To maintain control

Negotiations in the everyday life of older people who can no longer manage on their own

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Abstract

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The general aim of this thesis is to reach a more insightful understanding of how help is actually worked out in the everyday life of older people when they can no longer manage on their own. The overall research question is how individuals, representing different perspectives in the help arrangement process, think and act in order to organise needed help as well as how they may themselves apprehend the functions of the help.

It is a qualitative study, containing four papers looking at this issue from different perspectives: the older persons themselves, their next of kin who provide help and the municipal care managers who make decisions on formal help. The empirical material consists of qualitative interviews and participant observations with care managers, qualitative interviews with older people applying for formal eldercare, follow-up interviews with some of them and qualitative interviews with next of kin who provide help. The analysis of the material adopts an empirically oriented approach, involving several steps from open to focused coding. Earlier research and theory guided the analysis.

The results show that older people strive to maintain control over their everyday life (Paper I). When they can no longer manage unaided, they use various strategies to maintain control and the feeling of autonomy. Well-functioning formal and informal networks (Paper III) allow individuals to sustain autonomy and control in old age even when they have to depend on help from others. The care managers endeavour to make both ends meet in the decision process (Paper II). They develop various techniques and struck a balance between diverse demands and expectations. Helping an older relative is connected with a multiplicity of motives and experiences (Paper IV). The next of kin act both as bridges and buffers between their older relative and formal eldercare. This thesis emphasises the important functions of both formal and informal help to older people. To outline the working forms and methods of collaboration between older people and their informal and formal support networks is an important challenge that needs further attention.

LIST OF PUBLICATIONS

This thesis is based on the following papers:

I.   Dunér, Anna and Nordström, Monica (2005) Intentions and strategies among elderly people: Coping in everyday life. *Journal of aging studies*, **19**, 437-451.

II.   Dunér, Anna and Nordström, Monica (2006) The discretion and power of street-level bureaucrats: An example from Swedish municipal eldercare. Accepted for publication in *The European Journal of Social Work,* **9**, 425-44.

III.   Dunér, Anna and Nordström, Monica (2007) The roles and functions of informal support networks for older people who receive formal support: a Swedish qualitative study. *Ageing & Society,* **27**, 67-85.

IV.   Dunér, Anna. 'I want to do what I can': Next of kin helping older relatives who receive formal help – a Swedish qualitative study. *Health and Social Care in the community* (Submitted).

1. Help in the everyday life of older people

This thesis focuses on the arrangement of help in the everyday life of older Swedes who can no longer manage on their own. Help for older people has formal as well as informal elements, and the general aim of this thesis is to reach a more insightful understanding of how help is actually worked out when older people become dependent on others. It is a qualitative study, containing four papers looking at this issue from different perspectives: the older persons themselves, their next of kin who provide help and the municipal care managers who make decisions on formal (public) eldercare. The overall research question is how individuals, representing different groups in the help arrangement process, think and act in order to organise needed help as well as how they may apprehend the functions of the help.

Older people's dependence is often assumed, and research typically focuses on helpers in families and/or formal eldercare. Issues tend to centre on who will support older people, the nature of caregiver burdens or the situation of professional groups (Mossberg Sand, 2000; Connidis, 2001; Ingvad, 2003; Blomberg, 2004). How help is worked out for and by older people is a complex and multifaceted process, involving several different actors and concerning norms and regulations, obligations and commitments along with emotions and personal preferences (Finch and Mason, 1993; Daatland and Herlofson, 2003a; Larsson, 2004). In this thesis, older people are regarded as actors, actively manoeuvring their situation according to available resources in both their formal and informal networks. How and by whom help is carried out in everyday life is the outcome of the actions of different actors in these processes, which are interpreted as negotiations.

The knowledge of older Swedish people's reception of help from formal and informal eldercare is quite extensive on an aggregate level (see for example Socialstyrelsen, 2005a, 2005b; Larsson, 2004; Rauch, 2005). The decision-making process and the manner in which assistance is distributed to older people by municipal care managers according to the social services law have been addressed by several researchers (see for example Lindelöf and Rönnbäck, 2004; Andersson, 2004; Hellström Muhli, 2003). Janlöv (2006a) investigates the experiences of older persons, their family members and care managers during needs assessments. Organisational reforms within formal

eldercare authorities have been studied from a needs-assessment perspective by Blomberg (2004) and from a management perspective by Wolmesjö (2005). The conditions of ageing and dying at a nursing home, from the perspectives of both the older persons living there and their relatives was investigated by Whitaker (2004). Informal help from the next of kin of older people has been studied by a number of researchers (such as Mossberg Sand, 2000; Dahlberg, 2004; Forssell, 2004; Jegermalm, 2004). Prior research on the specific issues of this thesis is presented in the respective papers. Knowledge of the complex interplay between older individuals, members of their informal network, and decision makers from formal eldercare in the process of arranging help is still limited.

Help to older people in a Swedish context

The Swedish population, as most European populations, may be described as an ageing population. Three factors have contributed to this condition: a growth in the proportion of people aged 65 and above, an increase in the absolute number of older people and an improvement of life expectancy at birth (Lowenstein and Katz, 2003; Socialstyrelsen, 2006). The number of Swedes who are 65 years or older increased from 0.7 million to 1.6 million over the last 50 years. In 2000, 17.2% of the Swedish population were older than 65 years and in 2020 this proportion is estimated to grow to 21.1%. In 2000, Sweden became the first nation where more than 5% of the population were 80 years or over (Socialstyrelsen, 2004; 2005a). Life expectancy at birth for Swedish women was 82.7 years in 2004, an improvement of 2.8 years in the previous decade; for men it was 78.4 years in 2004, an improvement of 4.6 years in the same period (Socialstyrelsen, 2006).

Older people are a substantial group in Sweden, both in proportion of the population and in absolute numbers. Their expected need for social care and health services has been pointed out as a major challenge for the Swedish welfare state (Thorslund and Larsson, 2002). The retirement age for most Swedes is 65 years, and from that age formal eldercare is supposed to assist those who need help to manage everyday life. The actual age, however, when most older people need help in everyday life is a good deal higher. The economic situation for older people has been improved, and their average pensions have increased although female pensioners normally still encounter worse economic situations than men. The improved length of life makes it more common to have several generations of relatives alive. Four generations of the same family is not unusual and sometimes even five generations. Today, older people have more living relatives than ever before, and these relationships are presumed to increase their well-being positively (Thorslund and Larsson, 2002).

The actual balance between different sources of help for older people varies among countries according to their tradition, culture and social policy system, e.g., the structural context within which this balance is worked out. Sweden, as well as the other Scandinavian countries, may be described as a social service state (Anttonen, 1998) where benefits and services are universal and intended to cover the entire population at different stages of life. Social services such as eldercare are needs-tested benefits based on uniform rules; the current eldercare system was initiated in 1982 when the Social Services Act came into force (*Social Services Act,* 1980:620, 2001:453). Services are financed and often delivered by the public sector. Swedish eldercare strives for universality and extensive coverage (Government Bill, 1997/98:113). The legislation aims at securing social and economic assurance as well as the individual's independence of his or her family. This individual direction has implications for family life, intergenerational relations and women's participation on the labour market (Sand, 2004; 2005). Current policy is that older people should be able to live independently, managing with formal and informal help as long as possible.

Formal eldercare is a municipal responsibility, and before an older person receives formal help an authorised care manager assesses his or her needs to determine what help will be given (Lindelöf and Rönnbäck, 2004). Many local eldercare authorities have developed common guidelines for decision making according to the law (Andersson, 2004). The right to formal eldercare stated in the law has not been amended, even though the Act was revised in 2000. This means that the public goals and regulations for eldercare have remained the same since the 1980s. The financial resources for formal eldercare have decreased substantially during the 1990s, considering the increase of the absolute number of older people in the population (Szebehely, 2000). Together with the fact that the number of hospital beds has been almost cut in half and the treatment time in hospitals has been shortened quite drastically, the result has been an increasing pressure on municipal eldercare. The proportion of older people who receive help from municipal eldercare has decreased significantly during this period. There is reason to question how this has been possible within an unaltered legislation. The Social Services Act consists mainly of aims to strive for and a frame within which the needs of older people are to be assessed; municipalities may interpret this frame quite freely.

The legal rights of older people in Sweden could consequently be described as rather weak. Since around 1990, national policymakers have been increasingly interested in the help performed by the *families* of older people. In the Government Bill 1997/98:113, an amount of SEK 300 million was invested in a special program to support and develop services for relatives and friends providing help for their elders. In the budget proposals (Government Bill, 2005/06:1) there is an increased emphasis on the family as an important resource for both older persons and the welfare state. Similarly, an increased

interest in help provided by *voluntary organisations* has been noticed (Jeppsson Grassman and Svedberg, 1999). Legislative and organisational changes involving the separation of 'decisions on help' from 'execution of help' have opened up competition between privately and publicly operated help to older people. Help to older people undertaken by *private enterprises* contracted by the municipalities, became more frequent during the 1990s (Palme et al., 2003). This may be interpreted as a shift of policy from the previous main focus on formal eldercare.

The ways in which help to older people is organised reflect institutional ideas of eldercare (Berger and Luckmann, 1967; Scott, 1995). The thoughts and actions of the individuals involved in the help arrangement process are affected by their apprehension of moral obligations, norms and values. Human actions, as members of a society, are guided by the fact that individuals are organised and belong to different organisations (Ahrne, 1994). As a 'figuration', the organisation may help us to understand 'people as individuals at the same time as thinking of them as societies' (Elias, 1978:129). There is a continual interplay between institutions and organisations. Institutions, understood as ideas or assumptions taken for granted, are used in the creation and maintenance of organisations, and organisations may lead to the establishment of new institutions. Actions coordinated through organisations are guided and affected by institutions, as for instance 'help for older people' and connected assumptions and regulations such as 'what is best for older people', legal rules and moral obligations.

Many phenomena, such as the welfare state, exist both as organisations and institutions (Ahrne, 1994). Ahrne uses a broad definition of organisations and distinguishes four types: nation states, families, business enterprises and voluntary associations. The actions of individuals are coordinated through organisations and thereby they are filtered and transformed into social processes. Accordingly, help to older people could be regarded as coordinated through different organisations, such as formal eldercare, families, voluntary organisations and private enterprises. These organise and provide help to older people in different ways. The help may be depicted as work or labour. Different types of work/labour may be distinguished; typically gainful employment, informal work, household work and voluntary work are separated (Jeppson Grassman and Svedberg, 1999). The help carried out by formal eldercare is gainful employment only, whereas the help carried out by immediate family or other kin can be either informal work or household work depending on whether the work is done by someone living with the recipient or not; furthermore, it may sometimes be regarded as gainful employment when the helper is paid by the municipality for the work. The work of private enterprises is gainful employment, but the work of voluntary organisations normally is voluntary work.

Since the family, as a social institution, is not considered a sufficient guarantee for the citizens' social welfare, other institutional ideas, such as the welfare state, concerning the society's obligation to take responsibility for the social security of its citizens has led to the creation of organisations such as formal eldercare (cf. Wærness, 1990; Sand 2005). During the 1990s, the public sector in Sweden was the subject of many organisational reforms, and formal eldercare was no exception (Blomberg, 2004; Wolmesjö, 2005). These organisational reforms might be seen as attempts at constructing more complete organisations (Brunsson and Sahlin-Andersson, 2000). Organisations are hence regarded as institutions comprising a whole set of beliefs, norms and practices including the aspects of identity, hierarchy and rationality. These aspects are normally assumed to exist to a higher degree in private enterprises, which are seen as role-models. The concept of 'organisation' has led the content of these public sector reforms either explicitly or implicitly. Well-established institutions, such as 'family' and 'welfare state' may, according to this perspective, affect people's way of thinking, talking and acting without being directly referred to (Brunsson and Sahlin-Andersson, 2000).

Shifts in the help reception pattern

The notion of 'help reception pattern' is here used to describe older peoples' reception of help from different help-providing organisations, and the concept of 'institution' will be used to analyse the shifts in this pattern. Institutions, as stated earlier, are understood as important in the creation and maintenance of organisations and as implicitly affecting people's thoughts and actions. Actions of help, coordinated and filtered through organisations, are transmitted into social processes. To understand and interpret shifts in the help reception pattern, an analysis of the interplay between institutions and organisations will be of value here.

During the 1990s, the share of older people receiving help from *formal eldercare* have decreased. In 1990, approximately 25%[1] of people aged 80 and above received home help (Szebehely, 2000), and in 2000 the share of home help recipients in this age group were 18% (Socialstyrelsen, 2006). About 23% of people in the same age group lived in a nursing home in 1990 (Szebehely, 2000), and in 2000 this share was 20% (Socialstyrelsen, 2006). For the first four years of the 2000s, the total share of formal eldercare has stayed quite unaltered for older people aged 80 and above, i.e., 38% in 2000 and 37% in 2004 (Socialstyrelsen, 2006). The share of home help recipients has increased from 18% in 2000 to 20% in 2004 in the age group, and the share of older

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[1] All percentages have been rounded to whole numbers.

people living in nursing homes has decreased from 20% to 17% (Socialstyrelsen, 2006).

Even though formal eldercare has been regarded as the major help provider, several studies have shown that older people receive a significant amount of help from their *families* (Johansson, 1991; Johansson et al., 2003). According to a report based on a national survey (Socialstyrelsen, 2005a) the proportion of family help has increased to older people aged 80 and above, and this increase corresponds to the decrease of home help reception in this age group. In 1994, 34% of older people aged 75 or above received help from their family,[2] and in 2000 the share had increased to 37% (Johansson et al., 2003). Twelve percent of older people aged over 75 who lived alone received help from their children in 1994, and by 2000 this share had increased to 22% (ibid.). In 2002, the share of family help to older people living in the community was 70% (Sundström et al., 2002).

In Sweden, *voluntary organisations* have not traditionally been major providers of help to older people. Yet, they have been important as innovators of social services, as when the Red Cross initiated home help services in Sweden (Trydegård, 2000). In the tradition dominating social welfare research in Sweden there is no room for a voluntary sector. Thus, this sector has been ignored by researchers for a long time. In recent years there has been increased interest from official policy makers and decision makers has increased concerning voluntary organisations as providers of help (Jeppson Grassman and Svedberg, 1999). Though there is no evidence showing that this ideological change has led to an increased share of help received from voluntary organisations (ibid.; Szebehely, 2000; Lundström and Svedberg, 2003). On the contrary, research shows a high level of voluntarism rooted in a long history and tradition of mass movements. In 1998, 12% of the population had received help from a voluntary organisation at some time the past year. For older people, this share is a little smaller (Jeppsson Grassman and Svedberg, 1999; Lundström and Svedberg 2003).

Private enterprises have played a minor role in the help for older people in Sweden. Regarding the private enterprises financed and regulated by the municipalities, who are contracted to perform certain help, an amendment of the law in the early 1990s made it possible for the municipalities to contract private help providers. In 1999, 4% of home help services and 10% of the nursing homes were run by private enterprises, which is a threefold proportion compared with 1993. Concerning help from private enterprises financed by older help recipients themselves, the development is more uncertain. There are signs that an increase in the amount of practical help bought from private enterprises by older people themselves has taken place (Szebehely, 2000; Palme et al., 2003). Questions may be raised whether there exists a private market for

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[2] Also including small numbers of friends and neighbours.

these services in all parts of Sweden. There are reasons to believe that this development mostly has taken place in the major cities.

The changes described in this section show a transformation of the help reception pattern of older Swedes, which mainly took place in the 1990s. There has been a decreased proportion of formal eldercare and a corresponding increase in help from the families of older people. Also, there has been an increase in the share of help provided by voluntary organisations and private enterprises. These changes may be characterised as an informalisation and market orientation of eldercare (Szebehely, 2000; Palme et al., 2003). The changes in the help reception pattern show differences related to gender and social class. Women have been more affected by these changes than men. The proportion of both older women and older men receiving formal eldercare has decreased, but for women the reduction has been more considerable. Furthermore, the increase in help received from families occurred only among older women (Szebehely, 2005). The decreased share of formal eldercare has led to the increased share of family help (informalisation) for older people with a lower educational level, and an increased share of private help (market orientation) for older people with a higher educational level (SOU 2001:79).

Help for older people has been described as organised through formal eldercare, families, private enterprises and voluntary organisations. The interplay between these service providers is often discussed in terms of substitution and complement and has mainly focused on formal eldercare and help from families (Larsson, 2004; Kröger, 2005). These theories have their limitations and have been questioned. They have a moral undertone where family help is always preferred to formal eldercare and tend to implicitly assume traditional gender roles within the family. The theories are guided to a higher extent by the interests of occupational groups and the limiting of public expenses for formal eldercare than by the interests of older people who are the recipients of help (see Ward-Griffin and Marshall, 2003). There has been slight empirical support for these models, and there is reason to question the assumption of help to older people as a 'zero-sum game'. On the contrary, empirical results imply that reception of formal eldercare increases help provided by families (see Socialstyrelsen, 2005b). The models of substitution and complement are mainly discussed from a provider perspective, which limits their scope in the context of this thesis, which emphasises the importance of considering older people as active agents manoeuvring their situation.

As an alternative, changes in the help reception pattern may be understood as a response to the changes in ideas and assumptions guiding both the provision and reception of help. Changes in institutional ideas of proper 'help for older people' is reflected in the organisation and reception of eldercare. Formal eldercare has undergone many organisational reforms during the 1990s, which have been interpreted as attempts at constructing more complete 'organisations' where the private enterprises have served as role-models

(Brunsson and Sahlin Andersson, 2000). This has led to an emphasis on measurable results, causing an augmented standardisation of the tasks performed and the construction of older recipients of help as customers rather than clients or citizens (Eliasson-Lappalainen and Szebehely, 1998). The increased standardisation of the help carried out by formal eldercare may have led to the necessity of help from the families as older people in vulnerable situations are unable to act as customers. Furthermore, older persons may choose to receive help from their families instead of formal eldercare when they want the services to be carried out according to their individual requirements. As it seems, 'family' still stands as an important institution guiding the help for older people, and is stressed even more in recent national policy documents. As a result of ideological and legal changes, it became possible for municipalities to contract private help providers to perform helping services to older people. Together with the efforts made by formal eldercare to imitate private enterprises, this has led to a smaller difference between formal eldercare organisations and private enterprises. For older persons in need of help with household chores, the difference between receiving help from formal eldercare or private enterprises has become blurred. For some persons, their influence over the performance of the tasks may be greater as customers of a private enterprise. Finally, the absence of available help with personal care from voluntary organisations as well as private enterprises may be interpreted as non-acceptance of help for older people as a charity or market-product.

Our conception of proper help for older people seems to be connected foremost with help from families and/or formal eldercare. This view is also supported in a study by Daatland and Herlofson (2003a). They found that public opinion in five European countries favoured a partnership between the family and the welfare state in providing help to older people. Still, it is important to consider the gap between the help received and the help desired by older people, as shown in a recent study by Szebehely (2005). A smaller proportion of older people receive help from formal eldercare than the proportion that actually wants it, while a larger proportion of older people receive family help than the proportion that desires it. This gap is bigger for women than for men.

Disposition of the thesis

This thesis is divided into two parts. In the first part I provide background, general and specific aims, conceptual framework and methods of the thesis. A summary of the four papers, an overall analysis and interpretation of the results and the conclusions are presented in this part as well. The second part of the thesis contains the four original papers.

Before the next section, presenting the general and specific aims, I will add some delimiting remarks. This thesis focuses on the thoughts and actions of individuals representing three different groups and perspectives in the help arrangement process. First, I chose to present the perspective of the older persons themselves and show how they manoeuvre their situation according to available resources in both their formal and informal networks. Second, I present the perspective of the municipal care managers because they represent one of the organisations providing most help to older people, i.e., formal eldercare, and since they are the actors involved in the decisions and arrangements of formal help. Finally, I address the next-of-kin perspective because they represent the other major help-providing organisation, the family. Yet, it is important to point to some vital differences between the care managers and the next of kin. The relationship between the older person and the next of kin has lasted for a long time, and the next of kin have often provided help long before formal eldercare is contacted. The municipal care manager, on the other side, has no ongoing relationship with the older person, often meeting the person only once in the help arrangement process and not providing any direct help. There are, of course, other important actors, such as home-helpers and nurses, who provide help from formal eldercare to older people, but they were not selected for this study.

The concept of 'help' was chosen to describe the actions enabling older people to manage everyday life when they can no longer do so unaided. Alternative concepts were considered. Often, the concept of 'social care' is used to depict the performance of formal eldercare and the assistance of next of kin (cf. Johansson, 2001; Szebehely, 1996). The concept of 'social support' is frequently used to represent both practical and emotional assistance (cf. Morgan, 1990). Finally, the 'service' concept may be used (cf. Blomdahl Frej, 1998; Szebehely, 1996). My final decision was that 'help' is the word most frequently used in everyday conversations and that 'help' is a wider concept than any of the alternatives.

2. General and specific aims

The general aim of this thesis is to reach a more insightful understanding of how help is actually worked out in the everyday life of older people when they can no longer manage on their own. The overall research question is how individuals, representing different groups in the help arrangement process, think and act in order to organise needed help as well as how they may apprehend the functions of the help. The specific aims of the four supporting papers are as follows:

I. This research aims to increase our understanding of how older people *manage* when they can no longer do so unaided. Specifically, the purpose is to reveal how older people *act* in everyday life, asking the questions: What *intentions* do older people have in their actions? What *strategies* do they develop?

II. The overarching aim of this paper is to describe and analyse how some care managers, as examples of street-level bureaucrats, in four Swedish municipalities' eldercare authorities use their *discretion* and *power* when *acting to make decisions on assistance*. What alternative techniques do they use when making decisions in relation to the conditions that define the scope of their discretion? How do care managers strike a balance between various demands and expectations during the decision process? How do they use their power?

III. The aim of this paper is to investigate the experiences of older people in care-receiving situations to illuminate the roles and functions of their informal support networks. More specifically, the following research questions were posed: What is the *structure* of older people's support networks? What *interactions* take place in their informal support networks? What is the *function* of their informal support networks?

IV. The aim of this paper is to investigate the thoughts and actions of next of kin providing informal help to their old relatives. More specifically, the following research questions are posed: What are the *motives* of the next of kin for providing help? What *experiences* do the next of kin have of the help-giving situation? What *strategies* do they develop to resolve conflicting emotions and/or demands?

3. Conceptual framework

In this chapter I present the conceptual framework of the thesis. I describe the conceptual tools used to analyse and interpret the experiences and actions studied, within the wider frame of a symbolic interactionist theory. The use of concepts in social science has been discussed by Blumer (1954, 1969). Concepts are seen as the means to establish a connection between a theory and the empirical world: '…it is the concept that points to the empirical instances about which a theoretical proposal is made' (Blumer, 1954:4). Concepts may be both definitive and sensitizing. In the study of the social world the use of definitive concepts is problematic. A definitive concept has a clear definition, which allows us to identify its instance and relevant content in the empirical world. In contrast, a sensitizing concept does not have such a clear definition and may therefore not lead us directly to the instance or its relevant content. Instead, it directs the user when approaching the empirical instances by a general sense of reference and guidance. When studying the social world of everyday experience, it is the unique and specific character of this world that makes sensitizing concepts more usable, and that restricts the scope of definite concepts since they only capture limited parts of the empirical instances (Blumer, 1954). In this thesis I have endeavoured to do justice to the empirical material and to capture its unique and specific character. The concepts used are the means by which I have sought guidance in approaching the empirical data in the study and by which I have attempted to arrive at an understanding of the phenomena in the social world that are the focus of this work, i.e., using sensitizing concepts.

Framed interaction in everyday life

Everyday life is characterised by well-known and well-defined situations where routines and modes of action are taken for granted. These habits are seldom reflected upon unless something happens that involves a need to change routines and establish new ways of acting (Goffman, 1986; Åström, 2005). Symbolic interactionist theory describes individuals as active in the construction of their

social world and as acting consistently with the meaning they ascribe to the situation. The meaning of a situation is defined in the social interaction with other individuals (Blumer, 1969). According to Goffman (1986) individuals structure and organise their everyday life by creating frames, within which they interpret and define their experiences and actions to give them meaning. The way an individual frames a situation or an action is a key to understanding the meaning he or she attaches to the situation. When help for older people is worked out in everyday life, the actors in the social network of older people interact within the frames within which the situation is understood.

Together with others we establish shared understandings of situations and actions. Developing shared understandings of what situations are about and what individuals involved in the situations expect from one another may be seen as negotiations between the individuals involved (Strauss, 1978; Finch, 1989; Finch and Mason, 1993). As a way of paying attention to the importance of the structural conditions in which the negotiations take place, Strauss (1978) developed the concept of 'negotiated order'. The outcome of the negotiation is affected both by structural conditions as well as by individual actions. Nonetheless, the social order may be seen as a negotiated order, with at least a slight negotiated element even in the most repressive circumstances (Strauss, 1978, Finch, 1989). Even then, individuals develop strategies to defend themselves against the power exercised in order to achieve some room to manoeuvre (Goffman, 1961). The negotiation context (Strauss, 1978) surrounds and encompasses the negotiation. It refers to the structural properties entering directly as conditions into the negotiation process. In a specific welfare policy context, such as in Sweden, individuals establish shared meanings of how social life is worked out in general. These shared understandings provide us with the proper actions to take and what to expect in a specific situation. When a new situation arises, certain things will be taken for granted by the actors involved.

In this thesis I distinguish the perspectives of three different groups of actors in the everyday life of older people who can no longer manage on their own; I present and analyse empirical data from the different perspectives. I have used different conceptual tools of analysis to capture the meaning of the results. From the perspective of older people, the concepts are social action and coping. From the perspective of the municipal eldercare, the care managers are the focused actors and the concepts used are discretion and power. From the perspective of the help giving next of kin, the concepts used are motives and ambivalence.

Social action and coping

To understand the experiences of older persons who could no longer manage on their own, I applied social action theories and the concept of coping. Social

action theories regard social action as a human approach, a subjective signification. The individual is an actor who acts on his or her own initiative instead of being controlled by the environment (Weber, 1983; Engdahl, 2001). This approach corresponds with this thesis' view of older people as actors, actively manoeuvring their situation. Action comprises the intentions (goals), thoughts and considerations that help achieve the intentions and concrete efforts to achieve the goals. The intention is what gives the action meaning and makes it possible to understand (von Wright, 1971). Action aims to change conditions, or prevent change and preserve existing conditions, which may be achieved by either an active or a passive approach (von Wright, 1971; Israel, 1999). Central to our understanding of people's actions therefore are their intentions and the thoughts and actions by which these intentions are realized—their strategies. People's actions are based on their preferences, affected by instrumental, moral and emotional considerations. In a demanding situation, both individual and external resources help in realizing action. For older people participating in this study, individual resources may comprise their cognitive and emotional capacities and external resources may include material and supportive sources (cf. Engdahl, 2001; Gardberg Morner, 2003). The intentions and strategies used by the older people in this study may be seen as part of the help-seeking process (Eckenrode and Wethington, 1990), where the individual constantly engages in perceptions, decision making and acting according to the situation.

The help-seeking process is one aspect of support mobilisation, which in turn may be seen as a component of coping (Eckenrode and Wethington, 1990). Motivational aspects, such as general goals and situational intentions, are central to our understanding of how people cope with demanding situations (Lazarus, 1993). The concept of coping has been used in studies of how different groups, such as single mothers (Bak, 1997; Gardberg Morner, 2003) and people with chronic disease or disability (Gullacksen, 1998) manage demanding life situations and/or life adjustment. For older people, illness or functional disability leading to dependence on others in everyday life may be regarded as new and demanding circumstances and strains. Older people manage these situations through various types of coping, a concept used in interpreting the findings of this study.

Coping includes both the individual's cognitive interpretation of the situation as well as that individual's behaviour in the situation, thus emphasising the continual interplay between the individual and the environment. The concept may be defined as 'cognitive and behavioural efforts to manage specific … demands that are appraised as taxing or exceeding the resources of the person. These … efforts are constantly changing as a function of continuous appraisals and reappraisals of the person–environment relationship' (Folkman & Lazarus, 1988:309). Coping is thus situation-specific: there is interplay between one's judgement of a situation and the resources available for managing it. Individual and external resources vary, affecting both one's judgement of a situation and

how to manage it. The individual constantly interprets and reinterprets the specific circumstances. Research distinguishes between problem- and emotion-focused coping strategies (Monat & Lazarus, 1985; Lazarus, 1993).

In problem-focused strategies, the individual actively addresses a problem's causes in order to change the conditions creating the difficulties. Such coping is common when the individual feels able to change the situation. 'Planful problem-solving', information search, and confrontive coping are types of problem-focused coping strategies. In emotion-focused coping strategies, the individual reinterprets the situation causing difficulties or changes his feelings toward it. Such passive coping is common when the individual feels unable to change the situation. Positive reinterpretation and exercising self-control are terms indicating emotion-focused coping strategies.

Discretion and power

In the analysis of care managers' decision process, I have used the concepts of discretion and power. The care manager is the person in authority in the municipal eldercare system and is most often the first person to meet older people seeking help. In the research the role of care manager has been described as 'gatekeeper' and/or 'street-level bureaucrat' (cf. Blomberg, 2004; Lindelöf, Rönnbäck, 2004; Hellström Muhli, 2003; Christensen, 2001). Lipsky (1980) argues that discretion is fundamental to the professional practice of street-level bureaucrats and identifies three conditions that create discretion. First, the goals, laws and guidelines that street-level bureaucrats must follow may be vague and inconsistent. Accordingly, street-level bureaucrats must personally interpret the rules. Secondly, street-level bureaucrats work with people whose circumstances are unique, unpredictable and specific. The social context is complex and cannot be captured in detailed regulations. Thirdly, the discretion shaped by circumstances presumes that street-level bureaucrats will perform their tasks based on professional expertise, which provides latitude for personal discretion. Two perspectives on the study of discretion may be distinguished (Ellis et al., 1999). One perspective views discretion as fundamental and necessary for street-level bureaucrats to do their work, since they have to interpret laws and guidelines and by so doing they create the organisation's policy. According to the other perspective, street-level bureaucrats' discretion is regarded as circumscribed by laws and guidelines, the increased power of management and the current state of the economy.

Based on Lipsky's theory, three conditions are identified that constitute the framework for the analysis of the actions of the municipal care managers in the decision process. The legal conditions for care managers' discretion manifest the ideological orientation expressed in the Swedish Social

Services Act, where social norms and values have been concretised through political resolution. The law provides the framework for decision making and is an expression of national policy at a general level. The organisational conditions are guidelines adopted by local politicians and/or eldercare management. These guidelines are intended to make the legislation more exact, and they are more detailed in nature. The motives underlying the guidelines have to do with fair distribution, financial limitations and the staff's work environment. Guidelines may be either formal or informal. The moral conditions for exercising discretion emerge from (a) the beliefs held by citizens about society's responsibility for the disadvantaged and vulnerable among them and (b) the views of how assistance to older people provided by the eldercare system should be designed. On a general level, most people can agree on fundamental principles of action. Reaching consensus on how those principles should be concretised in specific cases is, however, a trickier matter (Dunér and Nordström, 2003; Dunér and Nordström, 2005).

When street-level bureaucrats such as care managers make decisions, it is presumed that they will base those decisions on their professional expertise and experience. The latter are considered a guarantee that private citizens' needs will be fairly assessed and available resources will be used efficiently.

Street-level bureaucrats' power over their clients comes into play through the use of various means of control such as laws, guidelines, material resources and personal relationship, as well as their knowledge and personal experience (Lipsky, 1980; Handler, 1992; Hasenfeld, 1992). According to Johansson (1992), power is relational: it is incorporated in all social situations and can be understood as an interaction between constantly mutable strength ratios whose utility is determined by the social context. A relational conception of power comprises aspects of both structural and intentional power, which are used in the analysis of the care manager's power in the decision-making process.

Structural power derives from the rights delegated by politicians to care managers to make decisions according to the law and their access (through their position in the organisation) to the organisation's material and human resources. It concerns the relationship between two or more parties in terms of superiority or subordination; the range and shape of power is central (Johansson, 1992). The relationship between the care managers and the older persons is asymmetrical, since the law and the organisation give the care managers a superior position. Care managers have the legitimate right to decide on distribution of resources among the older applicants, and this right in turn influences the encounter and interaction with them in the decision process.

Intentional power concerns the ability possessed by an acting subject. This actor is considered as striving to fulfil a purpose with his or her action, and this is what gives power a direction (Johansson, 1992). This form of power appears in the social interaction among older people, their relatives and care managers. The parties involved have more or less power. The care

managers base their actions on their knowledge and experience when they use intentional power to influence older people and their relatives, for example by means of the information they communicate and the advice they give.

All exercise of public authority involves the use of power. Power is about influence and dependency (see Lukes, 1974, 1995). The decision process is not influenced only by the relationship between care managers and older applicants; to make a decision, care managers must communicate with other actors and bring together discrete sources of information. That means they must make various choices and not merely follow guidelines (see Handler, 1992; Nordström, 1998).

Support network

In order to examine how individual's locations inside networks affect the way they act, think and feel, theories of social networks may be applied (Collins, 1988). Social network might be used as a metaphorical and/or an analytical construct in descriptions and analyses of relations between people, capturing both quantitative and qualitative aspects (Mitchell, 1969, 1974; Morgan, 1990; Phillips et al., 2000). A personal social network reveals the relations of one individual (ego). Different types of personal networks have been identified. The personal networks of people, or groups of people, who provide, or are believed to provide, material or symbolic support may be depicted as exchange networks (Milardo, 1992) or support networks (Wenger, Scott and Patterson, 2000). I have used the support network as an overall concept in the description and analysis of older people's experience of the roles and functions of their informal social networks. Research has shown that older people who lack network support use formal eldercare more and that they are less satisfied with their situation than others (Fyrand, 1995). Most research on social support has focused on its positive effects, yet findings reveal that there are negative aspects of both giving and receiving informal network support (La Gaipa, 1990; Antonucci et al. 1998). Rook (1990) emphasise the important role of companionships to balance the costs associated with social support.

Several aspects of these support networks, described in the literature, may be taken into consideration. I have treated the structural, interactional and functional features in my description and analysis of older people's support networks (Mitchell, 1969, 1974; Morgan, 1990; Phillips et al., 2000; Wenger, Scott and Patterson, 2000). In earlier studies of social networks and in theoretical discussions in which the concept evolved, the interactional and functional dimensions were regarded as one (Mitchell, 1969, 1974; Bø, 1993). In later studies they came to be considered as two separate dimensions interweaving with one another (Skårner, 2001).

The term 'structure of the support network' refers to the overall form and pattern of the relations within the network. In order to reveal the structure of

older people's support networks, the size and variation of both the formal and the informal support network of older people are described. By 'size' is meant the number of people or groups of people in an older person's support network while the 'variation' is the number of sectors, or classes, in which the network members are located. By 'accessibility of the informal support network' is meant an older person's ability to mobilise the interactions and functions of its members. A study of informal network support in Great Britain shows that it is mainly the closest family members who are mobilized when looking for support (Phillips et al., 2000). Additionally, friends were alternative or complementary sources of support for many older people.

The analysis of the interactions taking place within the support network of older people looks at the quality and quantity of the interactions between older people and each member of their network. To shed light on the character of the relationships in the informal network, 'frequency and duration' between the older person and each member of his or her informal support network is considered. This may be regarded as a way to pay attention to, and appreciate, social interaction for its own sake or as the relational benefits of social networks, as emphasised by Rook (1990). The 'symmetry and direction' of the links reveals the balance in the interaction between people with regard to services and power. Many researchers have stressed the importance of reciprocity in social relationships, to avoid the negative effects of not living up to norms and expectations (Tornstam, 2005; Antonucci and Jackson, 1990). The term 'negotiation' depicts what goes on in the interaction and how its outcome affects the functions of the informal support network.

The function of the informal support network relates to the content of the interaction, i.e. what it is used for. The functional content of the support network can be depicted as social support (Morgan, 1990; Pierce, Sarason and Sarason, 1990; Phillips et al., 2000). More specifically, it may be described as the aid and encouragement exchanged in the interpersonal transactions among the members of the older people's networks (cf. Rook, 1990). The social support provided by the support network can, then, be characterised as a qualitative dimension besides relational structure and interaction. Here, the functional dimension of the informal support network of older people is analysed by examining the network's ability to supply 'practical support' and 'emotional support'. When informal expected help is not forthcoming, this is termed 'lack of support'.

Motives and ambivalence

In the analysis of the thoughts and actions of the help-giving next of kin, a typology of motives for help giving and the concept of ambivalence were

applied. Economists and sociologists have long discussed the motives for help giving, and different suggestions about what motivates giving have been made. Often, economists define motives in terms of reactions to changing situational conditions and not in terms of psychological or socio-psychological realities, which may lead to conceptual constructions far removed from how people are really motivated.

Instead, it may be more worthwhile to use an approach emphasising that motives originate from interactions among individuals in a specific social policy context (Kohli and Künemund, 2003). Kohli and Künemund studied motives for family support, among other things, as a way to acknowledge the importance of motives in the structure of social relations. Motives are an important part of the quality of help, as it may make a difference for the help recipient whether the help is given and motivated by self-interest, love, generosity or social obligation. They worked out a typology of motives, which they tested empirically through a series of statements referring to the various motivational dimensions. The motives were altruism, sense of duty, direct exchange, delayed or indirect reciprocity and separation.

Altruism refers to the giver's concern for the well-being of others, whereas sense of duty relates to internalised normative obligation. Direct exchange is about the giver's interest in getting something in return. Delayed or indirect reciprocity concerns giving back what one has received earlier, passing it on to the next generation, or giving so that the recipient may give to others. Separation is about keeping autonomy or distance. The results show a complex pattern with a large amount of overlap and interaction among different motives. There was a strong support for altruism, sense of duty and indirect reciprocity. The frequently emphasised importance of the dichotomy of altruism versus exchange, sometimes supplemented with reciprocity was not supported in the empirical findings of this research. Instead, a dichotomy of unconditional versus conditional giving and the dimension of independence and separation between the generations were found to be of greater significance (Kohli and Künemund, 2003).

Other studies have found the acceptance for filial obligations to be both rather strong and quite similar in various European countries (Daatland and Herlofson, 2003a; Lowenstein and Daatland, 2006). Kompter and Vollebergh (1997) reported that gift giving to friends was more often accompanied by feelings of affection than gift giving to family members, which also sprang from feelings of moral obligation. This may be explained by the fact that family ties are given, whereas ties to friends are chosen.

Being an informal help-giver may lead to both positive experiences, as appreciation and improved relationships, and negative experiences, as feelings of insufficiency and failure leading to stress and fatigue (Walker et al., 1995; Johansson and Åhnfeldt, 1996; Sand, 2005; Szebehely, 2005). The concept of ambivalence has been developed to address the coexistence of

solidarity and conflict in intergenerational relationships (Connidis, 2001). Ambivalence has been defined as ' …simultaneously held opposing feelings or emotions that are due to countervailing expectations about how individuals should act' (Connidis and McMullin, 2002: 558; Lüscher and Pillemer, 1998). It has been conceptualised on two levels: at the social structural level, as sociological ambivalence and at the individual level, as psychological ambivalence. Sociological ambivalence refers to the contradictory normative expectations that occur in institutional statuses, roles and norms, whereas psychological ambivalence refers to individuals subjectively experienced contradictory cognitions, emotions and motivations (Connidis and McMullin, 2002; Lüscher and Pillemer, 1998). Lately, ambivalence has been reconceptualised in order to serve as a bridging concept between social structure and individual action, made evident in social interaction. Ambivalence is viewed as '…structurally created contradictions that are experienced by individuals in their interaction with others.' (Connidis and McMullin, 2002:559). In the analysis of individual experiences of interaction within the constraints of social structure the concept of ambivalence urges us to consider how ambivalence is resolved through various strategies employed by the actors involved (Connidis and McMullen, 2002).

Before presenting the summary of results from the four papers, I will describe and discuss the methodological procedure used to collect and analyse the empirical data of the thesis.

4. Methods

To investigate a field that is very familiar to you as a practitioner raises certain issues that must be handled. The familiarity may appear to have advantages as well as disadvantages. Among the advantages are the researcher's knowledge of problems previously experienced and the identification of important questions worth studying in order to develop the practical field work. The researcher's cultural competence involves the ability to identify the significance and centrality of situations that for an outsider may seems uninteresting or incomprehensible (Henriksson and Månsson, 1996). On the other hand, amid the disadvantages is the risk that the research results may only lead to confirmation of established 'truths' among practitioners within the field in question; this may be the consequence of the 'insider's' insufficient curiosity. One way to compensate for these risks is to collaborate with researchers who are 'outsiders' to the field (ibid.).

I have been working in the field of eldercare since I became a social worker in the late 1980s. Most of the time I worked as a care manager with supervision, needs assessment and decision-making as the main tasks. In 1998, I began studying at the master's level, which for me meant the beginning of a new orientation from practical social work to education, research and development in the same field. A couple of years later, I began to work at 'FoU i Väst', a research and development centre in the welfare field, where I worked in a research project studying municipal eldercare. In 2002, I started my doctoral education. Because of my extensive experience of practical social work, within the eldercare field, I have endeavoured to strike a balance between the use of my practical experience and knowledge and the necessity to distance myself from the eldercare field in order to establish a critical view. From 2001, I have not practised social work as I have entirely concentrated on theoretical studies, research, development and teaching in the eldercare field. This has enabled me to move away from my practical experience, but I still have been anxious to keep in contact with practitioners in the field to test the validity of my results and analysis. Further, I have had the advantage of having a supervisor who has not worked in the eldercare as a practitioner but has gained much knowledge and experience of the field as a researcher.

Study design

This thesis is mainly based on a qualitative case study conducted in one large city and two small towns with surrounding countryside in western Sweden. The case study took place in 2001 and 2002, and the empirical material was collected on an equal basis by Monica Nordström (MN), who was responsible for the study, and myself (AD). The case study design is considered to be preferable when 'how' and 'why' questions are posed and focus is on a contemporary phenomenon in an everyday context (Yin, 1994). This case study's main focus was to describe and analyse the actions taking place among the actors involved when older people contact eldercare authorities for the first time, from the perspectives of both older people and persons in authority (care managers).

In order to obtain data that were as richly varied and diverse as possible, the selected municipal eldercare authorities were organised in two different ways. Two municipal authorities, one in a large city and one in a small town, had traditional organisations where the care managers assessed the needs of older people, made the decisions according to the law and supervised the care and support that were provided. In two other eldercare authorities a newer organisational model was applied where the care managers' tasks were concentrated around needs assessment and decision making (see Blomberg, 2004).

The case study was conducted in three steps:

I. The first meeting between the older applicant and the care manager was studied by observing the care managers when they received applications from older people, in most cases by telephone. In addition to the observations, we interviewed the care managers with regard to the older applicants who were selected for an interview in Step II.
II. The selected older applicants were interviewed about their experience of applying to eldercare.
III. Follow-up interviews were carried out with some of older people interviewed in Step II. In addition, we interviewed some relatives and friends as well as some eldercare attendants.

During the research process, the importance of the informal social network became obvious and led to the description and analysis of older people's experience of the significance of their informal network. As the overall aim of this thesis evolved further, I identified a need to complement the empirical data further. The perspective of the older people's next of kin became important and I collected new material in a smaller qualitative interview study. These data made

it possible for me to describe and analyse the experiences of the supporting next of kin. To sum up; the case investigated in this thesis is *the process of working out help in the everyday life of older people who can no longer manage on their own.*

Study participants

The participants in this study were care managers, older persons who had contacted municipal eldercare and next of kin who performed help for an older relative.

Eight *care managers* were recruited through eldercare management in each municipality. The care manager's interest in participating in the study was the main selection criterion. Two care managers from each municipality was observed and interviewed. Each care manager was observed over a period of four to six days. In addition to the observations, semi-structured in-depth interviews with each care manager were conducted. All told, the researchers conducted 38 observations and 9 interviews.

The participating care managers were between 25 and 63 years old. Two of them had upper secondary school education in social care, and six had university degrees in social care or social work. Their care management experience ranged from one year to over 15 years. One of the care manager interviewees was male and the rest of them were female.

The municipal care managers recruited 22 *older persons* from those who had applied to eldercare during the period of observations. Initial contact was usually by telephone: when older people applied for eldercare they were asked to participate in the study and consent to be interviewed. We selected subjects who met one of the following criteria: first-time eldercare applicants, nursing home applicants, or applicants for eldercare who were refused or themselves refused offered help. Many of those who qualified were too frail to provide data: of the 39 who met our criteria, only 22 could be interviewed. Of these 22, only 12 could be interviewed again six months later, as several had dramatically weakened or died. A total of 34 interviews were conducted.

Older people interviewed were between 67 and 98 years old. Of these, five were older than 90 years, 13 were between 70 and 90, and four were younger than 70. Most had diagnosed diseases such as cancer or stroke and had regular contact with health services. We interviewed 14 women, five men, and three couples.[3] The interviewees were relatively homogeneous in ethnicity and social class. All were native-born Swedes who had previously been small business owners, and blue-collar or lower-level white-collar workers. Their

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[3] The interviews with the couples are counted as one interview per couple.

private networks comprised children, neighbours, and friends. Subjects had up to six children, and most interviewees had a few neighbours and/or close friends. Most interviewees were still living in their long-term residences, though some had moved to more convenient apartments; other interviewees had applied for nursing home rooms.

		City Authority 1	Town 1	City Authority 2	Town 2	Total
Step 1	Observations,/care managers	9	11	9	9	38
	Interviews/care managers	3	2	2	2	9
Step 2	Interviews/elders 1	4	6	6	6	22
Step 3	Interviews/elders 2	2	3	4	3	12

Figure 1. The total number of observations and interviews conducted in each municipality in the case study

Altogether twelve *next of kin* who provided help for an older person participated in the study. Different strategies for recruiting the interviewees were used. Four of the participants were recruited through the older persons interviewed in the case study, and eight participants were recruited either through notice-boards in shops and libraries, municipal meeting points or snowball sampling (Lee, 1993). The participants' age ranged from around 45 to 72 years; nine of them still had employment, and three had retired from the labour market. One half of the next of kin lived near their older relative, one of them in the same household. The other half of the participants lived within approximately 20–100 kilometres of their relatives. Ten of the participants were female and two were men. The participants were related to the older persons in different ways: nine were children, one was the spouse, one was a niece and one was a neighbour.

It is important to consider that the results obtained in this study were shaped by the process of recruiting and selecting participants. Since all the older participants had contacted formal eldercare and were recruited through formal eldercare authorities, the results on how they managed their situation and how they experienced the significance of their support networks cannot be generalised to older people in the same situation who managed without formal eldercare. Most of the help-giving next of kin participating in the study were not connected with the older participants or the care managers observed and interviewed. However, since the older persons helped by the interviewed next of kin all had some help from formal eldercare, there is no reason to assume that their experiences were considerably different from the next of kin of the participating older persons.

Data collection methods

The choice of data collection methods should be guided by the study's aim and research questions. My purpose, to investigate experiences of the process where arrangements of help are being worked out in the everyday life of older people, from different perspectives, led to the decision to apply a qualitative approach in this study. The data collection methods used in the studies of this thesis were participating observations and qualitative interviews, methods often used in studies inspired by ethnography (Gubrium and Holstein, 1997).

Data on the care managers were initially collected through participating observations where their assessment and decision-making practices were observed. The actions observed were care managers responding to phone calls, e-mail and referrals, as well as their performance of their other duties. The observations were aimed at studying how care managers treated and responded to enquiries and applications from older people. In order to gain more detailed information about the priorities assigned and choices made by the care managers, conversations between the researcher and the care manager took place during the observations. The observations took place in the care manager's offices at the municipal eldercare authorities, so it was the natural environment where the assessments and decisions were made. The loose structure of the observations, together with their location in the natural environment of care management practices, allowing the researcher to observe how participants defined the situation, identified problems to manage and acted to complete their tasks (see Kristiansen and Krogstrup, 1999; Henriksson and Månsson, 1996).

Observation as a research method when studying assessment and decision-making practices in social work is advocated by Ellis et al. (1999) as a method that can connect to 'bottom-up' decision making. Combining observations, conversations and interviews enabled the researchers to obtain different kinds of information: on the one hand, information about the care managers' actions when they received and responded to applications from older people and on the other hand, how care managers perceived the process of assessment and decision making (Silverman, 1993).

Despite efforts to obtain a fair picture of care managers' actions in the decision process, it is important to emphasise that the results have limitations. One might assume that care managers want to give the impression that they are acting properly in the decision process, which can make it difficult for researchers to study what they actually do. The presence of a researcher may have influenced the care managers to follow the procedures stated in the law more closely than they would have otherwise (see "impression management", Miles and Huberman, 1994). The fact that I too have experiences, both educational and occupational, similar to the participating care managers made me reflect on the possible impact this may have had on the results and analysis. I find it reasonable to suppose that the presence of a former 'colleague' might

have affected them in different ways. For some, it could be important to act even more properly and follow stated procedures more closely. Others might feel that they could 'loosen up' a little since they believed that I would understand the difficulties they met and the complexity involved. Moreover, my practical experience from the field helped me understand and identify significant situations during the observations and the interviews. I have tried to be aware of the risk that I would take certain situations and occurrences for granted and lose some of the necessary critical view. Here, my supervisor, who was responsible for the study, has been a very important support for me.

Most of the data were collected through qualitative interviews, professional conversations built on everyday talk with the care managers, the elders and the next of kin. Thematic interview forms were used in the interviews, which were open-ended to allow following up themes arising from the interviewees' statements. The interviews may thus be portrayed as 'semi-structured life-world interviews', defined by Kvale as: 'an interview whose purpose is to obtain descriptions of the life world of the interviewee with respect to interpreting the meaning of the described phenomena' (Kvale, 1996: 5-6).

Qualitative research interviews followed up the observations of the care managers. In these situations an interview form with the following themes was used, covering themes such as *the care manager's initial contact with the older applicant; the type of services requested; the care manager's assessments; how the care manager responded to the enquiries or applications; which circumstances or conditions influenced the care manager's decisions; and how the care manager planned the provision of services.* The interviews enabled the researchers to delve more deeply into questions and themes brought up during the observations. Each interview lasted about an hour and provided an opportunity for care managers to reflect upon their assessments and decisions.

The interview form used in the qualitative interviews with the older persons covered questions about *contact with eldercare, perception of own needs, types of help offered by eldercare, family, or friends, and the experience of receiving help.* Most interviewees willingly described their general circumstances; however, the difficulty was getting them to discuss specific needs in initial interviews, because of their new vulnerability. A follow-up interview with 12 of the elders interviewed, after about six months, allowed them to supplement their experiences and how they managed. In this way, a deeper exploration of the need for help and how interviewees saw their situations could be carried out.

The interview theme leading to the older people's description of the part of their informal social networks that provided (or that they thought provided) them with social support was *help received from others outside eldercare.* Questions asked were: 'Whom do you turn to if you need help?'; 'Do you receive help from others outside eldercare?'; 'From whom, and help with what?' The interviews gave us a picture of the subjectively described and

experienced personal support networks of the older persons. The information obtained was then drawn up on network maps, one for each older person. These maps, constructed to reflect the answers of the participant, contained four sectors, two formal and two informal. The formal sectors represented social care and health care. The informal sectors were family/relatives and friends/neighbours.
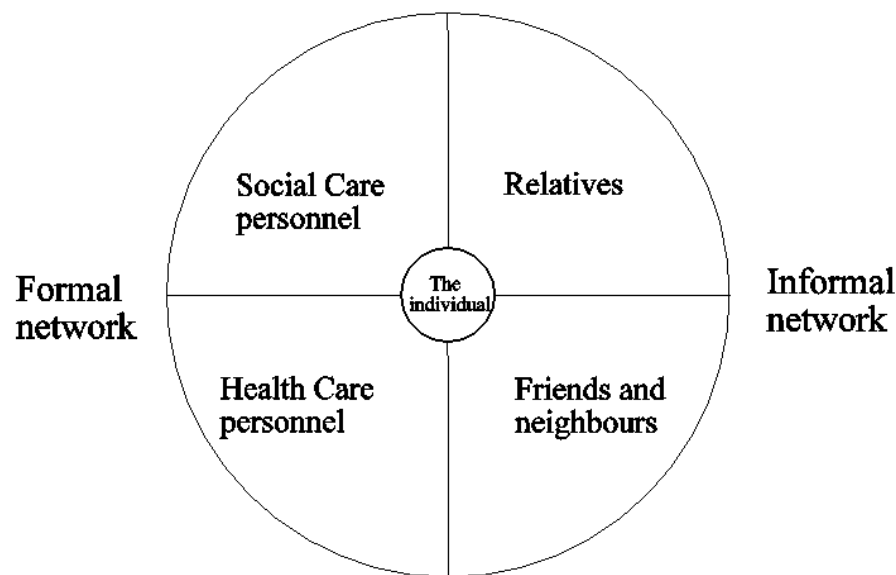

Figure 2. Network map

Qualitative in-depth interviews (Kvale, 1996) were carried out with the participating next of kin, using a thematic interview form with the following themes: *grounds and motives for performing the help, what help is given by the interviewee, other sources of help, received help from the older person, and the situation of the informal carer*. The interviews were open-ended, letting the researcher follow up themes arising from the experiences of the interviewees.

It is important to emphasise that, in qualitative interviews as well as in participating observations, knowledge may be seen as obtained in social interaction with the participants. The interview is a relation between two persons having a dialogue concerning a specific topic, where a context-bound meaning is constructed. My purpose in the interviews was to obtain knowledge on the process of working out needed help, from the perspective of the interviewee, to see reality as he or she understood it (Taylor and Bogdan, 1998; Kvale, 1996). It has therefore been essential for me to reflect on my own part in constructing and interpreting the participants' accounts.

Analysis

Most interviews with the older persons were taped and later transcribed verbatim; those that were not taped were transcribed immediately afterwards from memory, using notes made during the interview. The interviews with the care managers were recorded and transcribed verbatim. All but two of the interviews with the next of kin were taped and transcribed. The illustrative quotations from the interviews have been slightly edited, to accommodate the transition from spoken to written language (see Kvale, 1996) and increase intelligibility out of respect for the interviewees.

In this work the analysis interweaves with other aspects of the research process, which is characteristic of most qualitative research (Bryman et al., 1994). Analysis and interpretation were done concurrently with data collection (see Taylor and Bogdan, 1998; Widerberg, 2002). In processing, analysing and interpreting the material, a move from the factual level of the phenomenon in question to an abstract level took place (Emersson et al., 1995). When analyzing the material, an empirically oriented approach was used, and the analysis took several steps from open to focused coding. Earlier research and theory guided the first step of the analysis. In the following steps more specific concepts were developed and clarified to allow further interpretations of the subjective meaning of the empirical material from the perspective of the participants. Excerpts from the interviews and observations bearing meaning of the initial theoretical conceptualizations were organised together and a further conceptual analysis of the reorganized empirical material was made (Silverman, 1993; Emerson et al., 1995). The analysis from the perspectives of the older person, the care manager and the next of kin perspectives was made in Papers I-IV. Chapter 6 of this thesis, in order to accomplish the overall purpose of the thesis, comprises an analysis of the interactions taking place in the help arrangement process. The results obtained may be regarded as relying primarily on analytical generalisation, where the empirical findings are generalised to broader theoretical concepts (see Yin, 1994).

The writing of Papers I and II, including design, the theoretical conceptualisation as well as the analysis and interpretations of the empirical material, were divided equally between the first author (AD) and the second author (MN). The second author, as my supervisor, had a significant responsibility and influence over these products. In Paper III the first and second author had jointly collected the empirical data on which it is based but design, theoretical conceptualisation, analysis and interpretation was done by the first author. In Paper IV, as the single author, I was independently responsible for the whole process from design, data collection, and so on. In Papers III and IV, my supervisor again provided important support and advice.

Methodological discussion

Verification of knowledge in the social sciences is often made in relation to the concepts of validity, reliability and generalisation. The relevance of judging the value of qualitative research through validity, reliability and generalisation may be questioned, since they emanate from a positivist and quantitative research tradition. Different suggestions of how to handle this issue are recommended by qualitative researchers. Widerberg (2002) argues that qualitative research aims at neither reliability – that repeated measures by different researchers will obtain the same results – nor validity – that something given beforehand is measured correctly. She emphasises, though, that qualitative research ought to be both impartial and trustworthy, which may be achieved by documenting and reflecting choices made in the research process. Other qualitative researchers take another viewpoint and argue that the concepts of validity, reliability and generalisation are relevant but need to be evaluated and reformulated to fit into the demands posed within the frame of qualitative research. Lincoln and Guba (1985) demonstrate the inappropriateness of the conventional criteria but defend the use of the alternative criteria of credibility, transferability, dependability and confirmability in order to discuss the truthfulness of naturalistic inquiry. Kvale (1996) points out that our understanding of verified knowledge starts in our life-world and everyday language, thus it is important to recapture the everyday meaning. Although I understand Widerberg's scepticism, I will now discuss the method used in my study and what knowledge-claims may be posited with the help of Kvale's conception of validity, reliability and generalisation.

The validity, or internal validity, of the obtained results is affected of the performance of the research process as a whole. Validity concerns whether an investigation studies what it aims to study, if it accomplishes a reflection of the focused phenomena. Obtained knowledge may be regarded as a social construction of reality originating in a relation between the researcher and the participants. Competing interpretations are discussed, examined and assessed in order to argue for the relative validity of obtained knowledge. Kvale (1996) regards validity as good craftsmanship and as the everyday practice of research. It is about controlling, questioning and theorising. By critical considerations throughout the research process I have endeavoured to obtain validity in results and interpretations. In order to test the validity of the analysis and interpretations of the empirical data, I have discussed the results with both practitioners and researchers in the field as well as with representatives of pensioners' and next of kin organisations. It is also hoped that the description of how the study has been carried out will allows readers to make their own judgement of its validity.

Reliability concerns the consistency of the study's results – their trustworthiness. The researcher's sensitivity and ability to let the participants' experiences and understandings have free expression, among other things by avoiding guiding the results by the researcher's preconceived ideas and in trying to pose open questions. To achieve inter-subjectivity, in the sense that another researcher would be able to repeat the study and obtain the same results, is not possible in qualitative research like this, where the results are regarded as socially constructed in the relation between the researcher and the participants. Kvale (1996) calls for attention to putting too much emphasis on reliability at the cost of creativity and fresh ideas. What I have tried to accomplish is a description of how I have carried out this study that is thorough enough to permit other researchers to perform similar studies.

Finally, there is the question of generalisation, or external validity. This study is based on a fairly small, non-representative sample, and the results are therefore not statistically generalisable. Qualitative case study research, however, relies primarily on analytical generalisation, meaning that the researchers strive to generalise the results to a broader theory and to other research results (Yin, 1994; Kvale, 1996). The chosen conceptual framework and earlier research in the field have guided both the planning of the study and the analysis and interpretation of the empirical findings. Whether the obtained results are generalisable to instances in the social reality of other researchers and practitioners of the field is left to their decision.

Ethical considerations

The general ethical principles for research in the social sciences were followed in this research (Vetenskapsrådet, undated: http//www.vr.se/). The participants

were informed about the objects of the research and their informed consent was obtained. Both verbal and written information was provided to the participants, and they were all informed that their participation was voluntary and that they could interrupt at any time. The confidentiality in the further use of the data and the restriction of its utilisation for research purposes only was guaranteed. Even though these principles were followed carefully, it was ethically problematic to have such access to the older participants. Many had not completely understood their agreement to the study, and had difficulty distinguishing us from recently seen eldercare personnel. Consequently, we explained repeatedly that we were not from eldercare, and that anything said in the interview would be strictly confidential. It was important to inform them orally and in writing of the study and that their participation was voluntary.

In planning observations of the care managers the question arose whether the presence of researchers would affect the older applicants negatively in any way. Our presence may have influenced the care managers' way of carrying out their duties. Most probably, the effect would be that they were more careful in their case handling and decision making than they would otherwise have been. I find it, however, reasonable to believe that our presence did not involve any disadvantages for the older applicants. To set aside any suspicion that the researchers would use any information on eldercare applicants or recipients who had not agreed to participate in the study, we accepted and signed a form on professional secrecy.

In the original case study design, interviews with care managers, older people and their next of kin had been planned. In the interviews with the older applicants of formal eldercare, their wish to remain in control of their situation and to be independent of their family made us reconsider this design, out of respect of their integrity. In the first interviews with the older persons, therefore, they were asked if they would allow the researcher to interview a relative or friend who provided help or support to them. Some of the older persons seemed embarrassed by this question and hesitated to answer, which made us emphasise that this phase was voluntary and not at all necessary. This in turn led to the decision of the researchers not to interview any further next of kin of these older participants. Still, two daughters, one nephew and one neighbour of older people participating in the case study were interviewed. In the case study, the process of working out arrangements of help to older people was mainly studied from the perspectives of the older persons and the care managers. In the complementary interview study, the next of kin's perspective was accounted for by persons who were not associated with the older participants in the case study. Other researchers (see for example Finch and Mason 1993; 2000) have adopted different measures to avoid the disadvantages connected with letting one person account for the whole family or friendship group.

In the next chapter, I provide a summary of the main results of the four papers in this thesis.

5. Summary of results

Study I: Intentions and strategies among elderly people: Coping in everyday life

Aims

This study aimed to increase our understanding of how older people *manage* when they can no longer do so unaided. Specifically, our purpose was to reveal how older people *act* in everyday life, asking the questions: What *intentions* do older people have in their actions? What *strategies* do they develop?

Results and conclusions

Older persons' intentions reflect a desire for independence and control (Baltes & Baltes, 1990). The strategies used by older people are affected by both individual and external resources (Nordström and Dunér, 2003). External resources are crucial in letting older people be actors in everyday life. When individual resources are strained, appropriate external support allows older people to marshal their resources and again become actors.

Formal eldercare is an external resource older people use to maintain independence and control. They also use other external resources, such as family, neighbours, and private services. The results of this study indicate that older people do not wish to be dependent upon the welfare state, the family, or private service providers.

How older people *manage* their everyday lives – actively, adaptively, or passively – exemplifies either problem- or emotion-focused coping (Lazarus, 1993; Monat & Lazarus, 1985). Identifying how they manage does not imply that some ways are better than others: active, adaptive, and passive approaches all help older people manage under demanding circumstances.

The key findings of this study are summarized in Figure 3. This multidimensional model is based on qualitative analysis of a rather small sample and should be understood as a preliminary understanding of how older people manage. The approaches of older people to managing lie along a continuum,

ranging from maintaining independence as actors to becoming dependent on others as passive non-actors. The intentions and strategies of older people vary in intensity and degree, so the same intention or strategy might be found among active, adaptive, and passive elders. The general tendency is ultimately to move from active to passive behaviour; some people, however, may have always used a more active or passive approach to managing.

Actors   **Independence**

Various ways in which older people manage their circumstances	*Intentions*	*Strategies*
Active Acting to make their everyday lives work Ensuring it is possible to get help	Being free Having control over their circumstances Participating	Continuing to strive and keep busy Adapting to circumstances Getting help from various sources Receiving services and giving services in return
Adaptive Adapting to others' views of their needs Adapting to what eldercare offers	Partial control over their circumstances Participating	Continuing to strive and keep busy Adapting to circumstances Getting help from various sources Receiving services and giving services in return
Passive Giving up control over life	Peace and quiet	Adapting to circumstances Surrendering responsibility

Non-actors   **Dependence**

Figure 3. The influence of the intentions and strategies of older people on how they manage their circumstances

Older people apparently pass *turning points* that are decisive for their intentions and strategies. Such a turning point occurs when older people come to need practical help in their everyday lives, an observation also supported by findings of Hansen et al. (2002). The majority manage this transition through problem-

focused coping, taking action to alleviate difficulties. Some deny the problems exist, thus blocking constructive action.

Though such older people are no longer completely independent, their feeling of independence is maintained because they exercise control over their situation. Their individual resources are still relatively extensive, letting them take action to make everyday life run smoothly and ensure they can get help. As actors, they decide for themselves and use available external resources.

Another turning point is when older people start to need personal care. Along with Hansen et al. (2002) one may understand the difficulty of accepting personal care and still feeling independent. Older people feel forced to adapt and to accept unwanted help; they then manage their circumstances through emotion-focused coping. These older persons have now relinquished part of their control, allowing others to make certain decisions about the help they receive. Some still carefully keep certain everyday chores for themselves, using help from several sources so they can feel as independent as possible. Because they have *consciously* adapted themselves to others' views of their needs, they are still actors.

Others pass a turning point beyond which they become almost completely dependent, needing help in taking responsibility for their circumstances. Surrendering control, resigning oneself, and freeing oneself of problems all constitute emotion-focused coping that helps older people manage very difficult situations. When older people relinquish control, they become non-actors. They can still maintain a kind of intention, however, by deciding when others should take over, and by accepting circumstances as they are.

Study II: The discretion and power of street-level bureaucrats: an example from Swedish municipal eldercare

Aims
The overarching aim of this study was to describe and analyse how some care managers as examples of street-level bureaucrats in four Swedish municipalities' eldercare authorities use their *discretion* and *power* when *acting to make decisions on assistance*. What alternative techniques do they use when making decisions in relation to the conditions that define the scope of their discretion? How do care managers strike a balance between various demands and expectations during the decision process? How do they use their power?

Results and conclusions
This study comprised an analysis of how care managers, as street-level bureaucrats, act when they make a decision whether to grant assistance. Decisions are made in relation to the legal, organisational and moral conditions

that determine the extent of their discretion. These conditions are often vague, contradictory and fraught with conflict (Lipsky, 1980; Dunér and Nordström, 2003, 2005). In order to perform their tasks and carry out their mission, they develop various techniques and strike a balance among a variety of demands and expectations.

Conditions ⟍ Technique	Legal	Organisational	Moral
Reject	*Divert*	*Inform selectively*	*Compare*
Execute	*Adapt*	*Classify*	*Meet demands*
Transform needs	*Investigate individually*	*Grant according to available services*	*Negotiate*
Control	*Check that need exists*	*Ensure assistance is provided*	*Ascertain that assistance corresponds to needs*

Figure 4. Care managers´ techniques based on legal, organisational and moral conditions

In the decision process, care managers can be understood as using the power that has been allotted them through the right to make decisions according to the law and the right to distribute the resources of the eldercare system. This may be depicted as the structural aspect of power. They also use their power to influence the older applicants to adapt their needs and demands to prevailing conditions, which might be understood as the intentional aspect of power (Johansson, 1992). Supported by their professional expertise and personal experience of how applicable laws and guidelines may be interpreted, they negotiate on how assistance should be designed or assess enquiries that are not covered by the rights provided by law.

When assistance is needs-tested, care managers *reject* individuals whom they assess as not needing help. When they reject someone, it can be interpreted as the use of their structural power, in which they argue that a particular intervention cannot be provided within the framework of organisational policy or that an older individual's needs can be met by other means, such as through relatives or private service providers. This could be

understood in relation to the organisation's limited resources and efficiency measures (Szebehely, 2000; Blomberg, 2004), shifts to family- and market-orientation (Larsson, 2004; Szebehely, 2000) and the de-emphasis of home maintenance as a task for formal eldercare (Szebehely, 2000). It can be taken as the use of their intentional power when care managers inform people selectively about guidelines, thus influencing older people who cannot accept the services offered *not* to apply for assistance. The rejections may also be seen in relation to the moral conditions wherein street-level bureaucrats use their structural power to distribute resources fairly (Christensen, 2001). From the social perspective, this may seem fair, but on the individual level it may mean that some older people do not get the help they need.

Executing a case may be the most common technique applied by the care managers. They use their structural power by informing applicants how the application should formally be structured and categorise the application according to applicable interventions. Care managers in this study were extremely loyal to the organisation's guidelines and policy and made their decisions entirely in agreement with them, a conclusion that is also confirmed in findings by Lindelöf and Rönnbäck (2004). The 'execute' technique is based on care managers having common regulations. Here as well, the consequences may be that some older people do not get the assistance they need. Street-level bureaucrats' aspirations for common guidelines may in part be aimed at distributing resources fairly, but may also be a mechanism used to instil a sense of security in themselves in a decision situation characterised by conflicting demands and great uncertainty (see Andersson, 2004). When administering interventions, street-level bureaucrats can be seen as using their structural power and granting assistance based exclusively on available services. The interventions are taken for granted, and no departures from or adaptations of the standardised range of services are made. Administering interventions instead of individualising care services based on professional expertise makes it easier for street-level bureaucrats to make decisions and conceal the ethical dilemma inherent in the work (Dunér and Nordström, 2003).

When care managers in this study *transform the needs* of older people into the organisation's services, it can be understood as the use of both their structural and intentional power. Supported by legal regulations and their structural power, care managers are extremely thorough when they investigate and assess the needs and circumstances of older applicants, usually in their home environments. The meticulous work they perform in the needs assessment and the reflections on needs that we see in our material lack any correspondence with the formulation of decisions. This process may be interpreted as a way to persuade themselves that a professional needs assessment has been performed and that assistance has been designed jointly with the individual as intended by law (see Corazzini, 2000). Probably it is more of a myth that assessment of

individual needs leads to individualised assistance; instead, street-level bureaucrats classify the needs of older applicants into the administrative categories available (see Ellis, 1999). Care managers negotiate to reach an agreement that everyone can accept, and they balance and negotiate compromise in the wishes of older applicants and their relatives and available interventions. They use their intentional power to achieve consensus based on prevailing moral conditions. Transforming needs so that they can grant assistance can be taken as a way for street-level bureaucrats to avoid having to reject an application and, in so doing, avoid criticism and legal appeals.

The care managers in this study use the '*control*' technique by ascertaining whether older applicants genuinely need assistance. They ensure assistance is provided according to applicable guidelines and decisions and that the assistance corresponds to older people individual's needs. They also verify that assistance is being distributed fairly by monitoring the work of the people performing the service. When they do this, it can be interpreted as the use of their structural power in relation to legal and organisational conditions. By delegating control to others, such as home-helpers, healthcare workers and relatives, care managers relinquish some of their professional and legal responsibility, and decisions are shifted downwards in the organisation. Being monitored after assistance has been granted can be perceived as offensive by many older people. They may feel scrutinised and their sense of powerlessness may increase (see Hardy et al., 1999). Through the monitoring process, street-level bureaucrats may also use their intentional power to influence some older people to eventually accept more assistance. In this way, older people are given an opportunity to get used to being dependent on others, which may eventually make it possible for them to accept more help.

Study III: The roles and functions of informal support networks for older people who receive formal eldercare: a Swedish qualitative study

Aims

The aim of this paper was to investigate the experiences of older people in care-receiving situations and to illuminate the roles and functions of their informal support networks. More specifically, the following research questions were posed: What is the *structure* of older people's support networks? What *interactions* take place in their informal support networks? What is the *function* of their informal support networks?

Results and conclusions

The roles and functions of the informal support networks of older people receiving formal eldercare were described and analysed. The main results point to the importance of informal support with reciprocal relationships, and the value of confidants and emotional support.

In this paper the *structural dimension* of the support network as a whole was described, and the accessibility of the informal part was described and analysed. All of the participants nominated at least one person in their informal network who helped them, usually a relative. Two-thirds of the interviewees mentioned one or more friends or neighbours from whom they received social support. The findings reflect the importance of informal support to older people, even those who also receive formal support. As a consequence of their new circumstances, even nodding acquaintances may become of vital importance and constitute important resources for the individual, a phenomenon often described as the 'strength of weak ties' (Granovetter, 1983).

With regard to the accessibility of the informal support networks of older people, the geographic distance of separation emerged as important. Together with the size of the network, geographic separation affects both the relationships and the support within the networks. The importance of the structural dimension for the interactional and functional dimensions of the network also emerged very clearly. Changes in the accessible networks of older people occur over time, and it became obvious from the study that these occur in different directions. When family and friends pass away, the networks become smaller, but sometimes new contacts are established as a result of the older person's need. As an example, young neighbours may become important in providing a feeling of security for the elders. These findings both support and contradict results from earlier studies of older people's social networks that have shown that network size does not appear to decrease with age (Antonucci and Akiyama, 1987; Phillipson et al., 2001).

In the analysis of the *interactional dimension* of the informal support networks, the frequency and duration of the interactions were variable. Most of the interviewees had frequent contact with both their families and friends, but a few had very little contact with others and expressed feelings of loneliness. Still, the findings, like those of several others (Tomassini et al., 2004; Thorsen, 1990; Tornstam, 1988), do not support the idea of widespread loneliness among older people in modern society. The interviewees emphasised the significance of reciprocity in the symmetry and direction of the interactions. They expressed the importance of both giving and receiving in a relationship, thus reflecting the norm of mutual exchange in social relationships (Mauss, 1989; Finch and Mason, 1993; Kompter and Vollebergh, 1997). It became very clear in the interviews that following socially accepted norms and repaying received support made it easier for older people to ask for help from both family and friends.

Reciprocity was sustained both immediately and over time, and may be interpreted as a means of upholding dignity in a dependent situation.

By the *functional dimension* of the informal support network is meant its ability to provide social support. Many of the elders received regular practical support from both family and friends in their informal network. This support included both help with chores that could have been obtained from formal eldercare, and the execution of tasks that are not performed by formal care. Our results indicate that the availability of formal eldercare does not seem to decrease the level of informal help. The informal support networks adjust their roles and functions both to the wishes of the elders and to the availability of services within formal eldercare. When certain services are offered by formal eldercare, informal carers may carry out complementary tasks, which may lead to a greater coverage of the person's needs (Daatland and Herlofson, 2003a). The functioning of the informal network was problematic when there were family conflicts and restrictions caused by a lack of resources, and both impinged on the provision of both informal and formal help to the older people. When older people need help with duties that are not performed within formal eldercare, a well-functioning informal support network is especially important.

The elders received emotional support from their informal networks and sought advice when they had to make important decisions. This shows the importance of intimate relationships in new and demanding circumstances, and supports previous findings that family and friends provide a bridge between formal help and the older person (Geerlings et al., 2005). The informal support network provided both indirect help, for instance by supporting the elders in their contacts with formal eldercare, and direct help, by providing practical as well as emotional support. However, a few older people with weak informal support networks relied completely on formal eldercare. This group of older people are the most vulnerable, in terms of unsatisfied needs. National reports indicate that Swedish eldercare authorities are aware of the vulnerability of this group and concentrate much of their support on them (Socialstyrelsen, 2005b).

The findings of this paper support the view that informal network relationships and support are negotiated repeatedly over time. The interplay between formal and informal help is negotiated through the interactions among the actors. The outcome of the negotiations has previously been found to depend on the changing cultural norms of social obligation and filial responsibilities. Finch and Mason (1993) found that family members with full-time jobs and small children, who sometimes live far away, have socially acceptable motives for not being able to care for their older relatives. This is in line with the present finding that the older people expressed a fear of being intrusive which inhibited them from asking relatives and/or friends for help. These results confirm the ambivalence of inter-generational relationships (Luescher and Pillemer, 1998; Connidis and Mc Mullin, 2002), as well as the possible negative effects of informal care (La Gaipa, 1990). Informal network

relationships and support should perhaps be regarded as 'individual commitments' rather than as 'fixed obligations' (Phillipson et al*.,* 2001), a view supported by the findings of Daatland and Herlofson (2003a).

Many of the older people were rational actors who consciously used members of their informal support networks for the tasks they saw them as being most fit for. When they have a substantial informal as well as formal network to choose from, such older people may be equal participants in the negotiations about their help and support. This enables them to remain in control of their situation even when they are dependent on support in their everyday life (see Paper I). To conclude, the majority of the older people perceived their informal support network as vital to their lives. The relationships and support within the informal network often contributed to their feelings of belonging, security and well-being. As all of the participants received formal as well as informal help, one may conclude that many older people who need help in their everyday life use the available care resources both rationally and according to individual preferences and prospects. A well-functioning formal and informal network allows individuals to maintain a sense of autonomy in old age even when they have to depend on help from others.

Study IV: 'I want to do what I can': Next of kin helping older relatives who receive formal help - a Swedish qualitative study.

Aims
The aim of this paper was to investigate the thoughts and actions of next of kin providing informal help to their older relatives. More specifically the following research questions are posed: What are the motives of next of kin for providing help? What experiences do the next of kin have of the help-giving situation? What strategies do they develop to resolve conflicting emotions and/or demands?

Results and conclusions
The participation of next of kin in this study has provided information about their experiences of providing help to older relatives. The first conclusion to be highlighted is that helping an older relative is connected with a multiplicity experiences: conflicting emotions, interpersonal relationships characterised by solidarity, ambivalence or conflict as well as clashing roles and norms. The next of kin used various strategies, confrontive, balancing, consensus and evasive, to manage their situation and resolve ambivalence.

Aspects of help giving	Empirical themes	
Motives	Taking it on	Began gradually
		Started more abruptly
		Relatives refused formal help
		The situation enabled it
	Explaining it	Moral
		Emotional
		Out of necessity
Experiences	Positive experiences	Satisfaction
	Dilemmas and ambivalence	Clashing expectations
		Contradictory feelings
		Sense of powerlessness
Strategies	Active	Confrontive
		Balancing
		Consensus
	Accepting	Evasive

Figure 5. Summary scheme of the empirical themes reflecting the motives, experiences and strategies of next of kin

The results show that the motives of next of kin for providing help ranged from moral, apprehended both as personal and internalised values of the surrounding society, to emotional such as love and concern as well as perceived necessity. The motives overlapped with one another and were often conducive to the help giving in varied extent. The moral motives emerged as both context-bound, which may be understood as altruism (Kohli and Künemund, 2003) or personal responsibilities (Finch and Mason, 1993; Ganong and Coleman, 2005), as well as according to societal conventions, which could be interpreted as sense of duty (Kohli and Künemund, 2003) or normative (Ganong and Coleman, 2005). To have no other options than to help their older relatives emerged as a motive as well, thus supplementing the findings of other studies. This may be understood as the next of kin regarding formal eldercare as having the main responsibility to help older people in need but since formal service has failed to do so, they step in and rescue their elders. Considering the cutback of formal eldercare in Sweden, there is reason to believe that informal help given today is forced upon many of the next of kin, often daughters and wives of older people (Sand, 2004, 2005).

Help giving was experienced as leading to feelings of satisfaction as well as to difficult moments. This confirmed results from other studies revealing both positive and negative outcomes of help giving (Walker et al., 1995; Johansson and Åhnfeldt, 1996; Szebehely, 2005). Yet, reducing the conception of informal help giving to the dichotomy of negative versus positive outcomes does not reflect the complexity of the matter (Abel and Nelson, 1990). The findings support the idea of ambivalence as a significant feature of family relationships and interaction. The next of kin apprehended conflicting demands and expectations from their elders, other friends and family members. They perceived clashing demands from the family and work domains of everyday life. And they sensed a variance of emotions as well as a sense of powerlessness. This could be interpreted as both psychological and structurally created constraints (cf. Connidis and McMullin, 2002).

To fully understand these varying motives and experiences, the personal biographies of the next of kin and the history of their relationships with the elder have to be considered. The relationships between the next of kin and their elder have most often lasted over a long period of time. When the need of the elder occurs, an understanding may have emerged over time, implying what help the older person may expect from whom (Finch and Mason, 1993). It is reasonable to assume that the nature of the relationship has an impact on how this agreement looks and what the elder relative may expect from certain next of kin. The motives for help giving may likewise depend on the character of the relationship. The appearance of personal responsibilities and emotional motives such as love and concern may indicate closer relationships, whereas sense of duty and necessity do not imply much about the nature of the relationship. The help giving experiences are quite likely dependent on the history of the relationship between the next of kin and their elders. The more problematic the relationship has been, the more difficult and conflicting experiences may be anticipated.

The strategies employed by the next of kin to manage their situation may be interpreted as ways of coping, where subjective appraisal plays a critical role in adapting to potentially stressful situations (Lazarus, 1993; Paper I). Active strategies, such as confronting, balancing and consensus can be understood as problem-focused coping strategies, usually adopted when the individual perceives the possibility of changing the situation. It is reasonable to presume that available formal eldercare, understood as more structural opportunities, make possible the use of more active or confrontive strategies as the next of kin see more available options to meet the needs of their elder. Evasive or accepting strategies may be appreciated as emotion-focused coping strategies, often used when individuals see fewer options to change the situation.

All of the elders in this study, helped by their next of kin, had help from formal eldercare as well. This supports the idea of a joint responsibility between formal and informal care (Motel-Klingebiel, Tesch-Roemer and von

Kondratowitz, 2005; Sundström, Malmberg and Johansson, 2006). The results also point to the importance of the bridging function of the next of kin, supporting findings in other studies (Geerlings et al., 2005), and add to this understanding their important role as buffers between formal eldercare and their elders. The motives, experiences and strategies of the next of kin in helping an elder should be understood in relation to the specific welfare political context and institutionalised assumptions on how help to older people ought to be organised.

This study has limitations. It is a qualitative study based on a small, non-representative sample, and the results are therefore not statistically generalisable. The results of this study, however, contribute to the understanding that availability of formal help makes possible a shared responsibility between formal and informal help, which in turn enables the next of kin to take on some chores and leave others to home help. But this presupposes that formal help works properly and allows the next of kin and their elder relative to have influence over the formal help as well. Earlier studies have pointed out that interventions might be beneficial when family and professional helpers are conceptualised as partners (Harvath et al., 1994; Walker et al., 1995; Litwak et al., 2003). This study, as well as a recent study of family members' experience of participation in needs assessment of older people (Janlöv et al., 2006b), reveals that some next of kin feel left outside without the possibility of influence or participation. To outline working forms and methods of collaboration between older persons and their formal and informal support networks is an essential question that needs further attention, especially given that next of kin are the main contributors of help to older people living in their own homes.

In the next chapter I will present an overall analysis of the results from the four papers in relation to the general aim of the thesis.

6. Negotiated help in the everyday life of older people

The general aim of this thesis was to reach a more insightful understanding of how help is actually worked out in the everyday life of older people when they can no longer manage on their own. More specifically, the question was how individuals, representing different groups in the help arrangement process think and act in order to organise needed help as well as how they may apprehend the functions of the help. In the four papers of the thesis, the actions of the older persons themselves, the care managers and the next of kin providing help have been described and analysed. In this chapter, I will analyse and discuss these actions on an overall, or collective, level, as interactions among the actors in the everyday life of older people.

The concept of negotiation is applied as a means to understand the process of working out help for older people who can no longer manage their everyday life. Nevertheless, it is important to stress that I have not studied the negotiation process in itself. Instead, the negotiation concept has been my tool to establish a picture from the participants' accounts of how decisions on needed help were reached. The negotiation concept has been frequently used in family research in recent years as a way to emphasise that how families organise their lives is under continual change in our times, and norms and obligations are not fixed or evident. Help and support for kin in extended families has been explored by Finch and Mason (1993); Vabø (1998) has studied negotiations between older people, care managers and next of kin regarding needs assessment. How families negotiate money and work has been investigated by Ahrne and Roman (1997). Bäck-Wiklund and Bergsten (1997) and Bäck-Wiklund and Johansson (2003) have studied negotiations in families regarding the care of children. The way women and men manage equality and solidarity in family relations have been addressed by Björnberg and Kollind (2003).

How and by whom help to older people is carried out in everyday life is interpreted as the outcome of negotiations among the parties involved in the help arrangement process. To work out help needed by an older person is a new situation in everyday life, which involves a need to change routines and establish new ways of acting. The actors concerned negotiate within the frames

within which the situation is understood (Goffman, 1986; Åström, 2005). The negotiation context (Strauss, 1978) settles the shared meanings of individuals in a certain structural context including institutionalised notions of family and welfare state, affecting their view of the proper things to do when older people need help to manage everyday life. Regulations, norms and taken-for-granted assumptions concerning how help to older people should be accomplished influence what we apprehend as the proper thing to do. Due to the changing character of family obligations, gender roles and welfare state responsibility, help to older people is the subject of negotiations among the parties involved. As stated earlier in this thesis, 'help for older people' in Sweden seems to be connected foremost with help from families and/or formal eldercare and is mainly a question for formal eldercare and family. Only a limited share of older people receives help from voluntary organisations and/or private enterprises. The negotiations are subsequently carried out mainly within the families of older people and with formal eldercare. To receive help in everyday life is equally common among older women and older men. Formal help and informal help from someone outside the household are more frequent among women, whereas informal help from someone living in the same household is more common among men. Women carry out approximately 77% of the total amount of help to older or disabled persons (Szebehely, 2005). Thus, there is reason to believe that a majority of the participants in these negotiations are women.

   Strauss (1978) regards negotiations as a way of getting things done. Other possible ways are manipulation, coercion and persuasion. These ways of getting things done are not always possible to separate, though they often are intertwined with one another in the interaction process. A concept closely related to negotiations is bargaining. Since bargaining more often is regarded as an explicit and conscious process where two or more parties attempt to settle transactions between them, it has a more limited use when it comes to understanding how help to older people is worked out (Finch, 1989; Bacharach and Lawler, 1981). In this thesis, negotiation is used as an overarching concept comprising the foregoing ways of getting things done, and may be both explicit and implicit. The parties involved are understood as using both conscious and unconscious strategies in order to achieve aspired results.

   When an older person needs help to manage his or her everyday life, there may be a tacit understanding of what steps to take, who will take them and what older people can expect from whom. This understanding has emerged over time between the involved parties, the older person and his or her next of kin in the surrounding social policy context. The process of working out how needed help will be arranged will have probably started long before the actual need occurs and may be interpreted as a process of negotiation (Finch and Mason, 1993). In the explicit negotiations, two or more parties discuss openly in order to reach an agreement of how needed help will be accomplished in a specific situation. Often, one can presume that these kinds of negotiations will take place

when a sudden and possibly unexpected need occurs. In the implicit negotiations, on the other hand, people develop ways of communicating without open discussion to reach silent understandings of when and by whom something will be done. These communications occurs over time, and when a specific need arises it seems apparent who will help (Finch and Mason, 1993). The parties involved in the negotiation process are in general older people, their next of kin and the care managers. Since the nature of the relationships, assessments, expectations, personal preferences, emotions, institutions, norms and regulations influence the outcome of the negotiation process, it is important to emphasise its complex and multi-faceted character.

In the negotiations, it is vital to acknowledge the importance of power. Power has an objective as well as subjective side, which should both be treated. The objective side of power is the structural context that sets limits to what is possible to obtain within the negotiation. The subjective side includes the motives and intentions of the negotiators, which make the negotiating situation uncertain though the parties never have total control of the situation (Bacharach and Lawler, 1981). When analysing power, the dependence approach (Bacharach and Lawler, 1981) may be used. This approach emphasises that the nature of the parties' dependence on each other as well as the specific issues at hand are negotiated. The dependence of one of the negotiating parties increases the power of the other party. Dependence has two dimensions: alternative and commitment. The number of available alternative sources that may provide a desired outcome decreases this party's dependence on the other. The other dimension of dependence, commitment, refers to the ascribed importance of a certain outcome of the negotiation by one of the parties. An increase in one party's commitment decreases the other party's dependence. The exercise of power is possible when the counterpart is dependent on what you have to offer in an exchange relationship (Blau, 1967). Lines of conduct to remain independent and in control of the situation, even when one needs help from others, may be the possession of strategic resources in the exchange relationship, to have access to alternative exchange partners or to manage without help from others (ibid.).

The dependence approach may be applied in analysing the power of the actors in the negotiations that take place when help is arranged in the everyday life of older people. The alternatives available and the commitment to certain outcomes affects the dependence and thus the power of older people, their next of kin and the care managers involved.

Explicit and implicit negotiations

In the process of working out help to older people the negotiations can be both explicit and implicit (Strauss, 1978; Finch and Mason, 1993). The actors in this thesis have described some of the negotiations as more explicit and some as more implicit. The negotiations in the help arrangement process within the formal network are quite explicit, probably a consequence of the fact that the parties involved often meet for the first time. The arrangements of help are settled in face-to-face meetings between the care manager, the older persons and, most often, representatives from the elder's informal network. In these meetings, the explicit applications for formal help of older persons, sometimes made by their next of kin, are investigated.

The care managers in the study, before they could make their decision, needed an explicit statement from the older persons that they agreed to receiving formal help. The negotiation is limited by structural conditions, which may be described as the objective side of power in the negotiation (Bacharach and Lawler, 1981), but the knowledge of these conditions is not equally distributed among the actors in the negotiation. The care managers, through their professional expertise, have a thorough knowledge of the legal and organisational conditions encompassing the decision-making process, which increases their power. This knowledge may be used to achieve goals in the negotiation originating from their motives and intentions, which are understood as the subjective side of power in the negotiation (Bacharach and Lawler, 1981). Further, the care managers often have to negotiate with both the older people and their next of kin to reach agreements that can be accepted by all parties and fit in with the conditions encompassing their decision-making process (see Paper II). The older persons, on the other hand, may avoid applying for formal help which they do not think they could receive in order to prevent being denied. Conversely, they could agree to accept help which they do not think they need because they do not want to disappoint their next of kin. Further, they may adapt to applicable interventions within formal eldercare and avoid complaining about the help they receive (see Paper I).

The next of kin of older people often make the first contact with formal eldercare. At times this is done because their older relatives wanted them to and at other times it is done on their own initiative since they think their older relative needs help. The latter may be understood as implicitly making their older relative understand that they want him or her to accept formal eldercare. Yet, when the care manager from formal eldercare gets involved, he or she will need an explicit application from the older person, which sometimes puts the next of kin in a situation of perceived conflicts between respecting the integrity of their elder and their feeling of responsibility that their elder's needs were met (see Paper IV). Some of the next of kin may then feel 'left outside', with no possibility of influencing the outcome of the negotiations about formal help

since they have no legal rights to represent their elders or to be considered as equal partners in the needs assessment or help arrangement processes regarding formal help (cf. Janlöv et al., 2006b).

Within the informal network, the negotiations are more implicit and take place within established and long-lasting relationships. The older person and his or her next of kin may have established a tacit understanding on how to accomplish the help in a process starting long before the need occurs. This understanding includes expectations about what steps to take and who should take them. As Finch and Mason put it: 'The process of negotiation can only be understood with reference to the biographies of the individuals involved and the history of their relationships, as they have developed over time. … However, that does not mean that the outcomes of negotiations are predetermined' (1993: 79). Even though these negotiations may be interpreted as mainly implicit, probably because of their lengthy course, they include explicit elements as well. Sometimes, the older persons in the study declared explicitly that they did not want help from formal eldercare and that they expected their next of kin to help them. Certain older persons had worked out ideas about what to expect from whom in their informal support networks, taking into account other obligations that these individuals might have (see Paper III). These ideas implicitly affect the negotiations as the older persons sometimes hold back their explicit demands for help. On the other hand, some next of kin clearly stated what they could and could not help their old relatives with. Furthermore, the next of kin may have assumptive beliefs on what is expected from them, both from their elder and from the other kin group. Ideas about the older person's needs and expectations, their ability to cope without informal help and fear of disappointing the older relatives could restrain the next of kin from explicitly denying help. Some next of kin explicitly told their elders that they had to accept formal help. Others had open discussions among the kin group and agreed on a job sharing among them (see Paper IV). This witness about how the process of working out how and by whom needed help would be accomplished included many tacit understandings, established by negotiations within the informal network.

Dependence – independence balance

The power of the actors involved in the negotiation process in the everyday life of older people, namely the older persons, the care managers and the next of kin, may be analysed with the help of the dependence approach (Bacharach and Lawler, 1981). This approach emphasises that the actors involved negotiate not only the specific issues at hand, what help will be accomplished and by whom it will be performed, but also the nature of their dependence on each other. The dependence of one of the actors is seen as increasing the power of the other

actors involved. Dependence may be analysed through its two dimensions: alternative and commitment.

The older persons participating in this study wished to stay independent as long as possible; when a situation arose where they could not manage without help, they wanted to remain in control and thereby achieve a feeling of independence (see Paper I). They described various strategies to obtain a feeling of independence, such as continuing to struggle with their everyday chores, adapting to circumstances through playing down their requirements and getting help from several sources. These strategies may be interpreted as a way to increase their power in the negotiation process where the needed help is worked out. Their dependence is decreased by their efforts to use several available sources for help and thus using all available alternatives. The older persons may shape the importance of achieving help from other parts, i.e., limiting the commitment to this outcome, by struggling on without help or adjusting or playing down their demands. To have many alternative sources of help to choose from, both formal and informal, increases the older person's power. These modes of action, emerging from the empirical data, may be seen as increasing the older person's power in the negotiations by decreasing their dependence.

The care managers participating in this study strived to bring different opinions in line with each other to achieve solutions that could be accepted by the actors involved in the negotiations, as well as striking a balance among the legal, organisational and moral conditions encompassing the decision process (see Paper II). If these conditions afford the care managers many alternative ways to offer help, adjusted to the needs and preferences of the older persons and their next of kin, their power increases. If others cannot carry out the help performed by formal eldercare, the older persons' alternatives are few and they may be dependent on formal help, which increases the care manager's power. The care manager's commitment to certain outcomes is affected by its importance for their ability to fulfil their professional obligations. Their commitment may increase when it is perceived as important that the older persons accept help from formal eldercare, which increases the older person's power. This may be the case when older people are considered to be at risk of suffering if they do not accept help. The care manager might be accused of falling short in their moral obligations. At some instances it may be the next of kin that puts pressure on the care manager; when the risk for the older person is obvious, the power of the care manager decreases. If the risk is lesser, the care manager's power increases, as it may be the next of kin who are most committed to the outcome of the older person's acceptance of help.

Finally, the next of kin participating in this study described different circumstances leading to their help giving (see Paper IV). When they felt that they had the opportunity to provide expected help, this could be interpreted as a quite powerful situation, especially if the older person was dependent on their

help giving. The commitment of the next of kin to other solutions was low and the older person's alternatives were few. On the other hand, if the next of kin perceived no alternatives but performing help to the older person, their power decreased. This may well be the case when they felt forced to help because of moral obligations or lack of alternatives within formal eldercare. If the next of kin had other alternatives, such as formal help, to see to it that their relatives got the help they needed, they were not dependent on help giving. If it was very important for the next of kin, and they were very committed not to hurt the feelings of their older relative and to ensure that the elder was happy with the solutions accomplished, their dependence on a certain outcome increased and their power decreased. The outcome they strived to achieve could be to make their elder accept help, from themselves or formal eldercare, or to make their elder accept their limited scope of providing help.

Conclusions

My hope is that the results of this study may be a contribution to a knowledge base of how autonomy in old age can be promoted to enhance the well-being of older people and their next of kin. These issues are frequently discussed among professionals working out policy and plans on an overall level as well as among practitioners and interest groups on a local level, and I hope this thesis may be a useful input. I have endeavoured to illuminate the lived experiences of older persons who need help in their everyday life. Besides the older persons themselves, the experiences and actions of two other actors participating in the older person's everyday life have been described and analysed: the care manager and the next of kin. From the main results of the thesis, the following conclusions may be drawn.

The older persons' striving to maintain control became obvious. The desire for independence overshadowed other desires and directed their actions. When the older persons could not manage unaided, they used various strategies to maintain control and thereby the feeling of autonomy. They approached their situation along a continuum ranging from active through adaptive to passive. Older persons who needed help in their everyday life used available resources both rationally and according to individual preferences and prospects. A well-functioning formal and informal support network allowed individuals to sustain autonomy and control in old age even when they had to depend on help from others.

The care managers endeavoured to make both ends meet in the decision process. In order to perform their tasks and carry out their mission, the care managers developed various techniques and struck a balance between various demands and expectations. They used their discretion only to a limited

extent as they allowed themselves to be controlled by organisational and administrative guidelines rather than using their professional expertise to influence the organisation's services and meet the individual needs of the older applicants. I hope that these results will open up a professional discussion about the use of discretion in social work with older people and that such a discussion will increase the consciousness of social service professionals about the range of possibilities in mediating help.

The next of kin used various strategies, confrontive, balancing, consensus and evasive, to manage their situation and resolve ambivalence. Helping an elder is connected with a multitude of motives and experiences: conflicting emotions, interpersonal relationships characterised by solidarity, ambivalence or conflict as well as clashing roles and norms. The next of kin acted both as bridges and buffers between their elder and formal help. Some of them felt 'left outside', without any influence over the performance of formal help. Available formal eldercare may be understood as enabling the next of kin to have alternative ways to meet the needs of their elders, thus facilitating informal help giving as a free choice of both the next of kin and the elder. This presupposes that formal eldercare is capable of meeting the experienced needs of older people and their next of kin and allows them to have influence over the formal help as well. Considering the cutbacks in formal eldercare in Sweden, there is reason to believe that informal help giving today is forced upon many next of kin, especially the wives and daughters of older people.

The results of this thesis have informed us that both formal and informal help may function as resources, or means, for older people who can no longer manage unaided to maintain control and autonomy. For formal as well as informal help providers the help carried out by the other party may function as a relief of both responsibility and workload. To outline working forms and methods of collaboration between older people and their informal and formal support networks is an important question that needs further attention. There is a need to take both older people as well as their help-providing next of kin into account when developing existing and new methods of formal help. The results of this study indicate that the next of kin of older people are not considered to be equal partners in the negotiations surrounding the decisions and provision of formal help, presumably an effect of the individual direction of legislation. Considering that the majority of help to older people living in their own homes is carried out by their next of kin, the extended family seems to be a unit of great importance in Sweden today. This calls for a discussion on the roles and rights of help giving next of kin to older people in order to promote working methods and form partnerships between formal and informal help. Further, the role of the care managers in this process has to be highlighted and a professional discussion encouraged regarding the aims of social work with older people. To find ways to organise flexible and tailored help corresponding to experienced needs of both older people and their next of kin is of vital importance.

In the overall analysis of the interactions among the actors in everyday life of older people who can no longer manage on their own, the use of the negotiation concept has enabled us to acknowledge the variation and complexity of the process of organising needed help. The empirical data on which this thesis is based do not include evidence on the nature of the relationships between the actors involved or the personal biographies of the participating individuals, which most probably influence both the nature and outcomes of the negotiations. This is a consequence of the study's focus on the participants' understanding of the needs of the older people and how they act in order to arrange the fulfilment of these needs, which points to an important area for further studies.

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