continually and to have a close collaboration with the primary care appear, as in the case of reduction in ED visits not leading to hospitalisation, to be important features of the case management intervention for decreasing visits to physicians in outpatient care.

Another important result was the decrease in informal care among those receiving the intervention (**Study III**). This could be caused by the case managers' ability to discover and solve problems that otherwise had to be taken care of by the informal caregivers. To be an informal caregiver can be stressful and can have negative effects such as burden, stress, depression (249) and poorer health (250). A shift in the responsibility for the care of older people seems to have appeared, with responsibility transferred from public care to informal caregivers. In Sweden, the amount of informal care has increased during the 1990s to the same extent that municipal care has decreased (251), something that also has been concluded by Karlsson, Edberg, Westergren and Hallberg (252) This means that the risk of burden for informal caregivers has also increased; a risk which is even greater if the informal caregiver cares for someone with a complex health situation. It is important that distressed informal caregivers are provided with support that might ease the burden of caregiving (253). There are no single interventions that have been found to adequately address all the problems and concerns that informal caregivers are facing (254). Instead, combinations of interventions, such as case management programmes, seem to be more effective in reducing informal caregiver distress (253), especially if they are provided with high intensity (254). Weuve, Boult and Morishita (255), for example, conducted an RCT with community-dwelling older adults (n=568) and reported that caregivers of participants who had received an outpatient geriatric evaluation and a management intervention were less than half as likely to report increased burden during the one-year follow-up period (16.7 vs. 38.5%, $p=0.034$). The case management intervention in this thesis reduced the hours of help provided, probably by reducing and solving problems that the informal caregivers would otherwise have had to take care of themselves. It may also be that the intervention has reduced the burden and strain on the informal caregivers.

The lack of effects on inpatient care

No effects were seen on hospital stays or LOS (**Study II**). The reason for this could be that the group studied comprised a large proportion that was not frail enough to be admitted to hospital, and another part that were too frail, were hospital stays could

not be prevented. Another reason could be that the case manager prevented some hospital stays, but at the same time discovered conditions that needed inpatient care.

The first reason, that the studied group was not frail enough could partly be explained by the results in **Study I**. The results in **Study I** revealed that there were those with a high number of hospital stays and LOS and that there were those with no healthcare utilisation at all. This, together with the difficulties to find universal predictors of healthcare, supports that the older population is very heterogeneous. One of the core aims of case management interventions is to decrease hospital stays among those who are expected to utilise this to a great extent (95). The lack of universal predictors in **Study I** (except age) are in line with the theoretical assumptions according to the Neuman Systems Model (136), which describes that stressors could affect any of the five system variables and that this could lead to an impact on the basic core and, as a consequence, on healthcare utilisation. In addition, the model specifies that each individual has specific and unique client system variables, which means a higher extent of heterogeneity and thus greater difficulties in predicting healthcare utilisation. In **Study I** variables connected to four of the five system variables predicted healthcare utilisation in terms of hospital stays or LOS (Table 4). In addition, the physical (ADL) and psychosocial variables (MADRS) showed similar patterns (Figure 7a-d). Various studies have reported predictors representing all five client system variables (physical (68, 72, 256); psychosocial (257-259); sociocultural (72, 260); developmental (261); and spiritual (262)); this, together with low explanation rates in **Study I**, suggests that there are many different factors are associated with healthcare utilisation.

The inclusion criteria in **Studies II and III** were based on only three factors, age, ADL and previous healthcare utilisation, and it is possible that this was not enough to determine future hospital stays. At the same time, the result of **Study II** revealed that among those admitted the most common diagnosis registered as the primary causes of the hospital stay were circulatory diseases and respiratory diseases. In this group of frail older people these conditions may not be preventable and the intervention may therefore not be sufficient to avoid hospitalisation. The ability of having their needs met by the case manager could also be one explanation as this could lead to increased utilisation for some participants, simultaneously as some may have a reduced utilisation. **Study IV** gave examples where the participants in the category “The one who knows what to do or where to turn” expressed that the case manager gave advice about contacts in the health system. The case manager experienced their role in a similar way. In the category “The navigator” the case manager expressed that they helped the participant to contact health agencies (**Study IV**) which was also revealed in the case reports (**framework**). It has been reported that preventive programmes including case management could reduce these unmet needs (90, 248), and, also, that preventive programmes could satisfy unmet healthcare needs, resulting in increased healthcare utilisation (263). In addition, it has been reported that outreach case

management programmes could find people with healthcare needs previously unknown to the health agencies (3). There are only a few studies reporting significant results on hospital stays or LOS. In the study by Bernabei, *et al.* (13) the proportion participants in the intervention group that was admitted at least once to acute hospital care during the follow-up year was significantly smaller than that of the control group (36 vs. 51%, $p < 0.05$). The proportion with at least one acute hospitalisation in **Study II** decreased from the pre-baseline year to the post-baseline year in both the intervention group (41 to 35%) and in the control group (44 to 38%). This means, that there was a general reduction, possibly because of interventions made in the ordinary health system. Another study by Peikes, Chen, Schore and Brown (264) reviewed 12 different care coordination programmes which had many similarities with case management. Two of these programmes reported significantly lower rates of hospital stays in the experimental groups. Also Naylor, *et al.* (265) reported a reduction in hospital stays. The reason for this may have been that they had higher pre-baseline rates of hospital stays, thus those included may have been frailer than those in **Study II**. The rates in the first study by Peikes, Chen, Schore and Brown (264) were 1.5 and 1.4 of total hospital stays yearly for the intervention and control group respectively, and in the second study 2.9 and 3.1 respectively (264). In the study by Naylor, *et al.* (265), these were 0.9 and 1.0 for the six months preceding baseline. The corresponding numbers for **Study II** was 0.86 and 1.07, but for the whole year before entering the study. This reason for the lack of effects in hospital stays has also been discussed by others (107, 222, 241). In addition Lim, Lambert and Gray (109) found significant differences in LOS after a 6-month case management intervention (3.0 vs. 5.2, $p = 0.01$).

Thus, it seems difficult to reduce inpatient utilisation among a population which is heterogeneous, where some have no admissions and some have admissions for reasons that are not preventable. However, for groups with a higher mean number of hospital stays the literature suggests that some of the hospital stays may be preventable. To achieve a reduction in hospital stays it appears that a more homogenous and frail population with a higher mean number of hospital stays has to be identified.

Effects on HRQoL

Despite effects seen in **Studies II and III** concerning effects on utilisation of healthcare, and informal care, no significant effects were found on QALY. In addition, the intervention was cost neutral, and the only difference was significantly lower costs for informal care in the intervention group (**Study III**). This with one exception, a significant difference was found in EQ-VAS between 6 and 12 months after baseline. The reasons for the non-significant results could be many. One

important reason may be that HRQoL may not be sufficient as an outcome in such a frail group of older people.

Primary prevention includes lifestyle and behaviour changes and other time consuming processes and it is unclear whether it will have the same dramatic results as, for instance, effects achieved by immunisation and improved hygiene (232). In addition, for secondary prevention, where the case managers sometimes discover complicated conditions, it could take time to get the right treatment or a reduction of symptoms. In the **framework** it was reported that the case manager discovered breast cancer (case report no. three), and they initiated a hip surgery, which was delayed was not scheduled until after the intervention period (case report no. two). These participants will probably not increase their HRQoL during their study time, and perhaps not until after their treatments or rehabilitation. Nevertheless, they both received treatment for their diseases and they both expressed that they were very satisfied with the case managers. Therefore, other outcomes and other measures than HRQoL and QALY may be needed to determine the effectiveness of case management from an individual perspective. Qualitative studies, such as **Study IV**, could provide some insight in experiences and benefits of an intervention, but other quantitative measures are necessary as well in order to give a comprehensive evaluation of a complex evaluation (16).

One way could be to allow participants to rate different aspects of the intervention which, for instance, has been done in different technology based interventions (266, 267). One disadvantage with this would be that the questions could only be addressed to those in the intervention group. A more straightforward approach could be to measure the perceived care satisfaction. Client satisfaction relates conceptually to both interpersonal continuity of care and the coordination of care (268) and, as **Study IV** revealed, these aspects were found to be important features of the case management in this thesis. In addition, social relationships, financial situations, work-related issues, physical limitations, and intellectual challenges play a role in determining quality of life and satisfaction within the healthcare setting (269). Berra (269) investigated primary and secondary preventions aimed to reduce cardiovascular risk factors and concluded that these affected both quality of life as well as patient satisfaction. The question of whether a case management intervention could be applied effectively only by means of patient satisfaction, has been raised by, for instance, Latour, *et al.* (220). Counsell, *et al.* (14) and Gagnon, Schein, McVey and Bergman (15) evaluated client satisfaction, but without significant differences between the intervention and control group.

However, patient satisfaction could be an important outcome and give additional information about an intervention, because it could have been performed in accordance with the participant's expectations and desires, independent of changes in HRQoL. This was revealed in **Study IV** and in case report number two (**framework**)

as “dealing with barriers”. It was obvious that the case managers sometimes experienced that they could not reach the participants who did not want to be helped, did not follow their advice, or who did not want to be a burden. Patient/client satisfaction is an important form of programme evaluation and has received much attention in evaluations of social services (270), but has not received that much attention in the evaluation of case management for older people. With the conceptually close relationship between coordinated/managed care and care satisfaction (268), and the correlation to HRQoL (269), an evaluation of client satisfaction would be valuable in case management studies. A third option, somewhat deviating from patient related outcomes and the participants’ subjective perceptions, is to objectively investigate the quality of care and the extent to which the intervention leads to different actions. This form of process evaluation is recommended by the MRC for the evaluation of complex interventions (16). This may include such measures as the number of new geriatric diagnoses (for instance walking difficulties or depression), the number of performed medical reviews, the number of visits or referrals to an ophthalmologist, or the number of new prescriptions of incontinence aids. As in the case of care satisfaction, the intervention could have been performed in an excellent way with a lot of performed actions, without affecting the HRQoL. This has also been investigated by Counsell, *et al.* (14) who found that the intervention group, compared to the control group, was more likely to have documentation in the electronic medical records that their conditions were recognized or diagnosed, that they received specialty consultation, and that they were provided with appropriate information or treatment.

All-in-all, it seems to be difficult to find effects on HRQoL. The lack of significant effects in **Study III** is in line with other case management studies. Several studies have been unable to demonstrate significant effects (15, 115, 220, 222, 271). Hammar, Perala and Rissanen (271) conducted a cluster randomised study in Finland using EQ-5D to evaluate HRQoL. They discussed that their lack of results may depend on that the factors of age and frailty in the sample were persistent in the decline in HRQoL and that effects could better be seen in younger age-groups. Gagnon, Schein, McVey and Bergman (15) draw similar conclusions and discuss that effects of case management interventions are more likely in subgroups of the sample, often those considered as most frail, and therefore also those whose condition could be improved. This may also be one of the reasons for the non-significant result in the Dutch studies (115, 220), which studied a general population after discharge. Another explanation discussed is that the CM talked about diseases and other kinds of problems with the participants, making them more aware of their health status (115, 220). There are also some studies with significant improvements in HRQoL. Lim, Lambert and Gray (109) investigated HRQoL using the Assessment of Quality of Life questionnaire, a five dimensional Australian instrument (Illness, Independent Living, Social Relationships, Physical Senses, and Psychological Wellbeing) with in total 15 items

with four response alternatives for each item (272). They found significant greater improvements one month after discharge from hospital in the post-acute care group (case management) compared to the control group. The SF-36 was used to evaluate a study in USA with a two-year intervention (14). Those in the intervention group showed significant improvements in four of the eight subscales (general health, vitality, social functioning, and mental health) and in the Mental Component Scale (MCS). There was also improvement in HRQoL in a Canadian study with older people (75 years or older) where the case management group had a greater improvement in SF-36 MCS score and in SF-36 role functioning related to emotional health, but where these effects could be due to significant differences between groups in these components at baseline (221). The reason for effects in these studies could be that the study by Lim, Lambert and Gray (109) was hospital-based, and that the participants were particularly frail as they were included just after an admission and they all required community services after discharge. In the study by Counsell, *et al.* (14), the sample size was large (n=951) and the clinical relevance of the differences was questionable. In addition, the follow-up period was two years, which enabled a strong relationship, which they believed may have contributed to the positive effect. Gagnon, Schein, McVey and Bergman (15) also discussed the follow-up period. They believed that their 10-month follow-up could be too short a time to find differences and compared this with other studies that followed the participants for three years. In **Study III** the follow-up time was 12 months, and some improvements in EQ-VAS in favour of the intervention group were seen in the last six months, supporting the understanding that improvements in HRQoL may take time. But in general the EQ-5D and EQ-VAS scores were relatively stable during the one-year study. This was not expected since the sample consisted of frail older people. Here too, the reasons may be heterogeneity with participants with chronic diseases that are not possible to cure or prevent, and participants who are “too healthy”, where further improvements are difficult. In a more homogenous frail sample, effects may therefore have been possible. The inclusion criteria in **Studies II and III** targeted this group, even though the included sample was rather heterogeneous and the selection procedure may not have been sensitive enough to identify this population. Compromises have to be done between the criteria most suitable for the identification of frail older people and the criteria suitable for clinical practice.

Thus, there are not many case management interventions that seem to have evaluated the effects on HRQoL, and only very few have found significant effects. The reason for this may be that it might be questionable if case management affects HRQoL at all, or at least that it may take a substantial amount of time before any effect is seen. A comprehensive process evaluation should be undertaken and effects on other outcome measures, such as client satisfaction and quality of care, should be considered as a complement to HRQoL.

Conclusions and clinical implications

Case management had effects on ED visits not leading to hospitalisation, and visits to physician in outpatient care. Effects were also seen in informal care which implies that the case managers are able to provide some sort of support or relief for the informal caregivers. The result indicates that interpersonal continuity, coordination of care, someone that discovers problems and potential problems, as well as support in a long term strong relationship are important parts of the intervention. Other important aspects appear to be the case managers' ability to work in close collaboration with primary care and to do geriatric assessments. These features appear to be important for the effects seen in healthcare utilisation.

The population of older people is heterogeneous which may be one reason for the lack of result in hospital stays and LOS. Some people had high rates of inpatient care utilisation while other did not have any utilisation at all. The heterogeneity may also be a reason for the difficulties to find universal predictors for healthcare utilisation. This makes it also challenging to find the population of frail older people that was those targeted for the case management intervention. Even though the included sample targeted this group on this basis the selection procedure may not have been sensitive enough to identify this population. Compromises had to be done between criteria most suitable for identification of frail older people and criteria suitable for clinical practice.

The case management intervention did not have any effects on HRQoL but was on the other hand also cost neutral. It is possible that the used HRQoL was not sensitive enough to detect any changes. It may also be that it could be that HRQoL is not an optimal outcome for frail older people, where improvements perhaps are unlikely. Comprehensive process evaluations and patient satisfaction may provide additional information in determining the success of an intervention.

Despite no effects in HRQoL in this thesis case management could be regarded as effective. For preventive work for frail older people living at home these findings may have implications in community settings, as case management reduced utilisation without any increases in cost. Furthermore, the case management programme had a feasible design, and may also be integrated in the existing health system. However, this should then be done in close collaboration with primary care setting.

Further research

It was difficult to predict healthcare utilisation, the group that are most likely to need case management. This was also seen in the investigated sample in the case management intervention. Thus, more research is needed on how to identify those in greatest need for case management. There is also need for long-term follow-up to be able to see the full impact of case management on, for example, health-related quality of life. As a complement to health-related quality of life future research should also focus on care satisfaction. Also other outcome measures such as loneliness, depressed mood and health status should be investigated. In addition, there is also need for a process evaluation to evaluate to what extent the case management intervention and its different parts were performed.

The results showed a reduction on the help provided by the informal caregivers. However, no data on the perspective of the informal caregivers' were analysed in this thesis and needs to be investigated in the future. Both qualitative and quantitative methods should be used in order to give as comprehensive understanding as possible of how the informal caregivers are affected.

Finally, the case management study in this thesis is performed in one municipality in Sweden. The effects of such an intervention may be different in other contexts. Thus, to fully understand the impact of different contexts, there is a need for studies at various locations, for instance a multicentre study. In future research it is also a important to study the implementation of case management.

Summary in Swedish/ Svensk sammanfattning

Dagens vårdssystem står inför många stora utmaningar. Många av dem är relaterade till komplexa vårdbehov hos den allt större andelen sköra äldre personer. Denna andel ökar samtidigt som många vårdorganisationer har krav på sig att minska kostnaderna. Dessa äldre personer har ofta flera sjukdomar samtidigt och de har vanligtvis kontakter med många olika vårdgivare, på flera olika nivåer, samtidigt. Dessutom så står en liten grupp för en stor del av den totala vårdkonsumtionen. Fysiskt beroende och antalet sjukdomar ökar med ökad ålder. Detta tillsammans med att olika symptom – till exempel hörselproblem och minnesproblem – ökar, medför att många äldre personer kan ha svårt att hantera en situation som involverar många vårdgivare. Det är dessutom en stor risk att deras vård och omsorg blir splittrad, vilket kan leda till en sämre och osäkrare vård.

Det är viktigt att vårdsystemet är koordinerat och att det finns en kommunikation mellan olika vårdgivare. Det är också viktigt att det finns förebyggande insatser för att förbättra situationen för de äldre personerna. En modell som kan användas inom vård och omsorg är "case management". Det finns ingen bra översättning till svenska. Det finns inte heller någon enhetlig definition av case management, men många är eniga om att det handlar om en process som går ut på att en person bedömer/utvärderar, planerar, åtgärdar, utför åtgärderna, gör en ny bedömning, koordinerar olika insatser, och för personens talan för att kunna möta individens, och dennes familjs, hela vårdbehov.

Det finns en hel del studier som har undersökt effekterna av case management för sköra äldre, men med motstridiga resultat. Det finns studier som har visat att case management kan sänka vårdkonsumtion och öka hälsorelaterad livskvalitet och det finns de som inte kunnat hitta några sådana effekter. En del i förklaringen till att studierna gett så olika resultat kan ligga i komplexiteten i case management modellen där olika insatser inverkar individuellt eller tillsammans. En annan sak som gör det svårt att jämföra olika case management studier är att studierna utförts i olika länder och att miljön och vårdsystemet spelar stor roll. Många studier ger dessutom mycket knapphändig information om vad case management interventionen har innehållit och hur den utförts.

Hittills har case management för sköra äldre inte testats i någon större utsträckning i Sverige. Det finns således ett behov att prova och utvärdera case management, i det svenska vårdssystemet. Utvärderingen bör göras både med avseende på vårdutnyttjande och på kostnader, men även hur detta påverkar individen, med effekter på hälsorelaterad livskvalitet och upplevelser av interventionen.

Avhandlingen består av fyra delstudier med huvudsyftet att undersöka vårdkonsumtionsmönster och effekterna av en case management intervention för sköra äldre, med avseende på vårdutnyttjande och kostnader i relation till nytta. Vidare var syftet även att undersöka erfarenheter av interventionen, både från de sköra äldres perspektiv, men också från de som utfört interventionen, case managernas, perspektiv.

Den första delstudien var en kvantitativ studie som syftade till att undersöka vårdkonsumtionsmönster i termer av sjukhusvistelser och vård dagar över en sexårsperiod hos personer (60 år och äldre) och hur detta påverkas av nedsatt fysisk funktionsförmåga och risk för depression. Syftet var också att identifiera prediktorer för vårdkonsumtion. Studien baserades på ett material från ett av de fyra studieområdena i det nationella forskningsprojektet Swedish National Study on Aging and Care (SNAC). SNAC är en långsiktig nationell studie av åldrandet samt vården och omsorgen för äldre. Detta material omfattade 10 stycken ålderskohorter mellan 60 och 96 år, totalt 1402 individer. Baslinjedata samlades in mellan 2001 och 2003 och data angående antal vårdtillfällen på sjukhus och antal vård dagar på sjukhus samlades in från ett patientregister för de följande sex åren. De som inkluderats delades upp på två par av grupper. Dels de som klassificerats som beroende eller oberoende i fysisk funktionsförmåga (Aktiviteter i dagligt liv, ADL), och dels om de var i risk för/inte risk för depression.

Studien visade att alla fyra grupper hade ökning av sjukhusvistelser och vård dagar över sexårsperioden där särskilt det sjätte året, men även till viss del det femte året, hade högre värden än övriga år. Ökningen var dock större hos de som var beroende i ADL eller i risk för depression. De som var beroende i ADL hade också fler vårdtillfällen än de som var oberoende i ADL. Samma sak sågs för de som var i risk för depression jämfört med de som inte var i risk, men där var skillnaderna inte lika tydliga. Det var bara ålder som kunde förutsäga vårdtillfällen på sjukhus och vård dagar på sjukhus. Det fanns ett antal variabler som predikerade antingen sjukhusvistelser och/eller vård dagar för en eller flera av tidsperioderna. Mönstret som kunde urskiljas var att tidigare sjukhusvistelser och besvär med olika symptom predicerade vårdutnyttjande för 5-6 år efter baslinjen, medan olika diagnoser, och fysisk påverkan predicerade vårdutnyttjandet 1-2 år och 3-4 år efter baslinjemätningen. Detta betyder att det verkar vara svårt att förutsäga framtida vård.

Den visar också att det är en mängd olika variabler som verkar spela roll för framtida vårdbehov, däribland fysisk funktionsförmåga och risken för depression.

Den andra och tredje delstudien var delar i en randomiserad kontrollerad studie och ägde rum i en kommun i Sydsverige. Syftena i dessa studier var att undersöka effekterna av en case management intervention för sköra äldre med avseende på vårdutnyttjande och kostnader i relation till nytta. I dessa studier så lottades 153 äldre personer antingen till en kontrollgrupp (totalt 73 stycken) eller till en interventionsgrupp (totalt 80 stycken) som fick case management. För att kunna bli inkluderad skulle man vara 65 år eller äldre, bo i ett eget hem i den aktuella kommunen (dvs. inte bo på särskilt boende, gruppboende etc.), man skulle ha hjälp med minst två aktiviteter i dagligt liv, och man skulle ha vistats på sjukhus minst två gånger, eller besökt läkare minst fyra gånger det senaste året.

Case management interventionen bestod av fyra delar: 1) ”traditionell” case management (som till exempel att utvärdera, skapa vårdplaner, koordinera); 2) ge allmän information (om till exempel om kommunens olika aktiviteter, säkerhet i hemmet och fysisk aktivitet); 3) ge specifik information anpassat till personens specifika behov (till exempel att ge information om personens specifika sjukdomar eller läkemedel); och 4) säkerhet och tillgänglighet (att vara kontaktabar via mobiltelefon under kontorstid måndag till fredag). Sjuksköterskor och sjukgymnaster jobbade som case managers och gjorde hembesök till alla i interventionsgruppen minst en gång i månaden under ett år.

Information gällande öppenvård (t.ex. kontakter med läkare och andra professioner, och akutmottagningsbesök) och slutenvård (vårdtillfällen på sjukhus och vård dagar på sjukhus) och hämtades från olika patientregister. Dessa data inhämtades för året innan personerna inkluderades i studien och för hela det år som studien pågick. Utöver detta samlades det in data genom strukturerade intervjuer som genomfördes vid baslinje, och därefter vid 3-, 6-, 9- och 12 månader efter baslinjemätningen. Dessa data inkluderade enskilda frågor och olika standardiserade frågeinstrument.

Studierna visade att interventionsgruppen hade lägre andel akutmottagningsbesök som inte ledde till sjukhusinläggning, 6-12 månader efter baslinjemätningen. Detta gällde både i medeltal (0.08 besök i interventionsgruppen mot 0.37 i kontrollgruppen) samt andelen (16.7 mot 46.9% i respektive grupp). Vilket innebär att de som var i kontrollgruppen blev hemskickade från akutmottagningen i större utsträckning än de i interventionsgruppen. Interventionsgruppen hade också för denna period (6-12 månader efter baslinjemätningen) längre andel besök hos läkare i öppenvården, jämfört med kontrollgruppen (4.09 mot 5.29). Inga skillnader hittades för antalet vårdtillfällen på sjukhus, vård dagar på sjukhus eller omfattningen av hemstjänst eller hemsjukvård under interventionsåret. När man tittade på hela studieåret hade däremot interventionsgruppen även mindre hjälp från informella vårdgivare jämfört med kontrollgruppen, både vad gäller antalet timmars hjälp med

instrumentell ADL (s.k. IADL som innebär t.ex. städning, transport och matlagning), med 200 mot 333 timmar, och kostnader, SEK 34 186 mot SEK 57 020 (motsvaras ungefär av €3927 mot €6550). Inga skillnader fanns dock med avseende på totala kostnader för studieåret, och inte heller för skillnader i hälsorelaterad livskvalitet.

Den fjärde delstudien var en intervjustudie med syftet att belysa deltagarnas och case managerns erfarenheter av interventionen. Totalt intervjuades 14 deltagare som fått case management om sina upplevelser och erfarenheter. Dessutom intervjuades sex stycken case managers om totalt 15 stycken deltagare som de träffat i case managementstudien. Totalt 29 intervjuer togs med i analysen där de analyserades med innehållsanalys. Resultatet visade att case management interventionen kunde tolkas utifrån två områden, att ge/ta emot som en vårdmodell, och att jobba som/interagera med en case manager. Resultatet bestod av totalt fyra kategorier: 1) case management som att gå in i en ny yrkesroll; 2) case managern som en coachande bevakare, båda sett från case managerns synvinkel; och 3) case management som en möjlig ytterligare resurs; och 4) case managern som en hjälpande hand, sett från deltagarens synvinkel. Varje kategori innehåller olika subkategorier som alla speglade innehållet i respektive kategori.

Sammanfattningsvis så visade resultaten på att gruppen av äldre är väldigt heterogen, dvs. att det finns stora olikheter mellan olika individer, även bland de som betecknas som sköra. Detta kan vara en av anledningarna till att det var så svårt att hitta universella prediktorer för vårdutnyttjande. Det verkar som om case management är effektivt genom att minska antalet läkarbesök i öppenvården, minska omfattningen av anhörigas insatser och genom att färre i interventionsgruppen blev hemskickade när de besökte akutmottagningen. Interventionen var dessutom kostnadsneutral. Viktiga delar i case management som kan ha bidragit till detta är att kontakten med case managern gav en ökad kontinuitet och samordning av vården, att någon hade möjlighet att upptäcka potentiella och aktuella problem och att åtgärda dessa. Case managern kunde också ge olika former av stöd och bygga en relation baserad på förtroende. En annan viktig aspekt kan vara case managerns möjlighet att samarbeta med primärvården.

I framtida forskning av case management för denna grupp behövs en processutvärdering av interventionen för att undersöka i vilken utsträckning olika delar har utförts för att bättre kunna avgöra om interventionen och dess olika delar är effektiv. Det behövs också en längre uppföljningstid än 12 månader då detta kan vara för kort tid för att kunna se effekter för t.ex. hälsorelaterad livskvalitet.

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Papers I-IV