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## Case management for older persons with multi-morbidity. Experiences of an intervention from the perspectives of older persons, family members, case managers and health and social care staff members

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# Case management for older persons with multi-morbidity

Experiences of an intervention from the perspectives of older persons, family members, case managers and health and social care staff members

MARKUS HJELM | FACULTY OF MEDICINE | LUND UNIVERSITY

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# Case management for older persons with multi-morbidity

Experiences of an intervention from the perspectives of  
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Markus Hjelm



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*I want to understand the world from your point of view.  
I want to know what you know in the way you know it.  
I want to understand the meaning of your experience,  
to walk in your shoes, to feel things as you feel them,  
to explain things as you explain them.  
Will you become my teacher and help me understand?*

James P. Spradley, Ethnographer



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# Abstract

Complex health systems make it difficult to ensure a continuity of care for older persons with multi-morbidity, and risk fragmented care. Fragmented care could affect the quality and safety of the care provided. Case management could provide an approach to counteract this unfavourable situation. Case management is practised by case managers and aims to improve the coordination of healthcare and social services. To better understand and to advance the progress of case management, there is a need for knowledge that provides rich descriptions of case management in practice. This knowledge must come from different perspectives important for the intervention. Thus, the overall aim of this thesis was to explore the experiences of a case management intervention aimed at older persons with multi-morbidity, from the perspectives of case managers, older persons, family members and health and social care staff members.

The work of this thesis is based on an ethnographic approach and explores case management from multiple perspectives. For Study I, the sample consisted of case managers (n=9). Data were collected by a group interview, individual interviews and participant observations. Data analysis was informal and formal, and comprised a thematic analysis of the interview material. For Study II, the sample consisted of family members of older persons with multi-morbidity (n=16). Data were collected by individual interviews and analysed using interpretive phenomenology. For Study III, the sample consisted of older persons (75+) with multi-morbidity (n=13). Individual interviews and participant observations were part of the data collection. Data analysis was influenced by Roper and Shapira's framework for ethnographic analysis. For Study IV the sample consisted of health and social care staff members (n=10). Individual interviews were conducted and subsequently analysed using thematic analysis.

The findings from all studies (I-IV) illustrated different perspectives of a case management intervention, conducted by case managers. In Study I, the case managers' experiences of their everyday work could be interpreted as *challenging current professional identity*. Study II showed that the family members' experiences could be interpreted as *helps to fulfil my unmet needs*. In Study III, the older persons' experiences were interpreted into four themes which were *someone providing me with a trusting relationship*; *someone assisting me*; *someone who is on my side*; and *someone I do not need at present*. In Study IV, health and social care staff members' experiences were

interpreted into the following three themes: *could bridge gaps in an insufficient health system; emerging improvements call for engagement; and an intervention in the mist with vague goals and elements.*

In summary, the findings indicate that establishing trusting relationships was important and this trust enabled the case managers to conduct their everyday work. Consequently, case management interventions need to put emphasis on building trust between the case managers and the participants. To facilitate trusting relationships it is envisaged that it could be of help if the case managers are in a neutral position, act as an individual contact, and have regular contact with the participants. Continuity of the case managers' services seems to be important for developing trusting relationships. The case managers' everyday work put forth challenges of trying to make sense of their role as case manager. Thus, when intervening with case management it is important to present a clear description of the case manager's professional responsibility to all involved. Using working groups as an intermediate for conducting improvement work at an organisational level seems to show promises. But, engagement amongst its representatives is vital for it to be successful. Expectations regarding the working groups and the intervention needs be made clear and discussed throughout the course of the intervention. Thus, a vital part of the preparation for the case management intervention should be to explicitly set the expectations for all involved parties.

**Keywords:** Aged, case manager, case management, comorbidity, continuity of patient care, delivery of healthcare, ethnography, family members, focused ethnography, integrated care, intervention, interpretive phenomenology, multi-morbidity, older persons, qualitative research, thematic analysis

# Abbreviations

ACT	Assertive Community Treatment model
ANA	American Nurses Association
CMSA	Case Management Society of America
ICD	International Classification of Diseases
ICMM	Interrogative Case Management Model
ICT	Information and Communication Technology
PAM	Patient Advocacy Model
RCT	Randomised Controlled Trial
SALAR	Swedish Association of Local Authorities and Regions
SNBHW	Swedish National Board of Health and Welfare
TPB	Theory of Planned Behaviour
UK	United Kingdom
US	United States
WHO	World Health Organization

# Original papers

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

- I      **Gustafsson, M.**, Kristensson, J., Holst, G., Willman, A., & Bohman, D. (2013). Case managers for older persons with multi-morbidity and their everyday work - a focused ethnography. *BMC Health Services Research*, 13(1), 496. doi: 10.1186/1472-6963-13-496
- II     **Hjelm, M.**, Holmgren, A-C., Willman, A., Bohman, D., & Holst, G. (2015). Family members of older persons with multi-morbidity and their experiences of case managers in Sweden: an interpretive phenomenological approach. *International Journal of Integrated Care*, 15:e011. doi: <http://doi.org/10.5334/ijic.1538>
- III    **Hjelm, M.**, Holst, G., Willman, A., Bohman, D. & Kristensson J. (2015). The work of case managers as experienced by older persons (75+) with multimorbidity – a focused ethnography. *BMC Geriatrics*, 15(1). doi: 10.1186/s12877-015-0172-3
- IV    **Hjelm, M.**, Bohman, D., Willman, A., Kristensson, J., & Holst, G. (201x). Health and social care staff members' experiences of a case management intervention with a focus on improving continuity of care for older persons with complex health needs — a qualitative analysis. (In manuscript)

Papers I-III are available in open access.

# Introduction

Highly specialised health systems make it difficult to ensure a continuity of care for older persons with multi-morbidity and risk leading to a fragmented care for this group (1–5). Fragmented care could affect the quality and safety of the care provided because of a risk of duplication of services or a lack of provided services (6, 7). How to meet the often complex health needs of older persons with multi-morbidity is considered to be a challenge for health systems across the world (8). One way of trying to address this challenge could be by utilising case management (9, 10). Case management aims to improve coordination of healthcare and social services (9). In the ageing population of Europe a substantial number of older persons have multi-morbidity (11). In Sweden, multi-morbidity is considered to be the most common state of health for persons 75 years and over (12). These persons often have complex health needs and require contact with multiple healthcare and social services providers (2). Modern-day health systems have challenges to cater for these persons' complex health needs, and so they risk receiving a less satisfactory care (4, 13). This situation may also increase the older person's dependence on others, such as their family members (4). Thus if the health system does not meet the older person's needs, there may also be a negative impact on their family members (14).

Several studies have investigated the effects of case management interventions aimed at older persons with multi-morbidity, mainly focusing on healthcare costs and healthcare consumption. However, these studies are equivocal (1, 5, 10, 15–17). Some of these studies display positive effects of case management intervention, whereas other studies display no effect at all. Many of these studies contain little detail, making it difficult to comprehend what has actually been done (1, 5, 10, 15–17). Therefore, there is a need to further explore what aspects are of importance to conduct a successful case management intervention (15). One way to further advance this knowledge could be by exploring the experiences of case management amongst those utilising its services, i.e. older persons with multi-morbidity. To gain a deeper understanding, perspectives from the case managers, the older persons' family members as well as from staff from the involved healthcare and social services organisations ought to be of importance. This knowledge could be of help in the development and design of case management interventions aimed at older persons with multi-morbidity.





# Background

## Older persons with multi-morbidity

In most developed countries, life expectancy has been increasing for a long period of time (18). In Sweden, life expectancy for older persons has steadily increased over the recent decades and this is believed to be mainly related to better living conditions, falling tobacco use and lowering of cardiovascular disease mortality (18,19). In Sweden, the number of persons over 80 years old is expected to double from today's number of approximately 500,000 to one million by the year 2030 (20). In the whole of Europe, the age structure of its population is projected to change radically in the coming decades. This is due to the dynamics of life expectancy, fertility and migration rates (18). This forthcoming development of an ageing population will put great demands on the capacity of European countries' health systems (21).

Within this ageing population, a substantial number of older persons have multiple independent diseases – i.e. can be described as having multi-morbidity (22). Other terms used for this group have been “complex elderly” (23) and “oldest most sick” (4, 24). A systematic review conducted by Marengoni et al. (22) concluded that the prevalence of multi-morbidity ranges from 55 to 98% for persons aged 60 years and over and that the prevalence increases with age (22). In Sweden the prevalence for multi-morbidity has been estimated at 55% for persons aged 77 years and over (25), and is also considered as the most common state of health for persons aged 75 years and over (12). Similar figures are also seen in the United States (US), as about half the population aged 75 years and older have three or more chronic conditions (26). In Sweden, a quarter of its total population have multi-morbidity and a substantial amount of healthcare is directed towards these persons. This is manifested as 50% of the total healthcare costs and half of the emergency care visits are ascribed to persons with multi-morbidity (27). These figures highlight that the older persons' health should be a priority from a welfare perspective, an economic perspective and especially from an individual perspective (21). The above-mentioned figures are based on the assumption that multi-morbidity is defined as two or more co-existing chronic diseases (12, 22, 25). However, there is currently no single uniform definition of multi-morbidity, and the definitions may differ in published literature (2).

There are three major operational definitions of multi-morbidity (22). The first definition involves *the number of concurrent diseases in the same individual*. This definition is commonly used in epidemiological studies. The second definition involves *cumulative indices evaluating both number and severity of the concurrent diseases*. This definition is suitable for clinical studies where the major aim is to identify persons at risk for negative health outcomes. The third definition involves *the simultaneous presence of diseases/symptoms and cognitive and physical functional limitations*. This definition takes into account factors such as symptoms, cognitive and physical dysfunctions and psychosocial problems (22). In 2003, the Swedish National Board of Health and Welfare (SNBHW) proposed the following operational definition of multi-morbidity: “*Being 75 years and over, having three or more diagnoses from different ICD disease groups and also been admitted to hospital at least three times during the last twelve months*” (24, p.12). According to the SNBHW’s definition, in 2002 around seven per cent of the Swedish population 75 years and older adhered to this definition (28); more recent estimations have not been found in regard to this specific definition. One limitation with the above-mentioned definition is that it includes only those who have been admitted to the hospital, and therefore excludes those primarily having advanced needs of rehabilitation and care at home (4). The definition incorporates aspects of both the number and the severity of the concurrent diseases. The SNBHW definition of multi-morbidity has been applied throughout Study I-IV (29–31), included in this thesis.

Older persons with multi-morbidity often have complex health needs (2). In a study from Spain the most frequent health problems amongst older persons aged 65 years and over with multi-morbidity were dementia, diabetes, cognitive declines, arrhythmia, hypertension, urinary incontinence, immobility and falls (32). At Swedish nursing homes many older persons live with multiple chronic health problems. A study by Akner (33) concluded that nursing home residents had an average of 17 different chronic health problems. Most common were various neuropsychological, cardiovascular and gastrointestinal health problems (33). Older persons with multi-morbidity have also been found to have a high prevalence of social and psychiatric problems, such as depression (34). These persons could also need assistance to be able to cope with activities such as bathing, food preparation, dressing or shopping. These activities are referred to as social care services. Family members often provide these services, but also formal service providers, such as home care services, can be the providers. Formal social care services are often organised and funded separately from healthcare and could result in a fragmented care for persons needing both types of services (35). Major consequences of multi-morbidity have been found to be disability, high healthcare costs and functional decline (22). Furthermore multi-morbidity has been found to be associated with psychological distress (36), decreased quality of life (37), higher mortality, postoperative complications and longer hospital stays (2).

In an interview study, Bayliss et al. (3) explored processes of care desired amongst older persons, 65 and over, having multi-morbidity with a minimum of four chronic conditions. The older persons desired convenient access to their care providers. When they came in contact with the health system it was primarily in the form of appointments, seeking or receiving follow-up information regarding tests, or contacting providers with questions that did not require an appointment. For all of these contacts, they emphasised convenient access to a contact that was well known to them. They were unsatisfied with using telephone numbers that took them to a telephone exchange. Instead they wished for a number that could connect them directly to a care provider who knew them and their current situation. The older persons also wanted to be heard and understood. They knew themselves and their symptoms well and they felt that they could assist the providers with diagnosis and treatment planning. Because of the complexity of their health needs they emphasised the importance of good communication with their providers in regard to their care plans (3). Lindvall et al. (38) explored older persons' with multi-morbidity experiences of the care provided by family caregivers. It was concluded that the older persons needed to have opportunities to be more involved in and have more influence of their own healthcare, thus not solely be dependent on their family caregivers (38). Thus, there is some knowledge about the complexity and magnitude of providing for the needs of older persons with multi-morbidity. This emerging situation has put great challenges on modern-day health systems to be able to adequately provide for these persons' needs. This situation implies that these older persons should be a priority from a welfare perspective, an economic perspective and especially from an individual perspective.

## Continuity of care for older persons with multi-morbidity

Modern-day health systems are ill-equipped to face the rising population of older persons with multi-morbidity (1, 5, 15, 17). In countries such as the United Kingdom (UK) and the US, the health systems are often highly specialised and persons in need of healthcare risk receiving fragmented care (1, 5, 15, 17, 39). A similar situation is found in Sweden where fragmented care and a poor coordination of healthcare and social services is considered to be one of the biggest challenges for the Swedish health system (40). The risk of receiving a fragmented care is even more prevalent amongst older persons with multi-morbidity, who often have multiple contacts with different providers from healthcare and social services (2). This risk of receiving fragmented care has arisen out of a highly specialised health system focusing and acting on the parts without adequately acknowledge their relation to the whole (39). The current development of an ageing population stresses the importance of capable health systems that are able to cope with providing care to older persons with

complex health needs (1–4). The care of older persons with multi-morbidity requires a holistic approach to balance the competing priorities of a single-disease and target-based health system (41). Otherwise, this fragmented care could lead to a poor continuity of care.

Good continuity of care has been described as consisting of a chain of care in which the patient feels secure knowing that everyone collaborates on his/her problem, and where good information makes healthcare safe and effective (42). Thus, continuity of care is concerned with quality of care over time (43). In regard to older persons with multi-morbidity their chain of care usually includes all their contacts with the health system in addition to their direct contacts with care providers (3). The World Health Organization (WHO) has defined a health system as: “(i) *all the activities whose primary purpose is to promote, restore and/or maintain health*; (ii) *the people, institutions and resources, arranged together in accordance with established policies, to improve the health of the population they serve, while responding to people’s legitimate expectations and protecting them against the cost of ill-health through a variety of activities whose primary intent is to improve health.*” (44).

Continuity of care consists of two dimensions (43). The first dimension is continuity of care as a ‘continuous caring relationship’. This concerns the patient’s perspective. The quality of the relationship between the patient and the health professional is important to deliver a care catered to the individual (43). Relationship continuity is valued by both patients and clinicians and may lead to better health outcomes, more satisfied patients and staff, as well as reduced costs. However, because of an increasing specialisation within healthcare focusing on providing rapid care, achieving relationship continuity is very challenging. Moreover, a patient’s health needs are not likely to be met by only a single professional (45).

The second dimension of continuity of care is as a ‘seamless service’. This dimension concerns the providers’ perspective. Continuity of care is viewed as a seamless service provided through coordination and integration of information between different providers (43). Hence, it is more than barely an information transfer. It comprises negotiation of care plans and other communication between individuals and teams. Both of these dimensions make a central contribution to how the patient experiences their care being connected over time (45).

Older persons with multi-morbidity often lack a complete overview of their healthcare and social services providers. They can also experience difficulties when trying to coordinate their own care efforts (3, 4). This challenging situation is being imposed on them by a fragmented health system not catered towards their complex needs (4). The situation may lead them to experience a poor continuity of care and put the older persons’ health at risk as they might not receive a satisfactory care. Thus, as a consequence of not being properly cared for, after being discharged, they risk being hospitalised again (13).

For older persons with multi-morbidity, continuity of care has been experienced as knowing and being known by their providers for a period of time. This does not merely include their primary care physicians but also their continuing relationships with registered nurses, specialists and other providers. In regard to the complexity of their required care, continuity takes priority over the convenience of meeting with a provider. The older persons might rather wait for a longer period of time or travel to less convenient locations to receive care by an already known provider – in other words they want to have relationship continuity with their care providers (3). Moreover, older persons want to have an individual contact at the primary care clinic who would serve as their primary contact and care coordinator, enhancing their continuity of care (3). Experiencing a poor coordination between their different healthcare and social services providers could also drain their energy levels, thus complicate their daily lives (4). Based on previous knowledge, modern-day health systems appear to put older persons with multi-morbidity at a potential risk of receiving a poor continuity of care. Consequently, there is an urgent need to develop and evaluate feasible interventions that are able to improve the continuity of care for this group.

## Family members of older persons with multi-morbidity

The current development in many European countries is that informal care is substituting parts of the formal care i.e. the professional care (46). Informal care is widespread and provided by people of all ages in Sweden (14). Thus, informal care has a big impact on the welfare system of Sweden and many other European countries (46, 47). As a consequence of an ageing population, more and more old persons receive informal care by their family members (14). An informal caregiver has been defined as:

*“The person who spends most of the time with the frail elderly and/or from whom the frail elderly declares that he/she is his/her main informal caregiver, for care or support of care, and who does not take part in a formal network of organised care”* (48, pp.499-500)

In Sweden, every fourth person, 55 years and older, provides care on a regular basis to ill older persons or to a disabled person, inside or outside of their own household. Most of these informal caregivers are between 75–84 years old and care for their spouses (49). Thus, providing informal care is a part of many family members' everyday life. Besides providing personal care the family members also assist their relatives with social activities, practical things and coordinate contacts with healthcare and social services (50).

Family members often assume a great deal of responsibility for the older persons' well-being (50). In most cases, informal caregiving is a voluntary commitment but the extent and the forms of the caregiving are not always self-chosen (47). The role as an informal caregiver can be experienced as both a positive experience as well as being burdensome, in relation to the complexity of caring (51). Family members often consider that they have the main responsibility for the health and social care of their relatives. This responsibility may, by extension, lead to the family members starting to suffer from various health problems (52). Informal caregivers who provide extensive care can sometimes consider it to be too great a responsibility and that the public should take the primary responsibility. Furthermore, a large commitment of informal care amongst family members can have a risk of impairing the health and quality of life of those family members (47).

During the times when the health system is unable to sufficiently meet the older persons' needs, this can in turn negatively impact their family members. Family members are also adversely affected if the coordination of their older relatives' healthcare and social services is not satisfactory (50). This unsatisfactory care could increase the older persons' dependency on their family members (13). Also, it is not unusual for family members to feel being left out when dealing with care providers (53–55). Andershed (56) found that informal caregivers to relatives with a palliative diagnosis acted as the relatives' contact with the health system and also had a role as the patients' proxy. It was important for the informal caregivers that they felt involved in the care given to their relatives, while they also experienced it as a strain to coordinate all care efforts. In order for the relatives to handle this complex situation, it was important to receive support from the care providers (56). Informal caregivers have a need to experience trusting relationships with care providers and to have the possibility to contact a specific person or organisation, when in need of assistance (51). It can be assumed that some of these needs also exist amongst family members of older persons with multi-morbidity.

Findings in a report from SNBHW (47) conducted in Sweden showed that only a fourth of the informal caregivers were aware that the municipalities are obliged to offer support to aid people providing care to a relative. Also, the report showed that there are shortcomings in the coordination of care efforts within the healthcare and social services for persons with complex health needs. This situation increases the burden for the family members that need to compensate for these shortcomings (47). The informal caregivers needs to be acknowledged and understood by the care providers in order for them to be guided to different types of assistance, such as social services or voluntary organisations (51). In SNBHW's report (47) it was concluded that information given to family members needed to be improved. This concerns information regarding diagnoses and treatment, as well as information about available support to informal caregivers. If the family members have proper knowledge about their relatives' needs and the reasons behind them, this means that they can better account for both their relatives' and their own interests. As a consequence, this would

provide the family members with more stability and continuity in their role as informal caregivers (47).

The current situation of an increase in informal care in Europe has led to several countries prioritising different measures to relieve some of the burden put on the family members (46). For instance, in Sweden, the municipalities are obliged to offer support to family members caring for persons suffering from long-term illness and/or who have disabilities (57). Lopez-Hartmann et al. (58) gives examples of supportive services found in their systematic review i.e. psychosocial support, respite care and information and communication technology (ICT) support. Psychosocial support is aimed at improving the informal caregivers' ability to manage the caregiving situation and may include emotional support, education, information, counselling and skill building. Respite care can provide the informal caregivers a short-term pause in their caregiving. ICT support may include computer or telephone based education (58). Recent investigations regarding the quality of support services for informal caregivers in Sweden demonstrate that the support has not been properly implemented to fit the shifting needs of the caregivers. There is also a lack of availability for these services throughout Sweden (59). According to Lopez-Hartmann et al. (58), the effects of the above-mentioned supportive services are small and the results of studies concerning their efficacy are inconsistent. The authors suggested integrated support, tailored to the individual carers' needs. To achieve this, it is important to coordinate the support (58). Thus, based on previous knowledge, the current development in many European countries is that family members provide more and more informal care to their relatives. The family members also assume a big responsibility for their older relatives' well-being. Research indicates that the supportive services available today may not sufficiently cater for the needs of family members of an older person with multi-morbidity. Therefore, one potential approach to improve the family members' situation could be to intervene by providing assistance with the coordination and evaluation of their relatives' current health and social care needs.

## Case management

Various approaches have been tested in order to provide an integrated care (10, 60). These approaches may target different levels of integration. For instance, target organisational or professional integration, integrations across the continuum or utilising co-ordination to integrate. The basic idea of an integrated care is to combine parts so they work to form a whole. This is particularly important when fragmentation in care have led to negative experiences amongst the persons being cared for e.g. negatively influenced the patient's outcomes or negatively affecting their experience of the provided care. Integrated care could thus help to improve the

continuity of care (60). A common feature of integrated care is that it seeks to improve the quality of care for individual patients and caregivers. This is done by confirming that the services are sufficiently coordinated towards the patient's individual needs (35). Fragmented care could affect the quality and safety of the care provided because of a risk of duplication of services or a lack of provided services (6, 7). One approach of working against the challenges stipulated by a fragmented health system has been to utilise case management. As a consequence case management is considered to be a key factor for providing integrated care in countries such as the UK (61) and US (62).

## Definitions of case management

Case management is a generic term and has no single definition that is generally applied throughout the field of healthcare and social services (63). Case management aims to coordinate care for persons with complex health needs (9). Case management generally focuses on the populations that account for large parts of the healthcare costs in developed countries (1). Key factors of case management are: improve care outcomes, reduce expensive hospital utilisation and enhance the patient's experience of given care (63). Case management is a practice that could incorporate one or several different professions. It can be viewed as a function or as an advanced practice within various health professions (62). Those who practise case management on a regular basis, as a part of their work, are commonly called "case managers" (9). Within case management, nursing is the field dominating its practice. Nursing has a focus on the person as a whole and is very compatible with the main concepts of case management (64). Registered nurses have had a key role in case management in different interventions targeting older persons with complex health needs (17). Also other health professionals such as social workers are known to practice case management (64). Since there is no single definition of case management and because of its diverse utilisation in different contexts, this has initiated a confusion regarding its content and purpose (63). There are definitions of case management found in the literature. For example, The Case Management Society of America (CMSA) has defined case management as:

*"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."* (62, p.8)



Another definition in regard to nursing case management is provided by The American Nurse Credentialing Center, a subsidiary of the American Nurses Association (ANA):

*“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.”* (64, p.23)

Both definitions illustrate that case management may consist of a range of collaborative processes, rather than being a single intervention (62, 64). Hence, the processes to be included in case management interventions can vary widely (63). These collaborative processes have the aim to convey a better integrated care for older persons (10). The case management interventions can range in the focus they have from targeting purely financial matters to applying a more individualised approach and thus addressing the older person’s perceived needs (1, 5, 15, 17, 65–68). The interventions may also vary in the intensity at which the case management services are provided, as well as the deliverer of the services – the case manager themselves, or other health and social care staff (1, 5, 15, 17, 65–68). In a systematic review, Hallberg et al. (17) concluded that the concept of case management in regard to older persons with complex health needs is not universally defined. Since different countries need specific adaptations of case management in relation to their own health systems, this might not be conceivable (17). Thus, case management can take many forms, but has primarily been a targeted, pro-active and community-based approach to care (10). The CMSA definition also gives support to the multi-disciplinary role for case management – not focusing only on a single profession practising case management (64).

## **History of case management**

Case management has a long history of being applied in various settings such as mental healthcare, aged care, disability care and healthcare (15). According to Tahan (69) the roots of case management can be found as early as the 1860s, as it was used to coordinate and allocate healthcare resources for the immigrants and the poor (69). In the beginning of the 1900s, it was used as a means of providing healthcare and limiting financial costs. In the 1920s, case management started to appear within the fields of social work and psychiatry, focusing on the management of chronic diseases in the community (64). In the 1930s, the early public health nurse organised

community and family resources whilst also providing direct nursing care (62). At that time, conducting home visits was a common practice amongst the public health nurses. In the following decades, case management was primarily practised within the community (64). In the 1970s, case management started to be used as a way of assuring quality outcomes and cost containment. This was in regard to a health system starting to become more and more complex. At this time there were few incentives within the health system aiming to control costs. An increasingly old population and the incidence of chronic diseases placed a great burden on the health system. As a consequence of a complex health system, duplication and gaps in provided services started to become more common. This development led to the introduction of external case management – third party payers such as insurance companies who wanted to be able to have control over healthcare expenses (70). Case management also played a critical role during the 1970s in the US as the deinstitutionalisation of the mentally disabled occurred. Case management was recognised as a key factor to integration of services for the deinstitutionalised population (71). During the 1980s the prospective payment system was introduced to the health system. As a consequence, case management was widely spread within both the acute and post-acute settings – i.e. practised by providers within the health system (64). During the 1990s, case management models were used more in all care settings as a result of managed care organisations gaining more popularity. The focus was now on both cost containment and quality of care (69). Nowadays, case management is considered a key factor in the delivery of integrated care. Internationally it has been accepted as an intervention to be used when providing care to persons with long-term complex health needs (10).

## Components of case management

According to Ross et al. (63) there are certain core components important to case management – *case finding*, *assessment*, *care planning*, *care co-ordination* and *case closure*. The practice of these core components is complex and not a linear process, meaning that a person can undergo some of the components more than once, moving back and forth between the components before being able to close the case.

*Case finding* is the first core component and is used as a systematic method to find those individuals in most need of case management. For instance, if the case management intervention aims to prevent unplanned hospital admissions there is a need to find those persons with a high risk of hospital admission. This is done in order to ensure that the intervention is cost-effective (63). There are different methods used for case finding. One method is utilising predictive models – i.e. use statistical algorithms to predict which persons have a high level of risk of being admitted to the hospital (72). Predictive models are often used in conjunction with clinical assessment. The predictive models are first used to flag persons at high risk;

afterwards the clinician makes an assessment of whether the person would benefit or not from case management (63).

*Assessment* is the second core component. When a person has been admitted to a case management programme it is important that the person's individual needs of healthcare and social services are assessed. Thus, it is important to evaluate the current health status, medication review and formal and informal care arrangements. At this stage it is also essential that the informal caregiver's situation is taken into account and that they are listened to, as they are a key factor in the care of the person (63).

*Care planning* is the third core component, which plans for a person's own situation, such as the availability of informal care and current housing. All of these aspects are taken into consideration to create a plan able to match needs with available services. This care plan should be made in collaboration between the person and the case manager to encourage shared decision-making. The care plan will assist the case manager in his/her work and will allow the case manager to coordinate different services, make referrals to services, monitor the person to see if any progress has been made, and ensure that the persons receives his/her services (63). The care plan should be viewed as a plan under constant change and the case manager must systematically assess the person's health and social care needs to update the care plan according to the new situation (73).

*Care coordination* is the fourth core component and includes a continuous communication with the person receiving case management, his/her carers, and other health professionals and services they have contact with. This care coordination is done by case managers and they often work in teams with other health professionals or case managers. The case managers have a responsibility to monitor and coordinate care while helping the persons to navigate the health system (63). The role of being a navigator is important as the persons they assist often have complex health needs and thus often in need of multiple care providers (41). Some common services included into the care coordination are *medication management*, *monitoring and review*, *self-care support*, *advocacy and negotiation*, and *psychosocial support*. As a part of *medication management*, case managers put effort into confirming that the person's medication management is ok, that they have compliance and that they do not experience any side-effects (74). As a part of *monitoring and review*, the case manager monitors the progress of the care plan and observes if the person receives appropriate care. This monitoring takes place on a daily basis or during longer periods of time depending on what it is that needs to be assessed. This monitoring can be conducted through home visits or by telephone contacts. *Self-care support* can consist of activities such as providing health education and advice, or coaching the person to know about available services to contact when in need of assistance. As a part of *advocacy and negotiation*, the case managers advocate and negotiate so that the persons can gain access to the appropriate healthcare and social services assessed in their care plan. The case manager can negotiate directly with the providers if the person is not able to

do this by him- or herself. As a part of the *psychosocial support*, case managers spend more time with the person than many other health professionals. This can help the case managers to build good relationships (63). Establishing a good relationship is very important for the case managers and could make the person feel more confident (75). The psychosocial support is mediated through the therapeutic relationship being built up between the person and the case manager (63).

*Case closure* is the fifth and last core component. Case closure could happen because of self-discharge, death, or a decision by the case team that the person can manage to live independently without case managers. This could also happen in cases where the case management programme is time-limited in design (63).

Based on previous knowledge, there are core components important to case management. Hence, these components should be a part of case management interventions. However there could also be variations in the way these components are utilised in an intervention and thus give rise to different case management models.

## Case management models

Variations in case management delivery have been attributed to different case management models. Mueser et al. (76) describe different case management models based on a literature review in regard to case management and severe mental illness. The case management models described are the *brokerage model*, the *assertive community treatment model*, the *clinical case management model*, the *intensive case management model*, the *rehabilitation model* and the *strengths model*. The first model is the *brokerage model* and here the case manager's focus is to connect the patients to those services they need and to coordinate between various care providers (76). According to Intagliata (77) the brokerage model has five specific functions – i.e. assessment, planning, linking to services, monitoring and advocacy. According to Moore (78) the brokerage model appeared as a consequence of the deinstitutionalisation of the mental health system, since many patients had great challenges trying to navigate the health system. According to Mueser et al. (76), one limitation to the model is that the case managers in a brokerage model do not give any direct clinical services to their patients (76).

The second model described is the *assertive community treatment (ACT) model*. This model utilises a multi-professional team, typically comprising of: a registered nurse, a psychiatrist and two case managers or more. Basic features of the model include: low patient-to-staff ratio, 24-hour coverage, most services provided in the community (e.g. at the patient's home), most services provided directly by the team and not brokered to other providers, and no time-limit set for the intervention to end (79). The ACT model puts emphasis on treatment in the patient's everyday environment, and also provides practical support in daily living such as shopping and laundry (76).

The third model is the *clinical case management model*. This model was developed due to the recognition that case managers often have to act as clinicians and provide direct clinical services (80,81). Clinical case managers provide services within four broad areas. The first area is *the initial phase*, which comprises engagement, assessment and planning. The second area is *environmental interventions*, which comprises consultation with families and other caregivers, connection of community resources, maintenance and expansion of social networks, and advocacy and collaboration with physicians and hospitals. The third area is *patient interventions*, which comprises training in independent living skills and psychotherapy. The fourth area is *patient-environmental interventions*, which comprises monitoring and crisis intervention. The model clearly states that case managers are expected to be clinicians (76).

The fourth model is the *rehabilitation model*. This model emphasises the importance of providing case management services based on the individual patient's desires and goals. This is in contrast to services primarily decided by the mental health system. A distinct feature of the rehabilitation model is the focus on assessing and adapting social skills that could help to promote daily living in the community and the attainment of personal goals (76).

The fifth model is the *strengths model*. This model was developed as a response to other case management models that tended to mostly address the impairments of a psychiatric illness, rather than focusing on the person's own resources to achieve individual goals. The principles of the strengths model are: the focus is on individual strengths rather than on pathology; interventions are based on patient self-determination; the case manager-patient relationship is essential; the community is viewed as a resource and not an impediment; patient contacts take place in the community; and people suffering from severe mental illness are viewed as able to continue to learn, grow, and change (76).

Another classification of case management models was made by Long (9). Long argues that based on the underlying dynamics of the models, most of the case management models can be merged into two models: the Interrogative Case Management Model (ICMM) and the Patient Advocacy Model (PAM). ICMM puts the cost of care as a legitimate argument in the decision-making process. PAM instead highlights the coordination of services from a patient perspective. Here, all of the patient's circumstances are legitimate arguments in the decision-making. Thus, the treatment is not only governed by the medical needs but also by the patient's social, psychological and financial circumstances. Long concludes that ICMM can be seen to address quality of care through the financial cost and PAM through benefits (9). Hence, as illustrated, there are several different models described in literature which displays great variety of how case management can be practised. The different models have been developed as a consequence of trying to address certain problems in relation to specific contexts or purposes. Therefore, it might not be possible to just choose one model and apply it to another context. There is a need to adjust the case

management intervention to its current context. Hence, it would be preferable if case management interventions presented an in-detail and comprehensive description of the interventional parts themselves. By doing so, this detailed description could help to facilitate a deeper understanding of case management interventions.

## Different perspectives on case management for older persons

There has been research conducted concerning case management and its effectiveness in regard to older persons, especially during the recent decade. These studies have applied case management within different parts of the health system to meet the holistic needs of older persons with complex health needs (1, 5, 15, 17). Research has also tested the cost-effectiveness of different case management interventions (1, 5, 15, 17, 66). According to You et al. (15), countries such as Canada, the UK and Australia are trying to integrate different case management interventions as a part of their aged care systems (15). The recent focus on case management has been due to a growing need to coordinate and provide wide-ranging services for older persons with complex health needs (1, 5, 15, 17, 66). When it comes to case management also catering for the informal caregivers' educational needs and support, the research is scarce and more family-oriented approaches are warranted when it comes to case management (17).

In Sweden, there have been two research projects regarding case management targeting older persons, excluding the intervention being explored in this thesis. The first research project was a RCT (82, 83), started in 2006 in southern Sweden. It comprised of four different interventional elements: 1) *Traditional case management*: assessment, care coordination, telephone calls, advocacy and home visits; 2) *Safety and continuity*: availability of a case manager; 3) *General information*: information concerning the health system, nutrition and social activities; and 4) *Specific information*: information adjusted to the needs of the individual. The intervention was evaluated in terms of its effect on healthcare utilisation (82), cost and utility (84), and falls (85). These studies show that the intervention had the potential of reducing visits to emergency departments and outpatient care (82). The intervention was cost-neutral and did not affect the older persons' health-related quality of life. There was also a decline in number of hours spent on informal care, suggesting that the intervention provided relief to the informal caregivers (84). In regard to number of falls, no significant difference was found (85).

The second research project was named "Elderly persons in the risk zone", and investigated if health-promoting interventions such as pro-active home visits or multi-professional senior group meetings could postpone deterioration in frailty amongst

older persons (86). Findings indicate that it was possible to postpone a decline in health outcomes such as self-rated health, morbidity, and satisfaction with health (87). Furthermore, favourable effects in postponing the progression of frailty (measured as tiredness in daily activities) were shown (86).

There is also a Swedish study of interest that was conducted by Edgren et al. (88). They investigated if a telephone-based, nurse-led case management intervention could reduce healthcare consumption amongst frequent emergency department visitors. Findings indicate a decreased rate of hospitalisation, but the results are mixed. Furthermore, their sample was not specifically targeting older persons but comprised of other ages than 65 years and older (88).

Internationally, there have been many studies regarding case management targeting older persons. A systematic review by Eklund et al. (5) provided some evidence that integrated and coordinated care can decrease healthcare utilisation amongst frail elderly people living in the community (5). In a systematic review by You et al. (15) it was concluded that case management in community aged care interventions has the ability to improve unmet service needs as well as psychological health and well-being of the older persons. The authors also recommended that future research should investigate what components of case management are of importance to achieve improved patient and carer outcomes (15). In a systematic review by Oeseburg et al. (1) it was concluded that patient advocacy case management has the possibility to improve quality of care for older persons with chronic illness and/or impairment. However, the authors also conclude that the effectiveness of patient advocacy case management should be studied further (1). The origin of all articles in the above-mentioned systematic review are mainly derived from either the US or the UK (1, 5, 15). The systematic reviews also show that case management interventions have been inconsistent, and range from having positive outcomes to no effect at all. More rigorous research is emphasised and also that future research should focus on discovering what components and aspects are of importance for a successful intervention.

## **The older persons' perspective**

There have been few studies focusing on older persons' experiences of case management. In a study by Sargent et al. (74), both older persons with long-term conditions and carers were interviewed. The findings were categorised in five ways: *care co-ordination*, *clinical care*, *education*, *psychosocial support* and *advocacy*. The participants described that the case managers collaborated with a number of individuals and organisations to make sure that necessary health needs were provided for, and to prevent gaps or duplications of their care. The participants also acknowledged the case managers' ability to tie together their chain of care and to sort out any problems. They described that the case managers conducted clinical care such

as conducting physical examinations, ordering tests, giving vaccinations and referring patients to specialist care. The clinical care was a part of these case managers' work duties (74). In a study by Sandberg et al. (89) it was illustrated that the older persons considered their case managers to be an additional resource for help, support and guidance. The participants experienced the case managers to be knowledgeable. They recognised the case managers as a source of the getting right information to solve their problems. The participants experience the case managers to be a helping hand, able to assist and guide them. The case managers helped them to solve their problems and guide them in the right direction. Case management was also experienced to be something new to them and at the beginning they did not know what they should expect. Similar results were found in a study by Nelson et al. (73). They reported that the relationship between the case manager and the older person was of paramount importance. Through this relationship, case managers provided a security and a comfort to the older persons. This relationship also enabled the case manager to serve as a liaison between the patient and the physicians to assist the older person in the process of navigating the health system (73). Brown et al. (75) reported that older persons appreciated the support, care, and confidence-building that the matrons (nurse case managers) provided through their case management services. In particular, many of the participants valued the relationship with the case managers and often regarded the case manager as a friend, who they could rely on in times of challenges (75). Nevertheless, none of these above-mentioned studies had a specific focus on older persons with multi-morbidity and their experiences of case management. To gain a deeper understanding about the experiences of these persons, further research is needed to explore this area.

### **The informal caregivers' perspective**

There is a lack of research regarding family members' experiences of case management targeting older persons with multi-morbidity. In a study conducted by Sargent et al. (74) interview data from both the older person and their informal caregivers were analysed, making it difficult to distinguish their unique perspectives. Hallberg et al. (17) conclude that there is a lack of knowledge regarding how integrated and coordinated care affects the informal caregivers (17). Thus, research regarding family members' perspective and the importance of case managers for them seems to be warranted. This new knowledge could be of help to better understand the meaning family members attribute to the case manager's work.

### **The case managers' perspective**

There are few research studies focusing on the case managers' own experiences of case management. In a study by Sandberg et al. (89) the case managers viewed themselves



as being coaching guards – supporting and helping the older person if something happened to them. They navigated the older persons through the health system by interacting with different healthcare providers. The case managers also expressed that working with case management entailed a new role for them, opening up both opportunities and barriers. Possibilities could include being able to build stable and good relationships with the older persons, enabling the case managers to do their work. Barriers could include being powerless as they were not acknowledged by the care providers. As a result they did not get proper assistance from the care providers (89). Another study, by Russell et al. (90), explored the experiences of community matrons – registered nurses working as case managers. Their findings showed that the case managers encountered many challenges, such as the uncertainty of their caseloads (how many persons they would manage at a time). This uncertainty existed because many persons were kept on their caseload but they never knew at what time these persons would need their assistance. The case managers felt that they were under scrutiny from the persons they assisted and by the health professionals they came in contact with. This was believed to be related to case managers being a new role for them as well as for the health professionals they interacted with (90). Another study (91) illustrated that the initial collaboration between the case managers and the primary care physicians was based on a hierarchical relationship. As time progressed, additional trust was built into their relationships, which eventually led to an enhanced collaboration (91). Yau et al. (92) concluded that nurse case managers need to possess communication and interpersonal skills. They also need to be able cope with stress in relation to their work (92). Hence, there are only few studies exploring the case managers' own perspective of their work and only one study has been conducted in a Swedish context. There is a need for additional research that explores how case management is carried out in practice from the case managers' perspectives. This research is important as deeper knowledge of the case managers' everyday work could lead to better understanding regarding both contextual and interpersonal aspects that may affect the success or failure of a case management intervention.

### **The health and social care staff members' perspective**

The research is scarce when it comes to health and social care staff members' experiences of case management. Iliffe et al. (93) wanted to understand how the work of nurse case managers was experienced by general practitioners and community health service managers in the UK. Their findings illustrate that many general practitioners were sceptical about the ability of case managers to reduce admissions of patients with multiple diseases. However, this scepticism was able to be changed when getting positive experiences of case management. There was also an understanding present amongst the participants that both general practitioners and public health nurses were already practicing case management and that the resources could have been better managed (93). In a study by Manthorpe et al. (94), the perspective of

stakeholders in regard to case management was explored. The stakeholders saw the potential of case management in regard to their own area of interest, but not in a wider perspective as for the health system or from the patients' perspective (94). Presently, there is a need to extend knowledge regarding case management as experienced by staff working within the involved parts of the health system.

# Perspective and viewpoints

The work of this thesis is founded upon an ethnographic perspective and different qualitative approaches have been chosen in order to explore and gain a deeper understanding of case management conducted by case managers. The thesis focuses on experiences from the perspective of individuals, with the intent to seek a deeper understanding of meanings that are contributed to case management. Ethnography allows for a deeper understanding of a phenomenon amongst a group of people who all have something in common (95), such as the case managers and their everyday work. Roper et al. (96) have described ethnography as “*a research process of learning about people by learning from them*” (96, p.1). Ethnography views the researcher’s role to be an instrument and often makes use of method triangulation – i.e. the use of different methods during the exploration phase. The data collection is conducted in the everyday environment of the participants (97). Ethnography is inductive (98), meaning it is exploratory and uses an open-ended way of reasoning, following the logic from ground up (99). A central belief within ethnography is that people’s behaviour can only be understood in its context. Elements of human behaviour cannot be separated from their contexts of purpose and meanings. Thus the context is essential for understanding human behaviour (98).

According to Muecke (98), two different types of ethnography exist. One is conventional ethnography, comprising a variety of schools all sharing the value that ethnography emerges from the local context and takes a long time to conduct. The second type of ethnography is that which is conducted with a specific question in mind and applied in intent. This type is referred to as focused ethnography (98) and has been utilised in the work of this thesis. Focused ethnography targets a distinct issue or shared experiences within a group (100), rather than throughout entire communities. Focused ethnography has been adapted by health professionals and especially registered nurses because its approach allows for a more pragmatic way of meeting the needs of healthcare research (100).

In contrast to conventional ethnography, focused ethnography is problem-focused and context-specific and often consist of time-limited exploratory studies within a specific group or community (98). The use of focused ethnography means that the researcher has already from the beginning defined his/her view on case management by using predetermined research questions. These questions are based on what the researcher considers as important to explore in regard to case management. The

knowledge produced in this thesis originates from an interpretive view on research as illustrated by Clifford Geertz (101), anthropologist and founder of interpretive ethnography, in the following quote:

*“...what we call our data are really our own constructions of other people’s constructions of what they and their compatriots are up to.”* (101, p.9)

This thesis also draws inspiration from interpretive ethnography (98,101), which aims to explore the network of shared meanings, constituting the reality within a certain community. Interpretive ethnography is analytical and interpretive (98,101). The ethnographic analysis intends to discover and interpret the meanings of observed social interactions (98). Culture is concept utilised within ethnography and also a complex concept widely varying in its definition (96, 98, 101). Geertz argue that culture can be seen as ‘webs of meanings’ inherent in the lives of people. Meanings are encoded in symbolic forms such as rituals, language, etiquette and artefacts, and these meanings can only be understood through acts of interpretation (101). In regard to the work of this thesis, culture has not been viewed from a broad perspective but instead utilised the traits of focused ethnographies. Thus, the focus has been on meaning-making process amongst the subgroups of case managers and the older persons with multi-morbidity. Geertz has conveyed the spirit of interpretive ethnography in the following quote:

*“Believing that man is an animal suspended in webs of significance he himself has spun, I take culture to be those webs, and the analysis of it to be therefore not an experimental science in search of law but an interpretive one in search of meaning”.* (101, p.5)

In particular, this thesis has made use of the concept of thick description. Geertz emphasises that a good ethnography needs to achieve a thick description of a community’s structures of meanings (101). Thus, during data collection, the context needs to be described in detail as it gives meaning to why people act in a certain way. Angrosino (102) describes thick description as the presentation of the context, details, emotions, and the nuances of social relationships. In contrast, a thin description is merely stating facts without giving any meaning. According to Geertz (101) to achieve a thick description, the researcher needs to bring together two concepts, experience-near and experience-distant. The experience-near relates to the participant’s own perspective – e.g. their own thoughts, views and beliefs (101). The experience-near is the participants’ perspectives that are found in all studies in this thesis. The experience-distant relates to the perspective of a specialist such as an ethnographer, who employs their perspective to forward their philosophical, practical or scientific aims (101). The experience-distant is mainly found in the perspective of the researcher conducting the participant observations. This thesis has also made use of Benner’s interpretive phenomenology (103) in Study II. Interpretive

phenomenology focuses on the meaning-making processes and on understanding. Benner has herself been inspired by the work of Clifford Geertz when constructing her understanding of interpretive phenomenology.

Case management interventions need to be explored in terms of what has been conducted within its specific context. Since ethnography highlights an in-depth understanding of the context in which the participants' experiences occur, this approach is suitable to explore case management and therefore was chosen for this thesis.



# Rationale

Previous research (1, 5, 10, 15–17) acknowledges the need for case management interventions that aim to improve continuity of care for older persons with complex health needs. There have been several studies (1, 5, 10, 15–17) investigating the effects of case management targeting older persons, mainly focusing on healthcare consumption and costs. These studies display positive of effects intervening with case management, but other studies also indicate no effect at all following the intervention. Thus the evidence-base for case management is inconsistent. Furthermore, many of these case management interventions are described in insufficient detail to comprehend what has actually been done as an intervention (1, 5, 10, 15–17). There are few studies that presents findings regarding experiences of case management. In order to gain a deeper understanding of case management and to learn more about what aspects are of importance to conduct a successful intervention, there is a need to further explore this area. One way to go about this exploration could be to explore the experiences of case management from different perspectives of value to the intervention. Important perspectives could be said to originate from the older persons receiving the intervention, their family members, the case managers and the health and social care staff members involved in the intervention. Extending and deepening this knowledge from these perspectives could lead to a better understanding of case management interventions. Consequently, this knowledge could help to improve the development and design of case management interventions aimed at older persons with multi-morbidity.





# Aim

The overall aim was to explore the experiences of a case management intervention aimed at older persons with multi-morbidity, from the perspectives of case managers, older persons, family members and health and social care staff members.

## Specific aims

- To explore the everyday work undertaken by case managers within a case management intervention, with a focus on their experiences. (Study I).
- To understand the importance of case managers to family members of older persons (75+) with multi-morbidity. (Study II).
- To explore older persons' (75+) with multi-morbidity experiences of case managers. (Study III).
- To explore health and social care staff members' experiences with a case management intervention focusing on improving continuity of care for older persons, 65 and over, with complex health needs. (Study IV).



# Methodological approach

## Design and methods

The design of this thesis was based on an ethnographic approach (98, 101, 102). An overview of the studies and their designs can be found in Table 1. The studies provide different perspectives of a case management intervention practised by case managers. The perspectives consist of the case managers themselves (Study I), the family members (Study II), the older persons (Study III), and the health and social care staff members involved in the intervention (Study IV). Participant observations brings in an etic perspective (104) to the research – i.e. the outside perspective of a researcher. By exploring case management from different perspectives which are believed to be of value to the practice of and experiences of case management, this could help us to gain a deeper understanding of its content and meaning.

Studies I and III utilised a focused ethnographic approach (98,100), situated within interpretive ethnography (98, 101). Focused ethnography has been described to be of particular value to researchers wanting to explore a distinct situation or issue within a specific context (96). Focused ethnographies can target shared features of individuals in groups, focusing on common behaviours and experiences of those individuals (100). Thus, ethnographic methods were applied to explore the shared meanings of a group of case managers and amongst older persons with multi-morbidity. Focused ethnography is problem-focused and utilises both interviews and episodic observations to gain a deeper knowledge (100). Ethnography is characterised by the researcher's role as an instrument. Data collection includes method triangulation and is conducted in the participants' natural environment (102). Study III utilised an interpretive phenomenological approach, a suitable approach for identifying similarities and differences in experiences, as well as for learning how people make sense of something (103). Study IV utilised a thematic analysis (105) with an inductive approach to explore the shared meanings among health and social care staff members.

**Table 1.** Overview of papers included in this thesis.

	Study I	Study II	Study III	Study IV
Participants (n)	9 ♂=1, ♀=8	16 ♂=2, ♀=14	13 ♂=3, ♀=10	10 ♀=10
Design	Focused ethnography	Interpretive phenomenology	Focused ethnography	Qualitative design
Data collection	Individual interviews, group interview and participant observations with field notes	Individual interviews	Individual interviews and participant observations with field notes	Individual interviews
Analysis	Ethnographic analysis with informal and formal analysis	Interpretive phenomenology inspired by Benner	Roper and Shapira's framework for ethnographic analysis	Thematic analysis

## Recruitment and participants

### Setting

#### *The Swedish health system*

In Sweden, the county councils/regions and municipalities are responsible for providing healthcare to its population. Swedish healthcare is mainly financed through taxes. Sweden's health system is highly decentralised and healthcare and social services are provided by 17 county councils, 4 regional bodies and 290 municipalities. The county councils have the responsibility of funding and providing healthcare services to its population (106). The municipalities have the responsibility of providing long-term care and social services to older persons, living in ordinary housing or in special accommodation. A great majority of the older persons in Sweden live in ordinary homes. The municipalities provide home help services and services such as laundry help, municipal security alarm, personal care, preparation of meals and transport services (107). Privately-owned healthcare facilities exist but are commonly publicly funded. Healthcare that demands hospital treatment is conducted at regional and county hospitals, where regional hospitals have more highly specialised care than

county hospitals. There are more than 1100 public and private primary care units placed throughout Sweden providing a range of healthcare services to the community. Healthcare services provided at primary care units do not require access to advanced medical equipment (106); such services are available at the hospitals.

### *The case management intervention*

The case management intervention, named “Äldrelotsprojektet” in Swedish, was conducted from 2011 to 2013. The intervention was started as result of receiving funding from a national initiative aiming to improve continuity of care for older persons with complex health needs. The initiative was commissioned by the Swedish Government and conveyed by the Swedish Association of Local Authorities and Regions (SALAR) and SNBHW. The location of the intervention was Blekinge County in southern Sweden. Blekinge is divided into five municipalities and has a population of roughly 150 000 inhabitants living in both urban and rural areas. Blekinge has one regional and one local hospital and has around 20 primary care units spread throughout the county.

The case management intervention belonged to a new, temporary organisation. The reason behind this organisational structure was that the intervention was to be independent of those organisations active within Blekinge’s health system. This was done in order to facilitate a more neutral position. The intervention was conducted by a team of case managers. The case manager team was multi-professional, consisting of assistant nurses, nurse managers, registered nurses and an occupational therapist, allowing for the older persons’ needs to be discussed from multiple professional perspectives.

The intervention comprised of two parts. The first part involved case management at an *individual level*. As a part of their everyday work the case managers interacted with the older persons, their family members and with health and social care staff members. The case managers identified the different and varying needs of the older persons and their family members. The case managers regularly carried out home visits, commonly at admission, and after 3, 6, 9 and 12 months. At these home visits they assessed and planned tasks based on the current needs of the older persons and their family members. The case managers then coordinated so that other staff would cater for the older person’s needs. They interacted with staff from the county councils and from the municipalities and collaborated with differing staff depending on the older person’s needs. The case managers had follow-up contacts in the form of telephone contacts, home or hospital visits. The case managers could be of assistance at care planning sessions and at physician’s appointments. They could also offer a pharmaceutical review from a pharmacist. For the family members, the case managers’ assistance could include providing information regarding their older relatives’ right to effective care, or counselling by telephone or during a home visit. Furthermore, the case managers also put the family members in contact with the right person who

could assist them with their current concerns. The case managers had their own case manager team where they had meetings where they discussed their work cases, learnt from each other, and came up with solutions.

The second part involved case management at an *organisational level*. Collaborative working groups, operating as forum for improving work and learning, were started in each one of Blekinge's municipalities. Neither the older persons, nor their relatives took part at this level. The working groups consisted of a number of representatives – i.e. health and social care staff members, including managers. They ranged in number from six to thirteen representatives depending on the working group. The representatives all had professional experience of working with older persons with complex health needs, and they came from different professions. A majority of the representatives had their current employment within the municipalities. The case manager's role was to bring forth identified needs and improvement areas, which they had observed during their everyday work. These subjects were then discussed during the meetings, with the intention to come up with possible solutions and to learn from each other. The case managers also regularly updated the representatives with regard to the on-going process and results of the case management intervention.

The case management intervention was built upon using a constant learning process as a natural and central role in the development of the intervention. Because of this continuous learning the recruitment process shifted into six different phases over the period of the intervention. This shift was an attempt to find those older persons in most need of case management. The six phases are described below:

*Phase 1* (Initiated in April 2011, 87 persons recruited). Utilised the SNBHW definition of older persons with multi-morbidity i.e., being 75 years and over, having three or more diagnoses from different ICD disease groups and also been admitted to hospital at least three times during the last twelve months.

*Phase 2* (Initiated in November 2011, 40 persons recruited). The same criteria as described above.

*Phase 3* (Initiated in April 2012, 91 persons recruited). Utilised a new definition proposed by the SNBHW – i.e., the most ill older persons. The former criterion of multi-morbidity was still active. The new definition allowed recruitment of older persons 65 years and over, who also had extensive health and social care needs.

Another possibility to be included was that a home care manager assessed an extensive need of care. Very few participants were recruited this way.

*Phase 4* (Initiated in April 2012, 24 persons recruited). Older persons were offered a case manager because they or someone else contacted a case manager.

*Phase 5* (Initiated in June–September 2012 and February–April 2013, 25 persons recruited). Older persons interviewed as part of readmission enquiries, were offered a

case manager. This covered those aged 65 and over with an unplanned readmission for in-patient care within 30 days.

*Phase 6* (Initiated in October 2012 and January 2013, 41 persons recruited). Older persons with extensive health and social care needs as described in phase 3, but the age limit was changed to 75 years and over. Multi-morbidity was also one available criterion for recruitment.

In regard to the intervention's different recruitment phases, Table 2 illustrates how the sample of Study I-III relates to the different phases. This is to clarify which recruitment phases the participants in the respective study of the thesis have been part of. For Study IV it is not known which specific phases the participants have been a part of.

**Table 2.** Description of how the six phases relate to the participants in Study I-III.

	Phase 1	Phase 2	Phase 3	Phase 4	Phase 5	Phase 6
Start of phase	April 2011	Nov 2011	April 2012	April 2012	June 2012	Oct 2012
Study I	x	x	x	x	x	x
Study II	x					
Study III	x	x				

## Study I – Case managers

In Study I, purposive sampling was used (108). Potential participants were those who had experience of working as case managers in the current case management intervention. Since the year 2011, there had been a total of ten case managers involved in the intervention and three of them ended their involvement before the start of the study. Thus, seven case managers were still active. Two of the three inactive case managers were invited to participate, but we were unsuccessful in contacting the third, despite several attempts. The potential participants received both written and oral information in regard to the study and they were able to ask questions regarding the research and their involvement. The active case managers were recruited for individual interviews, a group interview and participant observations. The inactive case managers were recruited for individual interviews. The final sample consisted of nine participants, eight women and one man, with their age ranging from 40 to 61 years and a mean age of 50 years. Their professional backgrounds were: assistant nurse (n=3), nurse managers (n=3), registered nurses (n=2) and occupational therapist (n=1). The length of their professional experience ranged from 4-34 years and a mean length of 18 years. The participants had no

experience of working as case managers before joining the case management intervention.

## **Study II – Family members**

In Study II, purposive sampling (108) was used. The potential participants invited were those who had experience of being a family member of an older person with multi-morbidity. Their older relative had to participate in the case management intervention for at least one year. The family members in the study were defined as persons who provide assistance to relatives; while relatives were defined as older persons with multi-morbidity in need of that assistance. In regard to multi-morbidity, this was based on the SNBHW's definition (28): being 75 years and over, having three or more diagnoses from different ICD disease groups and also been admitted to hospital at least three times during the last twelve months. To get hold of contact information to potential participants, the case managers were asked. The case managers had at an earlier stage queried potential participants if they would agree to let a researcher contact them regarding participation in a study. This inquiry had resulted in 22 potential participants. They were contacted by the researcher through telephone calls, when they received oral information about the study. Subsequently, a written information letter, a written consent form, and a questionnaire for demographic data was sent out to them. A second call was made one week after sending out the written information, to ask if the potential participants were willing to participate in the study. These contacts were made from July to the end of September 2012. Out of 22 potential participants, a total of 16 agreed to participate. Thus, six of them declined, stating they had no or limited experience of the case management intervention. The final sample consisted of 16 participants, 14 women and 2 men, with their age ranging from 38 to 89 years and a mean age of 63 years. Their educational level was: secondary level (n=3), high school level (n=5) and university level (n=8). Their relationships with the older persons were: husband/wife (n=5), daughter/son (n=10) and sibling (n=1). They had been given care to their family members for a mean of 44 months and this ranged between 13-120 months. The distance to their family members were: the same household (n=5), the same building, but different household (n=2), at walking distance (n=2), less than one hour with car (n=6) and more than one hour with care (n=1).

## **Study III – Older persons**

In Study III potential participants were found utilising purposive sampling (108). Potential participants were older persons currently participating in the case management intervention and who also adhered to the SNBHW's definition of multi-morbidity (28). They had to been involved in the case management



intervention for a minimum of nine months. This duration was set to ensure that they had experienced many parts of the intervention. To find these potential participants who had utilised the case management services extensively, the case managers were contacted to help find those participants. This was done based on the assumption that these persons could provide rich and detailed narrations. The case managers informed these potential participants orally and gave an information letter concerning the study. Those persons who showed an interest in participating were contacted and given further information regarding the study. All of the 13 potential participants agreed to participate. The final sample consisted of 10 women and 3 men, with their age ranging from 77 to 88 years and a mean age of 82 years. Their educational level was: primary (n=9), secondary (n=3), and university (n=1). Their marital status was: married (n=2), widow/widower (n=9) and divorced (n=2). All of them had their own housing (n=13). In regard to home healthcare services, eight of them utilised it and five did not.

## **Study IV – Staff**

In Study IV, purposive sampling was used (108). Potential participants were health and social care staff members, including managers, who attended the working groups as representatives. They had to be active representatives in one of the municipalities' working groups at the time of recruitment. All of the working groups combined had a total of 51 potential participants comprising different professions. Consent to contact those potential participants for recruitment, was received from the intervention's steering committee. Variation in regard to professions was sought and thus potential participants were contacted based on their current professions. They were contacted by telephone and received information regarding the study's purpose. To recruit ten participants, a total of 18 potential participants were contacted. The eight potential participants declining the invitation did so because of a lack of engagement in the working groups (n=7) and one participant was non-contactable. The final sample consisted of ten participants. Their age ranged from 44 to 60 years with a mean age of 54 years. The ten participants' professional backgrounds were: public healthcare nurse (n=1), health and social care managers (n=2), local authority senior medicine advisor (n=2), home care organiser (n=1), auxiliary nurse (n=1), physiotherapist (n=1), occupational therapist (n=1) and relatives' coordinator (n=1). The length of their professional experience ranged from 4-36 years, with a mean length of 19 years. All were women (n=10).

# Data collection

## Interviews (Study I-IV)

Data for Study I-IV were collected by the use of individual interviews. This method was chosen because of its usefulness in exploring another human's knowledge and experiences of a particular phenomenon (99). All of the interviews utilised open-ended questions, i.e. questions that cannot be answered yes or no but require that the participants explain and describe in more detail. The interview questions were followed by the interviewer encouraging deeper and more detailed narrations by asking probing questions (109). According to Klein (110), the researcher in an interview situation can encourage the participant to take the word and also keep it. Thus, during the interviews the researcher tried to encourage the participants to take the word by actively listening, being curious and keeping eye-contact with the participants. In Study I, III and IV all the interviews were conducted by the researcher and in Study II the interviews were conducted by a co-author.

For Study I, a pilot group interview was conducted before the interviews began. A pilot interview can be used to test and refine the interview questions and to improve the procedure of the interview (99). The pilot group interview was conducted in September 2012 with five registered nurses, chosen as they had experience of working with older persons with multi-morbidity. A thematic interview guide (109) was tested for its ability to initiate in-depth narrations. As a result of the pilot group interview, some minor revisions were made in order to make the interview questions easier to understand. The revised thematic interview guide was then utilised during the group and individual interviews, and consisted of the following three themes: 1) the case managers' experiences of their everyday work; 2) the case managers' encounters with other professions within the health system; and 3) the case managers' experiences of continuity of care for older persons within the health system.

The group interview was conducted at the researcher's own university in September 2012, and included all of the active case managers (n=7). There was one interviewer and one moderator. The moderator wrote field notes about observations made during the interview and also kept track so that all of the participants contributed. Thus, the case managers' individual experiences were explored in a group context. The group interview lasted 103 minutes. Following the group interview nine in-depth individual interviews, with active case managers (n=7) and inactive case managers (n=2), were conducted in September and October 2012. The locations of the interviews were: the case managers' current workplace (n=7) and at the university (n=2). The interview sessions lasted between 47 to 111 minutes with the active case managers, and 25 and 41 minutes with the inactive case managers. The interviews were digitally recorded

and transcribed verbatim, partly by the researcher and by a secretary skilled in transcribing research material. Transcriptions were checked for accuracy.

For Study II, 16 individual interviews were conducted with the participants (the family members), from July to September 2012. The interviews used a semi-structured interview guide (99), that started with the open-ended question “Can you please tell me about your experiences of case managers?”. Two additional questions followed: “Can you please tell me what case managers mean for you in your role as a family member of an older person with multi-morbidity?” and “Can you please tell me about what you and the case manager do during your encounters”. Probing questions such as: “Can you tell me more?” and “What do you mean?” were used to deepen the participants’ interviews. The locations of the interviews were: at the university (n=2), at their own home (n=13) or through telephone contact (n=1). The interviews lasted between 23-121 minutes, with a mean length of 38 minutes. The interviews were digitally recorded and subsequently transcribed verbatim by the same secretary as in Study I. All transcriptions were checked for accuracy.

For Study III, 13 individual interviews were conducted in 2013. The participants consisted of older persons with multi-morbidity. The interviews used a semi-structured interview guide (99) comprising of questions such as: “Tell me, what were your first thoughts when the case manager contacted you?”, “Can you tell me about any situations where the case manager has assisted you in any way?”, “Tell me, what do you and your case manager talk about?” Probing questions were used to get richer narrations. The interviews were all conducted at the participants’ own homes (n=13). The interviews lasted around 40 minutes. All but one of the interviews were transcribed verbatim by the same secretary as in Study I+II; the other was transcribed verbatim by the researcher. All transcriptions were checked for accuracy.

For Study IV, in 2013 ten individual interviews were conducted with the participants – i.e. the health and social care staff, including managers. The interviews used a thematic interview guide (109), based on the study’s aim. The interview guide comprised of the following themes: “Case management as a new intervention in your organisation”, “Case management in regard to organisational development” and “Case management in regard to the older persons and their relatives”. The locations of the interviews were: at the participants’ workplace (n=9) and at a public place (n=1). The interviews lasted around 30 minutes. The interviews were digitally recorded and subsequently transcribed verbatim by the researcher.

## **Participant observations (Study I-IV)**

Data for Studies I and IV were collected by the use of participant observations. The process of being a participant observer has been described by Becker (111): “*The participant observer gathers data by participating in the daily life of the group or*

*organisation he studies. He watches the people he is studying to see what situations they ordinarily meet and how they behave in them. He enters into conversation with some or all of the participants in these situations and discovers their interpretation of the events he has observed.*" (111, p.652). Becker's general description fits well with the process of participant observation in this thesis. Participant observations as a method has been used for a long time within anthropology and has since the late 20<sup>th</sup> century gained an increased interest in various disciplines such as nursing, education and sociology (112).

Since the thesis is based on an approach of focused ethnography the methodology of the observations has been inspired by this approach. Thus, in line with a focused ethnography, the methodology is being characterised by episodic participant observations and by utilising predetermined research questions (98). Different approaches within participant observations exists, and the researcher in this thesis mainly took the stance of an 'observer-as-participant' (102) – i.e. observed and interacted with those being observed, but did so during pre-determined periods and did not become fully immersed in the lives of those being observed.

Participant observations were conducted during the period of August 2012 to January 2013 – a total of six months. The observations were more intensively conducted at the beginning of the time period and then became sparser as time passed. The focus of the observations was the case managers' everyday work, and the observations were conducted in the participants' natural environment – i.e. at their work place. The observations were conducted during the case managers' everyday work, at their weekly follow-up meetings, and also at reflective meetings. These reflective meetings dealt with the participants' experiences of being a case manager and here the researcher acted as both an observer and a moderator. The researcher observed while trying to keep an open mind and reflecting on the situations that emerged. The participant observations also included informal interviews (96), meaning that questions regarding observed situations were asked in conjunction with that situation. This was done to gain immediate feedback after observing a certain situation allowing the researcher to get an additional understanding of the situation. In total there were 36 periods of observations and these observations had a mix of all active case managers. The duration of the observations ranged between 0.75-8 hours, depending on the availability of the participants and what kind of activities that was to be observed. The total length of time conducting observations amounted to 125 hours. Of these observations, 26 hours, involving 17 observations, were conducted during the case managers' face-to-face interactions with older persons with multi-morbidity.

Field notes were continuously written, both during and after the observations. The field notes comprised of information regarding the current context, the participants, verbal interactions, own personal reflections and a chronological description of what occurred during the observations. The information was collected in order to gain detailed information about the observations and to be used as data (102). During the

course of the later observations, the researcher started to become more and more familiar with the daily situations being encountered by the case managers. Thus, as the researcher started to become familiarised, the researcher decided to finish conducting any additional observations. The data collected from the observations was used in various ways. In Studies I and III the field notes were used as a part of the data analysis. In Studies II and IV the field notes were used by the researcher as a means of coming back to the field. By reading and reflecting on the field notes, this helped the researcher to get an understanding being present during the data analysis, even though time had passed since the observations had been conducted.

## Data analysis

### Ethnographic analysis

In Study I and III an ethnographic analysis was conducted as a part of the focused ethnographies. The ethnographic analysis was interpretive and inductive. The purpose of an ethnographic analysis is to organise all of the data and then try to make sense of it (96). The process involves the search for patterns in data and for ideas that can assist in explaining the existence of those patterns (98). Ethnographic analysis requires time for reflection to understand complex events and the persons performing them (96). The data in Studies I and III consisted of interview material, and field notes about the case managers' everyday work that also included personal reflections.

The data analysis was performed by utilising both the emic perspective – the participants' perspective – and the etic perspective – the researcher's perspective (102). In Study I, the data analysis was described as both an informal and formal analysis (97, 104). The informal analysis was initiated when the participant observations started. Following observations, the gathered field notes were critically reflected upon as a continuous and interpretive process. The reason behind these reflections was to gain a deeper understanding of the case managers' everyday work. This continuous interpretive process took place in the light of the aims of the study and influenced how the observations were conducted. New insights gained from this iterative process led to the initiation of informal interviews with the case managers, as these insights needed to be explored in the field. Field notes were also used to form a narrative of a typical working day of a case manager, and were presented in the findings of Study I. The reason for providing this narrative was to help the reader understand the context and to illustrate a case manager's everyday work.

The formal analysis (meaning the analysis of the interview material) started when the observations were completed. The way in which the interview material was analysed was influenced by Morse and Fields' description of thematic analysis (105). The first

step was when the interviews were transcribed. According to Klein (110), transcription is not only a mechanical act but also an analytical act. During this step the researcher's pre-understanding may affect the transcription process. The interviews were listened to and read through to get an overall understanding. Overall impressions of the participants' experiences were noted and discussed amongst all researchers. The researcher regularly took a step back to reflect on the interviews as a whole. During this continuous iterative process three different themes later emerged, linking substantial portions of the interviews. These themes began to recur across the texts and no new themes emerged. The similarities and differences of these emerging themes were discussed and a consensus was reached amongst all researchers. An overarching theme was lifted from the themes and consequently acknowledged by the researchers. Due to the extensive data collection and as no new themes emerged from the interview data reflecting the aim of the study, it was deemed enough to finalise the analysis of the data.

In Study III, data analysis was inspired by Roper and Shapira's framework for ethnographic analysis (96), and the analysis aimed to describe the participants' shared experiences. Field notes from participant observations were read and reflected upon as a continuous and interwoven process of the data analysis. This continuous process assisted in gaining a deeper understanding of the older persons' experiences of case managers seen from an etic perspective. This formed a pre-understanding present during the data analysis. Roper and Shapira's framework for ethnographic analysis comprises five strategies and all strategies were used:

*Coding for descriptive labels.* The interview material was grouped into descriptive labels and then organised in order to compare, contrast and identify patterns.

*Sorting for patterns.* These descriptive labels were then used to explore potential connections within the material, after which themes were created.

*Identifying outliers.* Situations were identified that did not match the rest of the findings. These situations were used to critically reflect on the data in order to gain a deeper understanding.

*Generalising constructs and theories.* In the discussion, the findings were related to other literature and research as a way of discussing and enriching the findings.

*Memoing with reflective remarks.* Memos were written throughout the research process, and contained different insights regarding the data. These memos helped to keep track of assumptions throughout the research process.

During data analysis the five strategies were used and alternated, moving back and forth between the different strategies, consequently moving from parts to a whole and getting a deeper understanding of the data. Reflective meetings were held, critically discussing the analysis. This iterative process led to four themes illustrating how older persons with multi-morbidity experience case managers. Lastly, observational

data were compared with the content of the four emerging themes and thereby integrated an etic perspective to the findings.

## **Interpretive phenomenology**

In Study II an interpretive phenomenological approach inspired by the works of Benner (103) was used. This is a suitable approach for identifying similarities and differences, as well as for learning how people make sense of something. Interpretive phenomenology puts emphasis on the way people dwell in the world in terms of meaning and acting. Knowledge is sought after from an ever-changing world that has shaped human beings. The subjective experiences of humans and their behaviour houses different meanings.

The researcher's pre-understanding is important, as is the context in which the phenomena reside (103). Interpretive phenomenology advocates that to follow an approach that intends to explain the world of the individuals, the researcher first has to consider the relationships between the individuals and the world (113). Hence, the researcher must also consider the complexity of the specific context in which the individuals reside. Interpretive phenomenology has previously been utilised within healthcare research (103, 113). Since the interest in this study was pointed towards understanding the family members' experiences of case managers and the meaning of those experiences, interpretive phenomenology was found suitable as an approach.

The interpretive phenomenological analysis involved several interconnected steps. The data analysis aimed to reveal the meanings in the narratives of the family members. The interpretations moved back and forth between parts and the whole during the course of the data analysis. This allowed for a critical reflection and understanding of the narratives. The first step involved the narratives being read numerous times. This was done to acquire a general understanding in regard to the family members' experiences and the context of those narratives. Meetings were held where the researchers jointly reflected on the narratives and their content.

As a part of the second step all narratives were individually read, in order to interpret them in their own context. This allowed for a greater immersion into the perspective of the individuals. The focus was on significant episodes expressed by the participants, illuminating their experiences and meanings. The researchers wrote down notes in each of the transcripts during and after each reading. In these interpretive notes, there were comments filled in regarding the significant episodes found in the narratives.

As a part of the third step, a paradigm case was identified. A paradigm case consists of strong and significant episodes reflecting the family members' experiences of case managers (103). Utilising paradigm cases can serve as a way to gain new insights about the data and to illustrate the practical world. The paradigm case in this study

was used as a starting point for the results and provided the reader with an understanding of the context.

The final step comprised of a thematic analysis. The narratives were explored for descriptions containing similarities. Through this iterative process patterns emerged in the narratives. Continuous readings of the narratives confirmed these patterns and lead to the identification of three themes. The themes were reflected upon and as a consequence an overarching theme was lifted from the three themes. A consensus was reached and data analysis finished, resulting in an overarching theme with three sub-themes.

## **Thematic analysis**

In Study IV, thematic analysis was used (105). The thematic analysis was based on an inductive approach – i.e. using open-ended reasoning, being exploratory and following the logic from ground up (99). Morse and Fields' description of thematic analysis was used as inspiration for the analysis (105). The thematic analysis includes the search for and identification of common threads that connects the interviews or parts of the interviews. These themes are often challenging to identify and can be abstract. The themes can be underneath the surface of the text, being more latent in nature, but when they are identified they seem quite obvious. The themes usually link substantial portions of the interview text together (105).

The thematic analysis started as the interviews were read to gain an overall understanding of the data. Reflections were then made on the interviews as a whole. This was a continuous and iterative process, going back and forth to the data as new understandings emerged. The iterative process eventually led to the data being structured into potential themes. Throughout the data analysis, regular meetings were held comprising all researchers. The meetings were a forum for the researchers to discuss potential themes and content, thus providing their individual perspectives of the data. From this iterative process three themes emerged, linking considerable parts of the interviews. The three themes were re-confirmed by a continuous reading of the interviews. The themes were then compared with each other in regard to similarities and differences. As no new themes seemed to appear reflecting the aim of the study the data analysis was concluded and all researchers approved of the final analysis.



# Ethical considerations

According to the Ethical Review of Research Involving Humans (114), research needs to undergo ethical review in those cases where research is likely to influence the participants physically or mentally. This is particularly important for vulnerable groups of people (115), such as older persons with multi-morbidity. Studies included in this thesis received ethical approval from the Regional Ethical Review Board in Lund (Dnr 2012/228). Research was conducted according to the established ethical guidelines of the Declaration of Helsinki (116). The principle of respect for autonomy, principle of non-maleficence, principle of beneficence and principle of justice were all taken into sincere consideration (117).

## The principle of respect for autonomy

The principle of respect for autonomy relates to respecting the decision-making capacity of an autonomous person. This includes upholding the person's right to have his/her own view and to be able to make reasoned and informed choices (117). Thus, all of the participants received information, both written and oral, regarding the study and how the data material would be treated. To ensure that the participants would take part in the research voluntarily, they were provided information so that they could give an informed consent. They were informed that they could withdraw from the study without having to give any explanations. The withdrawal from the study would not in any way influence their current care situation, such as the older person's relationship with the case managers. The participants were able to contact the researcher by telephone or email, to ask any questions regarding their participation.

In Study II the case managers assisted with the recruitment of older persons and this was based on inclusion criteria. Information (names and telephone numbers) regarding potential participants was handed over to the researcher from the case managers. Ethical discussions were made prior to recruitment, as there was identified a potential risk that the older persons would agree to partake in the study since the case managers were the ones asking them. The researcher spoke to the case managers regarding this concern in order to make them aware of the issue. Furthermore, to ensure that their participation was voluntarily, the potential participants were

contacted by telephone to exchange information and to assess if they really wanted to participate.

Participant observations were a part of the methodology of this thesis, and according to Angrosino (102) this method can involve a range of ethical difficulties that the researcher must consider. One ethical difficulty is that if the researcher is in close contact with the participants for a long period of time, they risk being viewed as a friend. According to Alver et al. (118) it is important to continually assess whether the observed participants still want to participate in the research – i.e. assess a negotiated consent. Hence, it was highlighted to the participants that it was research being conducted and that data were being collected during the observations. Another important aspect was that the observations were conducted during the case managers' everyday work. Consequently, observations were made in contexts that could be considered to be sensitive – i.e. the older persons' home or at hospital wards. Thus, it was important to be careful of how the context was illustrated in the findings. Furthermore, the focus of the observations was on the case managers' work and not for instance on the hospital ward itself or the patients being admitted to that ward. Prior to conducting participant observations, the case managers gave information to the older persons, and oral consent was received. When the observations involved a care plan meeting, oral consent was also obtained from all professionals and relatives who were part of that care plan meeting.

## The principle of non-maleficence and beneficence

The principle of non-maleficence relates to avoid causing any harm to the participants, whereas beneficence relates to the wellbeing of the participants. The balance of benefit versus risk needs to be carefully accounted for (117). Thus, data originating from the participants, i.e. interviews and observational data have been treated with confidentiality, and when illustrating the findings the participants have been kept anonymous. Specific personal information that could compromise the identity of the participants has not been included in the findings. Furthermore the findings are presented as shared meanings and do not portray single individuals. The data material has been stored anonymously in a locked cabinet to ensure that no unauthorised person can gain access to the data. Throughout the studies, the patient's best interests have always been in focus, and regular discussions have taken place concerning ethical considerations. In all of the studies it has been the participants themselves choosing the location of the interviews. Thus, they were able to choose a place where they felt safe, which could contribute to making the interview situation feel less stressful. The risk of harm, physically or mentally, to the participants was considered to be very low. The focus of the interviews was on experiences of case management from different perspectives and not focused on very sensitive topics. The

benefits gained from the studies would primarily be indirect, as the findings could provide new knowledge to the research field. As a consequence of publishing scientific articles, attending conferences and giving public presentations, this transferred knowledge could possibly help in the work of improving care for older persons with complex health needs.

## The principle of justice

The principle of justice relates to the distribution of risks, benefits and costs in a fair manner. The participants should all be treated in a similar manner (117). The recruitment process was based on the aim of the study and did not discriminate because of gender, religion or values. Potential participants who declined participation were treated fairly and not judged in any way. All of the participants received the same information in the respective studies and all had the same possibilities to receive additional information.



# Summary of findings

## Study I – Case managers

The findings in Study I reflected the case managers' experiences of their everyday work and was reflected in an overarching theme: *Challenging current professional identity* with three sub-themes: *Adjusting to familiar work in an unfamiliar role*; *Striving to improve the health system through a new role* and *Trust is vital to advocacy*.

The overarching theme *Challenging current professional identity* revealed that the case managers performed work tasks familiar to them using both their own pre-understanding and the knowledge within the case manager team. Conducting this familiar work in a new context, with new conditions governing how they should perform their work, challenged their professional identity. The case managers had been assigned a role that offered them new ways to bring forth potential improvements, but it also presented them with new challenges. As a result they needed to adapt to these new conditions and by doing so this challenged their professional identity. To be able to advocate from the older person's perspective they needed to set aside their own professional values and past experiences of the health system and this challenged their professional identity. The new role as a case manager was moulded as time passed by and their experiences developed. As they strived to come together as a team working towards common goals, they had to challenge their professional identity.

The sub-theme *Adjusting to familiar work in an unfamiliar role* reflected that the case managers in their everyday work expressed that the work task they performed was not unfamiliar in relation to the work tasks of their professions. However, the new role as case managers meant that it influenced how they should or should not perform this familiar work. Familiar work included guiding the older person through the health system and was conducted by giving information regarding available services and directing them to the correct healthcare contact. Planning and evaluating was another familiar task. To identify the older persons' needs, the case managers needed to listen to the older persons' stories. The case managers emphasised that the identified needs should originate from the older persons and not be clouded by their own pre-understanding. The case managers regularly checked if the older persons had received the services that had been decided and if those services had been performed satisfactorily. The case managers were supportive to both to the older persons and to

their family members. The case managers were a source of guidance for the older person's family members and they supported them during their challenges of dealing with the health system. At times it was the family members that the case managers had most contact with, because the older person was too sick to remain in contact with them. They felt that they could help to relieve some of the family members' burden of responsibility, as the case managers helped to safeguard the interests of the older persons.

Another familiar task was to strengthen the older persons. This was mostly done during their home visits. The case managers acted as conversational support, listening and acknowledging the older persons. They felt that the older persons had trust in them and this trust was built up over time as the relationship between them developed. Without this trust they could not properly perform their work. The case managers always tried to encourage the older persons so that they themselves sought help, as a way of strengthening them in managing themselves. They did not want the older persons to be solely dependent on them. At times they also felt powerless being case managers as they could not always directly alleviate the older persons' problems.

The second sub-theme *Striving to improve the health system through a new role* reflected that the case managers had both challenges and achievements when striving to improve parts of the municipalities' health system. Their role as case managers helped them in their work towards improvement, but also presented them with challenges such as not being listened to, being seen as a threat or that the organisations did not do what they had promised to them. Their pre-understanding regarding shortcomings of the health system were beneficial as it helped them to identify what was needed to be improved. However, it could also be a hindrance as previous experiences made them doubt if it was even worth to put in effort towards improvement in certain areas. Nevertheless, they felt obligated to bring forth these more challenging improvement areas to the working groups, since they were representing the older persons' wishes. The improvement areas were mainly at an organisational level and not at an individual level. If the issue was on an individual level, the case managers directed those concerns to specific individuals that were a part of that concern. The case managers constantly gathered information about potential improvement areas as a part of their everyday work. This information was acquired through questionnaires, observations and by being an active listener during their everyday work.

Lastly the third sub-theme *Trust is vital to advocacy* was reflected as the case managers expressed mixed feelings of being the older persons' advocate. The case managers said that it felt natural to advocate and that it was a privilege to have gained the trust to act as the older person's representative. They sometimes had to trust what the older person told them and disregard their own professional values and pre-understanding of the health system. Thus, simply voice the opinions of the older persons. The case managers did not belong to a profession with an organisational affiliation and they felt that this neutral position was beneficial in gaining the older persons' trust. This

independent position also presented challenges, as it was difficult for the case managers to attach sufficient power to their words when they advocated for the older persons.

## Study II – Family members

The findings in Study II reflected the family members' experiences of case managers and were illustrated in an overarching theme: *Helps to fulfil my unmet needs* with three sub-themes: *Helps me feel secure – Experiencing a trusting relationship*; *Confirms and strengthens me – Challenging my sense of being alone* and *Being my personal guide – Increasing my competence*.

The overarching theme *Helps to fulfil my unmet needs* revealed that the family members experienced that the case managers were able to fulfil needs that the health system had not been able to meet. These unmet needs were fulfilled as the family members were provided with a person-centred service and received continuity in their contacts with the case managers. The family members established trusting relationships with the case managers and it made them feel more secure in their role of providing assistance to relatives. The family members' feelings of being alone were challenged by the case managers as their relationship with the case managers evolved and it gradually confirmed and strengthened them in their own role. Their relationship with the case managers also meant that they were provided with individualised information about the health system and this increased their own competence regarding the health system.

The first sub-theme was *Helps me feel secure – Experiencing a trusting relationship*. The family members contact with the case managers made them feel a sense of security and this sense of security evolved as their contact with the case managers turned into more trusting relationship. Both the family members and their older relatives needed to have confidence in the case managers' good intentions for the relationship to mature. The family members felt secure knowing that there was someone else besides them, who could take time to assist their relatives. However, they could also feel uncomfortable as they thought that their relatives might use the case managers as someone to complain to. The family members appreciated that the case managers were knowledgeable about their situation and there was continuity in their contacts with each other. These aspects helped to make them feel more secure as a family member to an older person with multi-morbidity.

The second sub-theme was *Confirms and strengthens me – Challenging my sense of being alone*. The family members often felt alone in their role providing assistance to their older relatives and this feeling was increased when they had to struggle to obtain healthcare and social services for their relatives. The family members expressed that

their needs were often forgotten by today's health system. As the family members came into contact with the case managers, this challenged their sense of being alone. They felt confirmed and valued by the case managers and these new experiences strengthened them.

Lastly the third sub-theme was *Being my personal guide – Increasing my competence*. The family members experienced the case managers to be their personal guides. The case managers could assist them in navigating to different healthcare and social services contacts. They appreciated that the case managers were aware of their situation and that they received information catering to their individual needs. The family members benefited from the case managers' knowledge of the health system. Through their contacts with the case managers they gained new knowledge about the health system and thus increased their own competence. The family members expressed that they made use of the case managers as contacts with whom they could reflect and discuss their current concerns. These reflections sometimes enabled the family members to gain new perspectives regarding the care of their relatives.

## Study III – Older persons

The findings in Study III reflected the older persons' experiences of case managers and were illustrated in four themes: *Someone providing me with a trusting relationship*; *Someone assisting me*; *Someone who is on my side* and *Someone I do not need at present*.

The first theme was *Someone providing me with a trusting relationship*. The older persons experienced a trusting relationship with the case managers and they had a genuine trust in the case managers' intentions and abilities to assist them. The personal traits of the case managers, such as being easy to talk to and being sensible, assisted the older persons to start trusting them. They felt that they could communicate in an honest way with the case managers and they appreciated that the case managers took time to sit down and listen to parts of their life history. This situation was something they were not accustomed to when previously interacting with healthcare and social services. Participant observations reflected the findings of the theme and also illustrated that the case managers tried to motivate the older persons in order to arrive at solutions for their concerns.

The second theme was *Someone assisting me*. The older persons expressed that they received assistance from the case managers in different ways, such as being guided to the correct healthcare and social services contact, being given advice in different matters and having their concerns being further investigated. The older persons were given both written and oral information by the case managers regarding parts of the health system and how to seek service. The older persons were also instructed by the case manager so that they themselves could proceed with certain tasks to get assistance



with their concerns. Sometimes the case managers took on a more active role and performed the tasks themselves for the older person. Participant observation captured the findings from the interviews and it was observed that the case managers listened actively to the older persons whilst recurrently asking follow-up questions to identify their individual needs.

The third theme was *Someone who is on my side*. The older persons experienced the case managers to be their personal representatives, being someone standing on their side when they had struggles with healthcare and social services. They appreciated that the case managers did not belong to any organisation being involved in providing them with care. Furthermore, they felt that they could receive honest opinions from the case managers. The older persons expressed that the case managers truly understood the importance of their concerns and that they would advocate for their concerns. Participant observations were found to reflect the findings. It was also observed at a care planning meeting how the case manager regularly changed the focus of the conversation to move towards the older person's needs.

Lastly the fourth theme was *Someone I do not need at present*. Some of the older persons expressed that they currently did not have any concerns needing to be addressed by the case managers. Some expressed that they could manage by themselves or with their relatives' assistance. This willingness to manage themselves was expressed to be due to stubbornness or that they were already content with their situation. They also saw the case manager as being insurance for later, since they did not know if they were able to manage their concerns later on in life. The participant observations reflected this willingness to manage themselves. But it was also observed how the older persons showed appreciation when being offered the case managers' assistance.

## Study IV – Staff

The findings in Study IV reflected the health and social care staff members' experiences of a case management intervention and were illustrated in three themes: *Could bridge gaps in an insufficient health system*; *Emerging improvements call for engagement* and *An intervention in the mist with vague goals and elements*.

The first theme was *Could bridge gaps in an insufficient health system*. The staff members expressed that a highly specialised health system had contributed to older persons with complex health needs experiencing a fragmented care. The complexity of the health system had put forth difficult challenges for the older persons navigating the health system. The staff members experienced that the case managers were effective as coordinators and could thus help the older persons navigate to the appropriate contact. They acknowledged that case management could be one way to

bridge gaps in a fragmented health system. They perceived the case managers to be important to the older persons and to their relatives as they were able to provide a more individualised approach than the existing health system was able to do. They also acknowledged the importance of the case managers not being bound by profession to any healthcare or social services organisation. This neutral position was perceived to be of help for the older persons to fully trust the case managers and their intentions.

The second theme was *Emerging improvements call for engagement*. The staff members expressed that the case managers offered promising approaches when working towards improvement of parts of the health system. However, engagement amongst the case managers and the staff members themselves was deemed crucial for the improvements to be implemented. These improvements were communicated by the case managers at the meetings of the working groups in all of the municipalities. The usefulness of these working groups depended on the level of commitment amongst those participating and also on the number of older persons recruited within that specific municipality. The staff members experienced that the case managers helped to shed light on shortcomings and by doing so the staff got an added confirmation concerning issues that they were already aware of. This confirmation could be an impetus for changing practice. The case management intervention also made the staff members start to reflect about not having conducted their own work properly, since the case management intervention had been needed in their municipalities.

Lastly the third theme was *An intervention in the mist with vague goals and elements*. The staff members had challenges when trying to grasp the overall goal of the case management intervention. The content of the intervention was experienced to be vague and the exact role of the case manager was unclear to them. For some of the staff members the intervention became clearer to them as time passed by. They expressed not receiving enough information and guidance from the project team of the intervention and from the case managers, to be able to properly understand its content. This uncertainty was also illustrated as the staff did not understand the characteristics of the older persons who had been recruited to the intervention. The staff had also expected that the case managers would have been able to solve more problems inherent within their own organisations.

The themes from Study I-IV are jointly illustrated in Figure 1.

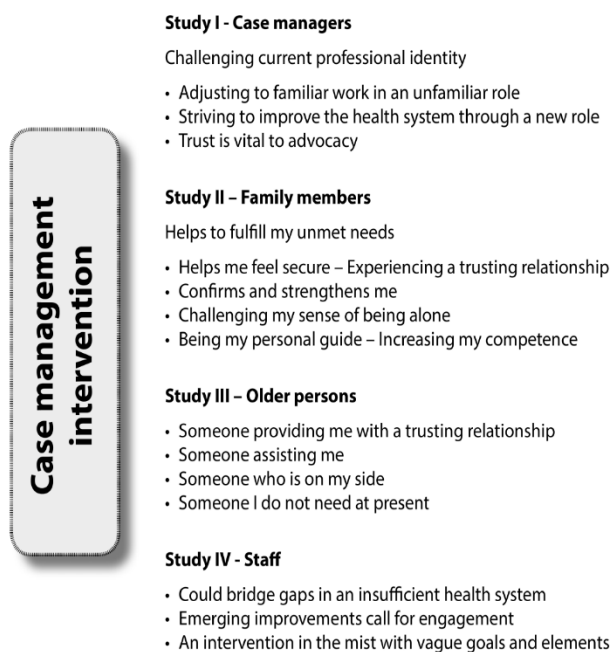


Figure 1. All themes from the findings of Study I-IV



# Discussion

## Methodological considerations

The Studies (I-IV) included in this thesis all have their methodological strengths and limitations that need to be taken into consideration by the reader when assessing the quality of the studies. Lincoln et al. (119) proposed the concept of trustworthiness, comprising a set of criteria, as a way of assessing the scientific rigour of qualitative research. These criteria are credibility, dependability, confirmability and transferability.

### Credibility

Credibility includes an assessment of the interpretation of the participants' original data. Thus, it concerns the truth of the data (119). In all of the studies, a purposive sampling strategy (99) was employed. Thus inclusion of all participants was based on the ability to purposefully inform an understanding about a specific subject, i.e. how they experienced the case managers and/or the intervention. For instance, in Study III one criterion for recruitment was that the participants must have been involved in the intervention for at least nine months, to make sure that they had experienced most parts of the intervention. By using a sampling technique, and having a clear description of how and why the sampling was done, the credibility of the study was enhanced (120). Clearly defining our sample can aid the reader in assessing whether parts of the findings can be generalised to their own context or not. Furthermore, to allow the reader to understand and to be able to judge the credibility of the findings, all of the studies have had the ambition to thoroughly describe the different methods and analytical procedures.

According to Lincoln et al. (119), prolonged engagement is one activity that can enhance the credibility, meaning it is important that the researcher spends enough time becoming oriented to the situation and getting an understanding of the context. In Study I, participant observations were conducted, comprising 125 hours with field notes. These observations were a part of a prolonged engagement and assisted in gaining a deeper understanding about the context. Collected field notes also allowed the researcher to return to the field of study in all the following studies. Since the

observer previously worked as a registered nurse, the observer had a contextual understanding of the health system. This understanding can be viewed as both a strength and a limitation as it influences the observations. This understanding could have advanced the data collection and analysis but could also have clouded the observer's vision. To work with this methodological challenge the observer, on a consistent basis, asked clarifying questions to those being observed, regarding specific situations. This was done to get knowledge about the perspective of those being observed in regard to the perspective of the observer. The observer consistently wrote down field notes consisting of critical reflections regarding the observations, which were then reflected upon by all researchers.

Conversely, the use of time-limited and episodic observations could also be viewed as a limitation if being compared to the extensive fieldwork conducted within conventional ethnography (121). Since focused ethnographies intend to concentrate the effort on distinct areas, such as the case managers' everyday work, the observations can be conducted over a shorter period of time (96, 98). The persons being observed in focused ethnographies are those with a specific experience and knowledge relevant to the research question. In conventional ethnography the persons observed are those persons the ethnographer has developed a close relationship with over a long time (98). Furthermore, in focused ethnography, observations are often more intensive compared with observations conducted in conventional ethnography and may thus result in an extensive amount of data (121). Hence, it is acknowledged by the researcher that the use of a more extensive and lengthy fieldwork could have generated deeper and richer data, both from an ethic and emic perspective. Nevertheless, the 36 episodic participant observations, comprising 125 hours, were deemed to be of great meaning for the researcher to gain a deeper understanding of the case managers' everyday work.

Another proposed activity to enhance credibility is the triangulation of methods (119). In Study I, individual interviews, group interview and observational data were used to gain a deeper understanding of the research question. Data from these different sources were also presented in the findings. In Study III, the observational data were used both as an understanding present during data analysis and to compare field notes with the findings originating from the individual interviews.

Interviews were part of data collection in all of the studies. Individual interviews contributed the majority of the data collected in this thesis. Because all of the studies were interpretive and in search of meanings, interviews providing deep and detailed narrations were sought. According to Kvale et al (109), the interviewer can facilitate narration by encouraging and asking questions that lead to a deepening of the conversation. One approach to interviewing is to make use of some kind of structuring of the interview questions (109). Both semi-structured (122) and thematic (109) interview guides were used to help guide the interviews. All of the interview questions were open-ended, meaning that the participants could not answer yes or no,

but needed to converse about the questions in greater detail. According to Klein (110), the researcher in an interview situation can encourage another person to take the word and also keep it. This was practised as the interviewer encouraged the participants to take the word and this was done by showing curiosity, being an active listener and asking probing questions.

## **Dependability**

Lincoln et al. (119) stated that there can be no credibility without dependability. Dependability refers to the stability of the findings and of the conditions. One limitation for this thesis was the sometimes moderate or short length of the interviews. Furthermore, some of the participants expressed having forgetfulness in regard to their experiences of the intervention. These moderate interview lengths could imply that some interviews were less rich in meaningful data. However, the interviews were focused, and the process of data analysis showed that the data were sufficient for interpreting and analysing their meaning. However, to enhance both the dependability and credibility of the findings, repeated interviews as a data collection method could have been used. Repeated interviews could have better facilitated the participants' memory of the intervention and possibly led to interviews comprising richer data. Dependability could also have been improved since the constantly changing context would have been better accounted for. The interviews, within each one of the studies, were conducted in a short time-frame, meaning that the current case management intervention was in a similar phase during the studies' own interview phases. Consequently, the conditions for respective study are believed to not have undergone any major changes during the interviews.

## **Confirmability**

Confirmability measures how well the findings are supported by the data. The findings need to reflect the participants' experiences and not the researcher's own values or perceptions. Thus the findings are assessed based on objectivity and neutrality (119). To show that the interpretations originated from the participants' experiences, quotes have been included in all of the studies. This was done to give transparency to the data analysis and to support the different themes of the findings. Furthermore, analysis of the data was conducted as a collaborative process amongst all researchers. Critical reflections and discussions regarding the interpretations were frequently held. These discussions brought multiple perspectives into the interpretations and thus enhanced the trustworthiness of the findings. Polit et al. (108) highlighted the writing of a reflexive journal as a method of improving confirmability. In relation to this thesis, the field notes comprised reflective notes written during the duration of participant observations. However as the period of

observations was finished the writing of reflective field notes was finished as well. Thus, to improve the confirmability a reflexive journal could have been kept throughout the entire work of the thesis. This reflexive journal would have allowed for an independent researcher to come to their own conclusions about the data.

## **Transferability**

Transferability refers to the extent to which the findings can be applied or transferred beyond the present study. Viewed from a naturalistic perspective, transferability in a general sense is not possible to achieve (119), since the context has influenced the results. Hence, throughout all the studies the context and the sample has been described in a detailed manner to allow the readers themselves to assess whether or not they can make use of our findings in their own contexts. Another consideration is the uneven distribution of gender in all of the studies, as women as participants are overrepresented. In Study IV all potential participants were women and in Study I the majority of potential participants were also women. Similar samples are found in both Study II and Study III. Consequently, this could possibly limit the transferability of the findings; since the gender ratio could vary depending on what context the findings would be applied to.

## **Reflections regarding being a researcher in the field**

Choosing an ethnographic approach made it possible to embark on an exploratory journey in search of a deeper understanding of meanings in relation to case management. During fieldwork, focused ethnography has been the guiding light and allowed for an exploration from both an inside and outside perspective. The use of an ethnographic approach has put forth methodological considerations, some of which will be discussed in this section. As a researcher I bring my own personal experiences into the context of study and I need to be aware of how they influence the field of study. Fägerborg (123) wrote that one must not forget that just as the participants have a template before their eyes, the researcher has a template influenced by pre-conceptions. This template will affect what I will experience in the field. According to Gunnemark (124), it is important that I as a researcher make it clear to the reader about my own pre-understanding. Before I started the work of this thesis my pre-understanding in regard to the research area was primarily based on my professional experience of working as a registered nurse and as an auxiliary nurse. During periods of work in healthcare I had first-hand experienced situations of the staff, including myself, were not able to understand or fulfil the older persons' needs. It also occurred that the older persons 'fell through the cracks', meaning that the collaborative processes put in place were not working sufficiently well to meet the needs of the older persons. The health system was perceived to be complex, both amongst the staff



and the older persons. This pre-understanding is something that I have brought with me into the work of this thesis and I need to be aware and reflect on that. The following reflections are built upon my first-hand experiences and thus this section will partly be written from that perspective. These personal reflections aim to increase the understanding for the reader of how the ethnography was constructed.

### *Participant observations and reflections*

Participant observations were chosen as a method for data collection in the field. During participant observations the researcher's personal involvement becomes more distinct, something which the researcher must take into account. The researcher has a role as a co-producer of the data being created in the field, and already when writing the first field note the researcher is interpreting. However, it can be difficult to detect whether one's own presence as a researcher affects the field and people's behaviour (123). According to Arvastson et al. (125), observation is something people do in their everyday life, but the researcher often does it with a predetermined purpose. The observations are affected by the researcher's earlier memories, feelings and experiences, and the researcher should therefore critically examine their own pre-understanding (125). Given my previous professional experience of working as a registered nurse within the health system, in which the case managers now operate, I could be said to have an inside perspective. This inside perspective has affected how I view my observations. However, this does not need to be solely negative, Labaree (126) highlights that previous experience of having worked in the context of the study can be something that is positive in that sense that pre-understanding can contribute to insight and if the researcher only has an outside perspective, insight would be difficult to access (126).

Before I went out to observe, I wrote down my naive understanding of the field. I did this because I knew as soon as I stepped out into the field I would be influenced by new experiences. According to Arvaston et al. (125), the researcher needs to write down his/her field notes during the actual observations to minimise the impact of forgetfulness on the collected data. Thus, I have continuously written down field notes and at the end of the observations I took additional time to elaborate on these notes. The field notes have described experienced situations but also included my own reflections regarding observed situations. These field notes have assisted me throughout the work of the entire thesis and been of help to bring me back to the field over the years of study.

### *The third presence*

The interviews in this thesis have been conducted based on specific purposes. However, even if there is a specific purpose, the third presence can affect the outcome of the interviews. The third presence means that the participants can choose to emphasise or de-emphasise certain interview questions depending on what the participant wants to be highlighted (123). I first became acquainted with the third

presence within my own data as I started to transcribe interviews from Study I. This insight illustrated that there is a simultaneous analysis associated with the transcription process involving me as a researcher. Klein (110) describes that the transcription is not only a mechanical task, but also an on-going analysis. To illustrate the third presence I bring forth one example, a quotation, from one of my interviews with the case managers: "*Yes ... it is a very personal reason that I decided to change my work situation, and maybe we should not bring it up here?*" At the same time the case manager told me this, she looked at me as if she wanted to get a confirmation of that claim that she just put forward. At this moment, I decided to just listen and did not say yes or no, in regard to the claim. She then decided to continue to talk about her previous work situation. By not confirming her third presence, it eventually led to information of value for my research. Similar situations can occur during observations, and the researcher is faced with the challenge that the field is unpredictable and situations requiring a high degree of flexibility can occur at any time (124). What would have happened if I had chosen to confirm her third presence? It is possible that the interview situation would have been completely different thereafter. But wouldn't that material have been just as interesting? It is impossible to predict, but one thing I can conclude is that I would definitely have lost an interesting viewpoint if I would have confirmed the third presence.

Research that involves people and their interactions, in different contexts and using ethnographic methods, requires a high level of reflective thinking by the researcher. By being out in the field as a researcher many unpredictable situations may appear requiring active methodological choices. These choices are influenced by my own understanding as a researcher, but also of my role as a human being in a society that is constantly changing. Therefore, I have throughout the work of this thesis, critically reflected on my role as a researcher in the field, as an interviewer, and as an active part of the data analysis. Important reflections have revolved around how I as a researcher may affect the participants and their own attitude towards me, both as a researcher and as a human being. By continuously writing down reflective notes, I have been able to go back and critically review my own data as an attempt to become more aware of the complex interactions affecting all phases of the research process. Finally, I also need to be aware that the only reality I can portray is my own interpretation of reality, and it is guided by my own focus. Thus, the knowledge produced in this thesis is mediated and bound by the interpreters in this work.

# Discussion of the findings

## Trusting relationships

A most important finding stemming from all the studies of this thesis was the importance of trusting relationships in regard to the case managers' everyday work. The importance of trust was captured in the different themes being illustrated in Figure 1. In Study I, the importance of trust was captured under the sub-themes of '*Trust is vital to advocacy*' and '*Adjusting to familiar work in an unfamiliar role*'. The case managers expressed that building trusting relationships with the older persons was fundamental for them to be able to do their everyday work. Similar results were illustrated in a study by Sandberg et al. (89), also conducted in Sweden, where the case managers experienced that they had to build a trust with the older persons in order to be able to perform the intervention. In a study by Yau et al. (92), the case managers, in a telephone-based case management intervention, experienced that a relationship built upon trust was crucial for them to be able to get their clients to comply with a management plan. If compared with the findings from Study I this trust was experienced to be of even greater worth to the case managers' everyday work. This trust enabled the case managers to plan and evaluate tasks, whilst also guiding and strengthening the older persons' ability to manage themselves in seeking needed care.

In Study II and III the importance of trust was reflected under the sub-themes of '*Helps me feel secure – Experiencing a trusting relationship*' and '*Someone providing me with a trusting relationship*' (See Figure 1). Both the older persons and the family members expressed that they felt a trust in the case managers' ability and good intentions to assist them with their current concerns. They also expressed that the case managers could be acting as their insurance in the future, if additional concerns were to arrive at a later stage of their lives. The older persons expressed a desire for the case managers to assist them as individuals and to cover for their emotional needs. According to Sargent et al. (74), there is a debate regarding the provision of psychosocial aid as an appropriate role for case managers. Sargent et al. argue that older persons with long-term conditions might be unable to access other sources of psychosocial aid and thus this aid could be warranted for this group. Their findings illustrated that often the case manager was the only source of psychosocial aid available to the older persons (74). In Study II and III the covering of emotional needs by the case managers was valued as being important by the older persons and by the family members. Even though the covering of the participants' emotional needs was not considered to be an active part of the case management intervention, this still had a big impact on them. Thus, this could indicate a need for the consideration of addressing such needs or at least identify such needs, as a part of the intervention. By

identifying such needs, the case manager could assess and coordinate services so that other health professionals would be able to assist.

The neutral position of the case managers was perceived to be beneficial for gaining trust and this was emphasised in all of the studies of this thesis. In Study IV the staff members' expressed that this neutrality could be beneficial in gaining trust. In Study III this was captured under the theme of '*Someone who is on my side*'. The older persons felt that they could receive a more honest opinion from the case managers in comparison to other professionals working within the health system. In Study II the family members expressed that since the case managers did not represent any of the existing healthcare or social services organisations linked to the care of their older relatives, they were more able to build a trusting relationship with the case managers. In Study I the case managers expressed that the older persons trusted them, partly because of their neutral position. Thus, findings combined from Studies I-IV point in the direction of a neutral position for case managers as being beneficial to the building of trusting relationships. This is also addressed by Kane (127) who suggests that for professional guidance to be effective, an informed but disinterested facilitator should be used (127). Consequently, the case managers may prove to be such facilitators in a case management intervention. It can be concluded that a trusting relationship developed with a case managers is important from all perspectives.

### **Importance for continuity of care**

All studies presented as part of this thesis show that the case managers were of importance for continuity of care. According to Fortin et al. (2), older persons with multi-morbidity often have multiple contacts with different providers of care and can be at risk of experiencing a poor continuity of care. Gulliford et al. (43) state that continuity of care consists of two dimensions: one is a continuous caring relationship and the other is seamless service. Continuous caring relationships can be measured by how many professionals the older person needs to have contact with and also by the quality of the relationships between the older person and the professionals. In Studies II and III the older persons and the family members highlighted the significance of a continuous caring relationship with their case managers. The older persons had their own individual case managers assigned to them and they experienced that the case managers were readily available to them, capable of assisting them with their concerns. In Study II the family members expressed appreciation, as the case managers were a regular contact to them. This was expressed to be in contrast to previous experiences of dealing with the health system, where the contacts had been more fragmented. In Study I the case managers felt that they were able to build relationships with the older persons, as well as plan and evaluate actions based on the individual needs of the older person. Findings from the thesis correspond with Freeman et al. (45), indicating that older persons and persons belonging to vulnerable

groups could be in greater need of having a continuous caring relationship with their care providers. This is also illustrated in an interview study by Bayliss et al. (3) where the older persons with multi-morbidity put value in having relationship continuity with their care providers, rather than having a more convenient access to care (3). Thus it seems important that case management interventions put emphasis on building continuous caring relationships with their participants, especially when it concerns vulnerable groups such as older persons with multi-morbidity.

In Study IV, the health and social care staff members acknowledged the worth of case managers in improving the continuity of care. But, they were unsure if case management was the most appropriate action in order to address a poor continuity of care. They also expressed a need for these challenges to be addressed by themselves within their own organisations. This uncertainty regarding the effectiveness of case management can be found in research as well. In an interview study by Iliffe et al. (93), GPs' attitudes toward case management were dependent on its perceived effectiveness to reduce hospital admissions. Scepticism against case management was widespread amongst the GPs, but positive experiences of case management could affect this scepticism (93). In an interview study by Manthorpe et al (94), stakeholders perceived that the use of case managers was not cost-effective. Currently, there is a shifting evidence base regarding the effectiveness of case management targeting older persons (1, 5, 13, 15–17, 66, 82, 84). For instance, in a review by You et al. (15), case management in community aged care was concluded to be able to improve psychological health and general well-being, and helped meet service needs. Results were mixed, however, when investigating other outcomes such as the clients' physical or cognitive functioning and carer stress or burden.

Previous findings from qualitative studies exploring older persons' experiences of case management have mainly illustrated positive aspects, such as the case managers being of importance in guiding them, solving problems, providing security and providing a continuous relationship (73–75, 89). However, none of these studies has had a particular focus on older persons with multi-morbidity. Findings from the studies included in this thesis (See Figure 1), illustrate many positive experiences of case management. Thus, there seems to be potential for case management interventions to improve care for older persons. However, as argued by Goodwin (10), case management interventions need to be properly designed for their context. Many of today's health systems have a poor level of care coordination leading to unnecessary costs and poor care experiences. The healthcare and social services need to be better catered and integrated towards the individual's needs. According to Goodwin, case management interventions that are well designed will have an important part to play if these goals are to be accomplished (10). Thus, it seems important that we increase the knowledgebase of case management for older persons with multi-morbidity to be able to design better interventions

Seamless service is the other dimension of continuity of care and concerns the quality of team-work, coordination between different health and social care staff members and the communication between care providers (43). This dimension of continuity of care was mainly captured in Studies I and IV. The case managers experienced how they interacted with numerous different professions and voluntary organisations in order to provide for the older persons' needs. At the organisational level, they experienced that they had the possibility to directly improve continuity of care through the actions of the working groups. Poor continuity of care was referred by the case managers to be a breakdown somewhere along the chain of organisations and this breakdown made the older persons suffer. The findings correspond with a study by Noel et al. (128), where older persons with multi-morbidity identified poor continuity of care between clinics as a problem for them. In Study IV this was captured under the theme 'Could bridge gaps in an insufficient health system'. The staff members experienced the health system to be highly specialised and it had contributed to a fragmented care for older persons. The case managers were able to navigate the older persons through the health system to the correct professional, as they had knowledge about its structure. Thus it seems to be central that a case management intervention targets both the relationship continuity and the seamless service to improve a poor continuity of care.

### **Relationship-centred care**

An important deduction based on the findings of this thesis is the value of trusting relationships in regard to case management. This concerns the relationships between the case managers and the older persons, and the case managers and the family members (See Figure 1). To interpret and deepen these findings concerning the value of relationships, the approach of relationship-centred care (129, 130) will be used. Nolan (129) argues that a relationship-centred approach to care is appropriate when it comes to caring for the older population and it can affect the quality of care in a positive way. According to Nolan, autonomy and individualism might not be the most suitable approach for enhancing the care of older persons. Nolan argues that relationship-centred care could be a more appropriate way of providing care than person-centred care, when addressing the needs of older persons (129). Relationship-centred care could provide a framework for understanding how relationships can influence the experiences and outcomes of healthcare (131).

Relationship-centred care places interaction between people as the foundation of any therapeutic or healing activity. In a caring situation, relationships exist on several levels including those between patients and their family members, their community and their health and social care providers. The interactions between these persons are as Nolan describes it "the defining force" in healthcare. These interactions operate as an intermediate for information exchange and are needed to gain a better

understanding of the older persons' situation (129). According to Beach (130), care, illness and healing processes occur in relationships. Relationship-centred care is founded upon four principles and these will be discussed in relation with the findings from the thesis.

The first principle is that relationships in healthcare ought to include dimensions of personhood as well as roles. Both the patient and the care provider are unique individuals having their own values and experiences (130). Findings from Studies I-IV indicated that the case management intervention was experienced as being able to improve the care of the older persons. For instance, when the case managers directed their attention towards providing for the older person's individual needs, this was expressed to be helpful and positive. In Study I, the case managers stressed the importance of taking time to listen to everything the older person had to say to them, as a part of assessing their needs. In Study II, the family members valued the understanding that the case managers had of their individual needs. Beach (130) highlighted that it is important for the care providers to be aware of their own biases and emotions. This reflective way of reasoning and self-awareness can be found in Study I. This was illustrated as the case managers emphasised that the older persons' identified needs had to originate from them and not be clouded by what they as case managers perceived to be most important needs.

The second principle is that affect and emotion are important components of relationships in healthcare. These components are important to develop, maintain and terminate relationships. The care provider should not be neutral and detached, but should rather be able to empathise with the persons. Empathy can aid the person to express his/her emotions and help the care provider to understand the person's needs (130). This was illustrated in Study II: the family members experienced that the case managers confirmed their value and effort as informal caregivers; a confirmation that also challenged their sense of being alone. In Study III, the older persons described the case managers to be sensible, friendly and light-hearted. These personal characteristics were found beneficial for the older persons to start trusting them

The third principle is that all healthcare relationships occur in the context of reciprocal influence. Health, and actions in any way related to the person's health, do not happen in isolation but are related to each other. The care provider and the person should be encouraged to develop a relationship where they both benefit from it. Thus, this principle acknowledges that the care provider also gains benefits from providing care (130). In Study I it was interpreted that the case managers challenged their current professional identity as they conducted their everyday work. These challenges led to personal developments in the form of gaining new experiences and knowledge. The case managers also expressed a feeling of being privileged to represent the older persons' concerns, indicating that the case managers gained benefit throughout their work.

The fourth principle involves having a moral foundation. The formation and maintenance of relationships is morally valuable in healthcare. If the caregiver is striving towards having genuine relationships, this is more morally desirable than if the caregiver is just acting out a role (130). The efforts towards achieving more genuine relationships are illustrated mainly in Study I-III where findings indicate that the case managers were able to develop trusting relationships. It can be concluded that the case managers seem to be successful in creating and maintaining relationships with the older persons and the family members. These trusting relationships were found to be imperative for the case managers to conduct their everyday work. Thus, case management intervention needs to be aware of the impact of relationships and thus consider this impact when designing interventions. Consequently, great attention should be given to relationship building, particularly in the beginning of the intervention. Based on the findings it is also argued that utilising the traits of relationship-centred care could be of value in improving care. This not only in regards to case management, but could also be considered in the context of general care of older persons with multi-morbidity.

### **Working groups - challenges and opportunities**

Another important finding originating from themes of Studies I and IV (See Figure 1) concerns the challenges of improving parts of the health system. At the organisational level of the case management intervention, working groups were created to serve as a forum for improvement work and learning. During these working group meetings the case managers presented potential improvement areas and discussions followed regarding feasible solutions. Findings from Study I and IV illustrated that the working groups were experienced to be a promising way of working towards improvement, but also that they had their challenges such as shifting levels of commitment amongst those attending. To interpret and discuss these findings from the perspective of the case managers and the representatives i.e. the health and social care staff members, Ajzen's Theory of Planned Behaviour (TPB) will be used (132). TPB is considered to one of the most influential models for predicting human social behaviour (133). The theory states that three types of consideration guide human behaviour and if these considerations are favourable, then the person's intention to perform the behaviour in question is increased (134). In a review by Fischer (135), it was concluded that potential barriers and facilitators need to be investigated in advance so that tailored strategies towards the context can be developed (135). Thus, with the help of TPB, both barriers and facilitators guiding the intention to perform improvement work, could be revealed and further discussed.

The first consideration is *behavioural beliefs* – beliefs about the likely outcomes of the behaviour and the evaluations of those outcomes (134). In Study I the positive beliefs expressed by the case managers were illustrated in the theme '*Striving to improve the*



*health system through a new role*’. The case managers expressed having unique opportunities to conduct improvement work through the context of the working groups. The working groups were valued to be a viable way of establishing a link between the older persons and the organisations. The case managers also had their challenges i.e. negative beliefs that some of the shortcomings were impossible to change, but they still presented them. In Study IV the positive beliefs expressed by the representatives were that the working groups were a promising way of working towards improvement. However, they experienced the usefulness of the working groups to be shifting. This was expressed in relation to attendance rates and to the number of older persons being recruited within their own municipalities. Based on the findings there seems to be an overall agreement that the working groups could be a viable medium for change. To further facilitate the behaviour of those attending, more emphasis could be put on discussions regarding the worth of the working groups from both perspectives. One way of identifying these personal beliefs, could be to utilize a questionnaire based on the theory of planned behaviour (134). The information gained from the questionnaire could be used to bring up discussions regarding the beliefs towards possible outcomes of the intervention, and thereby help to identify and facilitate the behavioural beliefs of the intervention.

The second consideration is *normative beliefs* – beliefs about the normative expectations of others and the motivation to comply with these expectations (134). From the representatives’ perspective, the case managers may have generated a social pressure on them to address shortcomings. The representatives conveyed that an added confirmation from the case managers could actually trigger a change of practice of these shortcomings. Additionally, the presence of case managers made some representatives start questioning whether they had conducted their own work properly or not, because if they had conducted their work properly, the intervention should not have been needed. Case managers expressed feeling frustrated at times when the representatives did not listen to their suggestions or if they did not attend the working group meetings. Thus, to address the normative beliefs, viable strategies could be to have the management of the representatives clearly state what is expected of them and also make it conceivable for them to actually live up to those expectations. Ajzen (134) suggests that persuasive communication can be used to maintain a positive behaviour. Thus, it could be warranted that on a regular basis, the management declare their support of the intervention and it’s worth (134). Another strategy could be to set up more explicit rules regarding the attendance and the individual responsibility amongst those participating in the working groups. Torrey et al. (136) highlights the importance of having the aims being clearly understood by the participants. Thus, the aim and purpose of the working groups needs to be clearly articulated and understood by the representatives. Moreover, discussions concerning everyone’s responsibility could be brought up as a regular part of the meetings, to induce a social pressure amongst the representatives.

The third consideration is *control beliefs* – beliefs about the presence of factors that may facilitate or impede performance of the behaviour and the perceived power of those factors (134). Both the case managers and the representatives stated that the constellation of the working groups was beneficial for its efficiency. The representatives had various mandates to directly influence parts of the health system in the municipalities, thus making the improvement work possible. However, a factor impeding the performance was the presence of too few older persons in some of the municipalities' working groups. This factor was experienced to be hindering for the improvement work, since the representatives did not get enough input. Thus, it seems that the working groups have the ability to perform improvement work, but to facilitate control beliefs there needs to be a sufficient number of cases to work with. Another important finding is that the case managers in Study I expressed that their role as case managers was unclear to them. Additionally, the staff members in Study IV experienced the purpose and content of the intervention to be vague. Thus, it seems that the intervention was not successful in properly delivering an understanding of its intended purpose and content to the case managers and to the staff members. Hence, attention is needed to make sure that the case management intervention is understood and such informative efforts should be done at a pre-intervention stage. This is important because if those conducting or being involved in the intervention are not certain about its purpose, then the purpose of the intervention could be lost. Consequently it will be difficult for them to know what kind of behaviour is warranted and thus it could impede the progress of the intervention.

To conclude, the knowledge brought forward by applying the theory of planned behaviour illustrates that working groups seems to be a viable medium for influencing the behaviour towards conducting improvement work. However, there are some challenges that could be addressed to further the effectiveness of such groups. This knowledge can be helpful in designing upcoming case management interventions comprising an organisational level, but this knowledge may also be of value if wanting to improve healthcare in general.

# Conclusions and clinical implications

The findings of this thesis recognise the importance of establishing trusting relationships. For the case managers this trust was imperative for them to even be able to conduct their everyday work. The older persons highlighted the case managers' ability to care for their emotional needs. The family members expressed that their trusting relationships with the case managers confirmed and strengthened them in their role of providing care to their older relatives. Consequently, case management interventions should put emphasise on creating trusting relationships between the case managers and the participants, especially at the admission of new participants. To facilitate trusting relationships it is envisaged that having an individual case manager assigned could be beneficial. Other beneficial aspects could be having a neutral position as case manager, conducting home visits, and having regular contact with the participants. Thus, the provision of continuity in regard to the case managers' services could prove useful for these trusting relationships to evolve. Furthermore, even if some participants might not need extensive and/or regular assistance from a case manager, by putting effort into the first contact with the participants, this strategy can be proven valuable at a later stage. Establishing contact could be one way of intervening pro-actively if the participants are to experience problems later on, since then they would have a known contact. The importance of trusting relationships could also be considered in the general care of older persons with multi-morbidity.

The findings of this thesis also show that the case managers' everyday work involved a challenge to their current professional identity. This challenge was instigated as a result of having difficulties trying to make sense of their role as case manager. Hence, it is important to present a clear description of the case manager's professional responsibility, both to the case managers and to the professionals working within the health system. By sorting out the roles and responsibilities, this could help facilitate the process of introducing case managers into a health system not accustomed to case management. Policymakers wanting to intervene with case management in an already well-established health system should be aware of these challenges. Consequently, they should provide attention and support to the case managers and their work. This effort should be employed especially at the beginning of the introduction of case managers. This effort could consist of extensive information regarding case management and its potential worth to all involved organisations. Such information

could be of help to further legitimise the role of case managers, thus giving case managers a stronger mandate to perform their everyday work.

Another conclusion to be made is that the utilisation of working groups as a medium for improvement work encompassed both unique opportunities and challenges. The working groups were experienced to be an innovative and potential medium for improving care at an organisational level. However, for this improvement work to actually be achieved, engagement amongst all representatives was fundamental. Aspects influencing this engagement were having too few cases tied to the working groups or having a low attendance rate. Thus, the caseload needs to be not too low, since this could affect the amount of input and experienced usefulness of the working groups in a negative way. Another challenge was the difficulty of fully grasping the purpose and content of the case management intervention. If those involved do not understand the purpose and the content of the intervention, its ability to improve care could be affected negatively. Since case management consists of complex processes and because of the design of the current intervention progressed over time, great effort should be given to inform stakeholders about its contents and purpose. This effort could be employed at a pre-intervention stage to promote a better understanding before launching the intervention. Furthermore, it is important that those involved as representatives get to express and discuss their expectations and that those expectations are made visible. Another strategy could be to employ explicit guidelines regarding the case managers' and the representatives' own responsibility in the working groups. A vital part of the preparation for the case management intervention should thus be to explicitly set the expectations for all involved parties. The findings from this thesis could also be utilised to enhance the awareness of the current challenges of providing a continuity of care for older persons with multi-morbidity, amongst health and social care staff members and stakeholders.

## Further research

This thesis highlights the importance of trusting relationships in a case management intervention. Further research is warranted to investigate the effects of trusting relationships on case management and its ability to improve care for older persons with multi-morbidity. There is also a need for additional research regarding which older persons are in greatest need of case management and which older persons could be at risk of needing help in the future. This knowledge could assist in targeting the recruitment of older persons, and also make it possible for case management interventions to be conducted pro-actively. Moreover, findings illustrate that case management was found to be of great worth to the family members of an older person with multi-morbidity. Thus, it would also be warranted to further investigate the effects of case management on the family members' situation, and of its cost-

effectiveness. This research would be of help in investigating and building evidence-based knowledge of case management. Working groups as a medium for improvement work seems to be a potential way of improving continuity of care at an organisational level. However, more research is warranted regarding the effect of such groups, as well as to get a deeper understanding concerning such improvement work. Finally, it seems to be important to further explore and investigate what organisational barriers and facilitators are of importance for a case management intervention. Such knowledge would be beneficial in the development of case management interventions designed with respect to organisational challenges.



# Svensk sammanfattning

Högspecialiserade hälso- och sjukvårdssystem kan göra det utmanande att säkerställa en god kontinuitet i vården för äldre personer med multisjuklighet. I Europas åldrande befolkning har en omfattande andel multisjuklighet och i Sverige är multisjuklighet det vanligast förekommande hälsotillståndet hos personer 75 år och äldre. Äldre personer med multisjuklighet har ofta komplexa hälso- och sjukvårdsbehov och kan behöva tillgång till flertalet hälso- och sjukvårdskontakter. Vidare erfar hälso- och sjukvårdssystem utmaningar i att kunna möta de äldre personernas komplexa behov, vilket riskerar att leda till en fragmenterad och mindre tillfredställande vård. Ett angreppssätt för att ta sig an ett fragmenterat hälso- och sjukvårdssystem skulle kunna vara att använda sig av case management som syftar till att förbättra samordning av vård och omsorg. Case management har beskrivits att innefatta en kollaborativ process bestående av bedömning, planering, främjande, koordinering och utvärdering av en persons behov. Vidare inbegriper case management förespråkandet av den service som är nödvändig för att kunna tillgodose en individs och en familjs hälsobehov och där kommunikation och tillgängliga resurser används för att framhäva kvalitet och kostnadseffektiva resultat. De personer som praktiserar case management tituleras case managers.

Avhandlingen utforskar en case management intervention som pågick under åren 2011 till 2013 i Blekinge län i södra Sverige. Interventionen benämndes *Äldrelotsprojektet* och de personer som utförde interventionen och arbetade som case managers hade titeln *äldrelots*. Interventionen startades som ett resultat av att medel beviljades utifrån ett nationellt initiativ som syftade till att förbättra kontinuiteten i vården för äldre personer med komplexa vårdbehov. Interventionen tillhörde en ny och tillfällig organisation och anledningen till detta var att interventionen skulle vara oberoende av övriga hälso- och sjukvårdsorganisationer i länet. Oberoendet skulle underlätta för interventionen och därmed för case managers att erhålla en mer neutral position i deras arbete. Alla case managers arbetade tillsammans i ett eget team som var multiprofessionellt vilket tillät att de äldre personernas behov kunde diskuteras utifrån flera olika professionella perspektiv.

Interventionen bestod av två delar. Den första delen inbegrep case management på individnivå. Som en del av det dagliga arbetet interagerade case managers med äldre personer, deras närstående såsom familjemedlemmar samt med hälso- och sjukvårdspersonal. Case managers identifierade varierande behov hos de äldre

personerna och deras familjemedlemmar. De utförde regelbundet hembesök, där de bedömde och planerade aktiviteter baserat på de nuvarande behoven hos de äldre personerna. De koordinerade sedan insatser så att annan hälso- och sjukvårdspersonal kunde tillmötesgå den äldre personens behov. Case managers kunde även vara behjälpliga som stöd vid vårdplaneringar och läkarbesök och hade uppföljning med de äldre personerna, vanligtvis via telefon eller hembesök. Case managers interagerade med personal ifrån landsting, kommun och frivilliga organisationer, beroende på den äldre personens behov. Vidare kunde de erbjuda en läkemedelsgenomgång via en farmaceut. För familjemedlemmarnas del innebar interventionen att de kunde få assistans i form av information rörande deras äldre släktingars rätt till effektiv och säker vård. De hade möjlighet att kontakta case managers för att få rådgivning, antingen via telefon eller i samband med ett hembesök. Case managers var också behjälpliga med att vägleda familjemedlemmarna till lämplig hälso- och sjukvårdspersonal, där de kunde få vidare hjälp med deras problem.

Den andra delen av interventionen inbegrep case management på en organisatorisk nivå. Referensgrupper startades upp i alla fem kommunerna i Blekinge och fungerade som ett forum för att bedriva frågor rörande förbättringsarbete och för att främja ett lärande under interventionens gång. På den organisatoriska nivån deltog varken de äldre personerna eller deras familjemedlemmar. Referensgrupperna bestod av ett flertal olika representanter rekryterade ifrån hälso- och sjukvårdspersonal, inkluderat chefer. Case managers roll vid referensgruppernas möten var att föra fram identifierade behov och förbättringsområden som de själva hade observerat under deras dagliga arbete. Information som fördes fram diskuterades sinsemellan representanterna och case managers i ett syfte att komma fram till möjliga lösningar och för att lära av varandra.

Internationellt har flera olika typer av case management interventioner prövats med syfte att förbättra vårdprocessen för äldre personer med multisjuklighet. Flertalet studier har undersökt effekter av case management interventioner på äldre personer med multisjuklighet. Studiernas fokus har framförallt varit på att undersöka vårdkostnader och sjukvårdskonsumtion. Studierna har uppvisa en diskrepans av deras resultat. Detta har illustrerats så till vida att en del studier uppvisar positiva effekter av case management i form av exempelvis ett minskat användande av vård och minskade vårdkostnader medan andra studier inte uppvisar någon effekt. Vidare är flera av studierna beskrivna i mindre detalj, vilket gör det svårt att få en god uppfattning av vad som faktiskt har utförts som en del av interventionen. Det finns ett behov av att djupare utforska vilka aspekter som är av betydelse för en framgångsrik case management intervention. Ett sätt att fördjupa kunskapen är att utforska erfarenheter av case management hos de som använder sig av dess service, det vill säga äldre personer med multisjuklighet. Vidare skulle det vara av värde att få mer kunskap om case management från case managers dem själva, familjemedlemmarna till den äldre personen samt från den hälso- och sjukvårdspersonal som har varit involverad i interventionen. En fördjupad kunskap skulle kunna vara till hjälp i



utformandet av case management interventioner som inriktar sig på äldre personer med multisjuklighet. Avhandlingens övergripande syfte var därmed att utforska upplevelserna av en case management intervention inriktad på äldre personer med multisjuklighet, utifrån perspektiven av case managers, de äldre personerna, familjemedlemmarna och hälso- och sjukvårdspersonalen.

Avhandlingen består av fyra delstudier. Studie I och III är fokuserade etnografier, Studie II bygger på tolkande fenomenologi och Studie IV har en kvalitativ design. I Studie I intervjuades nio stycken case managers (8 kvinnor och 1 man), i åldern 40 till 61 år. Det genomfördes även en gruppintervju samt så pågick deltagande observationer under perioden juni 2012 till januari 2013. I Studie II intervjuades 16 stycken familjemedlemmar till äldre personer med multisjuklighet (14 kvinnor och 2 män), i åldern 38 till 89 år. I Studie III intervjuades 13 stycken äldre personer med multisjuklighet (10 kvinnor och 3 män), i åldern 77 till 88 år. I Studie IV intervjuades 10 stycken hälso- och sjukvårdspersonal (10 kvinnor), i åldern 44 till 60 år. Samtliga intervjuer använde sig av en intervjuguide och de spelades in digitalt med hjälp av en diktafon. Det inspelade materialet transkriberades sedan ordagrant. Deltagande observationer i Studie I och III använde sig av nedskrivna fältanteckningar från observationstillfällena av case managers dagliga arbete.

Studie 1 illustrerade att case managers erfarenheter av deras dagliga arbete kunde tolkas utifrån ett övergripande tema som inbegrep: *En utmaning av nuvarande yrkesidentitet*. I deras dagliga arbete utförde case managers arbetsaktiviteter som tidigare varit kända för dem. Arbetsaktiviteterna utfördes genom att de använde sig av deras tidigare förståelse samt rådande kunskap inom deras case manager team. I samband med att de utförde ett sedan tidigare familjärt arbete, men i en ny kontext med nya förhållanden som styrde hur de kunde utföra arbetet, utmanade deras nuvarande yrkesidentitet. Deras nya roll som case managers formades i takt med att tiden passerade och deras erfarenheter utvecklades. Strävan mot att kunna arbeta tillsammans som ett case manager team mot gemensamma mål innebar att de var tvungna att utmana sin nuvarande yrkesidentitet. Det övergripande temat bestod av tre subteman. Det första subtemat var: *Att anpassa sig till ett familjärt arbete i en icke-familjär roll*. Temat reflekterade att case managers i deras dagliga arbete upplevde att deras arbetsaktiviteter inte var annorlunda i förhållande till deras tidigare arbetsaktiviteter i deras yrkesprofessioner. Men den nya rollen som case manager innebar att det påverkade hur de borde eller inte borde utföra detta familjära arbete. Arbetet inkluderade aktiviteter såsom att guida den äldre personen i hälso- och sjukvårdssystemet, att identifiera behov hos den äldre personen och att planera och utvärdera insatser. För att identifiera den äldre personens behov behövde de lyssna på dennes berättelse. Det var också viktigt att identifierade behov utgick ifrån den äldre personen egna behov och inte skuggades av deras egen förståelse. Case managers stöttade den äldre personen och dennes närstående i deras utmaningar med hälso- och sjukvårdssystemet. En annan familjär arbetsaktivitet var att stärka den äldre personen, vilket framförallt skedde under hembesök, genom att agera samtalspartner samt

genom att lyssna och bekräfta den äldre personen. De upplevde att den äldre personen litade på dem och över tiden så utvecklades deras kontakt till att bli en tillitsfylld relation. Det andra subtemat var: *Strävan efter att förbättra hälso- och sjukvårdssystemet genom en ny roll*. Temat reflekterade att det fanns både utmaningar och möjligheter i case managers strävan mot att förbättra delar av hälso- och sjukvårdssystemet. Utmaningarna bestod dels i att inte bli lyssnad på, att bli sedd som ett hot eller att olika organisationer inte gjorde det som de hade lovat att göra. Möjligheter bestod dels i deras unika roll att kunna bedriva förbättringsarbete utifrån de referensgrupper som startats upp i kommunerna. Förbättringsarbetet bedrevs även som en del i deras dagliga arbete, då de med hjälp av enkäter och observationer samlade in information som kunde användas i förbättringsarbetet. Det tredje subtemat var: *Tillit är avgörande för att kunna agera företrädare*. Temat reflekterade att case managers hade blandade känslor inför att företräda den äldre personen. De upplevde att det var naturligt för dem att företräda och att det var ett privilegium att ha fått den äldre personens tillit att göra det. Ibland behövde case managers bortse ifrån deras personliga värderingar för att kunna föra fram den äldre personens talan. Det var värdefullt att som case manager inte tillhöra någon hälso- och sjukvårdsorganisation, då det upplevdes främja tilliten hos de äldre personerna. Det var även utmanande när de företrädde de äldre personerna, då de upplevde att deras ord inte alltid gav tillräcklig tyngd i deras kommunikation med annan hälso- och sjukvårdspersonal.

Studie II illustrerade att familjemedlemmars upplevelser av case managers kunde tolkas utifrån det övergripande temat: *Bidrar till att uppfylla mina otillfredsställda behov*. Temat speglade att familjemedlemmarna upplevde att case managers kunde tillfredsställa behov hos dem, vilket den ordinarie hälso- och sjukvården inte hade kunnat göra tidigare. Dessa behov tillfredsställdes av att familjemedlemmarna fick en person-centrerad service, upplevde tillitsfyllda relationer och erhöll en god kontinuitet i deras kontakter med case managers. Det övergripande temat bestod av tre subteman. Det första subtemat var: *Hjälper mig att känna mig trygg – Upplever en tillitsfylld relation*. Temat reflekterade att kontakten med case managers fick familjemedlemmarna att känna en trygghet, och känslan av trygghet utvecklades när deras kontakt blev till en mer tillitsfylld relation. Familjemedlemmarna upplevde trygghet i det att någon mer förutom de själva hade möjlighet att kunna hjälpa deras äldre anhöriga. Vidare uppskattade de att case managers var kunniga om deras nuvarande situation och att det var en kontinuitet i deras kontakter. Det andra subtemat var: *Bekräftar och stärker mig – Utmanar min känsla av att vara ensam*. Familjemedlemmarna kände sig ofta ensamma i sin roll av att ge assistans till deras äldre anhöriga och känslan av ensamhet växte när de var tvungna att kämpa för att få vård till deras anhöriga. De upplevde att deras behov som familjemedlem ofta glömdes bort i dagens hälso- och sjukvård. När de kom i kontakt med case managers utmanades deras känsla av att vara ensam och de kände sig bekräftade och stärkta i sin roll som familjemedlem till en äldre anhörig med multisjuklighet. Det tredje

subtemat tolkades som: *Är min personliga guide – Ökar min kompetens*. Familjemedlemmarna upplevde att case managers assisterade dem i navigera till olika hälso- och sjukvårdskontakter. De uppskattade att den information som de fick av case managers var anpassad till deras situation och individuella behov. Med hjälp av case managers kunde familjemedlemmarna diskutera och reflektera över deras problem, och därigenom erhålla nya perspektiv på deras situation. Deras kontakt med case managers innebar att de fick ny kunskap om hälso- och sjukvårdssystemet och det ökade deras egen kompetens.

Studie III illustrerade att de äldre personernas upplevelser av case managers kunde speglas utifrån fyra teman. Det första temat tolkades som: *Någon som ger mig en tillitsfylld relation*. Temat reflekterade att de äldre personerna upplevde en tillitsfylld relation till case managers. Vidare hade de en tilltro till att case managers både hade intentionen och förmågan att kunna assistera dem. Personliga egenskaper hos case managers såsom att de var känsliga inför de äldre personernas behov, var lyssnande samt lätta att prata med, gjorde att det var enklare att börja lita på dem. De äldre personerna uppskattade känslan av att kunna kommunicera med case managers på ett ärligt sätt. Vidare uppskattades det att case managers tog sig tid att sitta ner och lyssna på delar av deras livshistoria. Det andra temat var: *Någon som assisterar mig*. De äldre personerna fick assistans av case managers på olika sätt, såsom att bli guidade till rätt hälso- och sjukvårdskontakt, få rådgivning om deras olika problem samt att de fick hjälp med att få deras problem vidare undersökta. De äldre personerna blev handledda av case managers om hur de själva skulle kunna ta sig an dessa problem. Ibland var case managers mer aktiva och utförde således aktiviteter för att kunna lösa problem åt den äldre personen. Det tredje temat tolkades som: *Någon som är på min sida*. Temat reflekterade att de äldre personerna upplevde att case managers var deras personliga företrädare, någon som stod på deras sida när de hade problem med deras hälso- och sjukvård. De uppskattade att case managers inte tillhörde en organisation som de själva fick vård utav. Vidare upplevde de att case managers gav dem ärliga svar i deras kommunikation. Det fanns en tillit hos de äldre personerna att case managers skulle företräda dem i de fall som problem skulle uppstå. Det fjärde temat var: *Någon som jag inte behöver nu*. Somliga av de äldre personerna uttryckte att de i nuläget inte hade några problem som behövde adresseras av case managers. De kunde ta hand om sig själva eller med hjälp av deras närstående. Viljan att klara sig själv beskrevs som att vara envis eller som att de var nöjda med deras situation så som den var. Vidare såg de nyttan av case managers mer utifrån att vara en försäkring inför framtiden, ifall deras situation skulle förändras och att de då skulle få ett större behov av assistans.

Studie IV illustrerade att hälso- och sjukvårdspersonalens upplevelser av case management kunde tolkas utifrån tre teman. Det första temat var: *Kan överbrygga klyftorna i ett otillräckligt hälso- och sjukvårdssystemet*. Personalen uttryckte att ett specialiserat hälso- och sjukvårdssystem hade bidragit till att äldre personer med komplexa vårdbehov upplevde en fragmenterad vård. Komplexiteten i systemet hade gjort det svårt för äldre personer att själva kunna navigera till rätt hälso- och

sjukvårdskontakter. Personalen erfor att case managers var effektiva på att koordinera till lämpliga kontakter och kunde därför vara behjälpliga åt den äldre personen. Vidare såg de case management som ett sätt att arbeta mot en mindre fragmenterad vård. De såg betydelsen av att case managers kunde bedriva ett mer individualiserat angreppssätt än vad dagens hälso- och sjukvårdssystem hade möjlighet att göra. Det andra temat var: *Nya förbättringar kräver engagemang*. Temat reflekterade att personalen upplevde att case managers presenterade lovande tillvägagångssätt för att arbeta mot förbättring av delar av hälso- och sjukvårdssystemet. Dock krävdes det engagemang, både hos case managers och hos personalen själva för att förbättringarna skulle kunna bli implementerade. Förbättringsområden förmedlades av case managers under referensgruppernas möten. Nyttan av dessa referensgrupper upplevdes bero på nivån av engagemang hos dem som var delaktiga samt hur många äldre personer som var rekryterade till interventionen i den specifika kommunen. Vidare upplevde personalen att case managers kunde hjälpa till att belysa brister. Genom att bristerna blev belysta fick personalen en bekräftelse på att detta var något som behövde göras någonting åt, även om de sedan tidigare varit bekanta med bristen. Bekräftelsen från case managers bidrog till att starta en impuls hos personalen att påbörja en process av att förändra. Det tredje temat var: *En intervention i dimman med vaga mål och innehåll*. Personalen upplevde svårigheter i att förstå det övergripande målet med interventionen. Vidare upplevdes innehållet av interventionen som vagt och rollen som case manager var oklar för dem. För somliga av personalen blev interventionen tydligare ju längre tiden gick. Personalen belyste även att tillräcklig information och vägledning hade saknats, vilket i sin tur hade lett till att de inte förstått interventionens innehåll.

Resultatet från avhandlingen visar på vikten av att etablera tillitsfyllda relationer. För case managers var denna tillit viktig för att de överhuvudtaget skulle kunna utföra sitt dagliga arbete. De äldre personerna uppskattade case managers förmåga att kunna bemöta deras emotionella behov. Familjemedlemmarna uttryckte att deras tillitsfyllda relationer med case managers bekräftade och stärkte dem i deras roll av att ge assistans till deras äldre släktingar. Således bör case management interventioner lägga fokus på att skapa tillitsfyllda relationer mellan case managers och deltagarna, särskilt i samband med inkluderandet av nya deltagare. För att främja tillitsfyllda relationer kan det vara av vikt att ha en personlig case manager. Andra aspekter som skulle kunna vara främjande är att case managers har en neutral position, att de gör hembesök samt att de har regelbundna kontakter med deltagarna. Således skulle en kontinuitet av case managers service kunna främja att dessa tillitsfyllda relationer utvecklas. Vidare, även då vissa av deltagarna inte hade ett behov av regelbundna eller mer omfattande kontakter, så kan det ändå vara värdefullt att lägga resurser på de första kontakttillfällena. Detta kan visa sig att vara värdefullt längre fram. Genom att etablera en kontakt, kan det vara ett sätt att arbeta pro-aktivt och deltagarna har då en känd kontakt ifall problem uppkommer längre fram. Vikten av tillitsfyllda relationer

är något som också skulle kunna övervägas i den allmänna vården av äldre personer med multisjuklighet.

Resultatet från avhandlingen visar på att case managers dagliga arbete innefattade en utmaning av deras professionella identitet. Utmaningen uppstod som ett resultat av att uppleva svårigheter i att förstå deras egen roll som case managers. Således är det av vikt att presentera en tydlig beskrivning av case managers professionella ansvar och deras befogenheter, både till case managers dem själva och till professionerna som arbetar inom hälso- och sjukvårdssystemet. Genom att klargöra roller och ansvar så skulle det kunna hjälpa till att främja processen av att introducera case managers in i ett system som tidigare inte är bekant med case management. Beslutsfattare som vill intervensera i ett redan etablerad hälso- och sjukvårdssystem bör därför vara medvetna om dessa utmaningar. Således, bör de ge uppmärksamhet och stödja case managers och deras arbete. Stödet bör särskilt ges vid introduktionen av case managers och kan bestå av att utförlig information om case management och dess potentiella betydelse i förhållande till de involverade organisationerna. Sådan information skulle kunna vara till hjälp för att legitimera rollen som case manager och därmed ge ett starkare mandat för case managers att utföra deras dagliga arbete.

Ytterligare en slutsats utifrån avhandlingens resultat är att referensgrupperna kunde ses som ett medium för förbättringsarbete som både innefattade möjligheter och utmaningar. Referensgrupperna ansågs vara innovativa och ett potentiellt medium för att bedriva förbättringsarbete på en organisatorisk nivå. Emellertid, för att förbättringsarbetet skulle kunna genomföras var ett engagemang hos personalen i referensgrupperna nödvändigt. En aspekt som hade betydelse för hur personalen såg på nyttan av referensgrupperna var närvarograden i gruppen samt hur många äldre personer som hade rekryterats inom den specifika kommunen. Ett fåtal rekryterade äldre personer och en låg närvaro bidrog till att personalen kände mindre nytta och ett minskat engagemang med referensgrupperna. Således behöver det finnas tillräckligt med rekryterade deltagare för att mängden information på mötena ska upplevas som tillräcklig. En annan utmaning var svårigheterna i att förstå interventionens mål och innehåll. Då case management består av komplexa processer och då även den aktuella interventionens design förändrades över tid, behöver ytterligare fokus riktas mot att informera om interventionen. Ansträngningarna kan göras som en del av en pre-interventions fas för att främja en ökad förståelse av innehållet innan själva interventionen startas. Vidare, så är det av vikt att personalen i referensgrupperna får möjlighet att uttrycka och diskutera deras förväntningar av interventionen. Ytterligare en strategi skulle kunna vara att sätta upp tydliga riktlinjer för personalens och case managers eget ansvar inom referensgruppernas arbete. Således, en viktig del av förberedelserna för en case management intervention bör vara att klargöra förväntningar hos alla inblandade parter. Resultatet från avhandlingen skulle också kunna vara till hjälp för att öka medvetenheten hos hälso- och sjukvårdspersonal om de rådande utmaningarna i att kunna ge en god kontinuitet i vården för äldre personer med multisjuklighet.



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