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## **PARTICIPATION IN NEEDS ASSESSMENT OF OLDER PEOPLE PRIOR TO PUBLIC HOME HELP Older persons', their family members', and assessing home help officers' experiences.**

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2006

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*Citation for published version (APA):*

Janlöv, A.-C. (2006). *PARTICIPATION IN NEEDS ASSESSMENT OF OLDER PEOPLE PRIOR TO PUBLIC HOME HELP Older persons', their family members', and assessing home help officers' experiences*. [Doctoral Thesis (compilation), Department of Health Sciences]. Department of Health Sciences, Lund University.

*Total number of authors:*

1

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Lund University, Sweden 2006

# **PARTICIPATION IN NEEDS ASSESSMENT OF OLDER PEOPLE PRIOR TO PUBLIC HOME HELP**

Older persons', their family members', and assessing  
home help officers' experiences

av

Ann-Christin Janlöv  
Leg sjukssköterska

AKADEMISK AVHANDLING

som med vederbörligt tillstånd av Medicinska Fakulteten vid Lunds universitet för avläggande av  
doktorexamen i medicinsk vetenskap kommer att offentligen försvaras i  
Hörsal 1, Vårdvetenskapens hus, Baravägen 3, Lund  
onsdagen den 11 oktober 2006 kl. 09.00.

Fakultetsopponent

Professor emeritus  
Margareta Grafström  
Stockholm

Organization LUND UNIVERSITY	Document name DOCTORAL DISSERTATION	
Department of Health Sciences P.O.Box 157 SE-221 00 LUND SWEDEN	Date of issue      October 11, 2006	
	Sponsoring organization	
Author      Ann-Christin Janlöv		
Title and subtitle PARTICIPATION IN NEEDS ASSESSMENT OF OLDER PEOPLE PRIOR TO PUBLIC HOME HELP. OLDER PERSONS', THEIR FAMILY MEMBERS' AND ASSESSING HOME HELP OFFICERS' EXPERIENCES.		
Abstract  <b>Aim:</b> The overall aim of this thesis was to illuminate older persons' experience of becoming in need of public home help and their family members' experience of this situation. Further, the aim was to illuminate experiences of participation in the needs assessment process of older people and influence on decisions about public home help from the perspective of older needs-assessed persons, their family members, assessing home help officers and external home help officers. <b>Method:</b> A qualitative hermeneutic approach and triangulation of sources was used as the methodological strategy. A purposive sample of older persons aged 75 and over, who had gone through the needs assessment process and lived in their ordinary homes, was selected consecutively, retrospectively from home help officers' files on decisions about public home help in two municipalities. Data were collected about the same topic – older needs-assessed persons and family members' participation in the needs assessment, through personal interviews with those involved, the older needs-assessed persons (n=28, age 75–96, Paper I–II), family members (n=27, age 42–93, Paper III) the assessing home help officers (n=5, age 29–50, 26 interviews), and an additional focus group interview with home help officers (n=9) (Paper IV). <b>Analysis:</b> A qualitative content analysis was used (Paper I–IV) to interpret concrete and abstract meaning content, the latter inspired by hermeneutics to convey the meaning of the utterance, which in each study was interpreted as one overarching category that encompassed principal categories and sub-categories. <b>Findings:</b> To the older persons becoming in need of public home help it meant "Experiencing discontinuity in life as a whole – the countdown has begun" (Paper I). Further, their participation and influence on decisions about public home help when undergoing needs assessment and receiving public home help meant "Having to be satisfied, adjust, and walk a fine line when balancing between needs and available help" (Paper II). To family members with an older next of kin becoming in need of public home help, their participation in the needs assessment procedure and the decisions about their next of kin's public home help meant "Feeling disconfirmed or confirmed in the needs assessment, when feeling pressed by the responsibility and struggling to balance the needs of the family" (Paper III). To home help officers, the participation of older help recipients and family members in the needs assessment procedure and the decisions made about public home help meant "Having to establish boundaries towards family influence and at the same time use them as a resource" (Paper IV). These findings seem to correspond to and provide an understanding of the meaning of older needs-assessed persons' and family members' participation in the needs assessment as a whole. <b>Conclusion:</b> The needs assessment marked a turning point that can be understood and framed as a larger distressing life transition for both older persons and family members, which could cause difficulties for adequate participation in the needs assessment. Both older persons and family members experienced the needs assessment as difficult to comprehend, they lacked knowledge regarding aims, procedures, and rights and had not perceived what was the actual needs assessment. The older persons' actual ability to participate and communicate varied, and family members could be necessary as representatives, which created a moral conflict for the home help officers. Home help officers' attitudes towards their professional responsibility seemed to influence their management of older persons' and family members' participation. The needs assessment focused solely on the older individual's present situation and mainly physical and practical disabilities and needs, while mental, existential, social and medical needs tended to be neglected. The older persons and family members had little opportunity to participate in the process or to influence the decisions. Older persons felt that help offered in accordance with municipal guidelines had to be accepted, and family members felt mainly disconfirmed in the needs assessment encounter. The forms of the needs assessment and organisational conditions must be reviewed to promote the sense of coherence and participation of those involved.		
Key words: age 75 and older, transition, experience, family participation, needs assessment, home help officer/care manager, public home help		
Classification system and/or index terms (if any):		
Supplementary bibliographical information:	Language English	
ISSN and key title: 1652-8220 Bulletin from the Department of Health Sciences, Lund University	ISBN 91-85559-20-2	
Recipient's notes	Number of pages    165	Price
	Security classification	

Distribution by Ann-Christin Janlöv, Lund University, Department of Health Sciences,  
P. O. Box 157, SE-221 00 Lund, SWEDEN

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ISSN 1652-8220

ISBN 91-85559-20-2

Printed in Sweden by Wallin & Dalholm Boktryckeri AB

Lund University, Department of Health Sciences Lund,

Listen to the body, otherwise it screams.  
Listen to the soul, otherwise it falls silent.

Bo Strömstedt



## CONTENTS

ABSTRACT .....	7
ABBREVIATIONS AND DEFINITIONS .....	8
ORIGINAL PAPERS .....	10
INTRODUCTION .....	11
BACKGROUND.....	12
Ageing, old age and becoming in need of public home help .....	12
Changing contexts and family help .....	16
The public home help context of older people .....	18
The needs assessment for public home help .....	19
Participation, influence and power .....	24
Those involved in the needs assessment.....	26
The older help-seeking persons .....	26
The family members .....	28
The home help officers .....	29
AIMS.....	33
METHODS .....	34
Context of Swedish public home help .....	34
Design.....	35
Methodological approach .....	35
Theoretical framework.....	37
Researcher's pre-understanding.....	37
Entering the field and gaining access.....	38
Participants and context .....	39
Participants.....	39
Context of the study .....	40
Instrument and data collection.....	40
Interviews .....	40
Data analysis .....	42
Qualitative analysis .....	42
Qualitative content analysis .....	43
Ethical considerations.....	44
FINDINGS.....	46
Context of the participants and the needs assessment.....	46
The overarching categories .....	47
Entering into the process of needs assessment .....	47
The older persons' perspective .....	48
The family members' perspective.....	50
The home help officers' perspective .....	51
The needs assessment and encounter.....	52
The older persons' perspective .....	52
The family members' perspective.....	53



The home help officers' perspective .....	54
The outcome and follow-up of the decision .....	56
The older persons' perspective .....	56
The family members' perspective.....	57
The home help officers' perspective .....	58
The focus group perspective .....	58
DISCUSSION .....	60
Methodological considerations.....	60
Trustworthiness .....	60
The qualitative design, triangulation and hermeneutic frame.....	61
Informants .....	62
Interviews .....	63
Analysis.....	65
General discussion of findings .....	66
Entering into the process of needs assessment.....	66
The needs assessment and encounter .....	70
The outcome and follow-up of the decision.....	75
CONCLUSIONS AND IMPLICATIONS .....	77
FURTHER RESEARCH .....	79
SUMMARY IN SWEDISH .....	80
ACKNOWLEDGEMENTS .....	86
REFERENCES .....	87
PAPER I–IV	

## ABSTRACT

**Aim:** The overall aim of this thesis was to illuminate older persons' experience of becoming in need of public home help and their family members' experience of this situation. Further, the aim was to illuminate experiences of participation in the needs assessment process of older people and influence on decisions about public home help from the perspective of older needs-assessed persons, their family members, assessing home help officers and external home help officers.

**Method:** A qualitative hermeneutic approach and triangulation of sources was used as the methodological strategy. A purposive sample of older persons aged 75 and over, who had gone through the needs assessment process and lived in their ordinary homes, was selected consecutively, retrospectively from home help officers' files on decisions about public home help in two municipalities. Data were collected about the same topic – older needs-assessed persons and family members' participation in the needs assessment, through personal interviews with those involved, the older needs-assessed persons (n=28, age 75–96, Paper I–II), family members (n=27, age 42–93, Paper III) the assessing home help officers (n=5, age 29–50, 26 interviews), and an additional focus group interview with home help officers (n=9) (Paper IV).

**Analysis:** A qualitative content analysis was used (Paper I–IV) to interpret concrete and abstract meaning content, the latter inspired by hermeneutics to convey the meaning of the utterance, which in each study was interpreted as one overarching category that encompassed principal categories and sub-categories.

**Findings:** To the older persons becoming in need of public home help it meant “Experiencing discontinuity in life as a whole – the countdown has begun” (Paper I). Further, their participation and influence on decisions about public home help when undergoing needs assessment and receiving public home help meant “Having to be satisfied, adjust, and walk a fine line when balancing between needs and available help” (Paper II). To family members with an older next of kin becoming in need of public home help, their participation in the needs assessment procedure and the decisions about their next of kin's public home help meant “Feeling disconfirmed or confirmed in the needs assessment, when feeling pressed by the responsibility and struggling to balance the needs of the family” (Paper III). To home help officers, the participation of older help recipients and family members in the needs assessment procedure and the decisions made about public home help meant “Having to establish boundaries towards family influence and at the same time use them as a resource” (Paper IV). These findings seem to correspond to and provide an understanding of the meaning of older needs-assessed persons' and family members' participation in the needs assessment as a whole.

**Conclusion:** The needs assessment marked a turning point that can be understood and framed as a larger distressing life transition for both older persons and family members, which could cause difficulties for adequate participation in the needs assessment. Both older persons and family members experienced the needs assessment as difficult to comprehend, they lacked knowledge regarding aims, procedures, and rights and had not perceived what was the actual needs assessment. The older persons' actual ability to participate and communicate varied, and family members could be necessary as representatives, which created a moral conflict for the home help officers. Home help officers' attitudes towards their professional responsibility seemed to influence their management of older persons' and family members' participation. The needs assessment focused solely on the older individual's present situation and mainly physical and practical disabilities and needs, while mental, existential, social and medical needs tended to be neglected. The older persons and family members had little opportunity to participate in the process or to influence the decisions. Older persons felt that help offered in accordance with municipal guidelines had to be accepted, and family members felt mainly disconfirmed in the needs assessment encounter. The forms of the needs assessment and organisational conditions must be reviewed to promote the sense of coherence and participation of those involved.

## ABBREVIATIONS AND DEFINITIONS

### ABBREVIATIONS

ICF	International Classification of Functioning, Disability and Health (WHO, 2002).
SOC	Sense Of Coherence, a construct that refers to the extent to which one sees one's world as comprehensible, manageable and meaningful (Antonovsky and Sourani, 1988).
FSOC	Family Sense Of Coherence (Antonovsky and Sourani, 1988).
QoL	Quality of Life

### DEFINITIONS

Client/contractor organisation	An organisation where the home help officer is responsible for needs assessment and decisions about public home help, but not for the delivery. Provision of public home help and management of the care workers is the responsibility of the contractor management.
Close family member	Synonymous with family member (see below), although the proximity is emphasised.
Family	The term family refers to the older person as well as spouse, children, siblings and other next of kin.
Family member	The individual related through family ties to the older needs-assessed person as spouse, child, sibling, and other next of kin.
Family help	Help provided to the older help recipient by family members.
Help	Synonymous with care and with no distinctions between informal or formal.
Help recipient	The older person receiving family help or public home help.

Help seeker	The older person seeking public home help, variously named help seeker, needs-assessed, help recipient, recipient, depending on the context and position in the needs assessment process.
Holism	A scientific direction arguing that phenomena should primarily be studied holistically, and that the whole cannot be viewed as just the sum of its parts (Eriksson, 1992).
Holistic view of person and needs	A comprehensive view of a person as a complex, integrated whole with bio/physical-psycho-social-existential dimensions and thereby needs.
Home help officer with integrated function	A professional within municipal elder care (often social worker) responsible for the needs assessment, the provision of public home help as well as management of staff providing the help.
Home help officer with specialised function	A professional within municipal elder care (often social worker) responsible of the needs assessment but not the actual provision and care workers, which is the responsibility of the manager of the contractor organisation.
Needs	Needs are related to individual bio/physical-psycho-social-existential dimensions (see holistic view of a person). In addition needs are viewed in line with von Wright (1995) as “things which it is bad to be without”.
Needs assessment	In relation to public home help needs assessment concerns application, assessment of needs and entitlement to public help, decision and follow-up (National Board of Health and Welfare, 2002b).
Older person	A person aged 75 years and older.
Public home help	Synonymous with municipal home help services and public care and service, providing “help in the home” (personal care and service).

## ORIGINAL PAPERS

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

- I Janlöv A-C., Hallberg IR., Petersson K. 2005. The experience of older people of entering into the phase of asking for public home help – a qualitative study. *International Journal of Social Welfare* 14, 326–336.
- II Janlöv A-C., Hallberg IR., Petersson K. 2006. Older persons' experience of being assessed for and receiving public home help: do they have any influence over it? *Health and Social Care in the Community* 14 (1), 26–36.
- III Janlöv A-C., Hallberg IR., Petersson K. Family members' experience of participation in the needs assessment when their older next of kin becomes in need of public home help: An interview study. *International Journal of Nursing Studies*, online publication, in press, to be published 2006.
- IV Janlöv A-C., Hallberg IR., Petersson K. Needs assessment prior to public home help from the home help officers' perspective: their view of older help recipients' and family members' participation – An interview study. *Health and Social Care in the Community* (Submitted 2006).

The papers have been reprinted with the kind permission of the respective journals.

## INTRODUCTION

To enter into the phase of becoming in need of public home help in old age, or to have a next of kin in this situation can be a straining life transition. Increased frailty in later life and becoming in need of help and/or having family members in this situation may be an inescapable fact of life, but individuals and families are variously equipped to handle these changes. Older people already have a low power position in society and are found to be disadvantaged in exercising power over their care and social service (Bentley, 2003), Family members and other next of kin may be needed to strengthen their position in contacts with care and service professionals and frequently do so. In both an international and a Swedish perspective families are estimated to become increasingly involved in help giving due to the growth in the share of elderly, reduced economy in the public sector, together with the common policy that older people should be able to remain living in their own homes in spite of extensive needs of care and social service (Lagergren, 2002). Families already provide a growing part of help to older members due to public cutbacks of municipal home help (Sundström et al., 2002). Public care and service is often not asked for until the help-giving situation has become unmanageable. The needs assessment of older people prior to getting access to public home help has received more attention. This due to the central importance of the home help officers' decisions as to what public home help individuals will receive. The formal processes of the needs assessment has been studied mainly from an institutional perspective. Little is known about how the home help officers view the encounter and interactions with the involved. Insufficiencies have been reported and it has been shown that older people's mental (Challis and Hughes, 2002), psychosocial, existential (Fernow, 1994; 1997; Hammarström, 2002) and social (National Board of Health and Welfare, 2002a) needs were inadequately addressed. The needs assessment encounter has received less attention. Family members frequently participate in needs assessment encounters to represent both the help seekers and themselves as helpers. This has been found to be an imbalanced encounter in terms of power, taking place on the home help officers' terms (Richards, 2000; Hellström Muhli, 2003; Duner and Nordström, 2005a). There is rather little research about the needs assessment encounter and even less about what happens between those involved. Thus, knowledge is needed about how older help-seeking persons, family members and assessing home help officers experience participation and potential for influence for the family, whether families are involved in the decision making about how best to match their needs for healthy transition processes into a manageable life situation.

## BACKGROUND

### Ageing, old age and becoming in need of public home help

When approaching the context of becoming in need of public home help in later life, there are aspects that need to be considered. While old age in general is spoken of in terms of chronological age, there are other dimensions of old age that may differ from this general conception of “being old”. There is no international consensus about how to define old age, although in Sweden and several other countries the retirement age (about age 65) is often defined as the start of old age. Different ways of dividing the span of old age into subgroups have been suggested, and one that is commonly used is: young old (age (65–74), mid old (age 75–84), and old old (aged 85 and over), (Given and Given, 1989). Ageing encompasses the whole life span and should be seen from e.g. biological, psychological and social perspectives (Bondevik, 1994; Dehlin et al., 2000). Ageing has by tradition been dominated by the medical perspective, with a focus on biological ageing concerning irreversible cell changes and dysfunctions. The psychological perspective on ageing concerns experiences of living through life and interpretation of one’s own life, feelings and meaning, while the social perspective on ageing concerns the impact of experiences and roles earlier in life and resources and abilities to adapt to the transitions in old age (Tornstam, 2005). These dimensions interact to give a highly individual totality, involving a gradual or speedy decline in bodily functions. The ageing process is not uniform, rather it is complex, varied and influenced by life stressors, lifestyles and social support systems (Koch and Webb, 1996). Longitudinal studies reflecting the past indicate that in general people are healthy up to the age of 79–80 (Lagergren, 2002). The natural ageing process and decline can be difficult to distinguish from morbidity and co-morbidity (Daatland and Solem, 2000) since health complaints are common in late life. A Swedish cross-sectional questionnaire study of older people aged 75–105 (n= 4277, mean age 83,6) investigated e.g. the patterns, type and degree of health complaints. Six categories of health complaints were identified, with communication (80.9%), mobility (66.6%), psychosocial (61%) being as most prevalent and thereafter elimination (42.5%), respiratory-circulatory (38.2%) and digestion-related problems (36.4). Age, socioeconomy and female gender most strongly predicted low physical quality of life (QoL), and psychosocial problems, age, socioeconomy and female gender most strongly predicted low mental QoL (Stenzelius et al., 2005). From the findings it was concluded that not only mobility but also psychosocial aspects need to be assessed and addressed in daily practice to a greater extent.

Theories about ageing usually start from questions about how the physiological changes, orientation towards new goals, acceptance of one’s own life and ending of life and death are handled (Schaie and Willis, 1991). Psychological and psychosocial ageing theories have tried to explain what influences individual ageing. Havighurst and Albrecht (1953) developed a theory that emphasised maintenance

of activities as essential for ageing well, while Cumming et al. (1960) developed a theory which upheld disengagement as a natural part of ageing. Erikson (1982) formed a psychosocial theory of personality development through the solution of specific problems of each of eight life-cycle stages. Achieved balance and successful solution of each stage were prerequisites for successful personality development and ageing, and the last stage would be wisdom rather than despair. Joan Erikson (1997), the wife and collaborator of Erik Erikson, extended the theory with a ninth stage of very old age, namely the eighties and nineties, not covered in the original theory. In this stage despair is viewed as a definite close companion due to the loss, demands, re-evaluations and daily difficulties that this stage entails. The societal context of individual ageing is highlighted and viewed as excluding rather than involving older people. Old age and ageing in western societies is viewed with shame and disregard rather than connected with wisdom. Further, Baltes and Baltes (1991), based on e.g. assumptions that the ageing process varies between individuals, developed a model of successful ageing named “selective optimisation with compensation.” The essential thing is balancing gains and increased loss in terms of a general adaptation process. Areas have to be selected due to limitations as a result of ageing, energy invested in chosen crucial areas and loss of specific abilities compensated by other abilities. This is viewed as offering most people a successful ageing.

Tornstam (1994), based on his own research, developed a theory suggesting that living into old age encompasses a potential for gero-transcendence, a final stage towards wisdom, similar to Erikson’s last life-cycle stage. Two dimensions, cosmic and ego transcendence, were identified. The former is connected with changes in perceptions of time, space, life and death, and the latter with the self and relations to other people. Gero-transcendence relates to a spiritual dimension with a shift from a materialistic to a more cosmic transcendence with concomitant increased life satisfaction. The process was believed to encompass redefinition of personal reality that could be obstructed or accelerated. Cosmic transcendence was found to correlate with higher social class. A recent cross-national European Study about life satisfaction (Ferring et al., 2004) included the Netherlands, Luxemburg, Italy, Austria, the UK and Sweden (n=12,478, aged 60–89). Factors of importance were: social resources, financial resources, feeling greatly hindered by health problems and low self-esteem, and there seemed to differ depending on one’s personal situation and the social and political system. This indicates that older people and their resources to achieve gero-transcendence and probably also life satisfaction may differ in relation to their own and environmental resources but that those can be promoted by support.

Antonovsky (1987) developed a model/theory of sense of coherence (SOC), derived from an analysis of “generalised resistance resources”. This suggested that resources such as social support, socioeconomy, religious faith, work role autonomy and cultural stability coloured life experiences in terms of consistency, underload-



overload balance and participation in socially valued decision making. SOC encompasses the three intertwined components comprehensibility, manageability and meaningfulness. According to Antonovsky and Sourani (1988/2003), SOC means flexibility in selecting appropriate coping behaviours. Assumptions that the family construction of their reality was related to perceived family adaptation resulted in “family sense of coherence (FSOC)” (adaptation) being tested in a study of 60 disabled men and their wives, who answered a FSOC questionnaire both separately and simultaneously. Disagreement constituted low FSOC, and vice versa. The findings strongly supported the hypothesis, in that – not surprisingly – the couples with strong FSOC were better adapted. This indicates the meaningfulness of taking more than the individual recipient into account when planning public care and service. These previously described theories are some of the prominent ones that have in common with other theories that they do not fully grasp and explain the ageing process and what is important for ageing well, although they all contribute parts of it that can increase the understanding as a whole.

Transitions occur through the whole life span, although late life is a time of multiple transitions that can be difficult to handle due to frailty. Many transitions are undesired but there are also welcomed ones. Barba and Selzer (1995) define a life transition as initiated when a person’s reality is disrupted through critical events or decisions, and they argue that the theory of life transition concerns the process that helps the person to bridge from the disrupted reality to a new construction of personal reality. To resolve the sense of uncertainty with a sense of control is part of the healing process. The main purpose of the restructuring is to create new meanings when old ones have been fractured. Schumacher et al. (1999) and Meleis et al. (2000) further described a transition as a passage between two stable periods of time, meaning a move from one life phase, situation or status to another. It is a process over time, when the person experiences upheavals in his or her world, often followed by a sense of loss of what has been familiar and valued. Therefore, transitions are risky phenomena since they are related to vulnerability in experiences, interactions and environmental circumstances, and thus lead to potential harm, problematic resilience or unhealthy coping. Further, transitions involve fundamental changes in one’s view of self and the world and are marked by a turning point, a process that takes time, changes in identity, roles and behaviour. For instance, in a Swedish study by Nilsson et al. (2000) fifteen persons aged 85–96 living in their own homes were interviewed, of whom eight felt old. Feeling old was characterised by: being able to date the beginning of this feeling, fear of helplessness and being unable manage one’s own situation, not recognising one’s former self and feeling different from others. The comprehensive understanding of the findings was that persons feeling old were in a phase of transition. In the latter study as well as according to Schumacher et al. (1999) it was concluded that professionals do not recognise or support older persons’ and their family members’ particular needs in transitions. If care and service professionals are to apply a more

holistic approach when encountering older people and their families, more knowledge about transition processes may be needed.

To become in need of help and become dependent on others to manage daily living is a major transition in later life. From a life-course perspective, Arber and Evandrou (1997) view transitions in health and help needs as one of three major transitions in old age (among transition from paid work, family roles and living arrangements). Fromm (1943 /1993) viewed the human struggle for independence and freedom as natural in relation to the desire to decide about one's situation and life. Gilleard (2002) argued that the moral identity of old age with wisdom from medieval Europe has been replaced with an identity of lack and neediness due to increased intellectual and commercial currents. Arber and Evandrou (1997) agreed that the identity of old age and ageing is culturally produced and socially structured. Contemporary societal value systems in most Western countries highly esteem people's capability and productivity (Torres, 2001; Strandberg, 2002), which pre-determines a lower societal value for people in old age. Adjustment to ageing in later life means having to cope with decreased social value, unclear role expectations, role discontinuity, loss of status and a low degree of motivation to learn new roles. This transition process influences perception of self in terms of how one's social value is perceived from the environment. These concern independence, efficiency and productivity. One's social worth is intertwined but can also be distinguished from how one's self-worth is perceived, which concerns the existential dimension, with meaning, hope and trust (cf. Tornstam, 2005). Decreased functional abilities and dependency tend to affect personal identity and sense of self since this is closely tied to what a person does and his/her relationships with others (Christiansen, 1999). The notion of dependency is symbolic and often associated with negative connotations, although dependency can be viewed as an inevitable term of life that varies over time. Thus, dependence and independence should not be seen as dichotomies, but rather as a part of a spectrum that encompasses varying interdependence and reciprocity (Arber and Evandrou, 1997). It is important to further develop measures of objective aspects of dependency and needs (becoming/-being in need of help, receiving help), whilst human experience and meaning require more attention since they are influenced by the individual's life course, family, social group and society. Individuals' and families' transitions to becoming in need of help and dependency are in turn dependent on societal values and norms that rather counteract healthy transition processes, thus a primary change that upgrades dysfunctional and older people's societal value is called for. This may be reflected within elder care and the public home help context, which can secondarily increase individuals' self-worth and empowerment to participation.

## Changing contexts and family help

The changing world and family structures as a whole also affect older people and family help. Ideas of the family as a concept vary with focus, discipline, epoch, social system and culture. The family system theory's fundamental assumption is that the family is a system more than the sum of its parts and should be viewed in holistic terms as one way to regard the family (Whitchurch and Constantine, 1993). Thus, the family can be viewed as a system in constant interaction with the larger social environment. Input from the environment and feedback in terms of family interactions is important for the family's ability to adapt to straining changes. Subsystems in the family system can be husband-wife, parent-child, and siblings with specific functions and roles in the family. Extended family such as grandparents and other relatives can also be added to the system (cf. Staab and Hodges, 1996). In this thesis a wide and flexible definition of family by Hanson and Boyd (1996, p. 6) was adopted: "family refers to two or more individuals who depend on one another for emotional, physical and/or economic support. The members of the family are self-defined." The older help seeking person is thus a part of a family in relation to spouse, children, siblings and other next of kin. Contemporary definitions state that the family includes whoever the individuals say it does, regardless of blood relationship (Hanson and Boyd, 1996).

The nuclear family structure with a male breadwinner and a full-time housewife taking care of the home, children and older people arose with the industrial era and peaked in the 1950s. Since then the family patterns have changed through interconnected aspects such as: growing ethnic cultural diversity, growing economism, a widening gap between rich and poor, the ageing of our society, the struggle for equality and social justice for discriminated groups such as women, gay men and lesbians (cf. Walsh, 1998). There is also a greater geographical dispersal and spread of families today (Wenger, 1999). Moreover, older generations have been brought up with traditional nuclear family norms and may define their family differently from younger people. Loss of family members and friends that have died is an unconditional term of old age, but loss through children's divorces may also be more common today. In the UK, Wenger (1999) recognised changes in family patterns and developed a typology of support networks determined by the availability and proximity of close kin, contact with family, friends and neighbours and involvement in the community. A conclusion was that due to structural changes of families' lives their help cannot be taken for granted. Something similar was discussed in a Swedish report by the National Board of Health and Welfare (2004a), where help between spouses was estimated to continue to the same extent, while help from live-aparts, children and others was more uncertain, particularly without adequate support. This indicates that the potential of families to give help has changed, which must be taken into account and met on a national and a local municipal level.

Increased knowledge that individual family members' disease, dysfunction and coping are influenced by the family, and vice versa, has contributed to increased awareness of the importance of involving the family in the care of the individual (Rolland, 1994; Hanson and Boyd, 1996; Wright and Leahey, 1998). There is a potential in the statement that the family as a whole is more than the sum of its parts (Wright and Leahey, 1998). A holistic approach to individuals' care is needed to strengthen the family in their particular social context (Rolland, 1994). This can be visible in health and social care policies, although it seems less reflected in practice. Even though family orientation in the care of the individual has developed during the past 20–30 years, this orientation appears less developed in elder care despite the help given by families. The family has a well-known role as a support system of a member needing help (Staab and Hodges, 1996). The international pattern that care which used to be provided in institutional settings has moved into people's homes (Arvidsson and Jönsson, 1997; Kirk and Glendinning, 1998) has led in Sweden to increased family help from older members, although this is not met by increased potential to provide help (National Board of Health and Welfare, 2006). There is mutual interplay between the family system and disease, disability, and ability to cope. Such an approach requires attention to family relations and interactions (Wright and Leahey, 1998). The family is mostly a resource in terms of emotional and practical support between meaningful near and dear ones. Families which are dysfunctional and/or pressed may adopt unhealthy transition processes that at worst can result in abuse. Elder abuse is multidimensional and reflected in an array of different ideas, and most often occurs in the context of family relations (Wilber and McNeilly, 2001). In Sweden the thesis by Saveman (1994) was the starting point for reports about elder abuse within the family context. A US study by Beach et al. (2005) of 265 help giver/recipient (aged 60 and over) dyads reported risk factors for potentially harmful help giver behaviour as more likely when recipients had greater need of help, help givers were more cognitively impaired, had more physical symptoms and were at risk of depression. In addition, previous bad relations within the family increased the risk of burden, which needs more attention from professionals. This indicate a need to take family members and the family situation as a whole into account within elder care, public home help and in relation to decisions about public help, such as the needs assessment.

Family members have always taken a large responsibility for their elderly in the Nordic countries, even though help within the family has been supposed to complement public elder care. Thus, Nordic families have no legal obligations to provide help to older family members, nor do those in the UK, where family help for older people has been more recognised even in research. That Nordic family help for older people has attracted less attention in research may be related to the fact that legislation is grounded on the individual and not the family, as well as the public eldercare responsibility (cf. Mossberg Sand, 2005). Research has shown that help/care of older people is provided mainly by (informal) family helpers. Spouses/-partners, children, in-laws and siblings are the main helpers, and women dominate,

that is, wives and daughters (Bond et al., 1999; Stark and Regnér, 2001). Friends, neighbours and other voluntary providers also contribute (Nolan, et al., 1996; Hellström and Hallberg, 2001). Families have individual needs in relation to the illness of their next of kin, help-giving commitments and circumstances. Giving help seem natural but threatens the balance in the family. In addition, it is known and shown that public help/care can counteract the family's adaptation to the changes needed (Staab and Hodges, 1996; Walsh, 1998), if it fails to facilitate their situation. Thus family members' help provision needs to be acknowledged to provide individually tailored support. The needs assessment of their next of kin allows an opportunity for this.

## **The public home help context of older people**

A current and future international issue is how to provide for the growing share of older people and their health and social service needs. European countries have the highest proportion of older people in the world (Ferring et al., 2004) and therefore countries have carried out vast structural changes within the health and social care services, in their efforts to handle the demographic changes (just as in e.g. the USA or Japan). De Jong Gierveld et al. (2001) emphasised the recommendation by the United Nations General Assembly in 2001, stating the promotion of social integration of older people and their participation in society. The authors pointed out living arrangements and relationships available within the household as important determinants of older people's financial and social situation, the family support available and actual level of well-being or loneliness. It was further pointed out that these circumstances were affected by country-based differences in sociostructural support, such as the quality of public welfare systems. Ageing women were singled out as a risk group in need of particular recognition and support, so also in the study by Ferring et al. (2004). Thus countries' welfare systems likely affect older people's life satisfaction if defined – as by Ferring et al. (2004) – as a transformation of experienced objective living conditions. The quality of care and social services thereby becomes crucial to the receivers. Bauld et al. (2000) claimed that its long-term and personal nature, being provided in the home, means that its quality can become synonymous with quality of life. Several studies have identified a relationship between satisfaction with services and general life satisfaction and perceived well-being (Davies et al., 1990; Rubinstein, 2000). It needs to be recognised that variation in quality of publicly financed and provided support and thus basic social security can affect older people's life satisfaction and ability to manage their daily lives.

Esping-Andersen (1990; 1999) viewed Scandinavian countries as “social democratic welfare states” since all citizens are incorporated in a universal insurance system of high quality, to guarantee help based on citizens' needs in spite of economic factors and to free families from the burden of helping. These countries have been

considered to give public care and social service of older people a central role. De Jong Gierveld et al. (2001) shared this view of quite similar welfare models characterised by generous rights to social security and community solidarity in comparison to the UK. Italy was viewed as moderate in these aspects, while there has been little research including welfare systems in countries in Central and East Europe. According to Szebehely (2005), contemporary researchers have claimed that some Scandinavian countries have departed from the original welfare model through decreased public commitment, increased fees, and increased family help as well as market orientation. A mutual trend to tighten up the provisions for practical service needs and social needs has been found. Two decades ago the presence of public home help was rather similar, while more contemporary research indicated that in Finland and Sweden fewer people received home help than in Denmark and Iceland (cf. Szebehely, 2005). Blackman et al. (2001) compared welfare regimes of social care in six European countries. Older people's needs were covered to a low degree by public support in Greece, Italy and Ireland, where the burden rested on the family. In the UK, Norway and Denmark the state had the responsibility to ensure the coverage – when there was no other alternative. This has developed further towards increased rationing and prioritisation of fewer people, frailest and oldest people, with increased risk of social exclusion and being left without help. These findings may indicate a weakened Swedish welfare system with weakened elder care support, and increased risk of the social exclusion of groups of older people that needs to be recognised and counteracted within the needs assessment context.

## **The needs assessment for public home help**

From an international perspective, aspects of needs assessments prior to receiving public home care are difficult to grasp, since management can vary between local authorities in a country. Even though international comparisons are difficult to make since legislation and social welfare systems differ, it can be argued that there are shared features already in that there exists a phenomenon of assessment regarding eligibility for public help. The complexity increases in that needs assessment often takes place in people's homes but also at hospitals during discharge planning (Westlund, 2001; Lindelöf and Rönnebeck, 2004). In both the USA and Canada needs assessment has been increasingly discussed as part of health care and social service allocation among older people. In Europe, countries such as Germany, the Netherlands, Finland, Belgium, Spain and Austria have discussed needs assessment and measures for a longer time (Svenska Kommunförbundet, 1997), and today seem to be struggling with similar issues to Sweden and the UK. Further, in the social care comparison by Blackman et al. (2001) Norway, Denmark and UK, older people with difficulties managing on their own had a formal right to a professional needs assessment, which seems to resemble Swedish circumstances. Italy, Ireland and Greece had no right to such needs assessment

since the state had no legal duty to provide care and social service, thus public support depended highly on local political circumstances. The professionals conducting needs assessment and their job titles vary. Examples from the UK are social worker, care manager, team leader, home care manager, monitoring and reviewing officer, carers' officer and social welfare officer (Arksey, 2002). In the UK district nurses assess health needs and "social workers" assess the social needs of older people. Assessment procedures and measures seem to vary between countries and within countries. Studies discuss what different professions should be responsible for and contribute, and whether the assessment should be conducted by systematic assessment forms (Crome and Phillipson, 2000) or that such management is too formal, excludes needs not included in the assessment forms (Cowley et al., 2004), and counteracts personal professional judgement (Campbell, 2001; Ceci 2006).

The UK has a longer research tradition of needs assessment of older people than other European countries and reports somewhat similar variation in management (Challis and Hughes, 2002). However, in the UK also family helpers are entitled to get their capacity and support needs-assessed (HMSO, 1995). Research from the UK has reported deficiencies in needs assessment procedures regarding e.g. documentation, variability in assessment strategies, recognition of needs in holistic terms, and decisions about help in similar cases (Challis and Hughes, 2002). Difficulties in separating social and health needs due to assessment by different agencies have been reported (Cowley et al., 2000). Recognition of needs proved to differ in relation to profession and knowledge base (Worth, 2002) and joint working in the assessment was lacking (Nolan and Caldock 1996). Other professionals such as physiotherapists and occupational therapists have not always been consulted when they might have been needed (Challis and Hughes, 2002). As a whole the professional agencies' provision lacked co-ordination and was insufficient for the recipients. Higher quality of needs assessments and health and service provision is expected through the implementation of the national service framework (NSF) for older people, which means a new multidisciplinary, inter-agency "single assessment process," whereby older people and their families can expect integrated assessment and health and social service (NSF, 2001). A nearby example of a form of comprehensive needs assessment comes from Denmark, where the needs assessment form was changed in 2004, since a functional (need) assessment instrument, "Felles Sprog", was implemented, whereby help seekers' needs are assessed and categorised by all the professions involved. Thereafter help is allocated in relation to a standardised catalogue (Højlund and Højlund, 2000). In an evaluation study by Peterson and Schmidt (2003) interviews with 13 older help recipients were compared with the formal assessment. The findings revealed that differences between the recipients were reduced and problems outside categories were ignored. Thus, research, particularly within the UK has pointed out problematic issues in relation to needs assessment, such as the necessity to obtain

adequate holistic needs assessments – a necessity that should be addressed in the Swedish context as well.

In Sweden, the Social Services Act (SFS 2001:453) states the ideological foundation of care and social services regarding municipalities' responsibilities for older people's care and service on a structural, general and individual level. Needs assessment in this thesis is viewed as the process and exercise of authority that takes place when older people seek help. This process is expected to follow the given order in terms of application, assessment of needs, entitlement to help, decision and follow-up (National Board of Health and Welfare, 2002b). Municipalities are responsible for needs assessments, and legislation controlling the handling of the needs assessment is mainly the framework law, the Social Services Act (SFS 2001:453, chap. 4), stating that a person who is unable to provide for his/her needs or to obtain provision for them in other ways is entitled to public help with livelihood and living in general. Further, it is to be ensured that the individual has the possibility to live in secure conditions and is treated with respect for his or her self-determination and integrity, and are given the possibility to have an active and meaningful existence together with others. The responsibility to visiting older people is also stated (chap. 5 § 4–6), although it is problematic that essential formulations are left open to interpretation. The meaning of "needs" is not defined more than that a person shall be secured a "reasonable level of living" that strengthens his/her possibilities to live independently. Nor does it clarify what is meant by "meaningful existence" or "needs provided for in other ways". The Administrative Procedure Act (SFS 1986:223) protects the individual in relation to public authorities' stronger power position, secure rights, transparency and possibility to have influence regarding the exercise of public authority (Amundberg, 1998). Guidelines for the needs assessment procedures are provided by the National Board of Health and Welfare (1996). Further general recommendations on the quality system in the care of the elderly and handicapped (National Board of Health and Welfare, 1998) state that needs assessments should be based on a holistic view of the individual's life situation, potential and needs, with due consideration given to his/her social, physical, medical, mental and existential needs, and that measures should be designed together with the individual and/or next of kin, or representative.

In relation to needs assessment some general aspects deserve attention. "Needs assessment" occurs in various contexts and should be linked to what needs it is supposed to assess, such as needs for care and social service and thus home help. The term "need" is complex and can be defined in ways which differ in relation to the professional disciplines defining them (Cowley et al., 2000). The National Board of Health and Welfare (1998) has recommended that individuals' needs should be viewed holistically when taken into account in needs assessment of older people. Needs are considered personal, subjective, variable, constantly changing, as well as relative, highly political and value-laden. Definitions of needs change in relation to available public resources to provide for the needs (Thorslund and



Larsson, 2002), which indicates more or less implicit prioritisation of needs. A contemporary definition of need is “A being needs things which it is bad to be without” (von Wright, 1995, p. 50), which indicates that needs vary between social classes and groups and over time. The term assessment seems to have been less discussed in the literature, which has more often concerned the aim of the assessment and the best way to do it.

The national framework legislation that concerns public home help and needs assessment is supposed to be implemented by the local municipalities, a responsibility that Trydegård (2000) found to be handled differently in relation to conditions and “local history” of eldercare management within the municipalities. Needs assessment of older people is a part of the responsibility introduced in the Social Services Act since 1982 (Norman and Schön, 2005). Through the organisational turnover in the majority of municipalities a new position as “home help officer” was initiated. Although Norman and Schön (2005) reported their professional titles, educational and professional background to differ, they mainly consisted of social workers and at times nurses. In the traditional organisation “integrated home help officers” had a comprehensive responsibility for needs assessment practices as well as the management of help provision, which was abandoned due to ideological beliefs and considerations of legal security and cost-efficiency. In the divided organisation specialised home help officers were assigned the responsibility for tasks focused on the needs assessment practices only, while managers of the contractor organisation became responsible for staff and provision of home help (cf. Blomberg, 2004). The divided organisation was criticised in the thesis by Nordström (1998) about “domestic help as an organisation” for forming an “organisational care gap” due to an increased distance between the “idea world” and the “practical world”, and hence contributing to the fragmentation of recipients’ help and daily lives. This indicates a difference between municipalities’ organisational potential to transform national legislation into public home help of adequate quality – which needs recognition.

Needs assessments have received increased attention in Sweden during the last decade, since studies have shown deficiencies regarding the needs assessment procedures conducted in people’s homes as well as in hospital settings. Common problematic issues have been e.g. insufficient documentation, variability in assessment strategies and decisions about help in similar cases (Lagergren, 2002; National Board of Health and Welfare, 2000; Lindelöf and Rönnebeck, 2004). In addition, studies and reports show that needs assessments have become more restricted and standardised through the use of local general guidelines that limit what help can be provided (Blomberg and Petersson, 2003; Andersson, 2004; Lindelöf and Rönnebeck, 2004). Systematic needs assessment instruments are used in rather few municipalities and great resistance has been reported (Board of Health and Welfare, 2004b). The needs assessment at hospital discharge planning is a critical point in the care trajectory to ensure that the frail person and family members can cope at

home. Here professionals from other agencies participate also, although co-operation and co-ordination of care and service provided by different agencies have been shown to be problematic (Gurner and Thorslund, 2003). Needs-assessed persons are also entitled to appeal against a decision, for instance rejection of the application, if they are dissatisfied. However, Lindelöf and Rönnebeck (2004) found formal rejections to be extremely rare, since help seekers' requests were not always accepted and documented, rather reformulated to match the help offered by the municipal general guidelines. Thus, research has focused on "task aspects" of the needs assessment procedure mainly from an institutional and professional perspective. These deficiencies need to be addressed, but for adequate interventions more must be known about the "user's" perspectives within the needs assessment process.

The encounter between the home help officer, the help seeker and any participating family members is little focused in research, particularly from the "user's" perspective, even though it constitutes the core of the needs assessment process. In this encounter a part of the elderly care policy and political goals are made concrete (Hellström Muhli, 2003). According to Blomberg (2004) new conditions for the needs assessment and encounter between the home help officer and the help seeker set boundaries for the establishment of a relation with the help seeker. The professional relationship and attitude is particularly important, since home help officers possess a strong power position in relation to the help seekers (Duner and Nordström, 2005). How the professional uses him/herself as an instrument in exercising his/her power has an ethical dimension (Skau, 1993), which entails a risk of violating the help seeker's integrity (Nordström, 2000). All professional encounters with the help seekers and family members within health care and social service encompass both natural and professional care (help). The natural care refers to the type anyone can give, while the professional care refers to the type of care that requires educational skills. Both encompass a task (instrumental) and a relational dimension (Athlin and Norberg, 1987): "what is to be done" and "how it should be done". The importance of conducting the task professionally is well acknowledged, while the importance of how it is done, the encounter in relational terms, is still rather underestimated in practice. The emphasis on legislation and formal regulations in relation to needs assessment practice and the home help officers' performance (Blomberg, 2004; Norman and Schön, 2005) support this assumption. An engaged confirming attitude can be experienced as helping in itself. If only one part of the home help officers' professional performance is emphasised by higher-level management, the human relational part risks being neglected in the needs assessment, which means older help seekers and their family members.

## Participation, influence and power

There is quite a lot of research about people's participation and influence in health and social care environments, and it is often aspects of the concepts in different contexts that are investigated. The concepts are complex, and even though they are often highlighted in international health and social welfare policies, there is no consensus about the interpretation (Cahill, 1996; Eldh et al., 2004). Participation is derived from the Latin *participare* and means to take part in. Participation as viewed from a human relations perspective emphasise "getting involved or being allowed to get involved" in decision making or delivery of services (Cahill, 1998). Interchangeable use of participation, influence, involvement, partnership and collaboration is just as common as various distinctions. Influence may have a somewhat stronger power dimension. Consequently research findings concerning people's participation and influence are difficult to grasp and compare.

International regulations and literature stress individuals' participation and influence over the public sector services they use (Jarl, 2001). Democratic ideals are fundamental, and the meaning of democracy is based on humanistic ideals of people's equal value. As a consequence the individual, alone or together with others, is assumed to be capable of influencing the rules and life circumstances which he/she lives with and under (Hermodsson, 1998). This requires power (SOU 1990:44), which older people may lack due to frailty and lack of knowledge about their rights and the elder care context. According to Foucault (1980), the study of power concerns relations, how individuals and groups obtain their goals in competition with others. Expert (professional) knowledge forms certain ways of thinking (discourses) which are means for power and control of societal contexts. However, power cannot be exercised without knowledge, just as knowledge engenders power (cf. Foucault, 1980). A possible future scenario for the growing group of elderly in Europe is difficulties attaining adequate care and service due to their position and insufficient societal resources, which exposes them to a higher risk of social exclusion (Blackman, et al., 2001).

Participation is a salient concept within the new WHO classification – the International Classification of Functioning, Disability and Health (ICF) 2002, which defines it as "a person's engagement in a life situation" (p. 18). Forms of participation are described in the Swedish version as involvement, taking part, being included, being accepted, engaged in an area of life and having access to necessary resources (National Health and Social Welfare, (ICF) 2003). Discussions related to the ICF may be of relevance for older people and their families' participation in their care and service and thus the needs assessment context. The ICF has been positively presented as based on a biopsychosocial view of human beings, although weaknesses of the classification and measurement that need attention have been discussed. Nordenfeldt (2004) related to the ICF and the treatment of "activity", remark that only ability and opportunity have been taken

into account, and not the human volition and meaningfulness that are necessary for activity. People mostly desire participation, while reluctance has been shown in some studies as by Waterworth and Luker (1990). Mohlin's (2004) concept analysis suggested components of participation in terms of activity, engagement, formal and informal belonging, autonomy, power and interaction. A dimension considered important was added, namely *prerequisites for participation*, since both internal and external aspects play a role. The former concerns both the will and ability to participate, and the latter availability and actual possibility. Further, a new definition based on minimum and maximum participation was suggested. Maximum participation required fulfilment of internal and external prerequisites, subjective and objective dimensions of participation and an interaction/interplay between the individual and his or her social and physical environment. Högberg (2004) argued that participation is difficult to measure and classify into categories and that aspects difficult to measure risk being excluded, for instance the subjective dimension that encompasses the deeper psychological and existential reality of disability – such a scenario may counteract health and healthy transition processes for ageing families. Ashworth et al. (1992) viewed participation as a mode of social interaction in the context of caring, which highlights the relationship between those who need help and the professional. Mutual assumptions of meaningfulness, intersubjectivity, and reciprocity in perspectives must be attained for interaction to proceed. A phenomenology of participation requires: attunement of a mutual stock of knowledge, emotional and motivational attunement to one another's concerns, taking for granted that both can contribute worthily, and feeling that one's identity is not under threat (cf. Ashworth et al. 1992). As a whole this points to the complexity of participation when trying to grasp it theoretically and in practice, and the need to take into account that also psychological and emotional circumstances play a role for experiencing participation.

To ensure older person's influence over decisions about personal health and social care remains high on the Swedish agenda, and is one of key issues for a parliamentary committee on elderly policy for the future (Ministry of Health and Social Affairs, 2005). User participation among the elderly is nationally supported, and reports have shown that municipalities are striving to enhance the individual's influence, but few have well thought-out strategies for it (National Board of Health and Welfare, 2002a). Older persons' user influence over care and service has been studied from both collective (institutional, organisational) and individual perspectives. Older people's collective user influence in Sweden was studied by Jarl (2001), who as a result questioned whether the more "powerful members" really protect the interests of the weaker older. However, when older people's individual influence over public home help services has been studied, the focus has mostly been on the direct contact with the home help workers (Jarl, 2001). Several studies have revealed that frail older people often express a high overall satisfaction in spite of dissatisfaction with several aspects of their help and care (Bauld et al., 2000). For instance, in a random sample of elderly Swedish help recipients (aged 65 and over,

n=143) Samuelsson (1999) interviewed 49 and found that the overall satisfaction was high but satisfaction with e.g. influence over how the help was provided had decreased significantly compared to 1992. Thus, to obtain views from the weaker “users” in relation to their participation appear important, particularly since it has been found difficult to grasp dependent older people’s views.

## **Those involved in the needs assessment**

### *The older help-seeking persons*

One essential circumstance of older people entering the needs assessment process is the change from independence to dependence that is feared by most people. People struggle as long as possible themselves, to avoid becoming in need of help from the public or diminish receipt of help (Richards, 2000). Roe et al. (2001), among 20 people (mean age 79 years) dependent on help, reported three types of “acceptance”: positive acceptance, resigned acceptance and passive acceptance. Further, in an interview study (n=10, mean age 68) by Strandberg, (2002), being dependent (on care) was experienced by the patients as a struggle for existence and against worthlessness, powerlessness, loneliness and being left without. Duner and Nordström, (2005b) interviewed people (n=22, aged 67–98) about how they managed when eventually needing help in their everyday living and found that it was important to stay independent and free. Having to adapt habits to those of public care was experienced as a loss of freedom. The persons managed through three strategies: active, adaptative or passive management, which were interpreted as coping strategies. Being confronted with loss of ability and help need is painful. Hewson (1997) argued that responses to loss of ability such as resistance, denial and even unrealistic hope can be understood as responses in highly threatening situations, to avoid being overwhelmed. Struggling with mental and existential difficulties together with the impairment caused by illness/disease may be difficult to cope with. In addition the risk of depression is higher in late life since older people have been found less likely to seek help for low spirits, depression or mild cognitive impairment (Gatz and Smyer, 2001). These difficulties may hinder participation in the needs assessment and also have to be recognised, adequately met and provided for within the needs assessment.

How older needs-assessed persons experience participation and possibilities to influence the decision making and planning of care and service has received little attention in research. In the UK, weaknesses in relation to needs assessment encounters between assessing home help officers and older help seekers have been revealed, even though their participation was not specifically focused. According to Vernon et al. (2000), older help seekers own views are seldom sought in needs assessments, and so it seems also in research. Richards (2000) aimed to understand how needs were negotiated and observed assessment interviews with older persons

(aged 70–93). They showed little knowledge about social services, about the needs assessment process they had been through, and the information given was not always understood. Three groups were identified in terms of internal resourcefulness (essential for coping): the decided – those who knew what they wanted, the undecided – those who did not know, and those overwhelmed by their situation when they entered the assessment. They thus entered the assessment encounter in different mental states for participation. Worth (2002), in a study conducted in 1998, observed needs assessment encounters between home help officers and older help seekers aged 75 and over and found that they often had difficulties accepting public help. It seemed to mean becoming another person – a help-needing person. The needs assessment seemed an unpleasant marker of dependency. Involvement in the process could be counteracted by help seekers' mental, hearing and/or speech disabilities, and ability to articulate needs. The needs assessment was not steered by the help seekers' views of their needs, but rather by resource constraints and eligibility criteria. When Ware et al. (2003) interviewed help seekers (n=55, aged 65 and over), helpers (n=37) and home help officers (n=28) about arranging, delivering and receiving care and service, a deeper focus on the needs assessment encounter was not part of the aim, although the majority of the help seekers expressed satisfaction with the assessment while a minority expressed dissatisfaction. As a whole, however, the help seekers expressed worries about the nature of their dependency, whether they fitted the eligibility criteria and whether their expectations and needs would correspond to available public help.

Few Swedish studies have focused on interactions between the parties involved in the needs assessment encounter, and rarely from the older help seekers' perspective. In the thesis by Hellström Muhli (2003) 16 needs assessment encounters between home help officers and help seekers (67–91) were video-taped. Findings revealed that the help seeker did not always understand the purpose of the encounter, the process, the information given or whom the home help officer represented. The report by Gurner (2001) studied 26 cases of older people (mean age 84) with comorbidity and their needs in relation to discharge planning in hospital settings. They felt unsatisfactorily involved in the planning of care and/or help they were to receive at home. In the thesis by Efraimsson (2005) eight older women's experiences of participating in their discharge planning conferences were sought. The encounters were video-taped and the women interviewed. The findings showed that they experienced existential difficulties due to their bodies failing them and their insecure future. Despite having resources they felt powerless, struggled for space in the dialogue, but experienced little possibility for influence or negotiation. Their experiences were interpreted as (1) being mutually involved in a joint project, (2) standing outside since they had difficulties participating, and (3) being in focus (as confirmed or exposed). The findings in these studies indicate that older help seekers may have little chance to actually take part in and influence the process of deciding about their care and service. Thus further knowledge is needed about how

the older person him/herself experiences participation and influence in relation to the needs assessment and decisions made.

### *The family members*

Circumstances of family members entering into the needs assessment process are influenced by being in the phase in life of having to face an older next of kin's decline. Regardless of whether it concerns a spouse or a parent, whether the development is acute or slow, it means emotional distress and also further commitments to help added to those already existing. Family members are the ones who have been found to help, represent, guard, initiate, monitor and negotiate in contacts with the public care system on behalf of their next of kin (Schumacher et al., 2000). Luescher and Pillemer (1998/2003) consider ambivalent feelings and conflicting norms to exist in all relationships, but these become strong in parent-child relationships in later life, and particularly in transition periods of lower stability. This means an increased tension that can be promoted as well as counteracted by how family members experience their own resources to cope with the situation. These circumstances likely influence their attitudes in contacts with care and service professionals and the needs assessment which professionals and thus home help officers have to be well prepared to encounter.

In the UK family members' participation has received increased interest in studies focusing on the needs assessments of older people; one reason for this may be that they provide extensive help and by legislation have received entitlement to have their own help capacity and need of support assessed if they give substantial help regularly (HMSO, 1995). However, the implementation of such assessment in practice has been reported as problematic and eligibility criteria are interpreted differently locally. When Seddon and Robinson (2001) interviewed help givers (n=64) of older people with dementia concerning how they experienced the needs assessment process, most of them were unfamiliar with the term assessment, unsure about its purpose, and unaware of any actual needs assessment. Carers experienced the comprehensive needs assessment as task-oriented, focused on their next of kin and as assuming that they were willing to continue with their helping. Affective and psychosocial aspects of family help giving were felt to be neglected, and they lacked the opportunity to talk about themselves and social/emotional support needs related to their helping. In a study by Arksey (2002) 51 help givers were interviewed twice, the first time focusing on the process of their own assessment and the second time on the perceived outcome of the assessment. Findings showed that help givers from the start lowered their expectations of help, and expressed fewer needs, as a sort of self-rationing due to their knowledge of limited resources of help. Some did not ask for help since they had been told previously that the help they asked for was not available. Others did not define themselves as help givers (carers) but rather viewed help as a family obligation. There were cases when the public home help failed, or was found not to meet families' needs, and thus the

public help was cancelled even though support was needed. Cancelling public home help was also reported due to the charges. Help givers could extend themselves in efforts to give help at the expense of their own physical and mental health until the help-giving situation broke down. These UK findings indicate that even though family members were entitled to a needs assessment in relation to their help-giving capacity and need of support, insufficient participation could be perceived. Thus, management of families' participation appears problematic in practice and needs more thorough attention and investigation.

In Swedish studies about the needs assessment and the actual assessment encounter family members participation has been sparsely noticed, and thus their perspectives have been rather absent. Nordström (1998), Hellström Muhli (2003) and Blomberg, (2004) in their theses mentioned aspects about family members who participate, but from the institutional and/or home help officers' perspective. Nordström and Duner (2003) studied interactions in the processes of the needs assessment context whereby some family members (n=6) of older help seekers (n=38) were interviewed, although how they experienced the process was diffuse. Gurner (2001) studied 26 cases of older people (mean age 84) with co-morbidity and their needs in relation to discharge planning in hospital settings, showing that family members had not always been contacted, felt unsatisfactorily involved in the planning and in some cases felt persuaded to take on help giving. They desired matched and more flexible public home help, more visiting work and follow-up, and involvement in the decision making about the public home help (Gurner and Thorslund, 2003). Altogether these findings indicate that family members taking part in the needs assessment may have little chance to get acknowledged in the needs assessment dialogue and influence the process of deciding about the care and service that they and the family as a whole are dependent on.

### *The home help officers*

Circumstances of the home help officers entering into the needs assessment are, as described by Wolmesjö (2005), their intermediate position in the eldercare organisation, squeezed between politicians and higher-level management on one side and staff members and help receivers on the other side. They are to exercise the power given to them as a public authority to assess older persons' needs and make decisions about help provision. According to Blomberg's (2004) findings, this takes place within an organisational framework that has been exposed to extensive changes, which may have altered the circumstances for the needs assessment including the encounter with the older persons and any family members. Moreover, conducting needs assessments has been considered a decidedly relational task (Nordström, 1998; Nordström and Duner, 2003; Andersson 2004; Duner and Nordström, 2005a). A question to be asked is whether these changes have altered also the relation between home help officers and involved help seekers within the needs assessment encounter.



In the UK, studies have focused on how the assessment was conducted by interviewing home help officers. The reported findings are relevant for how help seekers are viewed, their participation and power to exercise influence in the process, although not revealed from the home help officers' own perspective. Parry Jones and Soulsby (2001) interviewed health and social care practitioners about the assessment of older people's needs in a longitudinal study (n=64, follow-up n=30). The assessors viewed the aim of the assessment differently. The power of the social care assessors in deciding whether a person's need could be classified as a need in comparison to the eligibility for service was evident. They experienced a conflict in their role of identifying need, which in addition was difficult to define, and having to ration services. There was a shift of focus from assessment of needs to rationing. Help seekers were viewed as able to express "wants" while they themselves identified needs. Worth (2002) observed and compared needs assessments of older people conducted by district nurses and assessing social workers. Both similarities and differences were found, although their approaches differed in relation to their professional disciplines. They viewed communication skills as important to be able to go beyond what help seekers expressed verbally. Home help officers said that it was often difficult to involve the help seekers due to their disabilities. Help givers' needs were found to be inadequately recognised, and much time was spent negotiating disagreements about risks. Family helpers could be experienced as either exaggerating or understating risks. The observations revealed a gap between home help officers' expressed views of how the assessment process should be conducted in comparison to the reality and prioritisations that had to be made. Chevannes (2002) analysed relations between health and social care professionals (n=38 assessors) and older people in needs assessment within community care through interviews followed by a questionnaire. Findings showed the process to be dominated by the professionals who exercised control over and categorised the help seekers rather than involving them. A supply-led rather than a need-led approach was shown. Expressions in some instances revealed a partnership between the assessor and help seeker, while in others the latter was objectified. Richards (2002) observed 17 community care and home care assessors in encounters with older help seekers and found the procedures, filling in assessment forms, to be the main focus, and that these were believed to be more reliable in identifying needs than the person him/herself. Assessors could have preset solutions to a problem that could hinder eliciting the views of help seeker. The assessors' way of managing the procedures could vary, but tended to obstruct their understanding of the help seekers' needs. Thereby the help seekers could be objectified and marginalised through the way the assessment process was handled. Thus, the UK public home help and needs assessment appears complex, contradictory, and creating moral conflicts that home help officers may handle in a way that risks objectifying help seekers and their helpers. Further development of this scenario needs to be counteracted in the future.

In a thesis in Sweden a decade ago Gynnerstedt (1993) studied ethics among integrated home help officers, and described how public administration within public home help had changed from an authority culture to a new service culture with the emphasis on participation and influence for the help seekers. A question asked was how home help officers could manage being both “care givers” and persons in authority. Home help officers’ ethical consciousness was found to vary from full to not having considered ethical questions at all. In a thesis Nordström (1998) observed needs assessment encounters between 10 integrated home help officers and the help seeker. Home help officers were found to take charge of the communication, ask the questions and determine what topics were talked about. Further, different attitudes were identified in terms of user-oriented, authority-oriented, agency-oriented and balancing. A good relation was viewed to increase the help seeker’s possibility to influence the decisions. Subtle power dimensions of their interactions such as the help seeker’s subordinate position, were described. It was concluded that what actually happened in the needs assessment encounter between the involved was not entirely clear. These findings from an integrated organisation and function revealed that the way home help officers’ interact with help seekers may make a difference for their possibilities to influence the needs assessment process.

The thesis by Hellström Muhli (2003) focused on needs assessment dialogues between home help officers and help seekers. The opening phase was identified as the time when the relationship was established. Several weaknesses of importance for older help seekers’ and family members’ possibility to participate were found. Clarification of the purpose and prerequisites to conduct the task could be unclear, as could confirmation of participating parties. Giving information was found to be problematic since it touched on other professionals’ responsibility. Home help officers failed to clarify formal aspects and conditions for the decisions to the help seeker. It was done in a way that counteracted their rights in terms of legislation, information and participation in decision making. The needs assessment process was found to lack preparedness to handle existential and psychological help needs. The way home help officers handled the tension between everyday morals and bureaucratic rationality was found to influence how the older help seekers were encountered. Blomberg (2004) interviewed home help officers (n=19, from 8 municipalities) about their occupational practice. The home help officers considered it important to meet them in their homes to “read between the lines”, and get the whole picture of their situation and needs. Some emphasised knowledge of legislation as crucial while others emphasised empathetic ability. Clearly the help seekers’ perceived needs and desires were to be focused on in the decision making. The findings in these two studies indicate weaknesses regarding how the needs assessment is presented and conducted; individual needs tended to be overlooked and family members appeared difficult to handle and involve. These weaknesses require interventions so that help seekers’ and family members’ participation in the process is not counteracted.

The thesis by Lindelöf and Rönnebeck (2004) encompassed national surveys about distributing assistance to the elderly. The findings revealed that local general guidelines govern home help officers' decisions about home help and that "reasonable level of living" was not interpreted as intended by legislation. The needs assessment process was found to be governed by standardisation and informal routines, and not in accordance with the law, which jeopardised older people's right to individual needs assessments. Andersson (2004) interviewed six home help officers about their reasoning in relation to older help seekers' needs in the needs assessment. The themes found concerned whether there was a need, whether it could be provided for in another way, eligibility, and what was a "reasonable level of living." These were interpreted as focusing on general municipal guidelines and economic resources rather than the help seeker's individual needs. It was further revealed that healthy family members living together with a help seeker were expected to help with service since the Marriage Code was the guiding principle. This indicates that local general guidelines and not legislation governed and restricted the needs assessment and thus directed the home help officers' decisions. Since municipal guidelines probably do not encompass a holistic view of older people's needs there is a risk that needs other than practical ones may be neglected. Moreover, participating family members appeared to be a particularly difficult issue to deal with. Blomberg (2004) found that home help officers could desire family members' participation in the encounter, but simultaneously underlined that it was not a question of providing for their needs. That family members' supported their next of kin and gave information was positive. In spite of this, family members were considered as the greatest problem in their work, more difficult to deal with than help seekers. Andersson (2004) found that older help seekers were viewed as having low demands due to frailty, while representing family members created disagreement. Then it became important to mark their authority. These difficulties in encountering family members may be an obstacle to family members' involvement in the needs assessment. Further, these findings indicate problems regarding framing and presentation of the needs assessment, the way the actual needs assessment is conducted, as well as restrictions on what needs should be viewed as needs to be provided for. Nevertheless, how home help officers view help seekers' and family members' participation remains unclear. In Sweden, research has mainly focused on the institutional and professional perspective and less on older help seekers' and their family members' perspectives on needs assessment prior to public home help. Further knowledge is needed about their participation and influence in relation to needs assessment, and particularly from the older help seekers' and their family members' perspective.

## AIMS

The overall aim of this thesis was to illuminate older persons' experience of becoming in need of public home help and their family members' experience of this situation. Further, the aim was to illuminate experiences of participation in the needs assessment process of older people and influence on decisions about public home help from the perspective of older needs-assessed persons, their family members, assessing home help officers and external home help officers.

The specific aims were:

- To explore older persons' experience of becoming in need of public home help, their experience of participation and of having influence on the needs assessment procedure and the decisions made about public home help (Paper I).
- To explore older persons' experience of participation in and influence on decisions about public home help/care when undergoing needs assessment and receiving public home help (Paper II).
- To illuminate close family members' experience of having an older next of kin becoming in need of public home help, their participation in the needs assessment procedure and the decisions about their next of kin's public home help (Paper III).
- To illuminate assessing and external home help officers' experience of older help recipients and family members' participation in the needs assessment procedure and the decisions made about public home help (Paper IV).

## METHODS

### *Context of Swedish public home help*

In Sweden the public care and service in terms of home help to older people is viewed as beginning in the 1950s. Before this the public support was entirely institutional and older persons that could not manage by themselves had to rely on their family or poorhouses for help (Nordström 1998; Larsson 2004). Children had a legal obligation to help their parents as stated in social legislation until 1956, although in family legislation until 1979 (National Board of Health and Welfare, 2004a). The social legislation from now on emphasised public care and service directed to older people in general, in respect of their integrity, interests and individual desires. In the ensuing decades the use of public care and service increased and reached a peak at the end of the 1970s. Thereafter the number of older people receiving public home help has decreased even though the share of older people in the population has increased (Szebehely, 2005). Care and social service for older people is still a formal public responsibility, even though an increasing proportion of older people receive it in their homes, which almost always presuppose family members' participation. This is a restructuring of the elder care that is developing with increased speed (National Board of Health and Welfare, 2006). The Swedish policy of care and service for older people is to help people to live in their own homes, which a majority of older people (93%) actually do. Most of them live with their spouses or alone, the latter increasing with age. Very few live with their children, siblings or other close friends (Lagergren 2002; Ministry of Health and Social Affairs, 2005). Contemporary public home help encompasses "help in the home" such as with personal care and service. Personal care concerns help with personal hygiene, getting dressed, moving about and meals, while service concerns help with shopping, cleaning, laundry and errands. What is included in "help in the home" and limitations varies between municipalities, policies and general guidelines, as does the availability of other types of support such as security alarms, daytime activities, special accommodation, short-term care and transportation services. The policy of providing care and service in people's homes in spite of heavy care and service needs may at best function well but provides no choice for families. The National Board of Health and Welfare (2006) reported that the structural changes have led to increased help responsibility for families, while simultaneously their participation in and influence over their care and service is limited.

The 1990s were marked by a decentralisation of the welfare state in terms of expanded local duty and autonomy for the 290 Swedish municipalities to implement national public responsibilities (Blomberg, 2004). Through the elderly reform of 1992 municipalities were given overall responsibility for long-term service and care for older people and people with disabilities. This was followed by reforms regarding support for people with certain disabilities and psychiatric disorders. One aim was effective use of resources (Ministry of Health and Social Affairs, 2005).

This was a period marked by strong pressures for reform in municipalities, many of which strove for a market orientation. The traditional organisation of elderly care was abandoned within a rather short period of time (Blomberg, 2004). New public management organisations as various forms of the client/contractor organisation arose (in the Nordic countries, Vabö 2005) which in Sweden meant a more formalised and restricted needs assessment and a new role for home help officers, which Blomberg (2004) labels as a bureaucratic reform. In 2003, 82% of Swedish municipalities had adopted variants of client/contractor organisations (National Board of Health and Welfare, 2004b). It has been questioned whether the new forms of organisation mean a quality improvement and for whom (Blomberg, 2004), and some municipalities have returned to the traditional organisation (Norman and Schön, 2005). About 50% of municipalities have a comprehensive responsibility for older people's mental and physical health, and their care and social service needs (except acute health care, a responsibility for the county councils), having opted to take responsibility for home nursing care (Ministry of Health and Social Affairs 2005). Nevertheless, there is a problem with the parallel professional organisation, adhering to either legislation concerning health care (SFS, 1982:763) or social service (SFS, 2001:453), where the aim is to recognise, approach and provide for individuals' needs holistically. However reports have shown a lack of an overall picture of individuals' needs since co-operation and co-ordination have been problematic with a risk of fragmentary provision that disrupts rather than helps to reconstruct recipients' lives. This is since municipalities are responsible for the needs assessment of older people and it is up to each municipality to decide about the local allocation of public home help. Studies have shown that the provision of help and care differs depending on which municipality the older person is resident in (Trydegård, 2000; Lagergren, 2002; Blomberg and Petersson, 2003), and this also concerns the fees.

## **Design**

### *Methodological approach*

A qualitative research approach and design of this thesis was chosen as most appropriate to the aim of illuminating and exploring experiences of family participation in needs assessment of older people. This context has been sparsely studied from the perspective of those involved, and a qualitative design may be needed to approach the empirical world holistically. Through such an approach people are viewed as a whole in the context of their past and in the situations where they are (Taylor and Bogdan, 1998). A guiding assumption was that humans are complex beings with bio-psycho-social-existential dimensions constituting needs related to each dimension. This assumption corresponds to the view of Montgomery Dossey and Guzzetta (1995), Wong (1998) and Hummelvoll (1997), the two latter also distinguishing a cultural dimension. These are interdependent and interrelated and need to be taken into account in clinical practice, education as

well as research. A qualitative design facilitates what Taylor and Bogdan (1998) call obtaining first-hand knowledge by talking to people about what is in their minds and their experiences of their daily social lives. This kind of first-hand knowledge about people's lives is valuable in that it is unfiltered by concepts, operational definitions and rating scales. Patton (2002) argues that naturalistic design does not attempt to manipulate the research setting and is considered suitable to use in order to understand naturally occurring phenomena in natural states and circumstances; an openness to whatever emerges is required to make adequate changes to the design in order to capture the phenomena. These and similar assumptions are the basis for qualitative inquiry strategies (Taylor and Bogdan, 1998; Patton, 2002). Consequently, an approach was needed that captured people's unique perspectives, to understand them from their own frame of reference. A qualitative design provides a holistic approach, assuming the whole as a complex system that is greater than the sum of its parts and that understanding of people's social contexts is essential for overall understanding of the phenomenon under study (Eriksson, 1992; Patton, 2002).

Triangulation was also adapted in this thesis since it is considered particularly relevant for qualitative research to achieve many-sided information about a complex phenomenon (Eriksson, 1992). Denzin (1978) distinguishes between source, investigator, theory and methodology triangulation which adds rigour, breadth and depth to any study – strategies that reduce systematic bias in the data (Patton, 2002). The first means comparing multiple copies of one type of source or different sources with the same focus. This may concern different groups, locations and times. Investigator triangulation means that more than one researcher is involved in the research. The use of more than one analyst or interviewer can counteract potential bias in one single researcher. Theory triangulation means the use of different theoretical perspectives to look at the same data. Holloway and Wheeler (2002) view this as rather rare. Methodological triangulation may mean different kinds of data collection (i.e. interviews and questionnaires) or designs, or, as Holloway and Wheeler (2002) describe triangulation, within-method (also described by Patton, 2002) or between-methods. The types of triangulation used in this thesis were triangulation of sources through collecting data about the same topic from older needs-assessed persons' (Paper I–II), their family members (Paper III), the assessing home help officers (Paper IV) and home help officers' outside this context from another county (Paper IV and thesis). Investigator triangulation was used through two of the researchers (ACJ/KP) interviewing, and three (ACJ/KP/IRH) analysing the data (Paper I–IV). Triangulation of methods was used in terms of within-method triangulation through complementing the home help officers' perspective of personal interviews with a focus group interview with home help officers from outside this context (Paper IV and thesis).

### *Theoretical framework*

To obtain an understanding of what family participation meant to the persons involved in the needs assessment, interpretation was evidently required and a hermeneutic approach was chosen as the basis for the interpretation. Hermeneutics is a research tradition, interpretation theory and also a method for analysis of texts, actions or narratives (Nerheim, 1995; Skott, 2004), which focuses on people's total experience of their world and provides a holistic perspective on phenomena (Eriksson, 1992). The tradition emphasises the context and the fact that human beings experience the world through language, which provides both understanding and knowledge (Byrne, 2001). Hermeneutics has its origins in the 17th century when it was introduced as method for biblical interpretation, necessary to interpret the meaning of texts. Schleiermacher is viewed as the initiator of theory and systematic method of interpretation, after which Dilthey played a great role in broadening the hermeneutic field (Dahlberg et al., 2001). Later philosophers have developed hermeneutics further through their ideas about the nature of understanding and how to interpret texts, e.g. Heidegger (1962), Gadamer (1979) and Ricoeur (1976). Hermeneutic interpretation can be viewed, as by Ricoeur (1976), as based on the meaning of utterances in the text and the interpreter's pre-understanding. These philosophers all emphasise dimensions as the fusion of horizons (between the utterance and the interpreter) the hermeneutic circle and the temporality as important when interpreting (Whitehead, 2004). The hermeneutic circle is viewed as characterising hermeneutics and all understanding processes. It is a metaphor to describe understanding as a shift between the whole and its parts. Understanding of the whole presupposes understanding of its parts, while understanding of the parts simultaneously presupposes understanding of the whole (Geanellos, 2000). There is no consensus as to when this metaphor was first described, although Palmer (1969) refers to Ast and a description made in 1808.

### *Researcher's pre-understanding*

The researcher's awareness of his/her own pre-understanding is particularly important in qualitative research since it uses the self as a tool during the research process (Kvale, 1997). The pre-understanding or "horizon" encompasses what the researcher brings into the study, which influences the research process and therefore requires reflection. Pre-understandings enable us to make sense of events and people (Gadamer, 1979). This kind of foreknowledge is derived from human past experiences and is necessary to understand any communication experience. People interpret all the time (Koch, 1999; Finch, 2004). People cannot eliminate their pre-understanding since it is inseparably linked to interpretation. On the contrary, these are necessary for understanding (Gadamer, 1979). This way interpretation changes over time in relation to the evolution of one's personal horizon (Whitehead, 2004). In interpretative studies the researcher's pre-understanding can hinder openness to what is brought to the surface. To gain awareness of pre-understanding allows the researcher to take this into account to stay open to what



the world or text tells us (Koch, 1999). The researcher's pre-understanding is a part of the interpretation process. The first author (ACJ) had a professional background as a registered nurse, with previous professional experience in elder care, midwifery, mental health care and as a teacher of registered nurses. The second co-author (IRH) had a professional background as registered nurse, specialising in mental health care, an experienced nurse teacher with extensive research particularly in the field of psychiatric and elder care. The co-author (KP) had a professional background as registered nurse and nurse teacher, specialising in research in child health care, palliative nursing and home care nursing. The authors had experiences of needs assessment through life experiences and in their professional nursing context.

### *Entering the field and gaining access*

Prior to data collection the researchers strove to gain insight into the research field and conducted "pre-fieldwork" according to Taylor and Bogdan (1998). This was done to gain professional experience of needs assessments. Therefore two of the authors of Paper I–IV (ACJ/KP) accompanied home help officers and observed how needs assessments were conducted in a municipality not involved in the study. Getting access to the research field and municipalities willing to participate in the study meant prolonged pre-fieldwork. Contacts with gate-keepers started in August 1998, although no data collection could start until the late spring of 2000. Concerning qualitative research, Polit and Hungler (1999) recommend "advance planning" since getting entrance and pursuing data collection can take longer than expected. This was the case in this study. Gate keepers of the municipalities and later the home help officers viewed the focus of the study as interesting but participation was seen as time-consuming due to their already heavy workload. Several municipalities had given preliminary consent to take part, but repeatedly delayed actual start due to pressure of work and circumstances such as organisational changes, sick leave, courses, vacations and vacancies. For example, in one municipality the home help officers declined after the completion of preparations to start. In addition, the researchers not being home help officers may have contributed to their being viewed as "outsiders", even though this was not explicit. Home help officers in two municipalities agreed to participate in spite of their pressed work situation. This way the study was prolonged while similarly the researchers became more acquainted with the research field and home help officers through regular contacts.

## Participants and context

### *Participants*

Paper I–II. An initial purposive sample of older needs-assessed persons was made through selections from files on decisions about public home help in two municipalities (A/B). This was done between May and December 2000 (A) and between March and June 2001 (B). The selection was made by the home help officers from their own files consecutively from one date, retrospectively until estimated saturation was reached (15/municipality=30). The time between the needs assessment and the interviews varied between one and six months. The decisions had to be about “help in the home” and to ensure variations in the phenomenon no restrictions were made regarding duration, frequency, amount or continuity of home help. Criteria for inclusion in the study were that the older person was aged 75 and over, had gone through the needs assessment process, was living in his or her ordinary home together with a spouse or next of kin, or living alone with children living nearby, was judged as mentally competent by the home help officer who had performed the needs assessment and was able to communicate in Swedish. The person was to have one next of kin to be interviewed. In connection with the selection the home help officers contacted the recipients and requested informed consent. During the consecutive sampling twelve persons declined participation, of whom six gave reasons such as: not having enough strength (3), being afraid of letting unknown persons into their home (2), and being advised not to by their next of kin (1). Two interviews were excluded due to tape-recording or transcription problems. Paper I and II encompassed 28 persons (mean age 83 years, range 75–96 years), 15 women and 13 men. Twelve of them lived together with a spouse (n=11) or an adult child, and 16 lived alone. All had Swedish background except one who was married to a Swedish partner.

The sample of Paper III consisted of family members and was steered by the sample criteria of the initial sample in terms of being a family member chosen by the needs-assessed recipient to be interviewed (15/municipality). The study encompassed 27 close family members (mean age 63, range 42–93). All had Swedish background except one who was married to a Swedish partner. When asked to participate all gave their informed consent. Three interviews were excluded due to tape-recording or transcription problems.

The sample of Paper IV was also steered by the initial sample through having conducted the needs assessment of the older recipients (n=15/municipality) and consisted of 26 interviews with home help officers (n= 5, aged 29–50, women and men), each interview linked to a needs assessment they had conducted. Four interviews were excluded through tape-recording or transcription problems. The perspective of the home help officers was increased through purposive sample of home help officers (n=9 women), representing different municipalities from another county, who were invited and took part in a focus group interview.

### *Context of the study*

The study was conducted in two rather similar medium-sized rural agricultural municipalities (A/B) in the south of Sweden. At the time of the sampling the municipalities had about 15,000 and 13,000 inhabitants respectively, of whom 178 and 175 elderly people aged 75 and over received public home help (Statistics Sweden 1999; 2000). In 2005 the figures were 232 (171 women and 61 men) and 123 (81 women and 42 men) respectively (Statistics Social Welfare, 2006:3). Both municipalities had adopted a client/contractor organisation a few years previously and seemed to have ongoing changes within the organisation, among the management as well as among the home help officers. The home help officers had responsibility for one district each, where they were assigned to conduct needs assessments and decide about public home help. The decisions were thereafter documented on order forms and distributed to managers of the contractor organisation responsible for the provision of public home help. The home help officers had meetings with the contractor managers once a week, although this seemed more developed as team meetings in one municipality (B). In addition to the home help officer a team could consist of occupational therapist, physiotherapist and district nurse. The meetings mainly focused on new cases. Case documentation was made through computer programs, which also were in development.

## **Instrument and data collection**

### *Interviews*

Research interviews were used as method to collect data and based on Mishler's (1986) ideas, taking the form of an everyday jointly constructed conversation. In this way an effort was made to gain reciprocal understanding of context-bound meanings that occurred during the interview. Patton (2002) regards the interviewer's task as making it possible for the interviewee to bring the interviewer into his or her world. In a qualitative research interview the interviewer uses him/herself as a research instrument. Mishler (1986) particularly emphasises research interviews as a joint production in that the interviewer's presence and form of involvement, way of listening, attending, encouraging, interrupting, digressing, initiating topics and finishing off responses is an integral part of the production (p. 82). Questions in connection with themes in the interview guide were asked in relation to the flow of the dialogue and brought up by the interviewer later if the interviewee had not touched a topic of interest. Mishler (1986, p. 74) considers it important that the interviewer allows the interviewee to continue narrations at length without interruption, in that it is a way of presenting oneself. This form of interviewing is regarded as linked to empowering the interviewees, by striving for a more balanced power position and thereby encouraging narrations and speaking with their own voices (pp. 118–135). Although the interviews were guided by thematic interview guide, as recommended by Patton (2002), a checklist was used

to make sure that aspects in focus had been covered. Efforts were also made to create an open and secure atmosphere in which a meaningful discourse could take place.

The interviews were conducted case-wise. The older recipient was interviewed first, thereafter the family member, and lastly the assessing home help officer. In general the interviews began with getting to know each other and thereafter moved over to talk about the study and the purpose. After collection of demographic data the actual interview began with an overarching question about experiences in relation to the needs assessment, although adjusted to grasp the individual perspective in focus (that of older persons, family members or home help officers). The interviewees were encouraged to narrate their thoughts, feelings and experiences in relation to the needs assessment procedure in their own way. Probing and concluding questions were used during the interview. The interviews were mainly conducted by the author (ACJ), and some by one of the co-authors (KP). The interviews were audio-taped and transcribed verbatim into text. After each interview notes were made about hunches and reflections that occurred.

Interviews (Paper I–II) with the older needs-assessed persons were conducted in their homes and lasted from 30 to 85 minutes. Spouses were present at seven of the interviews since this was preferred by the couples. It began with the overarching question: Could you tell me about your reason for applying for home help and your taking part in the needs assessment procedure and decisions in relation to the help to be provided? It was ensured that certain topics related to the interview guide and the needs assessment were covered, such as the persons' expectations, experience of how the needs assessment was conducted, their own and family members' participation in and influence on the needs assessment procedure and the decision regarding public home help, along with why, when, where it took place.

Interviews (Paper III) with the family members chosen by the older help seeker to be interviewed were mainly conducted in their homes, but some in the home of their parent. One lasted 15 minutes, while the others lasted 30–90 minutes. The overarching question starting the interview was: Could you tell me about your frail family member's needs assessment and your participation in the procedure and decisions about help to be provided? Subsequent questions concerned the same topics as their older next of kin was asked, although participation and influence on the procedures and decisions was from their perspective. Spouses were present but rather passive at two of the interviews.

Interviews (Paper IV) with the home help officers that had assessed the recipients' needs in an encounter were conducted in their individual office. One interview lasted 20 minutes, while the others lasted 30–105 minutes. The overarching question at the start was: Could you tell me about carrying through this needs assessment and your view of the help recipients' and their family members'

participation in the procedures and the decisions made about public home help? Subsequent questions concerned similar topics to those the family was asked about, although home help officers were asked about the conduct of the assessment, any difficulties and what was taken into account for the decisions made, and their view of the help recipient's and their family members' participation in the needs assessment and influence on the decisions about public home help.

A focus group interview (related to Paper IV) was conducted to complement the home help officers' perspective and thereby control the face validity of the findings. A focus group interview means a planned designed group discussion to obtain perceptions regarding a defined area of interest in a non-threatening environment (cf. Kreuger, 1994). The interview was conducted in a conference room within a research department in another county (January, 2006). The first author (ACJ) conducted the interview and one of the co-authors (KP) assisted and made notes. The interview and discussion proceeded from the categories in Paper IV and the informants were encouraged to express experiences, thoughts and feelings in relation to it. All informants took part in the interview which was tape recorded, transcribed verbatim and lasted about 90 minutes.

Permission to conduct the study was received from the director of the social welfare office in both municipalities. All those involved as home help officers, help recipients and their family members gave informed consent to participate and on several occasions received oral and written information explaining the nature of the study, what was expected of them and their right to withdraw at any time. Due to the secrecy obligation of the social welfare office, the home help officers initially obtained informed consent from the recipients when contacting them in relation to the consecutive sampling. Thereafter the researcher was contacted and could phone the recipient for further information and arrange a time for interview. In addition the recipients' choice of family member was contacted, given further oral and written information about the study and thereby gave informed consent to be interviewed.

## **Data analysis**

### *Qualitative analysis*

Data analysis in qualitative research is an ongoing process since data collection and analysis go hand in hand (Taylor and Bogdan, 1998). The hermeneutic framing approach in this thesis meant that hermeneutic standpoints were chosen to guide analysis and interpretation of the texts. Patton (2002) describes the analysis, interpretation and presentation as the culmination activity of the qualitative analysis, and the natural aspect of discovering what researchers really would have wanted to know from the start but could not articulate at the time. These aspects were acknowledged in this study since the researcher's understanding of the

phenomenon increased during the research process through the three sources interviewed about participation in the needs assessment.

### *Qualitative content analysis*

A qualitative (interpretative) content analysis guided by Burnard (1991; 1995; 1996) was chosen, since it provided possibilities of different levels of interpretation. There is a distinction between basic descriptive analysis and interpretative analysis of texts (Patton, 2002). The use of content analysis makes both types possible. Textual data descriptions cannot be pure since it always includes interpretations. However, the dimension of interpretation can range between concrete surface level of the words used and deeper level of meanings, which makes many shades of interpretation possible (cf. Burnard 1995). Concrete and abstract level can be described in terms of analysis of manifest and latent content (Polit and Hungler, 1999; Berg, 2001). Content analysis can be traced back to World War II and the analysis of propaganda (Down-Wamboldt, 1992; Cavanaugh, 1997). Originally content analysis was defined as a research technique for objective, systematic, quantitative description of manifest communication content (Down-Wamboldt, 1992). Thereafter, qualitative content analysis interpreting the meaning of the text was developed. Bergh (2001) recommends the use of both manifest and latent analysis of the text whenever possible. This allows analysis of a manifest descriptive kind as well as interpretation of latent meaning, as was used in analysis in this thesis.

Content analysis in itself provides guidance regarding analysis technique but lacks philosophical ideas about the interpretation of texts. The interpretation theory of Ricoeur (1976; 1988) therefore guided the analysis when possible. Ricoeur (1976) describes the hermeneutic circle as encompassing a holistic process from, first, a naive surface understanding of the text as a whole, turning back to the text for explanation and validation or invalidation of the guessed understanding, to a second more comprehensive in-depth understanding of the text. As a consequence interpretation unfolds through a dialectic of explanation and understanding (pp. 71–88). Interpretation can disclose the utterer's meaning (the interviewee's meaning) as well as the meaning of the utterance (the meaning of the text) (pp. 12–13), wherein symbols and metaphors are emphasised as important bearers of meaning (pp. 45–63). What is to be appropriated is the meaning of the text itself, disclosed by the text as possible worlds opening up to be fused with the reader's world horizon (pp. 89–95). Since several meanings are possible, the interpretation made must be more probable than another interpretation (p. 79). Like Ricoeur (1976), Burnard (1995) also emphasises the autonomy of the text, interpretation of utterances and not the utterer, and the reader's pre-understanding as a natural part of the interpretation process.

The analysis process in Paper I–IV (and the focus group) was conducted in a similar way. The aim was to interpret the utterance when possible. However, since other aspects than meaning content were also in focus, and the depth of the interviews varied, the level of interpretation consequently varied. As a start the interviews were read one at the time, then altogether to capture a sense of the whole in relation to the aim of the study. Notes were made about topics that emerged from the data, a sort of naive understanding. Thereafter the interview texts as a whole were reread and questions varying in relation to aspects of the aim of each study were asked of the texts. After open coding of the text as a whole, the texts were condensed and rewritten into codes. Similar codes were grouped together into categories, at times collapsed, while simultaneously a sense of process and structure of principal categories and sub-categories developed. The interpreted meaning of the text, when appropriate, guided category names, the use of poetic expressions and metaphors (Lindseth and Norberg, 2004). The analysis process proceeded in a dialectic movement between the text as a whole and the parts of the text. In each study the essence of the interpreted meaning as a whole was captured in an overarching category.

## **Ethical considerations**

The studies were performed in accordance with research ethics (Government proposition, 2002/03:50) and estimations made in relation to the principle of autonomy, justice, non-maleficence and beneficence (Beauchamp and Childress, 1994). The two latter were incorporated, as according to Nilstun (1994), into one principle of utility. Certain aspects of the principles of ethics guided the research process due to the sensitive nature of this study. These concerned the three actors involved besides the researchers, (1) the older recipient, (2) the family member and (3) and the home help officer. *Considerations regarding the principle of autonomy:* There is a risk that the actors feel some kind of coercion to participate and a threat to their personal integrity. To minimise this risk the initial contact with the actors was not taken by the researchers. The home help officers were contacted by a contact person within the elder care unit, the recipient was contacted by the assessing home help officer, and the family member by the recipient. Informed consent was obtained after oral and written information, and the voluntariness of participation and the right to decline at any time was emphasised. The risk that dependence would influence the actors' standpoint was minimised by the fact that the researchers were not from the municipality, not working there or in dependence on the municipality. The recipients and their family members could feel discomfort in that the researchers would gain temporary entrance to their personal sphere, private home and aspects concerning their integrity. Therefore it was considered necessary to let family members be present during interviews when they desired. The home help officers could feel discomfort in that the researchers gained access to their handling of the needs assessment and documentation of their decisions about

public home help. This could be experienced as having their professionalism and integrity scrutinised and questioned, and in this way causing anxiety and distress. However, there was also a possibility that those involved would find it valuable, appreciate being listened to, and thus the interview situation could also be therapeutic. There was a risk that the actors could feel worried that the data collected by the researchers would be spread to staff within the municipality and other outsiders. The older needs-assessed persons and their family members could feel worried that information obtained would influence the public home help, relations and contacts with care workers. The home help officers could feel worried that information would be spread to staff within the municipality whom they were dependent on, and/or that the researchers would negatively influence relations with the recipients and their family members. To counteract these risks the researchers informed about their secrecy and that the collected data would be coded and handled to preserve confidentiality. The actors were also informed that the data would be grouped together, analysed and presented in a way that it could not be tied to any individual. *Considerations regarding the principle of justice:* The risk of conducting research involving vulnerable groups in the society was considered. The older recipients and their family members were regarded as a vulnerable group and as such more exposed and vulnerable to distress and harm. Simultaneously, refraining from research was considered as discrimination since research could gain knowledge of benefit to the group. *Considerations regarding the principle of utility:* During the research process and findings the intention was not to cause harm, rather to decrease and prevent harm and do well for all involved actors and for the future. The studies were approved by the Ethics Committee of the Medical Faculty of Lund University (LU-379-99).



## FINDINGS

### Context of the participants and the needs assessment

Some contextual and circumstantial aspects of the needs assessment are presented to help frame the experiences of those involved in the needs assessment before illuminating their experiences of older persons' and family members' participation and influence during the needs assessment process. Study II showed that contacts with the public home help services was initiated by the older help seekers, their family members or health or public home help professionals. The current needs assessment and public home help, according to themselves, was caused by needs for help due to diseases, falls/fractures, planned operations, generally increased frailty (own/partner's/both), co-morbidity, or a partner's vacation. The assessments were conducted either as home visits, or in connection with discharge planning in hospital contexts. Half of the older persons had been through previous needs assessments. The duration of public home help services received by this group varied between 1 and 25 years, while the other group had received help for at least a couple of months. The public home help consisted of personal care, service and some respite care that varied in frequency from one intervention every second week, to multiple interventions several times a day. Studies I–II showed that most of the older persons were born and had continued to live in the same municipalities. They were brought up in the shadow of the two world wars, a time of financial strain, and public help for people who could not manage by themselves was called poor relief. Many had been through rather difficult times in that most men had hard manual work in farming, forestry or factories. Most of the women had taken care of home and family while the children were growing up, although in combination with periods of gainful employment. Their financial situation seemed reasonable, except for a few cases of economic hardship and some instances of wealth. Study III showed that the interviewed family members were spouses (n=12), children (n=12), siblings (n=2) and niece (n=1). More were women (n=16) than men (n=11), and daughters (n=8) more often than sons (n=4). The spouses of help recipients had retired from work except one (n=11), while children mainly remained in working life (n=7) and had families of their own. Some had higher education. Not all took part in the needs assessment. According to the family members, reasons for this were not being invited, having difficulties getting time off from work or that their next of kin could manage single-handed. Family members' participation in the needs assessment encounter varied from being present and rather passive to totally representing their next of kin, although never as formally authorised proxies. All informants except one considered themselves as helping their next of kin.

## The overarching categories

The meaning of older persons' and their family members (family) participation in the needs assessment process and their influence over the decisions about public home help from the perspective of the older needs-assessed persons, their family members and the assessing home help officers was captured as a whole by following overarching categories. The older persons' experience of becoming in need of public home help and experience of participation in the needs assessment procedure and the decisions made about public home help were interpreted as *"Experiencing discontinuity in life as a whole – the countdown has begun"* (Paper I). Further their experience of participation and influence on decisions about public home help when undergoing needs assessment and receiving public home help was interpreted as *"Having to be satisfied, adjust, and walk a fine line when balancing between needs and available help"* (Paper II). The close family members' experience of having an older next of kin becoming in need of public home help, their participation in the needs assessment procedure and the decisions about their next of kin's public home help was interpreted as *"Feeling disconfirmed or confirmed in the needs assessment, when feeling pressed by the responsibility and struggling to balance the needs of the family"* (Paper III). The home help officers' view of older help recipients and family members' participation in the needs assessment procedure and the decisions made about public home help was interpreted as *"Having to establish boundaries towards family influence and at the same time use them as a resource"* (Paper IV). The studies further conveyed the needs assessment in phases of a somewhat similar process, here presented as: entering into the process of needs assessment, needs assessment process and encounter, and outcome and follow-up of the decisions.

## Entering into the process of needs assessment

The meaning of entering into the process of the needs assessment was interpreted in following principal categories from the perspective of those involved. The older persons' experience of becoming in need of home help embraced five principal categories with subcategories. The principal categories were: *Comparing the past with the present and losing parts of oneself and connectedness*; *Worrying about the losses and what they will bring about*; *Struggling against losing abilities to avoid dependency and public home help*; and *Struggling with conflicting feelings about being/becoming in need of help and from whom* (Paper I), and *Balancing the comfort and guilt – receiving help from the family at the limits of their capacity* (Paper II). The close family members' experience of having an older next of kin becoming in need of public home help embraced two principal categories: *Experiencing existential ruminations and the need to help*, and *Help giving and receiving as a difficult balance between needs* (Paper III). The home help officers' view of older help recipients and family

members' participation before the needs assessment embraced one principal category: *Bringing boundaries and preconceptions into the needs assessment* (Paper IV).

### *The older persons' perspective*

#### *Comparing the past with the present and losing parts of oneself and connectedness*

The older persons' were preoccupied with the loss of abilities and social network and less on the needs assessment. Past life and abilities were compared to the present situation, which conveyed loss of functional abilities and a part of their self and connection to their previous life and role. *Losing one's energy, abilities, social relations and activities* meant that the period of asking for help was marked by a distressing sense of decreasing abilities and increasing limitations. This could mean not recognising one's own body, and sensing strength and energy fading away. Diminished bodily functions were problematic, and illness, pain and lack of energy were hindering and time-consuming, also in terms of health care visits. Meaningful activities were more difficult to participate in. The life situation was marked by having lost persons or the ability to maintain the relationship because of diminishing abilities. Having to cope with the loss of a child or a life partner was experienced as losing parts of oneself. Losing one's home and familiar environment meant losing connectedness, security and involvement in social life. *Losing one's sense of self-worth* meant a loss in terms of an existential spiritual dimension, which had to do with reflections on their past in comparison with current. When earlier valued capabilities changed, a person's role and function at home also changed. Men taking over tasks previously performed by the women caused some tension, while the other way around was viewed as more natural. The self-worth was also impaired by feeling devalued by society in that other groups were interpreted as more valued. Not having the same value as before was perceived to a higher degree, as in contacts with health care and service staff. Reviewing life was stressful, as valued roles, functions and status faded away. Feelings of being of no use influenced the persons' sense of self-esteem and self-worth negatively. These overall changes meant losing a sense of meaningful connectedness and that "the countdown" had begun (Paper I).

#### *Worrying about the losses and what they will bring about*

The period of having to ask for public home help meant worrying about what the changes would mean for the present and future situation. The life situation could have changed from one day to another. *Worrying about one's present situation* meant anxiety and a struggle to grasp and understand the changing situation. It could also mean less awareness and and/or having handed over the responsibility for one's situation to family members. Difficulties in making plans and not knowing where to turn when needing help enhanced feelings of insecurity and vulnerability. Having healthy family members to help out was a consolation. *Worrying about one's future* meant not being able to grasp the future life situation. The likelihood of

experiencing future negative changes in health and abilities was not something to look forward to. Not knowing what to expect or and whether they would receive adequate help from society caused worries and thoughts of losing control and freedom (Paper I).

### *Struggling against losing abilities, to avoid dependency and home help*

The period prior to asking for public home help meant a struggle to manage daily life through one's "own ability" including help from others than the public. *Trying to handle the losses and the changing situation practically* meant a struggle to regain and/or maintain capabilities, to keep dependency on the public at bay as long as possible. This meant challenges to manage daily practical tasks. Preparations were made to feel safer through preventing delay in case of an urgent need of help. To "keep oneself going" meant maintaining self-determination and control over everyday life. New strategies to manage daily life, to avoid or decrease dependency and need for public home help became essential. Spouses jointly struggled against the need for public home help by compensating for each other's disabilities, with complementary help from children. For those living alone, public home help was avoided by enlisting help from next of kin. Efforts to give in return and recompense helpers seemed natural. *Trying to handle distress related to the losses and the changing situation mentally* meant emotional strain, grief and a mixture of distressing feelings, related to concrete losses and changes in the individual's life situation, life history and estimated remaining lifetime. These were experienced as changes for the worse and created anxiety. Difficulties in mentally handling the changes were evident, such as having to redefine one's previous role in life. Thoughts about the past could give relief as well as feelings of sadness. Expected compensation in later life for endeavours in previous life was not always fulfilled. Illness and disabilities could be experienced as natural, just as there was unawareness and/or denial. Efforts to handle the situation with humour or avoidance were salient (Paper I).

### *Struggling with conflicting feelings of being/becoming in need of help and from whom*

*Feelings regarding help from near and dear ones* revealed that "help from one's dearest" had a valued quality that enhanced a sense of belonging. It meant being seen not only as old and weak – but also in terms of their relationship and shared past. It was a joy to take part in the life and development of their loved ones. Having children nearby promoted comfort, security and confidence about being guarded and supported when impairment increased. The relational aspect of help from family members was emphasised more than the help, which at times received little or no attention. Spouses viewed themselves and their partner as a mutual unit. Receiving help evoked conflicting feelings and a fear of becoming a burden. There was a limit to how much help one could expect from other relatives than spouses, since they should have a life of their own. Receiving family members' help could conceal the older person's help need, and applying for public home help could be reluctantly agreed about with the family. *Feelings regarding public home help*

revealed reluctance about having to turn to the public for home help. Facing that one needed help evoked sadness, grief, and anxiety about the new, unknown and potentially unpleasant situation. Thoughts of having to let strangers into their home were threatening, and evoked fear of losing self-determination and control over daily life and becoming increasingly helpless and vulnerable (Paper I).

*Balancing the comfort and guilt – receiving help from the family at the limits of their capacity*

Entering into the process of receiving public home meant a start of an ongoing process with no turning back, in terms of frailty, vulnerability and humiliation to come which made the family and their help important. This meant balancing on the family's perceived capacity to help. *Balancing the comfort of receiving informal help with the envisioned discomfort of public home help* conveyed that help from the family was valuable before and all through the needs assessment process. Their extended help made them avert public home help as long as possible. Some understood the difficulties themselves, while others seemed unwillingly confronted with the need for help as unbearable for the family. Some denied their need for increased help. Fears of vulnerability and violation of integrity came out strongly. Having close family members as a safety net and as safeguards enhanced a sense of comfort, security and well-being. *Balancing receiving help from family, guilt and efforts to recompense* showed that a sense of gratitude for help from close family members simultaneously brought with it an urge to give something in return. Decreased ability to recompense for help received evoked guilt and efforts to find acceptable reasons for receiving the help. Fears of overstraining the family and becoming a burden at some critical point tipped the balance to accepting public help which relieved their immediate family (Paper II).

*The family members' perspective*

*Experiencing existential ruminations and the need to help*

To the family members, entering into the process of receiving public home help meant experiences of a transition into a new phase marked by a distressing awareness of the countdown for their next of kin. An unreflecting willingness to help promoted slipping into helping. *Becoming aware that "the tables are turned"* was a turning point meaning increased help giving and a reluctant awareness of their next of kin's decline. Ruminations involving previous, present and future family life together with thoughts of life and death became more noticeable. Sensing the deterioration of the next of kin evoked feelings of empathy, sorrow, grief and frustration. It became necessary to address feeling the main responsibility for the well-being of their next of kin. This turning point also meant that their relationship changed, as did relationships within the family. *Slipping into help giving* conveyed that none of the family members had reflected on what the help would mean in terms of demands; a determined willingness to help was evident. This seemed to be grounded on relationships of love or on moral obligation and duty. As

a whole an attitude of giving help in return for previous help received was evident. Spouses tried to compensate for each other's disabilities. It was important to avoid dependency on outsiders (Paper III).

### *Help giving and receiving as a difficult balance between needs*

Becoming involved in helping a family member was emotionally charged and marked by uncertainty. How to approach him/her about the increasing disability, and also the need to ask for public home help sooner or later, had to be handled with delicacy. There was a struggle to balance family needs and to help. *Helping – a charged encounter of conflicting feelings* revealed helping as an encounter between willpower, expectations and values to be grasped and balanced together. The willingness to help could be met by an unwillingness to receive help, which evoked disappointment and anger. Expectations concerning the help could collide or not be outspoken. It was a dilemma to balance between the risk of offending the next of kin and the risk that he/she would fare badly. *Helping as visible and invisible giving and receiving in return* revealed that the family members' new role meant giving practical help as well as less visible help, such as adjusting life in favour of the needs of the next of kin, and supporting a sense of self-worth and dignity. Helping could also mean receiving intangible things in return, such as mental capacities, or an enriching dimension, such as being present, a companion, a link to former mutual life context, a sense of connectedness and meaningfulness. Helping could be rewarding, give satisfaction and prevent feelings of guilt. *Struggling against increased imbalance* meant a struggle by balancing one's needs against those of the next of kin, which could be a physical, mental, social and financial strain. In deciding the priority of different needs, their own took second place and were thus neglected, and pain, mental stress and imbalance increased. Helping spouses had difficulties regarding sleep, relaxation, leaving home for short errands, and maintaining a social life. Being in working life meant difficulties getting free time to help, and spare time, days off, vacation and decreased degree of employment solved the situation. Children in weak social positions were strained by their own illness and financial restraints (Paper III).

### *The home help officers' perspective*

#### *Bringing boundaries and preconceptions into the needs assessment*

The phase before the needs assessment revealed the home help officers to be pressured by their professional responsibility and personal boundaries had to be set. Individual home help officers had a primary attitude through their narrated needs assessments, although it could vary partly. Both emotional and cognitive reasoning were shown. *Getting signals about needs assessments* showed that preconceptions about family participation were developed through signals of potential needs assessments. Recipients' own contact indicated an ability to speak for oneself, while contacts by family members indicated more disabilities. Family members' contacts often concerned worries about the recipients' (and their own) situation, particularly

if the recipients lacked awareness about the situation. Making family members understand that the older individual had to be involved in and willing to receive public home help took much time. Contact could also be initiated by health professionals, for instance by ward nurses as part of hospital discharge planning. *Setting boundaries deliberately and instinctively* showed that their responsibility concerned not only the needs assessments, but also other parties within the organisation, guiding local general principles and legislation. Legislation and doing right warranted caution and a need for self-protection. Reasoning about whether aspects were within one's professional responsibility or not, such as concerning diseases and home nursing care, tended to mark the handling of the needs assessment process. How boundaries for responsibility were set also had to do with personal experiences, feelings and values. These seemed intertwined with the professional responsibility and appeared connected to relational proximity to the recipient and/or family members. Here, legislation could be viewed in relation to one's own purposes, as marking and gaining power, or as a shield to hide behind (Paper IV).

## **The needs assessment and encounter**

The meaning of the actual needs assessment and encounter was interpreted in terms of the following principal categories from the perspective of those involved. The older persons' experience of participation and of having influence in the needs assessment and on the decisions about public home help was conveyed as "*A necessary evil*" – *balancing feelings and resources against having no choice but to accept* (Paper II). The close family members' experience of their participation in the needs assessment procedure and the decisions about their next of kin's public home help was revealed as *Feeling overlooked or acknowledged as having influence on the needs assessment* (Paper III). The home help officers' view of older help recipients' and family members' participation in the needs assessment procedure and the decisions made about public home help was revealed as: *The home help officers' attitude making a difference; Family members as contradictions to the assignment and Taken into account when deciding* (Paper IV).

### *The older persons' perspective*

*"A necessary evil – balancing feelings and resources against having no choice but to accept"*

The needs assessment process – when the public help was decided about – revealed that the older persons had mixed feelings and a cautious approach in the encounter. Former and current life situation influenced the feelings in the encounter and how it was handled. "*A necessary evil*" meant that having to seek public home help was experienced in terms of a strong resistance together with gratitude for the

possibility. The actual assessment encounter was difficult to grasp and talk about and there was no awareness of having been through any assessment, even with good recollection. *Resources make a difference for exerting influence* revealed that background, degree of disability and weakness, socio-economic situation, available help and support from the family made a difference. Knowledge about procedures, the content of the encounter, about public home help, availability, and rights was scarce and made a difference when encountering the home help officer. The needs assessment dialogue was experienced as governed by the home help officer, while the older persons seemed to be more passively looking on (Paper II).

*Feeling exposed or secure in relation to having guardian family members* showed that to the older person feeling exposed in the encounter meant loneliness and a burden in having to deal with the encounter single-handed. Aspects such as weak social position, also helping a family member and having their own disease or illness appeared to contribute. Rejections in previous assessments could give negative expectations that further shaped poor resources for influence. Having caring family members could strengthen informants' sense of security. Degree of involvement seemed to correspond with family members taking over, which could be necessary since informants' presence did not necessarily mean participation. Rather, being present yet "absent" was revealed, although feelings of being disregarded were absent. The family members' participation strongly compensated for the imbalance in power between the home help officer and the frail person. *Balancing on the edge of acceptance* revealed the balancing act when understanding that their individual needs were not the main concern. The officer offered home help according to restricted guidelines that had to be accepted. This insight meant a balancing that resulted in varied types of acceptance: adjusted, reluctant and resigned acceptance. *Adjusted acceptance* was shown mainly when having a rather indifferent attitude, and/or spouses/children had taken over the communication. *Reluctant acceptance* was coloured by feelings of frustration due to various kinds of denial. *Resigned acceptance* predominated and was marked by an attitude of powerlessness and "having to accept". Dissatisfaction with decisions could be changed as long as the person did not feel "steamrollered". Efforts to negotiate could occur regardless of the kind of acceptance, but spontaneous claims for help seemed rare; the home help officer was viewed as having the decision-making power (Paper II).

### *The family members' perspective*

#### *Feeling overlooked or acknowledged as having influence on the needs assessment*

The text showed the family members' knowledge of public home help services, their rights, the needs assessment process and procedures as scarce. Understanding of the actual assessment, grounds for the decisions, duration and follow-up was also vague. *Entering into the assessment encounter with hopes for the better* showed that the assessment process and encounter was difficult to comprehend. The role and function of the home help officer and other professionals were diffuse. Hopes of an



improved situation for the family seemed facilitating. Uncertainty about what was expected of them was evident, for instance fears about having to provide more help than possible. Guarding and to various degrees representing their next of kin was natural. Having resources such as familiarity with professionals in the context, socio-economic status, authority and ability to articulate needs facilitated influence. Being used to having influence meant being more confident in encountering the officer and about the outcome. The opposite was shown by people used to being powerless regarding influence. *Feelings of "it was decided" versus "we decided"* revealed that the family members guarding and representing their next of kin during the assessment felt mainly overlooked and that "it was decided". However, there were also feelings of being confirmed and "we decided." The way the home help officer was felt to treat and involve family members during the assessment encounter made a difference. Feeling overlooked and frustrated was exacerbated when feeling not sufficiently seen, acknowledged or involved in dialogues, not being asked to express one's own view of the situation. Feeling overlooked was also evident when expressing views not acknowledged or rejected by the officer, as within disagreements with their next of kin. This evoked fears that not enough help would be provided. Feeling acknowledged was enhanced by being encountered with a respectful and caring attitude that encouraged involvement. It promoted feelings of value to be encouraged to think of one's own health, or getting help to make the next of kin understand the necessity of help. Feelings that personal views were received as worthwhile, needs were acknowledged, involvement encouraged and mutual satisfaction with decisions was achieved promoted feelings of "we decided" (Paper III).

### *The home help officers' perspective*

#### *The home help officers' attitudes making a difference*

The home help officers' sense of responsibility and how boundaries were set worked as the screen through which recipients' and family members' participation was viewed. Legislation was perceived to emphasise the individual and his/her right to self-determination, while the complex reality caused conflicting feelings. *Forming the approach* showed that attitudes influenced how the participants were encouraged to be involved in the procedures. Attitudes were displayed as variations of two opposite poles on a continuum, as the most prominent detached/distancing attitude and an engaged/strengthening attitude. How boundaries were drawn shaped differing approaches to how the needs assessment was conducted and how the families were encountered. The needs assessment task could be the main goal, and then characterised by a distancing attitude with a narrow, superficial, here-and-now oriented approach all through the process. It could also be experienced as a means to achieve a larger goal and responsibility, then characterised by an engaged attitude with a broader, deeper, future-oriented approach with efforts to strengthen family's resilience and ease their situation. *Striving for "the whole picture" of the individual* showed the officers difficulties in talking about the needs assessment, how it was

conducted, and how the family participated and was taken into account. The need to get “the whole picture” seemed to steer the procedures. The common feature was a focus on physical abilities, needs and sources of help provision. A tendency to turn to general idealistic phrases and governing legislation was shown, although as “the theory”, often not applicable in reality. The Social Services Act was perceived to rule a focus on the recipients, and it was important not to override the individual’s will, a delicate matter, since ability to speak for oneself could fail and family members’ participation could become necessary. *Establishing contact and participation* showed a “good contact” as a prerequisite in the encounter. Failing contacts were experienced as difficult. Then body language or no sign of disagreement, and communication with a family member was satisfying. But it could be the opposite, and having just one person to communicate with seemed sufficient. Aspects of psychological and psychiatric nature seemed tricky to handle. Dementia or similar symptoms were spoken of as “forgetfulness” or “no insight” and were a sensitive matter. A reluctance to talk about how such participation was handled was apparent (Paper IV).

#### *Family members as contradictions to the assignment*

Family members’ participation in the needs assessment made a difference to the home help officers. It was important to make them understand that the needs assessment concerned the recipient and his/her will as being decisive for the decisions. *Family members for better or worse* meant that family members’ participation was viewed as positive, while a rather ambivalent, distancing attitude was evident. Expressions conveyed that having them present could counteract problems, despite being a potential source of complication. They could be opinionated about what was needed and even try to take over the assessment. Officers did not routinely elicit views of their situation and willingness to help. Their participation was experienced as positive in strengthening the recipients’ voice, and their help became easy to clarify – it was not necessary to provide municipal home help. Their help could be viewed with a distancing attitude, but proximity was also visible. Family members’ roles as guardians were understood, but viewed as troublesome. Suspicious attitudes were shown, for example concerning talking over recipients’ heads or behind their backs, and children could be experienced as trying to evade their responsibility. *Contradicting family situations* meant that some situations were particularly contradicting besides family members’ necessary involvement when perceiving difficulties in communicating with the recipient, as when needing to focus on the help giver instead of the recipient, or the latter refusing public home help despite extensive needs. Particularly husbands could indirectly force wives to stretch their limits, since the recipient’s will was the main concern. Wives were viewed as having rigid ties and feelings of guilt which were impossible to change, thus signals that they could not cope any longer were awaited. The application form when two impaired spouses needed help caused difficulties and could be written in the name of the person needing the most home help, or one for each person. An attitude of “married couples have certain

obligations to help each other” with service but not personal care, was evident. Expressions disclosed that some wives gave extensive personal care, while husbands tended to be excused from cooking and cleaning duties (Paper IV).

### *Taken into account when deciding*

To the home help officers the decision making was a more or less contradictory task – in weighing together “the whole picture” with guiding principles and legislation. How perceived tensions or weaknesses within family relationships were taken into account varied with the attitude to responsibility. *Gathering of impressions of relations and expressions* meant that the personality and behaviour of the recipient as well as interactions with family members were compared to verbal expressions in order to complete the picture for the decision making. These aspects were mostly experienced as being outside one’s responsibility, which could influence family members’ possibilities of involvement. When experienced as being within one’s responsibility it was spoken of openly as efforts to strengthen the weaker party or the situation in the background. *Weighing it together* meant that aspects of importance for the situation had to be weighed together. The general guiding principles were always in their mind, along with the legal requirement of individual needs assessments, which could be found contradictory. The routine was to offer help in accordance with municipal guidelines, and if no objections were put forward, it was interpreted as consent. Older people were experienced as mostly accepting proposals, while family members had demands. Mutual agreement was desired, but acceptance could be encouraged by pointing to the general principles. Having to act upon what was verbally expressed was a salient feature when experiencing difficulties about making decisions. This way the decisions were mostly made directly during the encounter (Paper IV).

## **The outcome and follow-up of the decision**

The meaning of the outcome and follow-up of the decisions was interpreted in terms of following principal categories from the perspective of those involved. The older persons’ experience of the phase of concerning the outcome of the decision was revealed as *Incorporating the home help into daily life to gain a sense of continuity* (Study II). The family members’ experiences was *Hopes about the home help being fulfilled or dashed* (Paper III), and the home help officers’ view of older help recipients and family members’ participation in the needs assessment was interpreted as *Experiences of responsibility for follow-up* (Paper IV).

### *The older persons’ perspective*

#### *Incorporating the home help into daily life to gain a sense of continuity*

The outcome of the decision – the actual help – was a phase revealing how the older persons struggled to balance feelings, attitudes, needs and help resources against having to make daily life as coherent and consistent as possible to

strengthen the sense of continuity and integrity. *Balancing daily life to gain a sense of control* showed that even though they received insufficient home help, guilt and an attitude of having to be grateful for any help at all was salient. Despite dissatisfaction with various aspects, the need to be satisfied to gain a sense of control was stressed. This meant balancing between one's own efforts, help from family members and public home help to manage. Not knowing about details of the delivery of home help threatened one's personal control, since it was important to make one's own routines and plans. Fears could be modified when a person got used to the care worker, but worries about new ones remained. *Balancing the relations with the care workers – to gain influence* showed that, for influence over the actual help, the quality of the relation with the care worker was essential. It opened possibilities for a deeper relationship that could mean a mutual exchange of confirmation and support. Care worker continuity was essential and meant knowing each other, being seen and treated as a person, and knowledge of what to do and how. Appreciated care workers treated the persons capably and kindly, whereas disliked workers treated them unpleasantly, were insolent and dictatorial, which was perceived as degrading. Balancing and "tiptoeing" to not fall into disfavour was important. Efforts to gain influence by coaxing with the care workers to get help over what was granted were mentioned. "Enough time" made a difference, although when time was insufficient it could not be blamed on the care workers (Paper II).

### *The family members' perspective*

#### *Hopes about the home help being fulfilled or dashed*

The outcome of the decision was a phase revealing that hopes and expectations of an improved help and life situation through the public home help were either fulfilled or dashed. Perceived quality and sufficiency of the help/care appeared important for facilitation of the situation as a whole. *Feeling relieved* and *having trust in the home help* conveyed that a change for the better meant feeling relieved of carrying the main responsibility for the well-being of their next of kin. Confidence in the public home help, relief of pressure, and satisfaction were shown if help was experienced as sufficient and caring, which meant time for one's own interests and social activities. Wives particularly seemed to need legitimate support, since partners were not always aware of the extensive help they provided, while children's visits to their next of kin were not dominated by helping. *Feeling pressure and frustration from still carrying the responsibility* was salient when improvement failed to come. Then there were feelings of having to keep on bearing the main responsibility and disappointment, anger, frustration and continued pressure. The public home help was perceived as insufficient or of low quality and not trustworthy. Spouses could experience it as being exposed to outsiders invading their daily life. Being uncomfortable with the provision could then mean cancelling the help. Children could experience lack of communication with the care workers when they wished to discuss the situation of their next of kin, but they were contacted

only in emergencies, and their own contact efforts could fail. As a whole, frustrated family members appeared passive or active in attempts to influence their help and life situation (Paper III).

### *The home help officers' perspective*

#### *Experiences of responsibility for follow-up*

The follow-up of the decision was the last phase of the needs assessment. The home help officers' new specialised function was experienced as positive even though it could have negative consequences for both home help officers and families. The follow-up of the decisions was handled in accordance with attitudes which could make a secondary difference for family participation. *Pros and cons* showed that being responsible solely for the needs assessment was viewed as a relief since it meant being spared the provision. It was also believed to have resulted in higher-quality needs assessments, and that their decisions were viewed as independent of actual resources. This was described as an improvement for the recipients since it ensured their legal rights. Simultaneously it was important that the politicians in charge of allocating resources were kept satisfied. Channels between decisions and provision/action were perceived as "longer", complicating recipients' and family members' contacts with professionals. The loss of a holistic vision of the situation was spoken of as negative for all parties. *Waiting for or preventing signals* showed that the home help officers' attitudes made a difference for the management. Regarding the follow-up of decisions about help, a rather distancing attitude to having handed over the responsibility to the contractors was salient. It was presupposed that professionals or families would signal any problems. In cases of a more engaged attitude, the provision of home help appeared to be followed through contacts with all those involved since the responsibility for follow-up was considered important to strengthen the family (Paper IV).

### *The focus group perspective*

As a whole, the text encompassing views of other home help officers as informants confirmed previously illuminated principal categories and conveyed two broad categories labelled as: *The public authority orientation* and *The person and family orientation*. Previously emerging categories in study IV were furthermore strengthened and influenced the home help officers' approach in the needs assessment process. The former, most prominent, attitude meant a *public authority orientation*. This approach formed a role with narrow boundaries. The task – authorisation to assess needs in relation to regulations and municipal guidelines (at times legislation) – was the focus and essential responsibility. It concerned solely the individual, here and now, and it appeared difficult to take family members into account simultaneously. This could be expressed as: "*I am assigned exercise public authority and legislation must be followed ... and I think many family members are*

*offended by this.*” Considerations of individuals as persons and individual needs were minimal. However, the latter attitude embraced a more holistic responsibility which emphasised a *person and family orientation* but also the task. Here the recipient as well as the family member and their needs were confirmed. This approach contained more prevention, empowerment and future orientation. Salient features of the text further confirmed these attitudes and approaches as influencing how home help officers viewed the recipient’s and family members’ participation, and thus their possibility to get involved in order to have an influence over the decisions about home help. One statement was: “*to secure the individual’s rights and needs means a need to actually grasp his or her life situation as a whole,*” although such an approach was perceived as more difficult (Paper IV, thesis).

## DISCUSSION

### Methodological considerations

The overall aim of this thesis was to illuminate older persons' experience of becoming in need of public home help and their family members' experience of this situation. Further, the aim was to illuminate experiences of participation in the needs assessment process of older people and influence on decisions about public home help from the perspective of older needs-assessed persons, their family members, assessing home help officers and external home help officers.

#### *Trustworthiness*

The qualitative methodology and findings in this thesis will be discussed in relation to *trustworthiness*, i.e. the credibility, transferability, dependability and confirmability throughout the research process as described by Lincoln and Guba (1985). To be understood from a quantitative perspective, these are concepts roughly parallel to the terms internal validity, external validity, reliability and objectivity. Qualitative and quantitative methodologies adhere to different paradigms, which constitute different terms of assessment of quality, but both are concerned with truth value, applicability, consistence and neutrality of findings. According to Holloway and Weeler (2002), "truth" in qualitative studies must be viewed differently since the aim is to capture and understand individuals' subjective experiences and "meaning making" and not an objective reality to be generalised. Moreover, the interviewer him/herself is an instrument. To judge findings in terms of their trustworthiness is therefore considered more appropriate (cf. Lincoln and Guba, 1985).

*Credibility (internal validity)* is used to judge the "truth value" in a study. It concerns whether the study has been carried out in a way that enhances a believable description of the participants' experiences and that the findings are reasonable. Recommended strategies to enhance the credibility are, for instance, prolonged engagement (to build trust) and triangulation (Lincoln and Guba 1985). In addition, Patton (2002) views credibility as having to do with several related elements: the use of rigorous techniques and methods, the credibility of the researcher, philosophical beliefs, appreciation of naturalistic inquiry and qualitative methodology, inductive analysis and holistic thinking. Kazdin (1998), with more research experience in quantitative methodology, describes credibility in a chapter about qualitative research methods as whether the methods and subjects are adequate to the goals and can represent the sample in focus. *Transferability (external validity)* concerns the context in which the study has been conducted and to what degree the findings from this particular context can be transferred to other contexts. This in turn concerns similarities between the participants and the settings. The responsibility of the researcher is to provide data enough for readers to make

transferable judgements (Lincoln and Guba, 1985). In the perspective of Kazdin (1998) transferability concerns the generality of findings. *Dependability (reliability)* is closely related to credibility, in the same way as validity is related to reliability. Thus, design and methodological steps taken to ensure credibility also strengthen dependability. It refers to the extent to which findings stay stable over time (Lincoln and Guba, 1985). Thus, dependability of findings has to do with replicability, which is more difficult in qualitative studies because people and their experiences may change in relation to environmental changes. Kazdin (1998) views dependability in terms of the reliability of the conclusions and the data evaluation leading to the conclusions. The *confirmability (objectivity)* of the findings concerns whether the findings are grounded in the collected data and conditions of the inquiry, or in other words the extent to which data and interpretations are based on events rather than the researcher's personal construction. Confirmability encompasses e.g. whether findings are presented in a way that can be followed from raw data, whether inferences based on the data are logical, whether analysis techniques are visible, the appropriateness of category labels and the utility of the structure (clarity, explanatory power and fit to the data), quality of the interpretations and whether there is any inquirer bias (cf. Lincoln and Guba 1985). Kazdin (1998) views confirmability as to the extent to which an independent audit of the procedures would generate the same findings.

### *The qualitative design, triangulation and hermeneutic frame*

The qualitative method was chosen to gain entrance into the informants' life worlds and their subjective experiences in a holistic sense. The complexity of the concepts of participation and influence was considered difficult to apply in a questionnaire, which led to the decision to use the qualitative method. In addition, there was little knowledge about the phenomenon under study, thus an explorative, descriptive approach and triangulation of data sources was chosen. That older help-seeking people and their family members could be frail, handicapped and lacking strength was also considered. The approach as a whole made a deeper level of understanding and concretisation of the concepts of participation and influence in the specific needs assessment context possible. Important aspects in terms of older people's and family members' experiences prior to the needs assessment were also conveyed, and differences and similarities between the three perspectives became clearer. The strength of the triangulation was a more comprehensive and balanced understanding of the focus of interest, by achieving an understanding of the parts in relation to the whole, the older persons (Paper I–II), family members (Paper III) and the home help officers (Paper IV) in different positions in relation to the needs assessment. That triangulated findings appeared to complement each other well may strengthen the credibility as a whole. The qualitative methodology probably captured a more holistic understanding of the phenomenon than would have been possible by a quantitative method with preset questions. To assess the *transferability* of the findings to similar groups or settings, contextual aspects that may differ from



this study context would need attention, such as the background and circumstances of the groups of informants, the Swedish context and welfare system, legislation, political management of the municipalities, elder care organisation, public home help, needs assessment procedures and the knowledge base of the assessing home help officers. It is important to bear in mind that these findings encompass informants with family members, meaning that those without family or other next of kin may be further exposed.

### *Informants*

To strengthen *dependability*, an initial purposive sample of older needs-assessed people was chosen to obtain informants able to illuminate their experience of becoming in need of public home help, their experience of participation and of having influence on the needs assessment procedure and the decisions made and receiving public home help. The selection took place in two municipalities which were willing to participate and had no contact with each other. The original plan envisaged three participating municipalities but this was revised due to heavy workload and organisational changes. The municipalities were rather similar in demography whilst organisation and teamwork appeared more developed in one of the municipalities. The consecutive initial retrospective sampling meant that the time between the needs assessment and the interview varied up to six months, which could threaten the *credibility* through recall problems, although most informants had a reasonable recollection of the needs assessment. Difficulties experienced concerned a few needs-assessed informants that appeared to suffer from various degrees of forgetfulness, although not diagnosed as dementia. However, older patients' (n=93, mean age 74) memory of telephone support was found to be accurate in 60% of the cases in a study (Berkham et al., 1999). Most likely the informants in this study were influenced by factors such as age, time since exposure, the significance and nature of the event and their emotional state, factors known to influence memory recall (Coughlin, 1990). A prospective selection could have been an alternative, but then experiences of importance would have been missed, particularly regarding the outcome of the decisions. In addition, the needs assessment process as a whole would not have been captured, and this kind of "forgetfulness" could still be evident.

The initial sample size of older needs-assessed persons (15/municipality=30) was estimated as reasonable to ensure breadth and variation among their experiences in relation to the needs assessment. Inclusion of decisions was restricted to "help in the home" although restrictions were not made regarding duration, frequency, amount or continuity, to enable rich variation of experiences of decisions about "help in the home". Patton (2002) argued that sample size is a minor issue since credibility in qualitative studies is rather grounded on insights generated from the study, validity, meaningfulness and the analytical capabilities of the researcher. In two cases of poorer recollection the needs assessment was conducted within hospital settings in

relation to discharge planning. In two other cases informants had difficulties articulating themselves due to aphasia. In some other cases more or less “forgetfulness” was shown. A threat to the *confirmability* of the findings can be that the selection had to be conducted by the home help officers from their own files and not the researchers due to confidentiality requirements of the social services. However, no indication of a biased selection manner was shown (Paper I–II). The sample mainly consisted of Swedish-born persons and failed to capture immigrants. The home help officers’ explanation for this was that immigrant family members of older help seekers mostly were employed as help givers. This is in agreement with findings by Hovde et al. (2006, submitted) comparing formal and informal care provided by the municipality by staff’s descriptions of care-related needs among non-Nordic and Nordic older immigrants (n=111/n=111). Significantly more of the non-Nordic immigrants had family members employed as help givers ( $p < 0.001$ ).

The sample of family members (Paper III) was governed by the initial sample of older needs-assessed persons to choose a family member to be interviewed. The sample of home help officers (Paper IV) was also governed by the initial sample since they had conducted and selected the cases from their own files. They formed a total sample of those responsible for decisions about public home help within the elder care in each municipality. It can be viewed as a threat to *credibility* that only five home help officers were interviewed. A focus group of nine home help officers from different municipalities in another county was chosen to counteract this threat. They were invited by their higher-level manager. All those invited took part, showed a great interest and asked for a follow-up after the discussion. The focus group was also a test of *credibility* in terms of the face validity of the findings (Paper IV), which moreover was strengthened. Patton (2002) views such tests of face validity, in terms of the response to the findings, as the ultimate test of the *credibility* of the findings.

### *Interviews*

In relation to *trustworthiness*, the interviewers’ professional background and pre-understanding could form a threat in terms of sparse knowledge and familiarity with the research context (Patton, 2002). The steps taken to promote familiarity with the needs assessment context and obtain a mutual sense of confidence with all informants were intended to counteract this threat. These circumstances can also be positive in that the researcher enters with an open mind and other “glasses” and may see new aspects, since professionals within a context are socialised into a certain way of thinking and may take things for granted (Taylor and Bogdan, 1998). The interviews were conducted case-wise in a somewhat similar way in the studies and, with a few exceptions, on the same day (I–IV). This meant that the interviewers’ pre-understanding about the case as a whole developed gradually, and also about the public home help context. The last interview in each case was mostly with home help officers. On the one hand this can threaten *credibility* and *dependability* in that the interviewer had already received two other perspectives about the needs

assessment. Therefore the interviewer struggled to not let pre-understanding from former interviews influence the current interview negatively. On the other hand, the interviewer received an increasingly holistic insight into each case, which may strengthen credibility and dependability. All the interviews (Paper I–IV) were conducted in a calm atmosphere and with no disturbing elements, although in some interviews with home help officers (Paper IV) there were interruptions by phone calls or colleagues. These disturbances could have influenced the home help officers' possibility to concentrate on the interview dialogue, although this happened only a few times and should not form a serious threat. However, the sensitive nature of the interviews could be considered to be a threat and evoke a sense of inspection of their work performance. To counteract recall problems they were encouraged to use documentation of each case, although documentation often seemed thin, in particular regarding the focus of this study. Some older persons (Paper I–II) and family members (Paper III) preferred having their spouse present during the interview, which could have influenced the dialogue. The interviewer approved of this since it seemed ethically right with reference to their vulnerability. Since all spouses were passive except one this should not threaten the *dependability*.

The interview form, as a mutually constructed dialogue focused on a shared meaning of questions and answers based on Mishler (1986), appeared fruitful. This is essential since questions can be interpreted differently. One advantage of this interview form was the possibility to ensure all through the dialogue that the interviewee had interpreted the questions adequately. If not, questions were reworded until mutual understanding was achieved. This was natural due to unfamiliarity (Paper I–III) or familiarity (Paper IV) with the needs assessment context. *Dependability* and *credibility* could thereby be strengthened. All seemed to narrate freely, but in a few cases (Paper I–III) the tape recorder had to be turned off when sensitive matters were disclosed. Even though painful aspects could be brought to the surface, the interview seemed to relieve and help the older persons and family members to frame the needs assessment. Both older persons and family members (Paper I–III) were pleased with being of interest and valued as informants. In spite of gratitude towards public home help, it was considered important to contribute to changes for the better. They seemed to have a pent-up need to talk about their situation. All interviewees (Paper I–IV) were encouraged to narrate their thoughts, feelings, and experiences in relation to the needs-assessed persons' and family members' participation and influence in the needs assessment and on the decisions made about help. A threat to the *trustworthiness* may be that the needs-assessed persons (Paper I–II) had difficulties talking directly about the assessment, and were more occupied with their loss than their influence in the assessment, although this was viewed as an interesting finding related to the needs assessment that indicated poor participation and influence. Due to their difficulties, the interviewer chose to tune in to their stories as recommended by literature (Mishler, 1986; Taylor and Bogdan 1998), a way that also increases credibility (West et al., 1991). There was a tension between the need to direct the informants'

narrations towards the current assessment and the important need to let them tell their stories. The interviewer tried to handle this by encouragement, body language and confirmation.

The *dependability* may be weakened in that the five home help officers (Paper IV) had conducted several needs assessments, were interviewed several times and thus the questions could become familiar to them. However, it may also strengthen *dependability* in that it is difficult to keep a frontage through several interviews without revealing one's attitude. In some cases the home help officers seemed restrained and asked about what the interviewer knew from the other informants involved in the case. It seemed difficult to deliberately withhold views. The interviewer could clearly sense the home help officers' frustration and engagement in cases viewed as difficult to handle. Due to the sensitivity of the study the interviewer strove to achieve confidence since she could be viewed as an outsider, despite being welcomed.

Ethics were considered in the interview situation in that interviewer worked with an awareness of the sensitivity of stepping into a confidential area and in a way "following up" the officers' assessments, while also interviewing their "clients", vulnerable older persons' in their homes, who furthermore were dependent on public home help. The aim to do no harm guided the interviews, which were performed with awareness that these are interventions that affect people. According to Patton (2002), interviews open thoughts, feelings, knowledge, and experience through the directed reflective process that is initiated. Unawareness can be changed to awareness and old wounds can be reopened. Interviews can hurt, as well as construct a framework and meaning, or they can have a healing effect. The latter appeared most salient among the interviewees.

## *Analysis*

To ensure *trustworthiness* in the analysis process and the dependability of the findings, procedures for development of the category system were presented all the way from the interview texts in the studies (I–IV). The benefit of using qualitative content analysis was that it made analysis of the texts possible at various levels of interpretation. This way both the utterers and the utterance of the text could be interpreted in relation to the depth of the interview texts. Qualitative content analysis is a frequently used analysis method (Burnard, 1995). In view of its usefulness it can be considered as rather underestimated (Cavanagh, 1997). The analysis approach and procedures was rather similar in all four studies. Attention deserves to be paid to the fact that the latent level of interpretation was inspired by Ricoeur (1976; 1988). This appeared natural, due to the first author's previous experience of the phenomenologic-hermeneutic method inspired by Ricoeur's thoughts in a master's thesis (Janlöv, 1997). Thus it was a part of the author's pre-understanding. The findings were formulated in everyday language as close to the informants' experiences as possible. This strategy is recommended by Lindseth and

Norberg (2004), who view it as appropriate in efforts to express semantic content, along with the use of metaphors and poetic language to enhance the polysemy of language. Ricoeur wrote (1976): “a metaphor, in short, tells us something new about reality” (p. 53) and “poetic language does not tell how things literally are, but what they are like”. These assumptions guided the analysis all through the studies (Paper I–IV) and were used whenever possible. Bergh (2001) suggests a way to enhance the *credibility* and *dependability* of latent symbolic meaning through agreement between independent coders regarding the content. In the studies the authors independently reviewed codes and categories in relation to each interview text and the interview texts as a whole, discussed these and reached a consensus about the category system. Polit and Hungler (1999) view this strategy as investigator triangulation, in that two or more trained researchers analyse and interpret a set of data. *The credibility* of qualitative findings can be enhanced by “member checks”, thus checking the findings with the informants (Lincoln and Guba, 1985), which was not done in this study. However, Holloway and Weeler (2002) point out that with currently developed latent interpretation techniques focusing on the utterance of the text, member checks may be difficult in efforts to confirm *credibility* of the findings. During the analysis process efforts were constantly made to be open to the utterances of the text and not let author pre-understanding or preconceptions stand in the way. This was particularly noticeable when a perspective was being analysed and a pre-understanding from previously analysed perspectives could interfere. These findings from the perspectives of those involved about older persons’ and family members’ participation in the needs assessment process and influence on decisions about public home help can probably be transferred to other similar contexts: needs assessment, public home help and elder care. This also concerns findings revealing older persons’ and family members’ life transition to coincide with the needs assessment. The focus group can in particular be viewed as confirming the *transferability* of the findings.

## General discussion of findings

The structure of the discussion consists of the three phases: Entering into the process of needs assessment; the needs assessment and encounter; and the outcome and follow-up of the decision.

### *Entering into the process of needs assessment*

An interesting finding in the phase prior to the actual needs assessment encounter was that having to ask for public home help and entering into the process of needs assessment was difficult for both older persons and family members. Thus, it was not only a matter of solving practical help needs related to physical disabilities as one might think, but rather having to ask for public home help in late life was a distressing turning point and marker of (increased) dependency, a sudden

awareness of death and fear of what the road towards death would mean, since life was nearing its end for the older person. This was met by reluctance, grief and sorrow. This was particularly shown in *“Comparing the past with the present and losing parts of oneself and connectedness”* (Paper I). This was a turning point that encompassed and affected physical, mental, social and existential dimensions in life as a whole. A sense of loss of connectedness and self-worth was salient among the older persons. These difficulties were particularly evident in this phase, although noticeable during the whole needs assessment process. *“Worrying about the losses and what they will bring about”* (Paper I), revealed that older people evidently had fears about the future that may correspond to Kastenbaum’s (1996) findings that the road towards death was more feared than death itself. Cicirelli (2002) found a peak of death anxiety between the ages of 80 and 85 (the mean age of the older persons in Paper I–II). It calls for attention that these studies (Paper I–II) possibly illuminated a peak of such anxiety about decline, dying and death among the older people. Having to receive public home help seemed to arouse such anxiety and fear of losing personal control of identity, integrity, dignity and autonomy. Thus, having caring family members in this phase was highly valued, although with an awareness that there had to be a limit for their help, as shown in *“Balancing the comfort and guilt – receiving help from the family at the limits of their capacity”* (Paper II). This period of anxiety likely evokes needs that are brought into the needs assessments and should be recognised, if the needs assessment is to have the holistic approach recommended by the National Board of Health and Welfare (1998), but seemingly this is not so. Why this issue is disregarded within the needs assessment may be a consequence of the scarcity of knowledge about older people’s views of dying and death, as Hallberg (2004) concluded in a literature review. Rolland (1994) meant that ageing, chronic illness and death in the Western society has been considered as a normal task for the elderly to cope with. A consequence of Rolland’s view could be that older people may not disclose thoughts and worries about the last phase in life and death since people want to be perceived as “normal”. Human decline and death are sad issues that people do not talk about, and if the matter is brought up it risks being waved aside. This may be related to Whitaker’s (2004) suggestion that death and dying, which used to be a natural problem, today is an “unnatural” problem. According to Giddens (1999), this is a consequence of the fact that dying and death have been removed from people’s everyday life to institutions, becoming invisible and disappearing from family routines. Decline and death may have become more of a biomedical problem. Thus, it seems as if dying and death need to be demystified as the normal end of life, which older people may need to be encouraged to talk about and plan for. Those responsible should include such needs and learn to identify them in the assessment as needs to be provided for. However, the needs assessment process has been found to focus on physical/practical needs, neglecting social, mental health and existential needs (Lindelöf and Rönnebeck, 2004) and lacking preparedness to handle the needs that were neglected (Hellström Muhli, 2003). This indicates a need for improvement.

*“Experiencing existential ruminations and the need to help”* (Paper III) disclosed how the family members’ transition process was different from that of their older next of kin, although initiated by and related to it. A difficult turning point for the family members was when they realised the change of roles. Their relationship and roles within the family also changed and there was a new responsibility to address. It was striking how family members willingly took on help giving without any deep thought about the consequences and necessary knowledge skills. This may be due to profound emotional ties, a sense of obligation, but mostly it meant ignorance about what their help giving would mean. Their help mostly started with invisible support in line with the typology of Nolan et al. (1995), and expanded gradually, and could conceal the actual help need of the older person, which could cause a problematic denial of need of public help. Gradually family helpers became more or less occupied with efforts to balance help duties until the situation became unbearable. Being prepared for help giving through adequate knowledge and skills is a prerequisite for helpers to cope well with it (Schumacher et al., 2000). *“Help giving and receiving as a difficult balance between needs”* (Paper III) showed that, even though helping could be rewarding, it also mean tensions and conflicts between the helping family member and the older receiving help. The need and difficulty to discuss the decline and help needs with their next of kin has been found previously by Smerglia and Deimling (1997). Tensions may be unresolved and brought into the needs assessment encounter and become necessary for the home help officer to deal with. A more thorough investigation of family members’ preparedness for helping and whether they have necessary knowledge, prerequisites and skills would also be needed to identify and meet support needs.

In line with the transition theory of Meleis et al. (2000), these overall changes can be framed within a larger developmental or lifespan transition. In relation to the position in the transition process, families had various degrees of difficulties coping with their changed reality (Paper I–III). Meleis et al. (2000) emphasise that transition processes can be facilitated or inhibited by personal, environmental and societal conditions. With this in mind, according to Schumacher et al. (1999) these findings indicate unhealthy transition processes among both older persons and family members, as for instance: lack of connectedness, self-worth/integrity, continuity (Paper I), meaning, choice, knowledge and empowerment (Paper I–III). People going through transitions are particularly vulnerable to risks that can affect health, such as inadequate coping, and may need support to identify personal and environmental conditions that facilitate or inhibit healthy transitions (Meleis et al., 2000). That the transitional experiences help seeking persons and family members go through coincide with the needs assessment process has, to the author’s knowledge, received little attention in literature and practice and thus needs acknowledgement to be met adequately.

The findings (Paper I–III) revealed families' efforts to grasp and comprehend their changing situation, along with their efforts to manage the situation mentally as well as practically. The existential ruminations can be viewed as efforts to create a meaning in their new changing situation. These overall efforts can be seen as a span of various coping strategies (Folkman and Moskowitz, 2004) within the transition. Ekwall Kristensson and Hallberg (in press), in a postal survey study of 171 elderly care givers, found that men used other coping strategies and were more satisfied with help giving. It was concluded that early detection to support those at risk of unsuccessful coping (more often women) is important. Unsuccessful coping may cause depression, which is common and often undetected in old age (Bauld et al., 2000; Cole and Dendokuri, 2003), and thereby hinders adjustment among both older persons and family members. This problem needs more attention within the needs assessment since old people seldom seek professional help for coping difficulties or depression. Erikson's (1982) psychosocial theory points to the state of wisdom as a potential in late life. Thus it does not come automatically. This view is supported by Tornstam's (1994) theory of gero-transcendence, towards potential wisdom. Erikson (1997) describes despair as a closer companion in the ninth and last stage than in earlier stages of life. Moreover, families, due to the difficulties in coping with the situation, appeared to be marked by decreased participation in societal activities as a whole in this phase (Paper I–III), which may be brought into the needs assessment process. A way to understand their coping difficulties is through the theory by Antonovsky (1987) and the need to find a situation comprehensible, manageable and meaningful (Antonovsky and Sourani 1988/2003). This indicates that the needs assessment and home help officers need to be adequately prepared for, recognising and promoting an individual state of mind and SOC as well as that of the family (FSOC) during the handling of the needs assessment, in order to facilitate a healthy transition process.

In this phase of entering into the process of needs assessment, the families coloured by their life span transitions were to meet home help officers in a pressed work situation and with responsibility towards several parties. This was shown in "*Getting signals about assessments*" (Paper IV). Already in this phase preconceptions about the "case", and older help seekers' and family members' participation could be made. It also showed that a great part of the time in this phase of the needs assessment was occupied with contacts from worried family members, also found by Nordström (1998). A question is whether some of this pressure could be removed from the home help officers through preventive home visits. It could also defuse the issue of suddenly confronted dependency, need of public help, the needs assessment, and other issues concerning late life. For example Theander and Edberg (2005) conducted preventive home visits to older people (n=150, aged 78 years) in southern Sweden and reported that three annual visits had a positive impact on participants and visitors. Preventive home visits have been a legal obligation in Denmark since 1998 (Vass et al., 2002). Preventive home visits could prepare older people living in their homes adequately for their future.



### *The needs assessment and encounter*

The power of older help seekers' and family members' participation and influence when encountering the home help officer need attention. To the older persons, taking part was "*a necessary evil*". Family members appeared unaware of their next of kin's transition struggle but seemed deliberately to aim to be a strengthening force, as if suspecting their next of kin of being too modest. However, they may have felt unease about being expected to degrade their next of kin by emphasising only disabilities. Actually, neither of the parties wanted to be there but they had to, as a result of their ongoing transitions. At worst, there could also be disagreement about help needs. Mohlin (2004) suggested in relation to participation that individual conditions for it must be considered. There are inner conditions in terms of ability and will to participate, and outer conditions in terms of accessible physical and social environments, rules and norms that make participation possible – and thus give an opportunity for participation. Conditions and power in relation to participation in the procedures and decision making for older persons were revealed in "*A necessary evil – balancing the feelings and resources against having no choice but to accept*" (Paper II) and for family members "*Feeling overlooked or acknowledged as having influence on the needs assessment*" (Paper III). A sense of resources to appeared influence whether older persons felt exposed or secure or family members felt overlooked or acknowledged. Empowering or disempowering resources appeared rather similar for both parties and related to their background, socioeconomic situation, degree of disability, familiarity with staff and context, authority and ability to express oneself and available help within the family. There was a striking lack of knowledge about the needs assessment process and procedures, and the difficulty of framing and understanding it concerned both parties in the family. Knowledge of rights was scarce and family members had no idea about any obligations to give help. This corresponds to the findings in "*Striving for the whole picture*" (Paper IV) showing that home help officers' had difficulties describing how the needs assessment was conducted and what was taken into account. With the focus of this thesis in mind it needs to be emphasised that poor knowledge and difficulties understanding what goes on gives a poor basis for sense of control and influence. According to Antonovsky (1987), feelings, cognitive processes and knowledge together are significant for whether a situation is interpreted as rational, structured, explainable and coherent. Then a sense of predictability and control is enhanced, whereas if it is interpreted as incoherent the result is a sense of chaos. Viewed from this perspective the families' transition process together with difficulties understanding the needs assessments give a poor basis for participation and can obstruct the comprehensibility of the needs assessment and their situation. This can be further highlighted by Foucault's (1980) statement that power cannot be exercised without knowledge – and knowledge engenders power. In Antonovsky's theory (1987) comprehensibility contributes to a sense of manageability and meaningfulness that together forms a sense of coherence. These aspects could form basic goals for the needs assessment to facilitate healthy transition

processes for families. Whether families have what is required for participation needs more thorough attention since the state of the transition may be an obstacle.

Conditions for the dialogue in the needs assessment encounter need to be particularly addressed, such as the issue of the older help seekers actual ability to participate. It was evident that, as long as the person was mentally competent and could communicate, there was no problem. But help seekers' ability varied, as shown in "*Feeling exposed or secure in relation to having guardian family members*" (Paper II) and family members had to represent them, as in "*Entering into the assessment encounter with hopes for the better*" (Paper III), which caused home help officers problems due to the perceived obligation to focus on the help seekers' will, as shown in "*The home help officers' attitude making a difference*" (Paper IV). Fatigue and aphasia could hinder but more or less "forgetfulness" seemed to be a sensitive and particularly tricky matter to handle. The common solution to this dilemma of uncertain competence, even though officers were not comfortable with it, was collecting information from the family member, without further interventions. This appears to be unsteady management. Adequate management of older help seekers participation difficulties (not only being present) in the needs assessment is tricky but needs more attention. Ethical issues related to informed consent, and legal issues in terms of family members as proxies, need more thorough management. In addition, such situations are difficult to document accurately in the act, which is necessary for quality assessment and development (National Board of Health and Welfare, 1998). That documentation does not always correspond to the reality was reported by Lindelöf and Rönnebeck (2004). Thus, intervention and improved management on this issue could secure help seekers' legal rights and also highlight family members' important roles in the needs assessment process.

Seemingly older help seekers did not have any actual influence over the decisions; presented with a standard set of municipal help, they had no choice but to accept. It can be questioned whether they received any individual needs assessment. Nor were decisions about the help to be provided tailored to fit their individual needs. This was not problematic to anyone as long as the needs did not exceed the guidelines, but this could marginalise help seekers that did not fit in. A perception of having to accept and be satisfied was salient. This was revealed in "*Feeling exposed or secure in relation to having guardian family members*" (Paper II). The varying attitudes of reluctant acceptance shown in this category and in the study by Roe et al. (2001) may not only be a reaction towards realising that offers of help were pre-decided, but may be influenced by the ongoing transition process in their lives. In either case the attitudes convey a sense of resigned powerlessness that indicates unhealthy transition processes and coping. The strategy among home help officers was to present restricting municipal guidelines as shown in "*Taken into account when deciding*" (Paper IV). This was successful and commonly used and received little objection from help seekers, but more from family members and particularly children. The practice of matching needs to guidelines concerning available

resources has received attention in recent studies in the UK (Arksey, 2002) and in Sweden (Svensson and Rosen, 2004). Duner and Nordström (in press) also found similar “transformation of needs” in an interview and observation study including eight home help officers. This can be viewed as a prioritisation between help seekers and needs that should preferably be done on a higher level instead of concealed within the needs assessment context. It would be appropriate to clarify prerequisites for elder care to the general public, to facilitate for families needing help and the home help officers in their daily lives and work. Moreover, presentation of predecided solutions tended to hinder help seekers own views and other alternatives of help to be discussed, as found by (Richards, 2002). The findings in several instances showed that only physical and practical help needs were in focus, and help was offered in accordance with the municipal guidelines, just as shown in previous studies (Andersson, 2004; Lindelöf and Rönnebeck, 2004). Thus older people’s mental, social and existential needs were neglected, as was legislation (SFS 2001:453) and recommendations (National Board of Health and Welfare, 1998) underpinning the needs assessment. A fragmented instead of holistic needs assessment hinders healthy transition processes and increases human and societal costs in the long run. This emphasises a need for an assessment worth the name, which holistically takes both older people’s and their families’ needs into account.

The question of what chances home help officers have to facilitate participation for the both in the family in the decision-making process requires attention. The findings revealed that older help seekers’ and family members’ requests could be experienced as poorly acknowledged, and needs not included in the municipal guidelines were neglected. Decisions could be experienced as providing help with the wrong things or lacking flexibility. However, in spite of having no actual influence on the decisions, the home help officers’ way of encountering could promote a sense of participation and thus being helped. This was shown in relation to the older persons in “*A necessary evil – balancing feelings and resources against having no choice but to accept*” (Paper II) and in relation to family members in “*Feeling overlooked or acknowledged as having influence on the needs assessment*” (Paper III). This phenomenon was further confirmed and clarified in the study focusing on the assessing home help officers’ views. This probably has to do with being confirmed by the home help officer in the encounter. As in Gustavsson’s (1992) thesis, being listened to, being taken seriously, being confirmed as a person and in experiences in a similar way gave a sense of being helped. Kennedy and Garvin (1986) describe confirmation as a relational quality of communication with the message that the other exists, there is a relation, the other’s worth and views are valued equally to one’s own. Confirmation was first described by Buber (1957) and is an essential human need in all personal encounters. All professional encounters between helpers and help seekers encompass a degree of relational placebo/nocebo effect (Moore and Komras, 1993), which means a potential for well-being and empowerment. The principal category “*The home help officers’ attitudes making a difference*” (Paper IV) showed that the way in which individual boundaries of

professional responsibility were set, influenced their view and management of help seekers' and family members' participation during the needs assessment process. One way to understand the *detached/distancing* and *engaged/strengthening* attitudes that were found is by a framework of professional relationship boundaries by Davidson (2005) placing these on a continuum between "Rigid" and "Entangled" and with the middle range representing "Balanced" boundaries. The detached/distancing attitude in this study corresponds to rigid boundaries described to create distanced relationships, restraints, neglect or uninformed assessments. The other extreme, although not found in this study, was entangled boundaries, described as creating over-involvement. The engaged/strengthening attitude (Paper IV) encompassed both institutional/task and person/relational responsibilities. This corresponds to balanced boundaries that are described as recognising individuals' unique needs while withholding the key aspects of the professional role. The ability to balance both institutional and relational responsibilities appears to form an "ideal ethical attitude", which was found difficult in this study.

It is problematic that family members were guardians and representatives of their next of kin and themselves as help givers, but mainly felt overlooked and of little value in the dialogue that took place, as shown in "*Feeling overlooked or acknowledged as having influence on the needs assessment*" (Paper III). That home help officers viewed family members with conflicting feelings and actually tended to recognise them solely as information givers was shown in "*Family members as contradictions to the assignment*" (Paper IV). Findings within these principal categories showed that family members could be more or less overlooked as worthy participants in dialogues, apparently since having no right to expect being taken into account – with the exception of possible demands on spouses to help each other. This kind of management does not create a legal dilemma, since family members' participation is not supported in legislation (SFS 2001:453), but it creates ethical and moral demands that need attention. Aged help-giving wives stood out as particularly vulnerable, in need of recognition and support due to their tendency to neglect their own health, while children may be more relieved of expectations to help, in the case of mentally competent parents. The excluding attitude seemed to be rooted among home help officers since it was also confirmed by the home help officers in the focus group interview (Paper IV). The National Board of Health and Welfare (2002b) reported a smaller intervention study showing that this attitude can be changed. The study aimed to develop a flexible, holistic needs assessment with the focus on help seekers and family members (n=22) and the development of support. The intervention consisted of an additional dialogue with the family member to build trust and confidence. In addition a follow-up of the decisions about help should be conducted. Home help officers perceived an improved understanding of family members' situation, increased capacity to assess the needs of both parties in a holistic manner, and that relevance of support to family members appeared related to their background and situation.

*“Setting boundaries deliberately and instinctively”* (Paper IV) indicated a need for self-protection, probably related to their work situation and daily exposure to legal and ethical dilemmas, as for instance shown in *“The home help officers’ attitudes making a difference”* and *“Family members as contradictions to the assignment”* (Paper IV). The distancing and excluding attitude can be interpreted as efforts to protect oneself from distress, helplessness and feelings of guilt by avoiding proximity to help seekers and family members due to not being able to provide the public help they needed. Findings by Häggström (2005) and Strandberg (2002) revealed a somewhat similar phenomenon which confirms that this may be the case. This escape from the moral responsibility can also be interpreted in terms of the ethics of Lögstrup (1956), that the unspoken ethical demand to meet the other and act in the way that is of most benefit to the other is rejected. This ethical problem within the needs assessment needs more attention. Municipal management of public home help and home help officers may have to be shown the benefits of also including family members in the process.

No doubt home help officers possess a stronger power position than the family, through their authority, professional preferential right of interpretation, access to help resources and right to decide about the distribution of public home help. Duner and Nordström (2005a) add their power in terms of knowledge and information about the agency, the relation and situation, administrative techniques, profession-specific strategies as well as their own intentions and motives. Despite their advantaged position, actually conducting the needs assessment seemed like a complex contradictory task in several ways. Their position squeezed between several parties inside and outside the organisation seemed to contribute (Wolmesjö, 2005), as did contradictory goals in legislation and municipal guidelines, heavy case load, time limits, and restricted resources. These circumstances correspond to street-level bureaucrats as social workers’ (home help officers’) and health workers’ daily situation as viewed by Lipsky (1980), further describing lack of resources for client-centred goals in contrast to organisation-centred ones. This creates a pressed work situation that cannot be questioned. Home help officers have a critical position in having to handle the tension between families’ needs and expectations of help and municipal resources, which seems to contribute to their moral dilemma in practice. This dilemma needs to be addressed on a higher political level.

In the encounter home help officers mainly focused on “the task” of the needs assessment. This may be a consequence of changed prerequisites for the needs assessment encounter through the client/contractor organisation, as suggested by Blomberg (2004). It may also be rooted in higher-level management’s emphasis on legislation and formal regulations and the importance of keeping within the municipal budget. The latter was shown in this thesis (Paper IV), which corresponds to Andersson’s (2004) findings that municipal finances instead of individuals’ needs constituted the guiding principles applied by home help officers. If higher-level management and politicians praise care professionals for achieving

the “task” of keeping within the budget, this will be considered as the valued goal. A risk of overlooking the humanising part of the professional performance then becomes evident. This part must always be recognised and prioritised to ensure that it is not forgotten (Hermerén, oral lecture in ethics, 12 June 2006, Lund). Kane and Kane (2000) emphasised, in relation to assessment of older people, that much attention was given to the development of assessment tools but little to the use of them and the relational management in practice when encountering older persons, such as how to deal with people’s emotional reactions – as well as their own. These findings indicate that the relational and human part of home help officers’ professional work, and thus ethics, needs higher recognition to improve the professional relationship ability – the ability to better balance the task and the relational aspect – which is particularly needed in times of more restricted resources. The risk of inhumane public health care and service must be counteracted.

### *The outcome and follow-up of the decision*

An important issue was the decisions about help to be made by care workers, and integrating this with the help from family members to arrive at a manageable situation. The two sole sub-categories “*Balancing daily life to get a sense of control*” and “*Balancing the relations with the care workers – to gain influence*” (Paper II) showed that, in spite of attitudes of “*having to be satisfied*”, influence could be possible through the care workers. At best, good relations could change fears of public home help to comfort, and help facilitate understand and manage the changing situation. It could mean a mutual exchange, being treated as a person, and even a deeper relationship. At worst it could be the other way around. The quality of the outcome – the home help received varied, as did the organisational conditions for it. Ingvad (2003) focused on care workers’ and home help recipients’ emotional interactions and found these relations essential for the recipients’ influence over the home help provided to them. The relations varied between strong bonds of intimacy and highly-charged conflict. Ingvad (2003) identified problems regarding mutual expectations of respect, acknowledgement and appreciation. The help recipients interpreted care workers’ behaviour as showing how they were valued as persons. Also emphasised was a need for adequately balanced relationships (intimacy/distance), and management’s confirmation of care workers. Consequently there is a greater risk of badly balanced relationships (see Davidson, 2005) if care workers do not get appreciation from the higher-level management or the general public, since this can cause decreased self-worth and thus compensation is sought from the help recipients. Wikström (2005) found the organisation of management and work groups to be related to variations in older help recipients’ (n=20) possibilities to influence their daily public home help. Different social norm systems gave different conditions for the care workers and thus help recipients. In this thesis family members’ experiences of the outcome of the decision varied, and were probably influenced by experiences of their next of kin. Different experiences were shown in “*Hopes about the public home help being*

*fulfilled or dashed*” (Paper III). Here spouses were directly affected by the quality of the outcome. At best the help gave relief but could also mean further pressure and frustration in carrying the responsibility alone. The public provision had to be of help to both parties (the family). When spouses’ efforts to influence inadequate help failed this could end up with them cancelling the public home help and trying to manage by themselves – a questionable coping strategy in that these families may be in serious need of support. Children unable to be present suffered from a lack of communication about the status and situation of their next of kin. There was a struggle to influence the situation positively – which at times could succeed. Thus, the possibility that families have to influence the practical home help requires further clarification.

In this last phase of the needs assessment the home help officers were mainly absent, as shown in “*Experiences of responsibility for follow-up*” (Paper IV). How the family and possible participation were viewed differed according to attitudes, as did the management of follow-up. As a consequence the family could be excluded and not seen as home help officers’ responsibility, as shown in “*Waiting for or preventing signals*” (Paper IV). This management could press families to overextend themselves. As shown in “*Experiences of responsibility for follow-up*”, the client/contractor organisation seemed to play a role for this management since it could cause a responsibility gap regarding home help recipients’ and family members’ situation as a whole. Although it is strange that several negative aspects of it were brought up, such as loss of holistic outlook, a longer way from decision to execution and complicated contact possibilities for families, the client/contractor organisation was upheld as positive. There was a salient belief that their decisions now were more professional, independent, and secured the help seekers’ legal rights. This view may, however, be a way to justify and secure their role as specialised home help officers – in any organisation. It may also be a consequence of the fact that escaping the moral relational responsibility was implicitly legitimated by higher-level management. Goffman (1959) described how both formal and informal norms of professional relationships exist among colleagues, and that violating these norms can cost – from gentle admonition to being banished from the setting. Thus having an engaged/strengthening attitude may even be difficult if one is in a minority. These findings emphasise a need for an organisational structure of public home help and the needs assessment that allows older help recipients and family members, as a family, to be viewed as worthy of participation in decisions, planning and provision of their public home help and receiving a holistic assessment of their needs – being individually and adequately encountered in a way that is comprehensible, manageable and meaningful.

## CONCLUSIONS AND IMPLICATIONS

To the older help-seeking persons, becoming in need of public home help meant *“Experiencing discontinuity in life as a whole – the countdown has begun”*. Further, their participation and influence on decisions about public home help when undergoing needs assessment and receiving public home help meant *“Having to be satisfied, adjust, and walk a fine line when balancing between needs and available help”*. To family members having an older next of kin becoming in need of public home help, their participation in the needs assessment procedure and the decisions about their next of kin’s public home help meant *“Feeling disconfirmed or confirmed in the needs assessment, when feeling pressed by the responsibility and struggling to balance the needs of the family”*. To home help officers, older help recipients and family members’ participation in the needs assessment procedure and the decisions made about public home help meant *“Having to establish boundaries towards family influence and at the same time use them as a resource”*. These findings seem to correspond and thus provide an understanding of the meaning of older needs-assessed persons’ and family members’ participation in the needs assessment as a whole.

The needs assessment marked a turning point to a new life phase that can be understood as undesired separate but related larger life transitions for both older persons and their family members. To the older person this meant a sense of decreased self-worth, reduced autonomy and sudden awareness of the finiteness of life, of death and dying. In this state the public home help could be perceived as threatening, which in addition to the cause of their help need could make it difficult to participate in the needs assessment. The family members’ transition was initiated by their next of kin’s decline and need for help. Indications of unhealthy transition processes were shown among both older older persons and family members, such as existential illness, anxiety about dying and death, depression, cognitive and mental difficulties, signs of dementia, suboptimal functioning, disconnectedness, disempowerment, loss of integrity and difficulties coping. These aspects need recognition and adequate intervention, since these, together with the disability causing the needs assessment, give poor conditions for a sense of participation in the needs assessment and managing their life situation.

The older persons’ actual ability to participate and communicate and their degree of mental competence varied, making it difficult to conduct the needs assessment as required by legislation, since family members could be necessary as representatives. This legal and ethical issue together with family members’ important role as representatives, without formal authorisation as proxies, needs further recognition and intervention. Education and professional supervision may facilitate the home help officers’ situation.



Both older persons and family members lacked knowledge about the aims, structure and procedures of the needs assessment process. None of them could identify the actual needs assessment, how it was performed, grounds for the decisions, their rights or obligations, which probably makes participation difficult. Information must be ensured and understood by the involved. An additional way of improvement is through preventive home visits which can include dialogues about this matter.

The older persons and family members had little possibility for actual participation in the process to influence the decisions about their home help. The assessment was focused on older persons', the present situation and mainly physical and practical disabilities and needs. As a whole mental, existential, social and medical needs were neglected. This also meant neglecting the needs of family members and the family as a whole. A sense of forced acceptance was evident among the older persons, although a sense of participation seemed possible depending on the home help officers' attitude. None of those involved experienced the decisions about help as individual or flexible. Needs were compared to a policy of municipal guidelines that decided what needs should be provided for and to what degree. Family members mainly felt disconfirmed in the needs assessment encounter, not valued and welcome to take part in the dialogue about home help – except as information givers. Their role as help givers was poorly recognised, as were their will and ability to continue with the help giving. The perceived obligation to merely focus on the older person seeking help may contribute to this situation and must be changed, so that family members are included and their help acknowledged and supported. The needs assessment and home help officers require preparation to recognise and include needs in a holistic manner, framed with a family- and future-oriented approach.

Home help officers' attitudes appeared to influence their management of older help seekers' and family members' participation during the needs assessment process. Attitudes varied between detached/distancing and engaged/strengthening. The tendency to focus on the task and distance the family and particularly family members can be understood as self-protection and efforts to cope with their complex and conflicting work situation. The risk of objectifying and disconfirming families increases, as does the risk that they do not receive the public help they need. The most vulnerable families are further exposed, particularly women. This indicates a need to create organisational conditions for home help officers, so that their professional responsibility can encompass both task and relation, and a balanced ethical attitude. This can promote healthy transition completions for families, meaning manageability and control of their situation. The findings as a whole indicate the necessity of reviewing organisational conditions, assuring the quality of the assessment process, making it comprehensible and helpful for the family in terms of participation, and less conflicting to the home help officers in practice.

## FURTHER RESEARCH

Further research within this area is needed regarding:

- Exploration of individual cases where perspectives of the older needs-assessed person, their next of kin, and the home help officer are compared regarding the needs-assessed person's and family member's participation in the needs assessment process, including documentation.
- Exploration of what a holistic view of needs within the needs assessment means to home help officers, and how such an approach is or could be managed.
- Exploration of the meaning of concepts such as psychological, physical, medical, social and existential needs (and responsibilities) used in eldercare and the public home help context – as experienced by the professional groups involved.
- The issue of what are the main concerns of the older person, family member and home help officer, the management of the contractor organisation and higher-level management in relation to the needs assessment process.
- The ethical issue of older help seeking persons' varying mental competence and ability to participate and communicate and thus their self-determination capacity and how this and the use of proxies and representatives is handled within the needs assessment context.
- The issue of how older persons' and family members' participation, influence and empowerment can be promoted in the needs assessment process, and how comprehensibility, manageability, meaningfulness and family orientation can be promoted, structured and implemented.
- The issue of particularly vulnerable older persons' experiences of the needs assessment, such as those without family, those living in poor socioeconomic circumstances, with mental dysfunction, helping women, immigrants, their experience of participation, and empowerment in the needs assessment process.
- The issue of home help officers' reasoning and the management of national legislation and recommendations underpinning the needs assessment process.

## SUMMARY IN SWEDISH

### Svensk sammanfattning

Delaktighet i biståndsbedömning av äldre personer inför kommunalt bistånd.  
Äldre personers, familjemedlemmars och biståndsbedömares upplevelser

Den äldre generationen förväntas snabbt öka i Sverige och i övriga Europa under de kommande årtiondena. De äldres vårdbehov kommer att öka och därmed förväntas svårigheter att ombesörja tillräcklig kommunal vård och omsorg. Åldrandet i livets senare skede innebär ofta sjuklighet eller t.o.m. en situation av multisjuklighet. Det är en stor förändring i en människas liv att komma in i en fas i livet då krafterna och den egna förmågan att klara sig själv successivt avtar och att behöva efterfråga kommunal hemtjänst. Samhällets ekonomiska åtstramning har lett till en mer selektiv och återhållsam fördelning och vård och omsorg kan skilja sig åt beroende på i vilken kommun den äldre bor. Det kan tyckas självklart att personen som är i behov av hjälp borde ha något att säga till om beträffande innehållet av erhållen hjälp och hur denna ska ges för att tillförsäkra en god livskvalitet. Kunskapen är bristfällig om äldres upplevelse av vad det innebär att få kommunal hjälp i hemmet och i vilken utsträckning de har haft möjlighet till delaktighet och inflytande över beslut om hjälp och hur denna ska ges. Den samhälleliga policyn är att de äldre ska kunna vårdas i sitt eget hem trots omfattande vårdbehov och hjälp med att klara sitt dagliga liv. Detta innebär att de närstående familjemedlemmarna i hög grad är involverade i vården. Den mest omfattande hjälpen till äldre kommer från en annan äldre person; make eller maka. Tidigare forskning har visat att den informella vården, d.v.s. närståendes vård i Sverige, utgörs av två till tre gånger mer insatser i termer av timmar än vad den kommunala hemtjänsten ger. En angelägenhet är därför att undersöka möjligheterna för att stödja deras situation. De närståendes deltagande i bedömningsprocessen av de äldres behov har avgörande betydelse för utfallet. Forskning har visat att äldre upplevt bristande inflytande och delaktighet i biståndsbedömningsprocessen. De få studier som undersökt närståendes upplevelse av delaktighet i bedömningen av den hjälpsökande äldres behov har visat brister, och studier som belyst familjens delaktighet i biståndsbedömning och dess process ur biståndsbedömarens perspektiv är sällsynta.

*Det övergripande syftet* med avhandlingen var att belysa äldres upplevelse av att bli i behov av kommunal vård och omsorg och deras familjemedlemmars upplevelser av denna situation. Vidare var syftet att belysa äldres och familjens delaktighet i behovsbedömningsprocessen av de äldre samt deras inflytande i besluten av hemhjälp ur de biståndsbedömda äldres perspektiv, familjemedlemmars och bedömande och externa biståndsbedömares perspektiv.

Avhandlingen omfattar fyra delstudier baserade på intervjuer (I–IV). Den grundläggande metodologiska strategin var kvalitativ och data samlades in från källor med olika position i förhållande till problemet för att få en mera precis och

mångfacetterad förståelse av fenomenet. Källorna utgjordes av äldre, närstående, och biståndsbedömare (IV) samt fokusgruppsintervjuer med biståndsbedömare från ett annat landsting i södra Sverige (IV, ramberättelse). Urvalet för samtliga utgjordes av 28 äldre personer (75–96 år) biståndsbedömda inför att få kommunal vård och omsorg, 27 av deras närstående (42–93 år) och fem biståndsbedömare (29–50 år) omfattande flera intervjuer med var och en av biståndsbedömare relaterat till respektive äldre och deras familjer, sammanlagt 26 intervjuer. Därutöver tillkom biståndsbedömare (n=9) i fokusgrupp. Studierna genomfördes i två medelstora landsortskommuner i södra Sverige vilka hade äldreomsorg utformad utifrån beställar-utförarorganisation och således specialiserad bistånds-handläggning. Intervjuerna hade formen av ett samtal som utvecklades efterhand. Som stöd användes en intervjuguide med teman rörande äldre och familjemedlemmars delaktighet och inflytande i samband med biståndsbedömningsprocessen. Alla intervjuer bandinspelades och skrevs ut ordagrant till text som analyserades med hjälp av kvalitativ innehållsanalys. Resultaten i varje delstudie kom till uttryck i en övergripande kategori omfattande delstudiens huvudkategorier samt underkategorier.

*Delstudie I:* Syftet med denna studie var att belysa äldre personers upplevelse av att bli i behov av kommunal vård och omsorg, deras upplevelse av delaktighet och av att ha inflytande i biståndsbedömning, tillvägagångssätt och beslut om kommunal vård och omsorg. Resultaten visade den övergripande innebörden som *att uppleva brist på sammanhang i livet som helhet – nedräkningen har börjat*. Det var tydligt att de äldre var upptagna av tankar och känslor relaterade till sina upplevelser av att behöva be om hjälp i hemmet och inte så mycket själva biståndsbedömningen. Processen av att bli utsatt för bedömning av behov av hjälp hade en djupare innebörd än att enbart få hjälp. Vidare visade huvudkategorin *att jämföra det förgångna med nuet och förlora delar av sig själv och sin tillhörighet* att de äldre var upptagna med tankar och känslor om förlusterna av tidigare förmågor, deras minskade värde och deras sociala nätverk. Reaktionerna varierade alltifrån känslor av motstånd, förnekelse, likgiltighet och brist på självförtroende till att motvilligt acceptera sin situation. Det framkom förvånande lite påståenden om behov av praktiska hjälpbehov i relation till biståndsbedömningen. Huvudkategorin *att oroa sig för förlusterna och vad de kommer att föra med sig* visade intressant nog att resan mot slutet av livet i termer ”att nedräkningen börjat” orsakade mest rädsla och oro och således inte rädslan för döden i sig. Huvudkategorin *att kämpa mot avtagande förmågor för att undvika beroende och kommunal hemhjälp* visade hur de äldre förde en kamp mot att förlora sina förmågor och att bli beroende av andra och framför allt hjälp i hemmet av okända. De kämpade med att försöka hantera sin situation och de avtagande förmågorna praktiskt likväl som psykiskt. De emotionella och existentiella svårigheterna av att klara av sina förluster uttrycktes genom nedstämdhet och sorg. Huvudkategorin *att kämpa med motstridiga känslor gällande att bli i behov av hjälp – och av vem* visade att de äldre förknippade hjälp från nära och kära respektive kommunal vård och omsorg med olika kvalitet. Familjemedlemmars

hjälp förknippades med välbefinnande och trygghet med en samtidig insikt om att det fanns en gräns för deras möjlighet att hjälpa. Det fanns en rädsla för att av de närmaste bli upplevd som en börda – de närmaste för vilka man upplevde sig fortfarande ha ett värde. Tankar på att behöva ta emot hjälp av okända från kommunen väckte motstånd och oro för att vid ökad hjälplöshet och utsatthet inte bli väl omhändertagen. Motstridiga känslor och tankar tycktes kunna hindra de äldres aktiva medverkan i bedömningsprocessen om hjälp i hemmet. Biståndsbedömningen markerade en vändpunkt i livet mot minskad autonomi och social tillhörighet samt innebar en påminnelse om att livet började ta slut. Resultaten tyder på att biståndsbedömarna bör vara förberedda på att de äldres behov inte enbart är de praktiska/instrumentella utan att andra existentiella och psykologiska aspekter kan vara de mest problematiska.

*Delstudie II:* Syftet med denna studie var att belysa äldre personers upplevelse av delaktighet och inflytande över beslut om kommunal vård och omsorg under biståndsbedömning, samt erhållandet av praktisk vård och omsorg. Resultaten från denna studie visade sig ha en övergripande innebörd som *att försöka balansera mellan behov och tillgänglig hjälp – och vara tvungen att anpassa sig och vara nöjd*. De äldre uppvisade tydlig motvilja till att behöva ta emot hjälp. Vissa hade insikt om sina hjälpbehov medan andra kunde vara omedvetna eller förneka behov av hjälp från kommunen i samband med biståndsbedömningen. Huvudkategorin *att balansera mellan känslor av trygghet och skuld genom att ta emot hjälp från familjen på gränsen till deras förmåga* förtydligade att de äldre upplevde situationen som förnedrande och balanserade mellan dessa känslor när de mottog hjälp från familjen vilken var viktig för dem. Det framstod vara viktigt att som motvikt kunna ge något i utbyte eller kompensera för hjälpen, vilket efterhand som förmågorna försämrades tycktes öka rädslan för att bli en börda. Vid någon kritisk punkt kunde denna balansakt resultera i att de äldre kände sig tvungna att söka kommunal hjälp och omsorg. Själva innebörden av biståndsbedömningsmötet visade sig i en huvudkategori som *ett nödvändigt ont – att balansera känslor och resurser mot att inte ha annat val än att acceptera*. Behovet av hjälp utgjorde ett hot mot identitet, integritet, autonomi och kontinuitet i livssituationen som helhet. De äldre upplevde att det var hemskt att behöva ta emot hemhjälp, men var tacksamma över att kunna få hjälp. I mötet mellan den äldre och biståndsbedömaren fanns en tydlig maktobalans och den äldres sårbarhet ökade av sitt beroende av biståndsbedömarens välvillighet. Möjlighet till delaktighet i dialogen dem emellan framstod påverkas av den äldres resurser, av vilka möjlighet till familjestöd framträdde vara betydelsefullt. De äldre tog mer eller mindre aktiv del i själva mötet beroende på förmåga och familjestöd. Balanserandet av känslor och resurser blev tydligt då de äldre, alltmer orkeslösa, upptäckte att de inte hade något faktiskt inflytande över beslutet om den kommunala hjälpen, utan var tvungna att acceptera den hjälp som erbjöds. Detta innebar en slags tilltvingad acceptans som kunde urskiljas som tre ibland sammanflätande former, såsom anpassning, motvillighet och resignerad acceptans. Kommunens allmänna riktlinjer för att erhålla hemtjänst uppfattades

bestämma vilken hjälp som kunde ges. Det framkom också att delaktighet i behovsbedömningen kunde vara svårt för de orkeslösa äldre på grund av deras psykiska tillstånd. Det framkom även svårigheter att förstå biståndsbedömningen, hur själva bedömningen gick till, samt rättigheter till hjälp. Huvudkategorin *att integrera hemhjälpen i vardagslivet för att få en känsla av kontinuitet* visade hur de äldre försökte anpassa sina behov i relation till tillgänglig hjälp från familj och kommun, och samtidigt pussla ihop vardagslivet till en hanterbar helhet. Här framstod relationerna med vårdpersonalen ha stor betydelse för de äldres välbefinnande och möjlighet att påverka sin vardagsituation. Detta indikerar att behovsbedömningen och biståndshandläggningen måste vara öppen för individuella behov ur ett mera holistiskt perspektiv och att man mera måste sträva efter att göra biståndsbedömningen begriplig och uppmuntra de äldres delaktighet och att stärka deras möjlighet att hantera biståndsbedömningen. Detta skulle kunna stärka de äldres känsla av sammanhang och möjlighet till kontroll över livssituationen. Äldre hjälpsökande är ingen homogen grupp, eftersom det finns variationer i social/ekonomisk bakgrund och förmåga att artikulera behov samt om de har familjemedlemmar till hjälp.

*Delstudie III:* Syftet med denna studie var att belysa nära familjemedlemmars upplevelse av att ha en närstående i behov av kommunalvård och omsorg, deras delaktighet i biståndsbedömning, tillvägagångssätt och beslut om närståendes vård och omsorg. Resultaten från denna studie framstod ha den övergripande innebörden *att kämpa med att balansera mellan behov i familjen, känna sig pressad av ansvaret och känna sig obekräftad eller bekräftad i biståndsbedömningen*. Det var tydligt att familjemedlemmarna brottades med känslor av ansvar för att tillgodose och balansera familjens hjälpbehov. Huvudkategorin *att uppleva existentiella funderingar och behovet att hjälpa* visade att familjemedlemmarna upplevde en övergång till en ny fas i livet som markerades genom en smärtsam medvetenhet om att nedräkningen för deras äldre närstående hade påbörjats. Denna fas utmärktes av en vändpunkt markerad genom ökade hjälpinsatser och en motvillig medvetenhet om ”ombytta roller” och att deras äldre närstående inte längre kunde betraktas som en självklarhet i livet. Det framstod som en självklarhet att hjälpa, och familjemedlemmarna tycktes halka in i hjälpgivandet utan djupare reflektioner kring vad åtagandet skulle kunna komma att innebära. Huvudkategorin *att ge hjälp och bli hjälpt, en svår balans mellan behov* visade att trots att hjälpgivandet kunde upplevas som positivt framstod det som svårt och känsligt att närma sig den närstående för att diskutera behovet av hjälp och hur detta skulle tillgodoses. Uttalade såväl som outtalade förväntningar kunde bidra till att känslomässigt laddade situationer och konflikter kunde uppstå. Subkategorin hjälpanDET som synligt och osynligt givande och tagande visade att familjemedlemmarna gav olika typer av hjälp. Det kunde innebära allt ifrån osynlig hjälp som att hålla uppsikt och att anpassa egen livsföring efter den närståendes behov, till att ge konkret praktisk hjälp med inköp, personlig hygien eller att vara med och representera och stödja vid olika kontakter. Det framkom att hjälpgivande familjemedlemmar kunde ta emot kompenserande hjälp i

form av materiella eller mänskliga resurser. Närståendes blotta närvaro framstod kunna vara berikande i sig genom att representera gemensamma band och livssammanhang. Huvudkategorin *att känna sig förbisedd eller bekräftad gällande inflytande under biståndsbedömningen* visade att familjemedlemmarnas kunskaper om biståndsbedömning och process som helhet var vaga, så också när det gällde deras rättigheter till kommunal hemtjänst. Medhavda inre och yttre resurser framstod ha betydelse för känsla av möjlig delaktighet under biståndsbedömningsmötet. Osäkerhet om vad som förväntades av dem var tydlig, liksom känslor av att biståndsbedömningen inte tog någon notis om deras hjälpinsatser och önskemål. Familjemedlemmarna kände sig främst förbisedda och att det hade beslutats om hjälp över huvudet på dem. Det förekom emellertid även motsatsen, att de kände sig bekräftade och att de varit delaktiga i besluten. Familjemedlemmarnas upplevelser i samband med bedömning av behov av hjälp var huvudsakligen präglade av känslor av vanmakt, att inte vara sedda, eller vara värdefulla att beakta i samband med besluten. Huvudkategorin *grusade eller uppfyllda förhoppningar om hemhjälp* visade att hopp om en förbättrad livssituation genom hemhjälp inte alltid uppfylldes. Om hjälpen var tillräcklig och av god kvalitet upplevdes ett delat ansvar, medan familjemedlemmarna upplevde sig fortfarande ha ansvaret för närståendes vård och omsorg om familjen inte hade förtroende för den. Resultaten indikerar ett behov att inkludera även hjälpgivande familjemedlemmar i biståndsbedömningsprocessen med syfte att stödja deras behov och familjens situation som helhet.

*Delstudie IV:* Syftet med denna studie var att belysa biståndsbedömares syn på äldre hjälpmottagares och familjemedlemmars delaktighet i biståndsbedömning, tillvägagångssätt och beslut om kommunalvård och omsorg. Resultaten från denna studie framstod ha den övergripande innebörden *att vara nödgad att sätta gränser för familjens inflytande men samtidigt använda medlemmarna som en resurs*. Detta resultat visade hur familjens delaktighet och möjligheter till inflytande hanterades i biståndsbedömningsprocessen som helhet. Huvudkategorin *att ta med gränser och förutfattade meningar in i biståndsbedömningen* visade att biståndsbedömarna kände sig pressade av ansvar gentemot flera parter i relation till biståndsbedömningen, utöver den enskilde äldre, som till exempel gentemot utförarorganisation, ledning för äldreomsorg, kommunens riktlinjer samt socialtjänstlagen, vilket tycktes bidra till egen gränssättning för det professionella ansvaret i biståndsbedömningsprocessen. Gränssättningen framstod kunna vara både medveten och omedveten och hade också att göra med personliga erfarenheter, känslor och värderingar. Genom vem som initierade kontakt skapade biståndsbedömarna en uppfattning om kommande familjedelaktighet redan innan biståndsbedömningen. Huvudkategorin *biståndsbedömarens attityd gör skillnad* visade anmärkningsvärt nog att hur ansvaret avgränsades kom att avspegla attityder i relation till två motsatta poler på ett kontinuum. Attityderna framstod variera mellan en oengagerad/distanserad attityd vilken dominerade på bekostnad av en engagerad/stärkande attityd gentemot familjen. Dessa attityder tycktes prägla biståndsbedömarens syn och approach vad gällde den äldres och familjemedlemmarnas delaktighet och inflytande under

biståndsbedömningen. Huvudkategorin *familjemedlemmar står i strid med uppdraget* visade det överraskande resultatet att biståndsbedömaren upplevde familjemedlemmarna som att stå i strid med uppdraget om tilldelning av kommunal hjälp utifrån socialtjänstlagens fokus på den enskilde äldre. Familjemedlemmarnas delaktighet i bedömningsmötet gällande hjälpbehov kom att utgöra ett etiskt dilemma som tenderade hanteras på ett sätt som snarast uteslöt deras delaktighet. Att familjemedlemmarna framstod som utanför deras uppdrag var tydligt oavsett vilken attityd som biståndsbedömaren uppvisade. Huvudkategorin *beaktanden vid beslutandet* visade hur konkreta såväl subtila aspekter av betydelse för beslutet vägdes samman. Biståndsbedömarens bild av situationen jämfördes med vad familjen verbalt uttryckte. De äldres och deras familjemedlemmars uppfattade behov jämfördes med kommunens riktlinjer, vilka kom att sätta gränser för den hjälp som gavs. Huvudkategorin *upplevt ansvar för uppföljning* visade att organisatoriska förutsättningar och biståndsbedömarens attityd tycktes prägla inställning till, och hanterandet av uppföljning av beslut. Detta kunde ha sekundär betydelse för familjens möjlighet till delaktighet rörande resultat av beslutet – den reella hjälpen. Detta tycktes även ha betydelse för om biståndsbedömarnas arbetssätt kom att präglas av en attityd att förebygga eller invänta signaler om problem för familjen. Resultaten indikerar ett behov av organisatoriska förändringar som skapar förutsättningar för ett professionellt etiskt balanserat arbetssätt som kan främja de äldres och deras familjemedlemmars delaktighet i biståndsbedömningsprocessen.

*Sammanfattningsvis* framträder utifrån resultaten att äldre och familjemedlemmar riskerar att inte få ett personligt och professionellt moraliskt gott bemötande under biståndsbedömningsprocessen utan riskerar bli förbisedda och att inte få den hjälp de behöver, vilket kan bidra till att försvåra deras ansträngningar att hantera deras situation på ett hälsofrämjande sätt. De mest svaga individerna och familjerna blir än mera utsatta och då framförallt kvinnor. Av resultaten framträder ett behov av att skapa organisatoriska förutsättningar för en engagerad/stärkande attityd hos biståndsbedömarna, som främjar förhållningssätt där ansvaret inte enbart avgränsas till genomförandet av "uppgiften" utan även omfattar en bekräftande relation med den äldre och familjen som helhet. Ett bekräftande bemötande och attityd kan främja känslan av delaktighet och även innebära hjälp i sig. Att stärka äldre och deras familjer att ta sig igenom livsomställningen på ett sätt som främjar deras hälsa, kan utifrån avhandlingens resultat innebära att stärka deras upplevelse av begriplighet, hanterbarhet och meningsfullhet och därmed deras känsla av sammanhang i biståndsbedömningsprocess och livssituation som helhet. Resultaten tyder vidare på att biståndsbedömarna upplever en moralisk konflikt i mötet med familjens behov och förväntningar om hjälp och möjligheterna att ge hjälp utifrån kommunens begränsade resurser. Det tyder också på att det är angeläget att vidareutveckla kvalitetssystem inom organisationen av äldreomsorgen och framförallt kvalitetssäkra biståndsbedömningsprocessen och dess form så att den blir begriplig för äldre och deras familjer, främjar deras delaktighet och inflytande och underlättar biståndsbedömarnas arbetssituation.



## ACKNOWLEDGEMENTS

This thesis was carried out at the Department of Nursing, Lund University.

I wish to express my sincere gratitude to all those who have contributed in any way to the completion of this work. I want to particularly thank:

My dear family for being there and for all your support:

- Tally Loyd Janlöv, my son, and Marie Sundholm. Thank you Tally for helping out when acutely needed, as with proofreading of articles and solving computer difficulties, and so on ...
- Siv and Ulf Kronfeldt, my parents.
- Susanne Samuel, my sister, Danny Janlöv her son, and Tomas Palmblad.
- Bosse Nilsson, my brother, Sanna, Louise and Jacob Nilsson, his children, Mia Valtonen and Markus her son.
- Valter Nilsson and Annika Hegdahl.
- The late Greta Berglund, my grandmother.

Colleagues:

- Kerstin Petersson, my supervisor, for your encouraging pedagogical supervision, fruitful collaboration and friendship.
- Ingalill Rahm Hallberg, my supervisor, for supervision which showed me what extraordinary research skill, capacity and scientific thinking means. Thank you for sharing your knowledge and for your support.
- Colleagues in the doctoral seminars at the Department of Nursing.
- Colleagues in “Skånegruppen” for shared experiences in our work in the population study concerning the health situation of older people aged 75 and over in southern Sweden: Magdalena Andersson, Gunilla Borglin, Anna Ekwall, Ulf Jacobsson, Ylva Hellström, Karin Stenzelius, Bibbi Thomé.
- Staffan Karlsson, my colleague since the time of our bachelor’s degree in nursing, for fruitful discussions along the way towards our dissertations.
- Karl Seebach, distant discussion partner and friend.
- The study participants – the elderly men and women and the home help officers – for sharing your experiences with me as my co-workers.
- Alan Crozier, for revising my English, Ylva Johansson for help with transcriptions, Anna Blomgren (my birthday mate) for making life easier for doctoral students. All at the library, IT section, and other service or administrative functions within the Department of Nursing.
- Ola Nannesson and Eddie Andersson, my health promoters.
- The LF Research Foundation, Council for Medical Health Care Research in the South of Sweden (HSF), the Faculty of Medicine and the Department of Health Science, Lund University, for supporting this study with grants.

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