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## **OLDER PEOPLE'S PUBLIC HEALTH CARE AND SOCIAL SERVICES**

**Functional ability, health complaints, agreement  
in needs assessment and care satisfaction**

Staffan Karlsson



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*In memory of my parents Kerstin and Stig*



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## ABSTRACT

The overall aim was to describe and compare functional ability and health complaints of older people receiving municipal care in relation to housing and informal care, and factors associated with medical health care, municipal care and informal care. Further, the aim was to investigate agreement in needs assessments between personnel and older people and to investigate care satisfaction and health-related quality of life among older people receiving municipal care and services. Study I and II included 1958 persons aged 65 years and above, who were assessed for functional ability, health complaints, and level of informal and municipal care and service. Study II in addition included data from a register including medical health care. In study III (n=152), standardised needs assessments were performed by the staff. Later, the older person's view was collected in a personal interview concerning functional ability, health complaints, public and informal care. In addition (Study IV, n=166), SF-12 was used for measuring health-related quality of life and for measuring care satisfaction.

Cohabitation was a predictor of a combination of municipal and informal care at home (OR: 5.935), while assistance with Instrumental Activities of Daily Living (IADL) provided by municipal home care and services predicted municipal care only (OR: 0.344). Care in special accommodation was predicted by advanced age (OR: 1.051), dependency in IADL (OR: 19.883), Personal Activities of Daily Living (PADL) (OR: 02.695), and impaired cognitive ability (OR: 3.849) with receiving municipal care only as a reference. Living alone (OR: 0.106), dependency in IADL (OR: 11.348) and PADL (OR: 2.506), impaired cognitive ability (OR: 3.448), impaired vision or blindness (OR: 1.812) and the absence of slowly healing wounds (OR: 0.407) were predictors of special accommodation with a combination of informal and municipal care at home as a reference. 35% of those with public care at home were admitted to hospital and 76% had contact with outpatient care by physician compared to 26% and 87% respectively of those in special accommodation. Living in special accommodation was associated with more contacts with primary health care (B=0.643) and fewer contacts with specialist care (B=-0.722). Informal care was associated with more contacts with primary health care (B=0.413), specialist care (B=0.787), admissions to (B=0.265) and days in hospital (B=1.573).

Agreement for dependency in IADL and PADL varied between good ( $\kappa=0.78$ ) and moderate ( $\kappa=0.43$ ). Poor agreement was found for dizziness ( $\kappa_w=0.17$ ) and fair agreement for impaired hearing, urinary incontinence, pain, anxiety and depressed mood ( $\kappa_w$  between 0.21 and 0.37). Older persons reported more health complaints than were found in the personnel's assessments, although significantly lower estimation was found only for incontinence and vision. Agreement for provided public care at home was poor, while for informal care it varied between very good and moderate. Low care satisfaction was associated with dependency in IADL (B=-1.338 and B=-1.630), impaired mobility (B=-12.579), blindness (B=-26.143), faeces incontinence (B=-11.898 and B=-17.529) and anxiety (B=-6.105 and B=-27.197), while high care satisfaction was associated with dependency in PADL (B=2.109) and receiving informal care with IADL from spouse (B=8.738). In special accommodation, low care satisfaction had to do with continuity, timing, the staff's personal characteristics and with their ability to give service. At home, the older people were the least satisfied with the staff's ability to do housework and to give medical care, with the staff's amount of time and with their own influence over their care.



## ABBREVIATIONS AND DEFINITIONS

ADL	Activities in Daily Living
CI	Confidence Interval
FSI model	The Family Systems Illness model
GAS	Good Aging in Skåne
HRQoL	Health-Related Quality of Life
IADL	Instrumental Activities of Daily Living
ICF	International Classification of Functioning, Disability and Health
LR	Logistic regression
MAUT	Multiattribute Utility Technology
MCS	Mental Component Summary (SF-12)
MSA	The Health and Medical Service Act
OR	Odds Ratio
PADL	Personal Activities of Daily Living
PASiS	Patient Administrative Support in Skåne
PCS	Physical Component Summary (SF-12)
QoL	Quality of Life
SALAR	The Swedish Association of Local Authorities and Regions
SD	Standard Deviation
SF-12	Short-Form Health Survey
SNAC	Swedish National study on Aging and Care
SSA	The Social Services Act
WHO	World Health Organisation
Ordinary home, at home	A home of one's own.
Special accommodation	Housing for older people in extensive need of care and attention with access to around-the-clock service and care, equivalent to a nursing home.
Informal care	Care and service from another person (non-professional), for example spouse or child.
Public care	Care from municipality and county council.

## ORIGINAL PAPERS

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

- I Karlsson, S., Edberg, A-K., Westergren, A., Hallberg, I. R. (2008). Functional ability and health complaints among older people with a combination of public and informal care vs. public care only. *Scandinavian Journal of Caring Sciences*, 22, 136-148.
- II Karlsson, S., Edberg, A-K., Westergren, A., Hallberg, I. R. (2008). Older People Receiving Public Long-Term Care in Relation to Consumption of Medical Health Care and Informal Care. *The Open Geriatric Medicine Journal*, 1, 1-9
- III Karlsson, S., Edberg, A-K., Hallberg, I. R. Personnel's and older people's assessments of functional ability, health complaints and received care and service. (Submitted)
- IV Karlsson, S., Edberg, A-K., Jakobsson, U., Hallberg, I. R Care satisfaction among older people receiving municipal care and service, at home and in special accommodation. (Submitted).

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

## INTRODUCTION

The connection between advanced age and an increase in the number of diseases and functional impairments is well known and implies a greater need of care and services (Fried et al., 2001). Knowledge is needed about the extent to which individual care needs related to functional impairment are fulfilled by the care and services provided by municipal or informal carers, as well as an understanding of the factors that determine whether the individual is cared for at home or in special accommodation. Such knowledge has implications for nursing competence, as well as for the elderly individuals themselves and their closest family members trying to make an informed decision. Diseases and various forms of functional impairment imply a complex life situation for the individual, but is also a challenge for public medical health care and long-term care and service, as well as for families (Åhgren, 2005). As in many other countries, the municipalities and the county councils are the two main public providers of health care and social services in Sweden, which makes it difficult to obtain an overall view of care consumption in individual cases. There may be a risk that older people get stuck in the middle or that one provider tries to pass the responsibility on to another provider. The split between authorities within the care system has been found to increase the risk that older people receive inadequate care and service (Clarfield et al., 2001). However, few studies have integrated data from both providers at the same time, or taken informal care into account when investigating medical health care consumption. Such knowledge is needed to further develop medical health and long-term care and to understand how the public system works in relation to individual cases.

Municipal care and social service is based on a needs assessment. How well needs assessments of public personnel agrees with the view of older people as a basis for decisions about public care and service may have an impact on provided care. However, knowledge is sparse about this relationship. Poor agreement may have consequences for the person receiving care and service with essential needs undetected (Challis & Hughes, 2002) and in addition, it may result in that public care is not distributed in accordance to needs. The allocation of resources in terms of care and service, but also in terms of care satisfaction and quality of life for older persons receiving care may be affected. Knowledge about the agreement between the personnel's assessment and the views of the older person about to receive care and service is needed in order to improve the needs assessment so that it is more in line with older people's own perception of what needs to be addressed. Care satisfaction is regarded as an important aspect in care quality. This may be so in particular for older people receiving care and services because their health is poor. Those receiving care and service have been found to have lower Health-Related Quality of Life (HRQoL) compared to those who do not (Hellström et al., 2004a). However, it is not fully investigated whether functional dependency, health complaints and HRQoL are associated with care satisfaction. In addition, more knowledge is needed regarding how these aspects relate to care at home compared to care in special accommodation. Also, it is important to learn more about the determinants of care satisfaction in order to understand and take actions toward shortcomings.

## BACKGROUND

The growing ageing population is a triumph, but also a great challenge to society. During the 21st century, global ageing will put increased economic as well as social demands on every country. Globally, the proportion of people 60 years and above increases more rapidly than other age groups and the fastest growing age group is that consisting of people over the age of 80. The continued growth of the ageing population is related to decreasing birth rates and increasing longevity (WHO, 2002). More than 17 percent of the Swedish population (1.6 million people) were 65 years and above in 2006. In 2005, the average life expectancy in Sweden was 83 years for women and 78 years for men. As in many other countries, there has been an increase in the number of the oldest old people during the last decades in Sweden. Between 1980 and 2000, the number of people 80 or older increased by 72%, and this age group is projected to nearly double until 2050. The growing ageing population means a greater demand for care and service, as the need of health care and social care increases after the age of 80 (Swedish Association of Local Authorities and Regions, SALAR, 2007). As increasing numbers of older people implies increasing numbers of persons with age-related diseases and health complaints, the demands on the systems for medical health care and public long-term care, as well as on family members, will increase. It is sparsely investigated how those systems work and the impact of provided care in individual cases.

When people live longer they have an increased risk of illness, including functional impairment and health complaints, which in turn may contribute to the need of care and services. Changes due to old age per se have only a moderate effect on functional abilities, while the increasing morbidity in old age implies functional decline and health complaints. However, natural ageing can be difficult to distinguish from morbidity and comorbidity (Daatland & Solem, 2000). Longitudinal studies have shown that people are generally healthy up to the age of 79-80 (Lagergren, 2002). There seems to be a breaking point around the age of 80 when functional impairment and health complaints increase (Brayne et al., 2001). Earlier studies have shown that the proportion of older people with health complaints due to various diseases has increased. In Sweden, the SWEOLD study indicated that the health of the very oldest got worse in several respects between 1992 and 2002 (Parker et al., 2005; Thorslund et al., 2004). Functional decline is an age related condition, affecting about one third of people 75 years and older (von Strauss et al., 2003; Agüero-Torres et al., 1998). Previous studies have shown a connection between increasing age and cognitive impairment (Fratiglioni et al., 2000, von Strauss et al., 1999). Women live longer than men and they more often suffer from age specific diseases and functional impairments. It is well known that functional impairments and health complaints have an impact on older people's quality of life (QoL) (Borglin et al., 2005; Hellström & Hallberg, 2001; Tsen & Wang, 2001). Therefore, it is important to get more knowledge about how these problems are approached in care and service and about how the assessment agrees with the older person receiving care and service.

Within countries in the European Union, major differences exist regarding older people's care and service. Differences are obvious between countries in the south and countries in the north of Europe, between financing from insurances and taxes and between rural areas and urban areas, but also religious traditions have an impact. Almost all European countries offer access to medical health care services for their inhabitants, while the availability of care and services for older people differs. It is common that local authorities are responsible for older people's care and services with an infrastructure for professional care. However, there are variations regarding the amount of available care and service and how professional care relates to the role of the family (European Commission, 2003). Thus, different systems in care and service have an impact on the distribution of public care and services to older people, and how it relates to care from the family. Two models for family involvement have been suggested: the substitution or the complementary model. The substitution model means that public care is a substitute for informal care (Lingsom, 1997), while the complementary model puts forward that public care complements informal care. Municipal care is added as a complement when the needs of older persons exceed the informal caregiver's resources (Attias-Donfut & Wolff, 2000). The complementary model is considered to be strongest in southern Europe due to a tradition of family solidarity in the care of older people and a low level of public long-term care. The complementary model connects to theories arguing that care and service at home is a dynamic relationship between municipal and informal care. Such theories imply a work transfer from municipal to informal care and vice versa (Glazer, 1990). In Sweden and northern European countries with a public welfare system, the individual's right to public care with no obligation for relatives is in line with the substitution model (Ministry of Health and Social Affairs, 2007). According to the model, public care is the main provider and older people should not rely on family for help or support (Lingsom, 1997). From an official political view the substitution model is stated, while it may well be the complementary model that is in use in care and service to older people.

Sweden has a public welfare system similar to the Nordic model and it contains economic security and services for older people (Ministry of Health and Social Affairs 2007). About 94% of those 65 years and above live in their homes, while among those 80 years and older 84% live at home (National Board of Health and Welfare, 2008). For older people in need of care and service, the municipalities are responsible for providing care and service. 16% (about 253 000 individuals) of the people over 65 receive public care and service, where 61% receive help at home and 39% in special accommodation. The corresponding proportion for people 80 years and older is 39% receiving care and service, 58% at home and 42% in special accommodation (National Board of Health and Welfare, 2007). Statistics from 2006 have been used regarding older people's care and service since changes in inclusion criteria have been introduced in the official statistics from 2007. The inclusion criteria are now wider and include more older people, which means that the data are less comparable with previous statistics. Help from the municipality includes home help services, home nursing care, rehabilitation and special accommodation while the County council is responsible for medical health care, hospital care and outpatient care (National Board

of Health and Welfare, 2008). The trend in Sweden is that older people, in spite of functional status, should be able to remain in their own homes for as long as possible. For those who no longer manage to live in their own homes, care in special accommodation is provided (Ministry of Health and Social Affairs, 2007). The meaning of not managing in their own home is open to interpretation and may differ between the elderly and the public officer and the public officer makes the decision. A development where more older people are cared for at home has been implemented (National Board of Health and Welfare, 2004), although there is a lack of knowledge about factors that determine whether the elderly are cared for at home or in special accommodation or how distribution of municipal care relates to medical health care and informal care.

## **International Classification of Functioning, Disability and Health (ICF)**

International Classification of Functioning, Disability and Health (ICF) is a multipurpose classification and useful as a framework to explore older people's care and services (WHO, 2001). The ageing process and morbidity may imply functional impairments and health complaints, which can have a negative impact on activities of daily living and QoL. ICF may be valuable for structuring functional ability, health complaints and activities towards a more standardised and comprehensive needs assessment prior to receiving care and service. The needs assessment is the basis for which interventions in care and service are provided, and in turn affects older persons' QoL and care satisfaction. ICF may give a clearer picture of the relationship between older persons' needs and contextual factors, as well as about care and service from different providers and the environment in which the person lives. ICF provides a framework for the entire health experience, including environmental factors, and is helpful when comparing the experience of patients with different conditions (Üstün et al., 2001). A standardised and structured model such as ICF may also guide documentation of care and service, and improve communication between professionals.

The World Health Organisation (WHO) has developed the International Classification of Functioning, Disability and Health (ICF), which provides a standardised language and framework for health and disability. ICF provides a system for descriptions and comparisons of patient groups regarding care load and planning, without any association to specific diseases. It organises information in two parts: functioning and disability, and contextual factors (Table 1). Further, each part has two components. Firstly, functioning and disability includes the bodily component which is comprised of two classifications: body functions and body structures. Those classifications are ordered according to the body system. The model of disability in ICF reflects a biological, individual as well as social perspective of health. Secondly, functioning and disability includes the component of activities and participation which covers domains that represent aspects of functioning from an individual as well as a societal perspective. The first component of contextual factors contains a list of environmental

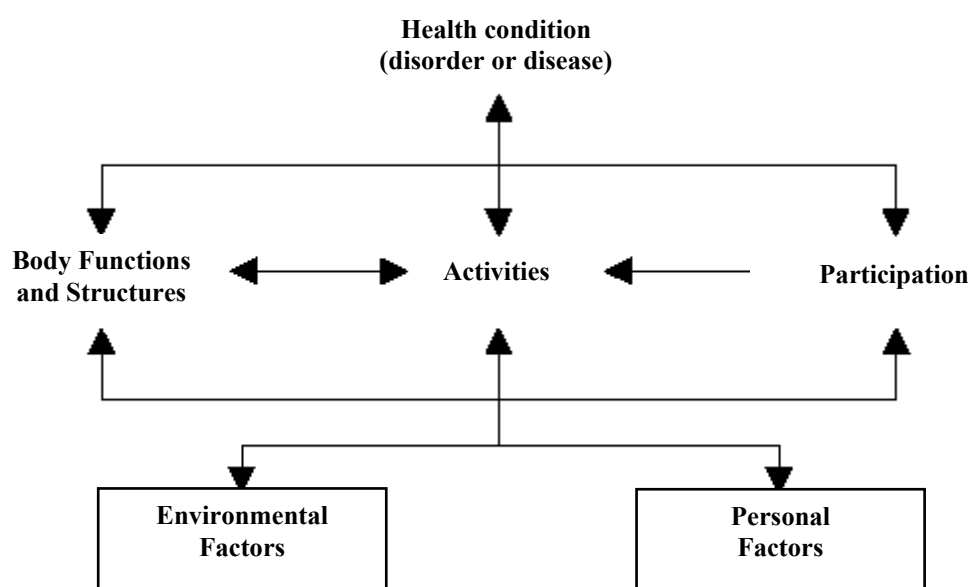
factors which have an impact on functioning and disability. The environmental factors are ordered from the person's local to the general environment. The second component of contextual factors is personal factors. Personal factors are not classified in ICF, since they are associated with social and cultural variance (WHO, 2001). In the structure of the model, health-related quality of life (HRQoL) could be considered a general concept which relates to all components of ICF (Cieza & Stucki, 2005). The process of functioning and disability can be understood as a complex interaction between a person's health condition, including body functions, structure and activities, and personal and contextual factors (Figure 1). ICF deals with these factors as components in an interactive and dynamic interaction based on the person's situation. Each component includes a number of domains, except for the personal factor which has no developed domains yet. Activities in a particular health status can be assessed as a capacity to do something in a standard environment but also as what a person actually performs in a certain environment. ICF is a conceptual source for the definition, measurement and policy formulations of health and disability. It is universal for use in health and health-related care (WHO, 2001).

**Table 1.** Overview of ICF (WHO 2001).

	<b>Part 1: Functioning and disability</b>		<b>Part 2: Contextual factors</b>	
<b>Incorporated concept*</b>	HRQoL		HRQoL	
<b>Components</b>	Body functions and structures	Activities and participation	Environmental factors	Personal factors
<b>Domains</b>	Body functions and structures	Life areas (tasks, actions)	External influences on functioning and disability	Internal influences on functioning and disability
<b>Constructs</b>	Change in body functions (physiological)	Capacity Executing tasks in a standard environment	Facilitating or hindering impact of features of the physical, social and attitudinal world	Impact of attributes of the person
	Changes in body structures (anatomical)	Performance Executing tasks in the current environment		
<b>Positive aspect</b>	Functional structural integrity	Activities Participation Functioning	Facilitators	Not applicable
<b>Negative aspect</b>	Impairment	Activities limitation Participation restrictions Disability	Barriers, hindrances	Not applicable

\* Added concept and used as an outcome

ICF may be used as a framework for a better understanding and a more comprehensive view on older people receiving care and service. Older people's health status is affected by the ageing process as well as by diseases which make them frail. The overall aim of the ICF classification is to provide a standardised description of health and health status (WHO, 2001). Frailty of older people is observed in body structures and body functions, but also in health complaints. These factors have an impact on their activities and participation, which ADL form a part of. Contextual factors refer to municipal care and service, medical health care and informal care, but also to aid equipment and adaptation in housing. The contextual factors aim to prevent, relieve or eliminate functional impairments and health complaints, and to increase activities and participation. Since functional impairments and health complaints are known to have a negative impact on older people's QoL, it is important that care and services correspond to the specific needs in the individual case. Poor agreement between the assessment of needs of professionals and older persons may be shown in low care satisfaction in the older person receiving care.



**Figure 1.** Interaction of concepts, ICF (WHO, 2001, pp. 22)

## Personal factors

A person's life story and living is represented by personal factors and consists of characteristics that may have no part in the health condition or health status. Examples of characteristics are gender, age, lifestyle, habits, coping styles, social background, education, profession, past and present experience and behavioural patterns. Personal factors are not classified in ICF. However, they contribute to body functions and structures as well as to activities and participation and may have an impact on the outcome of interventions (WHO, 2001). Ageing cannot be understood without considering gender, since men and women face old age under different circumstances.



The ageing process varies; women grow older than men and have more functional limitations than men. A previous study has found that older women have a higher prevalence of disability than men of the same age, but that they live longer with their disabilities (Guralnik et al., 1997). As women live longer than men do, the probability of living without a spouse in the last period of life is higher for women than for men (Guralnik et al., 2000). The fact that women often marry men older than themselves and that they have lower remarriage rates than men is another part of why women are overrepresented in single households (Statistics Sweden, 1999). Gender may also have an impact when receiving care and service in old age. One Swedish study showed that men had higher odds of receiving public or informal care compared to women, after controlling for age, education, functional and cognitive impairments and dependency in IADL. However, when controlling for cohabitation no gender differences were found concerning the distribution of public or informal care (Larsson & Thorslund, 2002). Further, women are about three times more likely than men to be informal caregivers to older relatives (Johansson et al., 2003). Thus, when doing research about conditions regarding functional ability and health as well as about how care and service is provided, gender may have an impact and should be taken in to consideration.

## **Body functions, structures and impairments**

Body functions are the physiological and psychological functions, while body structures are the anatomical parts. “Body” refers to the organism as a whole, including both the physical and the mental functions. Body functions and body structures are classified in two separate sections, but are used in parallel. As an example, body functions consist of basic senses such as “hearing functions” and the corresponding structures are “ear and related structures” (WHO, 2001). The ageing process has a negative impact on older people’s functional ability related to various structures in the body. Ageing involves biological and genetic processes that gradually affect the person’s reserve capacity throughout life. The deterioration differs, with great variations between persons and between organs and organ systems. Thus, generalisations are to be made cautiously (Persson et al., 2001). Biological ageing becomes more obvious the older the person grows, with a significant decrease in physical and mental ability, for example hearing, vision and mobility (Baltes & Smith, 2003). Impairments imply problems in body function or structure as a considerable deviation or loss, and correspond to a generally accepted population standard of the health condition of the body and its functions. The concept of impairments is more comprehensive than disorders and diseases. For example, the loss of an arm is an impairment of body structure, but not a disease (WHO, 2001).

Advanced age may mean living with a number of diseases that cause functional decline and health complaints (John et al., 2003; van Dijk et al., 2005). During this period of life chronic conditions, e.g. arthritis, heart and stroke diseases and cancer occur more frequently than earlier in life (Fries, 2000). Due to increased morbidity and comorbidity, older people will be in need of medical health care from a variety of

health care agencies (Condelius et al., 2008). Health complaints and functional decline may predict the need of care and services. Previous studies have shown that health complaints and functional decline have a great impact on older people's QoL (Hellström & Hallberg, 2001; Borglin et al., 2005). The definition of impairment is undertaken by professionals qualified to assess physical and mental functioning according to these standards. Impairments can appear temporary or permanent, be progressive, regressive or stationary, and intermittent or continuous. The discrepancy from the population standard may be assessed as slight or severe and vary over time. Impairments do not necessarily relate to a disease, but are more a part or an expression of a person's health status. Through defined criteria for identification, impairments are classified in categories and determine presence versus absence of impairment according to a threshold level. Criteria for body functions as well as for body structure are loss or lack, reduction, addition or excess and deviation. Impairment can be graded in terms of its severity with the generic qualifier in the ICF (WHO, 2001). In care and services it is important to approach health complaints and functional decline in an appropriate way in order to increase or preserve older people's QoL. A needs assessment including functional impairment and health complaints is essential for providing adequate interventions for older people. Body functions and structures interact with the environment as seeing may interact with light, hearing with sounds, balance to ground texture etc. (WHO, 2001). Functional impairments and environmental barriers cause older people limitations in activities, ADL as well as other activities. Adapting the environment and using aid equipment may make older persons more independent and increase their QoL.

### ***Health complaints***

Many older people stay healthy even into high age, but a considerable number of older people have several diseases and health complaints, especially among those receiving care and services. One study in Sweden (n=4277, 75+) showed that women reported more health complaints than men (9.5 and 9.0 respectively). The most frequently reported health complaints for both genders were associated with communication, mobility and psychosocial problems. (Stenzelius et al., 2005). It is common that older people suffer from more than one disease, which means that focus on one disease at a time may be more relevant in younger populations. However, research usually focuses on one disease at a time, and the same is true for health complaints, for instance pain (Stuck et al., 1999). Research providing knowledge about patterns of health complaints would be appropriate and in line with the actual situation of older people receiving care and service. A previous study in Sweden (>75 years, n=448) investigating the prevalence of health complaints in older people, showed that the respondents suffered from in median 10 out of 26 health complaints. The most common health complaints were musculoskeletal pain, impaired mobility, vision and hearing problems and dizziness (Hellström & Hallberg, 2001). Patterns of health complaints have been presented from various perspectives. One approach has been to cluster health complaints from an anatomical or structural point of view, proposing that health complaints from a specific area of the body should have similarities (WHO, 2001; Tibblin, 1990). In another study, relations between health complaints analyses were

based on empirical data. This approach gave a different pattern with a more functional perspective (Stenzelius et al., 2005). The function of the body is to a high degree what the individual views it as, while the structure of the body is the physiological component (Verbrugge, 1990). Systematic and more comprehensive assessments of older people's functional ability and health complaints will be an important guide for interventions that improve QoL for older people receiving care and service. Thus, it is crucial to include functional ability and health complaints in needs assessments, but it is not clear whether these problems are viewed as a part of the personnel's assignment.

### ***Cognitive ability***

Impaired cognitive ability is often associated with dementia. The proportion of people with dementia is strongly related to age and length of life. In 2000, the number of persons with dementia diseases in Sweden was counted to about 130 000, and an estimation of 25 000–30 000 people annually develop the condition (Wimo & Jönsson, 2000). However, the incidence appears not to have increased over time; the large number of people with dementia being due to the increase in the proportion of very old people in the population (Fratiglioni & Rocca, 2001). Older persons with cognitive impairment are less likely to live alone, most of them live with a close relative, often spouse, who usually serves as informal caregiver. Persons with dementia may need around-the-clock supervision and surveillance in order to prevent dangerous events and to manage behavioural disturbances (Wimo et al., 2002). Cognitive impairment has also been found to be a strong predictor for care in special accommodation (St John et al. 2002; Agüero-Torres et al., 2001), often together with behavioural problems (Gaugler et al., 2003; Yaffe et al., 2002). Almost 75 % of older people living in special accommodations have been found to be impaired in their cognitive ability (Macdonald et al., 2002). However, little is known about these people's quality of life, due to the difficulties in measurement. Previous studies in dementia have used the person's subjective ratings, proxy ratings or both. The golden standard for measuring quality of life seems to be the subjective ratings from the person, but proxy ratings may be useful for those with severely impaired cognition (Whitehouse et al., 2003; Brod et al., 1999). Mood and environmental factors are suggested to have the biggest impact on quality of life in dementia, and this is so independently of the severity of the dementia (Hoe et al., 2005; Thorgrimsen et al., 2003). Thus, knowledge about cognitive decline is important in the view of providing appropriate care and service for older people, at home or in special accommodation.

### ***Health complaints and cognitive ability related to QoL***

Health and functional status are two variables that are often found to explain QoL of older people. A review of research on the perceived health of older people and QoL, reported a positive relationship between these two variables (Moore et al., 1993). Raphael et al. (1997) also found a positive relationship between QoL and health status of older people. Health complaints are known to negatively affect quality of life (QoL) (Borglin et al., 2005). Several health complaints in a complex relationship at the same time predict low QoL (Hellström & Hallberg, 2001; Jakobsson, 2004). One study in

Sweden including people aged 75 to 99 (n=469) showed that pain, fatigue, anxiety and sleeping problems were associated with low QoL (Borglin et al., 2005). Also, other studies have indicated that anginal pain, urinary incontinence, mobility problems, hearing and vision problems have a negative impact on QoL (Tseng & Wang, 2001; Grimby & Svanborg, 1997). Dizziness has been found to be an important symptom with a negative impact on the quality of life of older people (Hsu et al., 2005), and in addition a risk factor for falls (Moreland et al., 2003). Also, previous studies have found that memory complaints related to cognitive impairments have a negative impact on quality of life (Mol et al., 2007). Needs assessments of health and functional status in line with the older person gives qualifications for appropriate interventions and in turn improves the person's QoL and care satisfaction. However, it is unclear how functional ability and health complaints are covered in needs assessments.

### ***Measurement of health complaints and cognitive ability***

Health complaints and functional ability may be either observed or asked for by the professionals, but also assessed with standardised instruments. Professionals' observation of older people's pain has been found to be poor. One study showed that professionals in general overestimated levels of low pain and underestimated levels of severe pain (Bergh & Sjöström, 1999). A common instrument for measuring pain is by visual analogue scale (VAS) (Huskisson, 1974), or similar instruments such as a verbal descriptor scale (VDS) or a numerical rating scale (NRS). This type of instrument measures only pain intensity and not the entire subjective experience. Instruments for assessment of urinary incontinence are often divided into use for men versus for women. Examples of instruments addressing men is the International Continence Society- male questionnaire (ICS-male) (Donovan et al., 1996) and for women the Bristol Female-Lower Urinary Tract Symptom questionnaire (BF-LUTS) (Jackson et al., 1996). Both instruments measure urinary symptoms and have been used in older populations. However, no instruments for faecal incontinence seem to be developed yet for older people. An instrument regarding dizziness is The Dizziness Handicap Inventory (DHI), which has been developed to measure self-perceived handicapping effects of dizziness. It comprises 25 items organised into three content domains representing functional, emotional, and physical aspects of dizziness and unsteadiness (Jacobson & Newman, 1990). The Berger scale is an instrument for assessment of cognitive ability which classifies dependency on the basis of the carer's assessment (Berger, 1980). The instrument correlates well with the characteristic clinical course of Alzheimer's disease, and clinical experience has found it to be a valid and reliable means of obtaining an overview of cognitive status. The scale is divided into seven predefined levels, ranging from no cognitive decline to severe impaired mobility and mutistic. Thus, there are a number of examples of reliable methods for assessing health complaints and functional decline in older people. Those methods provide assessments more in line with older people's own perceptions, which may give a more fair distribution of care and services, but also interventions that may improve QoL and care satisfaction for older persons. Knowledge is sparse concerning the use of reliable methods in needs assessment and how the assessments agree with the older person's view.

## Activities and participation

Activity is the performance of a task or action by a person, while participation is the person's involvement in a life situation. Activities and participation separately, or both together can represent the component. The activities and participation component consists of the domains learning and applying knowledge, general tasks and demands, communication, mobility, self care, domestic life, interpersonal interactions and relationships, major life areas, and community, social and civic life (WHO, 2001). An activity that is crucial for older people is their ability to perform activities of every day life. The ability to perform daily activities is complex since these are developed throughout life and are affected by the ageing process, life history, habits, health status, impairments, living arrangements etc. For social participation, social contacts with other people and walking outdoors may be essential for older people. Each domain in activities and participation is related to the qualifiers of performance and capacity. Performance illustrates what a person performs in his or her present environment, while capacity illustrates a person's ability to perform a task or an action on the highest probable level. A gap between capacity and performance reflects the diversity between the impact of the existing and the ultimate environment. Such information can be used as a guide for intervention in the person's environment in order to improve performance. Qualifiers regarding capacity as well as performance can be used with and without aid equipment or personal assistance. Neither aid equipment nor personal assistance can remove impairments, but they may eliminate limitations on specific functions. It is particularly helpful for the identification of the amount of functional limitation in a person without the aid equipments (WHO, 2001). Functional impairments and health complaints cause activity limitation and participation restrictions in older people and have a negative impact on activities in daily life (ADL), but also on other activities such as walking outdoors and social contacts. Previous studies have showed that older people dependent in ADL and in need of help from others have reduced QoL (Hellström et al., 2004a; Hellström et al. 2004b). Therefore, it is central that provided care and service aims to maintain and develop older persons ADL. In order to reduce limitations in activities and increase participation of people with decreased ability in ADL, it is important that provided care creates a propitious environment and offers suitable equipment for reducing dependency and increasing QoL.

### *Activities in daily living (ADL)*

Activities are usually described in relation to activities in daily living (ADL). ADL ability is often influenced by diseases or health complaints and is crucial for people to live an independent life (Sonn & Lundgren-Lindquist, 2004). For example, a subsequent loss of independence in ADL is the most visible manifestation of dementia with a progressive inability proportional to the severity of the disease (Potkin, 2002). ADL may be divided into two main categories: instrumental activities in daily living (IADL) and personal activities in daily living (PADL). Dependency in ADL is more common among older people than among younger. A study by Borg et al., (2006) including 522 people 65+ showed that problems in managing IADL were the most

frequent, and also that it was in these activities that limitations first occur, while limitations in PADL arise later on. Thus, there is a hierarchical relation between IADL and PADL (Sonn et al., 1996). In the US, approximately 6% of elderly people living at home reported limitations in PADL (e.g., bathing or dressing) due to chronic illnesses, while 11.5% indicated limitations in IADL (e.g., preparing meals, using a telephone) (National Center for Health Statistics, 2006). Wu and Chiou (1997) in Taiwan found that 4 % of people 65 years and above required assistance with ADL. In Sweden, older people's ability in ADL has increased between 1980 and 2005. Especially the ability to manage IADL has improved, while the ability to perform PADL is almost on the same level (SALAR, 2007). Previous studies in the US have shown the same pattern with increased ability in IADL, while no improvement regarding PADL was found (Spillman, 2004; Freedman et al., 2002). A review of eight countries by Organisation for Economic Cooperation and Development (OECD) showed a predominance of improvement of older people's activities in ADL (Jacobzone, 2000). However, in Sweden, SWEOLD showed no significant change in ADL or IADL activity between 1992 and 2002 (Parker et al., 2005). Differences in results from different studies may be related to that ADL activity is also connected to gender, environmental factors, adaptation in housing, available aid equipment etc.

Participation in daily life is essential for living a satisfactory and independent life at home in very old age (Avlund et al., 2004). Functional impairment and health complaints affect ADL, which in turn affects QoL. Help with IADL and PADL have been found to be associated with low QoL (Hellström et al., 2004b). For older people with dementia it has been found that QoL decreases when the severity and dependency increases (Andersen et al., 2004). In studies of older people with a variety of chronic illnesses, positive QoL has been found among those perceiving themselves to be in good health and independent with their activities of daily living (ADL) (Bowling et al., 2002; Hellstrom & Hallberg, 2001; Hillerås et al., 2001). An approach in care and service to relieve health complaints and increase functional ability, but also to accomplish a propitious environment, may give older people an optimal level in ADL, and increased QoL. It is not well known how ADL and environmental factors are included in needs assessments and how the subsequent interventions in care and services support the activities and participation of older people.

In assessments of ADL, Katz' ADL index is commonly used regarding PADL. Katz' index was specially developed for the measurement of activity status among older people and it summarises a person's overall performance based on six activities: hygiene, dressing, toileting, mobility, ability to control bowels and bladder, and feeding. Each function is graded as independent, partly independent or dependent. (Katz & Akpom, 1976). An extended measurement which also includes IADL is called the ADL-staircase (Sonn & Åsberg, 1991). When IADL (cleaning, shopping, transportation and cooking) is included, a 10-point scale (the ADL-staircase) is used, based on a hierarchical structure (Sonn & Asberg, 1991; Sonn, 1996). Zero signifies independence in all activities, 1-9 signifies dependency in one to nine activities, whereas 10 indicates total dependency. Others (O) means being dependent on help in a minimum of two and a maximum of nine activities and is not classifiable as 1-10, that

is, it does not follow the hierarchical structure of the index (Katz & Akpom, 1976; Sonn & Åsberg, 1991). The ADL-staircase has shown good validity and reliability (Sonn, 1996). For example, interobserver reliability has been reported as high ( $r=0.81-0.88$ ) between graders in a study in which nurses assessed older people (Brorsson & Åsberg, 1984). Such a measurement would probably be suitable for needs assessments before a decision about public care was made.

## **Contextual factors**

The comprehensive background of a person's life and living represents contextual factors. These factors include the components environmental factors and personal factors (see page 15). Environmental factors consist of the physical, social and attitudinal environment where persons live their lives. They are external to persons and can affect the performance as a society member, or the person's functional performance and capacity, or the person's body function or body structure (WHO, 2001). Frailty in combination with the surroundings makes older people in need of help and support from others. The ability to have social contacts with other people and to walk outdoors is important for the participation in society and may be facilitated or counteracted by the environment. Environmental factors are ordered in the classification to focus on the individual as well as the societal level. The individual level implies the immediate environment, such as home, workplace and school. It includes those physical and material attributes that a person comes face to face with, as well as contacts with other persons such as family, friends and strangers (WHO, 2001). The main care philosophy of Sweden is that older people are best cared for at home (Ministry of Health and Social Affairs, 2007), even though there is no evidence supporting such a view. Previous studies have found that the family (informal care) plays a leading role in home-based care and service for older people (Johansson & Sundström, 2002, Thorslund et al., 1997; Johansson, 1991). The societal level implies formal and informal social services and overall approaches and systems in the society that influence persons. It consists of organisations and services associated with the community sector, government agencies, communication and transportation services, and informal social networks, but also of laws and regulations (WHO, 2001). A needs assessment by the personnel is performed before the provision of care and service, home help, home nursing care and rehabilitation by the municipality. It is not well known how provided care is related to the individual case or how the care is experienced by the older person in terms of care satisfaction. Further, more knowledge is needed regarding how municipal, informal and medical health care are related to each other. Environmental factors interact with body functions and body structures as well as with activities and participation. Disability is described as the consequences of a relationship between a person's health condition, personal factors and the environment in which the person lives. Different environments may have a diverse impact on the same person with a given health status. An environment without barriers and with facilitators will increase a person's performance, while barriers and a lack of facilitators will restrict performance (WHO, 2001). Beside health status, environmental factors are important to take into account in needs assessments which

consequently provide intervention including facilitators and remove barriers. Probably, needs assessments like that will make older people more independent and in turn may increase their QoL and care satisfaction.

### *Informal care*

Informal care has been found to be the main source of care and service for older people living at home. The amount of informal care has been estimated to be two to three times greater, in terms of hours, than municipal care (Johansson, 1991). Studies have shown that the bulk of care and service for older people is provided by informal sources and that the family plays an important role for older people in need of care and service at home (Jeppsson-Grassman, 2001; Johansson & Sundström, 2002). Support for older people comes mainly from the close family, and the most common helpers are spouse and children (Hellström & Hallberg, 2001). The Family Systems Illness (FSI) model may be a useful framework for evaluation, formulation and intervention with families dealing with morbidity and functional impairments of older people. The FSI model is based on a strength-oriented perspective, which considers family relationships as a probable resource and emphasises their potential for resilience and growth, not just their problems and risks (Rolland, 1994). The structure of ICF describes morbidity the same way, but are more focused on the older person with the family as an environmental factor or related to activities and participation. Activities and participation include the older person's ability to maintain interaction within the family, while the environmental factor implies receiving practical or emotional support, but also the impact of attitudes from family members (WHO, 2001). In the FSI model with morbidity and functional impairments, a psychosocial orientation is conceptualised from a systems perspective, with the family as the main focus. In order to enable a systematic interaction between the older person's health status and the family, it is useful to consider the health complaints and functional impairments according to patterns of psychosocial demands over time (Rolland, 1994). In ICF, the family has an external impact on the person's functioning and disability. The family can have a facilitating or hindering impact on a person's activities and participations in daily life (WHO, 2001). The FSI model is divided into three dimensions: psychosocial types of morbidity and functional impairments, developmental phases of morbidity and essential family system variables. The model illustrates the expected psychosocial demands of a disorder through its various phases, family systems dynamics that emphasise familial and individual development, multigenerational patterns of coping with illness and loss, and belief systems. Further, it pays attention to the goodness of fit between the psychosocial demands of the health complaints and functional impairments, and the strengths and vulnerabilities of a family. In a practical way it identifies predictable strains and facilitators for optimal coping and adaptation (Rolland, 1994). ICF is a classification and provides a standardised language to describe health and disability. As a complement, the FSI model may be useful to describe from a wider perspective informal care and the interaction within a family when an older person becomes in need of care and service. A needs assessment including the family perspective may provide a basis for interventions which may be



more adequate to informal caregivers and in turn increase QoL and care satisfaction for both older people receiving care and service and informal care givers.

### ***Informal care in relation to municipal care***

Responsibility for older people's care and service appears to some extent to have been transferred from public care to informal care. In Sweden, the recent decline in municipal care has been matched by an increase in informal care (Szebehely et al., 2001). One study indicated that informal care related to older people has increased from 60 % in 1994 to 70 % in 2000 (Sundström et al., 2002). It seems that the family fills the gap between the care needs of older people and the public care provided. Especially older persons living together were affected by the decrease in public care and service, leaving the spouse to care for his or her partner (Szebehely, 1998; Daatland, 1997). Older people living alone have also become more dependent on care and service from informal helpers. Help from adult children have been found to nearly double during the 1990s (Johansson et al., 2003). The frailest older people seem to have a combination of municipal and informal care. One study showed that older people receiving a combination of municipal and informal care had more help in IADL and PADL compared to those who received either only municipal or only informal care (Hellström & Hallberg 2004). Among people with a cognitive impairment, being able to stay in their home seems to depend on the availability of an informal caregiver (Hebert et al., 2001). Being cared for at home as opposed to in special accommodation implies receiving care and help from family members (informal caregivers), although there is no legal obligation in Sweden for family members to provide care for their relatives. Thus, informal caregivers seemingly contribute extensively to the care and service of the older persons, although determinants or the distribution of informal care are not fully understood and also need to be investigated repeatedly. Legislation governing the needs assessment specifies a focus on the older person in need of care (SFS, 2001; SFS, 1986) while the family (informal caregivers) is neglected. Such legislation may have a negative impact on interventions for the person in need of care as well as on the support for and collaboration with informal caregivers, and in turn may affect their QoL and care satisfaction.

### ***Needs assessment***

A needs assessment prior to a decision about the provision of care and service for older people may include functional ability, health complaints common in old age and social network. The comprehensive geriatric assessment (CGA) is a validated and multidisciplinary process for defining a person's functional, social and psychological problems. One commonly included component is a functional assessment of instrumental activities of daily living (IADL) and personal activities of daily living (PADL). The medical assessment concerns the presence of comorbidity as well as cognition and mental status, such as the presence of depression. The social assessment estimates the amount of informal care and care resources, and the environmental assess home safety and transportation (Wieland & Hirth, 2003). Even though there are developed methods for adequate needs assessments of older people as a basis for

receiving care and service, there seems to be a deficiency in needs assessments. A review in the UK indicated that needs assessments as a basis for receiving care and service was standardised and detailed regarding ADL, whereas cognition and depression were assessed more superficially and with a great variation (Challis & Hughes, 2002). One study in the UK ( $n=55$ ) of patients 75 years and older showed that the personnel mostly assessed physical impairment, mobility and ability to prepare food, while they less frequently assessed health complaints such as vision/hearing, psychological distress and incontinence (Walters et al., 2000). Nurses appeared unaware of the importance of addressing the particular pain needs of older patients (Brown & McCormack, 2006), although it is well known that health complaints like pain determine quality of life. Thus, needs assessments of older people as a basis for receiving care and service seems not to include sufficient information. Health complaints and functional impairments have a negative impact on older people's QoL and are consequently important to include in needs assessments. However, it is not well known to what extent those issues are included in needs assessments and the following interventions.

Assessments of needs as a basis for decisions about care and service have been found to differ between older care recipients and professionals. A previous study in the US ( $n=85$ ) indicated that professionals rated the need of care to a lower level than the older care recipients did. The professionals simultaneously rated physical functioning lower than the older persons themselves did (Morrow-Howell et al., 2001). Also, a study in the UK showed that agreement between patients 75+ ( $n=52$ ), general practitioners and health professionals using the Camberwell Assessment of Need for Elderly (CANE) was poor ( $k<0.4$ ). The variables "self care", "company" and "caring for someone else" indicated moderate agreement ( $k=0.4-0.6$ ), while "physical illness", "food intake" and "mobility" showed good agreement ( $k=0.6-0.8$ ) (Walters et al., 2000). An investigation of the agreement between the professionals and the older care recipients provides knowledge about how the provided care is identifying the needs of care and services from the view of the older person. Assessments in line with older persons' perception may give a more fair distribution of care and services, and target resources to those most in need.

A previous study indicated that older people's needs were often described in terms of solutions or services rather than taking a comprehensive view of their requests and problems (Lindelöf & Rönnbäck, 2004). Another study found that needs assessments prioritised institutional goals and municipal guidelines, which only allow certain needs to be disclosed (Challis & Hughes, 2002). For a more comprehensive view, a preventive and palliative approach in addition to compensating for functional decline may be useful in older people's care and services. A preventive approach implies early symptoms identification and following interventions, medication management and adjustment to chronic diseases (Hallberg & Kristensson, 2004). For instance, detecting risk factors for falls makes it possible to intervene with reversible factors and prevent suffering and morbidity in old people (Cesari et al., 2002). Recently, palliative care has been expanded to emphasise its incorporation throughout chronic illness (Zwerdling et al., 2005). Palliative care with a focus on relief of health complaints,

psychosocial and existential issues is argued to be an appropriate approach for older people's care and services (Hallberg, 2006). In needs assessments it is reasonable to view all the components in ICF; functioning and disability as well as contextual factors have to be taken into consideration. A more comprehensive needs assessment gives opportunities to provide adequate care and service that improves the quality of life for older people.

### ***Municipal care and services***

According to Swedish policy it is best for older people to remain at home for as long as possible, also when they need extensive care and service (Ministry of Social Affairs, 2007). It is assumed that it is best for older people to remain at home, although a comparison of those with the same functional ability and social network living at home or in special accommodation provides no hard evidence to support such an assumption. No differences in quality of life (QoL) were found between older people living at home or in special accommodation when controlling for functional ability (Hellström et al., 2004a). In Sweden, the number of places in special accommodation has decreased by 11% between 2000 and 2004, while care and services in the home have increased by 9% (National Board of Health and Welfare, 2005). Simultaneously, care and service at home has been concentrated more on those in need of extensive care (Thorslund et al., 1997), indicating that those cared for at home have a poorer health status nowadays than previously was the case. In the 1960s home help was provided to older persons who mainly required assistance with IADL. In recent years more municipal care time at home is devoted to PADL, while IADL needs have to be dealt with by the old person him/herself or by informal care (Johansson et al., 2003). Factors determining the distribution of care tasks are not well understood. Earlier studies, for example by Herlitz (1997), have shown that living alone and needing more help with PADL than with IADL was associated with municipal care. It is known that a majority of older people receive municipal care at home, while increased dependence in Instrumental Activities of Daily Living (IADL) and Personal Activities of Daily Living (PADL) is supposed to result in the need for care in special accommodation (Trydegård, 1998). Those living in special accommodation (nursing home) have been found to be older, more functionally dependent and to have a higher number of health complaints than those living at home (Hellström et al., 2004b). A Finnish study (n=5652) investigated the ADL ability of people over the age of 65 years in different care settings. Those in long-term care in a hospital or special accommodation were most dependent in ADL, followed by clients in short-term care in a hospital or special accommodation, while those who received home nursing care or home help were least dependent (Laukkanen et al., 2001). Cognitive impairment was found to be a predictor of care in special accommodation (Aguero-Torres et al., 2001) and was often combined with behavioural problems (Gaugler et al., 2003). In ICF, municipal care is regarded to be an environmental factor that has an impact on functioning and disability, and facilitates activities and participation of older person's (WHO, 2001). An understanding of factors determining the distribution of municipal resources may be useful for providing appropriate care and support to older people, and also feedback to the municipalities in order to ensure adequate knowledge among the staff in care

and services. Knowledge about determinants for municipal care may guide an improved needs assessment followed by suitable interventions and perhaps a more fair distribution of care and service to older people.

### ***Medical health care***

In ICF, medical health care is regarded as an environmental factor that influences functioning and disability. The supposed aim is to improve body functions and body structures, which in turn may facilitate activities and participation. The growing elderly population, consisting of more people who have to live with a number of diseases and various forms of functional dependence, entail a complex life situation for the individual and also a challenge for public medical health. Findings by McGrail et al. (2000) in Canada indicated that the consumption of emergency health care increased with age. In Sweden the total of days in hospital was about 9 million in 2002, whereas 52% of these were used by people 65 years and older, 23% used by those between 75 and 84 years old and 13% by people 85 years and above (National Board of Health and Welfare, 2008). It may well be that the pattern of health care consumption differs during the period from 65 years of age to death. A study including persons aged 75+ (n=278, US) investigated the total cost of health care, including hospital care, outpatient visits and durable medical equipment. The oldest age group (90+) received less extensive treatment than the younger age group (75-79 years) (Long & Marshall, 2000). Another study in the US (n=53 195) showed that the medical expenditure on older people in the last year of life was lower among people aged 85 and over compared to those between 65 and 74 (Levinsky et al., 2001). The explanation for this may be that the oldest people were not prioritised or that they received care elsewhere, either at home or in special accommodation. However, a small group of older people seem to consume a large amount of medical care. One study (n=4907) showed that 15% of those 65 years and older were accounting for 35% of the hospital admissions. Those who were frequently admitted to hospital also tended to consume a great deal of outpatient care (Condelius et al., 2008). Another study showed that frequent visits in the emergency room were associated with more hospital stays and contacts in primary outpatient care (Hansagi et al., 2001). Thus, older people's medical health care consumption is extensive and follows different patterns. However, knowledge is sparse concerning factors associated with older people's medical health care consumption. A large amount of hospital care may also be related to municipal care and services. One study (n=362) found a break point about 5 months before receiving municipal care and service and 15% having a large amount of hospital admissions (Kristensson et al., 2007). Due to the lack of statistics on an individual level and to that health care and social services are divided between county councils and municipalities, it is difficult to obtain an overall view of care consumption in individual cases. Few studies have integrated data from both providers, and informal care has seldom been taken into consideration when investigating health care consumption. Thus, there is a need for more knowledge of how care consumption is distributed among different agencies and about the relationship between public care and service at home or in special accommodation, and medical care consumption. Knowledge about determinants for medical health care

consumption may provide an important complement to needs assessments and preventive interventions, which in turn may improve older people's QoL.

### ***Care satisfaction***

Care satisfaction seems to be important to take into consideration when trying to improve care, but it is not well known how it relates to QoL of older people receiving care and service. Donabedian's (1988) theory of how the quality of care can be assessed and the role of patient satisfaction in that context include a three part approach to quality assessment: the structure of the setting, the process of what is done and the outcome. It implies that patient satisfaction may be considered to be one of the desired outcomes of care. Patient satisfaction is the patient's judgement of the quality of care in all its aspects, particularly regarding the interpersonal process (Donabedian, 1988). Care satisfaction is difficult to measure because of the broad and intimate nature of care and service provided and the recipient's dependency on it (Geron, 1998). Different aspects of importance may determine when receiving care and service, at home or in special accommodation. One study in the US (n=176) concerning care satisfaction in care and service at home indicated that women and those not married were more satisfied with the interpersonal aspects of care (Curtis et al., 2005). Older people receiving home care in one study expressed the importance of planned adapted care matching their needs, delivered by personnel with appropriate knowledge and skills and that timing were crucial (Woodward et al., 2004). Living in small facilities and increased care hours in special accommodation were associated with care satisfaction (Chou et al., 2003; Chong, 2003). Functional ability and perceived health have earlier shown to have an impact on Health-Related Quality of Life (HRQoL) (Hellström et al., 2004a) and may also have an impact on care satisfaction. Previous studies found a relationship between pain, distress and anxiety and poor care satisfaction (Baldock & Ungerson, 1994; Rubinstein, 2000), while cognitive impairment was associated with higher care satisfaction (Curtis et al., 2005). Among those receiving care and service at home, care satisfaction was associated with high functional ability (Geron, 2000; Sikorska, 1999), while there was no such relationship for those living in special accommodation (Chou et al., 2003; Curtis et al., 2005). Care satisfaction in special accommodation has been found to be positively associated with perceived health (Chong, 2003; Curtis et al., 2005, n=405 and n=176 respectively). Health status and functional ability have an impact on HRQoL, but HRQoL in turn may have an impact on care satisfaction.

Different types of care and service characterise environmental factors that affect frail old people in need of care. Besides care from the family, public care and service is provided, at home or in special accommodation, but also medical health care when needed. How those environmental factors affect older people's QoL has been sparsely investigated. One study in Taiwan showed that support from families and frequent family interaction contributed positively to QoL (Tseng & Wang, 2001), while another study in the US found that older persons react negatively to being helped by a spouse and that these negative reactions may influence QoL (Newsom, 2002). A comparative study between four countries investigated the relationship between family care and

QoL and how it relates to the welfare system. The results showed that family care was associated with QoL only if the available public care and service was low (Tesch-Römer et al., 2002). Prior to receiving public care and service, a comprehensive needs assessment is crucial for determining what care is required in the individual case. Since functional impairment, health complaints and ADL are important for older people's QoL, they should be included and in line with older person's perception when assessments are carried out. Previous studies have found lower levels of QoL among older people receiving care and service, compared to older populations of the same age from the general population (Jakobsson, 2007; Hellström et al., 2004a). One study found lower QoL in older people living in special accommodation compared to those receiving care and service at home. However, the same study showed no differences between the groups regarding QoL when controlling for functional ability (Hellström et al., 2004b). The majority of those receiving care and service at home have a combination of public and informal care. Hellström et al. (2004b) found that those older people receiving care from a combination of public and informal care had lower QoL compared to those with public care only. The physical environment also has an impact on the level of dependency among older people receiving care and service. Living in a physical environment with few barriers to being active has been significantly and positively associated with QoL (Stuifbergen et al., 2000; Bowling et al., 2002). Thus, there are many factors that have an impact on older people's functional ability, health complaints and ADL when receiving care and service. How well care and service correspond to the needs in the individual case may be reflected in the older person's expression of care satisfaction and QoL. The multimorbidity of older people means decreased QoL but also more contacts with the health care system. Further knowledge is needed regarding how municipal care and service, informal care and medical health care are related to each other. Only then can there be a comprehensive view of the total needs in the individual case.

Older people receiving public care and service are affected by frailty, related to their functional impairments, health complaints and limited ADL. Functional impairments and health complaints are well known to have a great impact on older persons QoL, but also on their ADL. To obtain an optimal QoL, it may be appropriate that care and service focuses on functional impairments and health complaints. Knowledge of how care and service is distributed and how it corresponds to older people's needs is therefore important, but also how public care interacts with informal care. A main issue is to investigate how well needs assessments agrees with the older people's view as a basis for decisions about public care and service. In order to improve care and service it is also important to understand the determinants of care satisfaction. As older people have complex needs and diseases, studies investigating the relationship between public long-term care, medical health care and informal care may be helpful in order to get an overall view of the care in the individual case.

## **AIMS**

The overall aim of this thesis was to describe and compare functional ability and health complaints of older people receiving municipal care in relation to housing and informal care, and in addition to investigate factors associated with medical health care, municipal care and informal care. Further, the aim was to investigate agreement in needs assessment between personnel and older people and to investigate care satisfaction and health-related quality of life among older people receiving municipal care and services.

The specific aims were:

- To describe and compare functional ability and health complaints of older people living in special accommodation and their counterparts who live at home and receive municipal care or a combination of municipal and informal care. An additional aim was to identify determinants for receiving municipal and/or informal care at home compared to special accommodation (Paper I).
- To investigate older people receiving public long-term care and services either at home or in special accommodation in relation to medical health care and informal care consumption, and to investigate factors associated with medical health care consumption (Paper II).
- To investigate the agreement between the needs assessment by home help officers or registered nurses and the view of older people receiving care concerning their functional ability, health complaints and the amount of received public as well as informal care and service (Paper III).
- To explore care satisfaction in relation to health-related quality of life, functional dependency and health complaints among people 65 years or older, receiving municipal care and service at home or in special accommodation (Paper IV).

## METHOD

### Context

About 17 percent of the Swedish population (1.6 million) were 65 years or older in 2006 (SALAR, 2007). A majority (94%) lived at home, of which about 40% lived alone. Some 16% (about 253 000 individuals) of people over 65 years of age received public long-term care and services in 2006, 10% at home and 6% in special accommodation (National Board of Health and Welfare, 2007) (Statistics from 2006 are used due to changes in inclusion criteria from 2007.) Special accommodation is defined as a municipal institution providing care around-the-clock, including care from a registered nurse, and resembles what is internationally called nursing homes (SALAR, 2006). In Sweden, care and services have been a primarily public responsibility, and provided care and services for older people are mainly financed by taxes. Each individual municipality allocates long-term care and services to older people on the basis of frameworks such as laws and current financial and policy documents (Ministry of Social Affairs, 2007). The Social Services Act (SSA) regulates municipal care and services for older people, including home care and services and care in special accommodation (SFS, 2001). Those who need help in their activities of daily life have the right to claim care assistance. Care and service is preceded by a needs assessment and a decision about how much care and how to provide care and service. Charges for the care and services are levied under the SSA, while national rules protect the individual against high costs (Ministry of Social Affairs, 2007). The Health and Medical Services Act (MSA) regulates medical health care in county councils as well as in municipalities (SFS, 1982). The county councils are responsible for medical health care, hospital and outpatient care, while the municipalities are responsible for providing long-term care and service, including home care and service, home nursing care and rehabilitation (Ministry of Social Affairs, 2007).

This study was carried out in 2001 (Study I and II) and in 2003 (Study III and IV) in the county of Skåne, in which 1, 1 million people live and about 18% were 65 years or older (Table 2). Five municipalities were included in the data collection.

**Table 2.** Demography for the included municipalities, the county of Skåne and the country (SCB 2002)

	Inhabitants, number	People 65 years and above, number (%)	Average life expectancy, year Women / men	Women, number (%)	Foreign born, number (%)
Sweden	8 909 128	1 532 064 (17.2)	81.4 / 76.2	4 500 683 (51)	1 027 974 (11.5)
County of Skåne	1 129 424	199 769 (17.7)	81.7 / 76.4	578 838 (51)	152 187 (13.4)
Municipality 1	28 703	4 773 (16.6)	81.5 / 76.9	14 238 (50)	3 109 (10.8)
Municipality 2	48 519	9 575 (19.7)	81.8 / 76.8	24 383 (50)	3 749 (7.7)
Municipality 3	262 397	47 478 (18.1)	81.0 / 74.7	134 775 (52)	62 252 (23.7)
Municipality 4	12 735	2 702 (21.2)	81.2 / 77.2	6 343 (50)	905 (7.1)
Municipality 5	26 235	5 737 (21.9)	82.0 / 75.5	13 562 (52)	1 715 (6.5)



The five municipalities represented urban as well as rural areas. Municipality 3 represented a population from a big town and has the largest proportion of foreign born inhabitants. Municipality 2 represented a population from a medium sized town, but also included rural areas. Municipality 1 and 5 are small towns with partly rural districts, while municipality 4 represents a typical rural area. The municipalities in the study were chosen to reflect Sweden as a whole with regards to the distribution between urban and rural areas and the amount of older people (65+) receiving municipal care and services (Table 3). About 11% of these received municipal care at home and 7% received it in special accommodation in 2001 (National Board of Health and Welfare, 2002). The development from 2000 to 2003 has been a decrease in the proportion of older people receiving care and service, in the five municipalities as well as in Sweden as a whole. The development over time was more received care and service at home in relation to special accommodation (Table 3).

**Table 3.** People 65+ receiving care and service during four years in five municipalities as well as in the country as a whole (National Board of Health and Welfare 2001, 2002, 2003 and 2004)

	Municipality 1	Municipality 2	Municipality 3 <sup>a</sup>	Municipality 4	Municipality 5	Total	Sweden
<b>2000-10-01</b>							
Care and service at home	512 (63)	1 364 (61)	5 331 (63)	312 (58)	519 (77)	8 038 (63)	143 181 (54)
Special accommodation	314 (37)	889 (39)	3 121 (37)	226 (42)	152 (23)	4 702 (37)	121 305 (46)
Care and service, total (part of the population 65+)	826 (17)	2 253 (24)	8 452 (18)	538 (20)	671 (12)	12 740 (18)	264 486 (17)
<b>2001-10-01</b>							
Care and service at home	507 (63)	1 253 (59)	4 633 (60)	246 (52)	863 (77)	7 502 (61)	139 661 (54)
Special accommodation	296 (37)	879 (41)	3 043 (40)	225 (48)	263 (23)	4 706 (39)	118 621 (46)
Care and service, total (part of the population 65+)	803 (17)	2 132 (22)	7 676 (16)	471 (17)	1 126 (20)	12 208 (18)	258 282 (17)
<b>2002-10-01</b>							
Care and service at home	468 (62)	1 275 (63)	4 896 (63)	313 (60)	757 (75)	7 709 (63)	140 487 (55)
Special accommodation	287 (38)	748 (37)	2 906 (37)	209 (40)	249 (25)	4 399 (37)	115 522 (45)
Care and service, total (part of the population 65+)	755 (16)	2 023 (21)	7 802 (17)	522 (19)	1 006 (17)	12 108 (18)	256 009 (17)
<b>2003-10-01</b>							
Care and service at home	408 (58)	1 159 (61)	4 977 (64)	252 (56)	689 (73)	7 485 (64)	146 858 (58)
Special accommodation	291 (42)	721 (39)	2 821 (36)	197 (44)	254 (27)	4 284 (36)	104 787 (42)
Care and service, total (part of the population 65+)	699 (14)	1 880 (19)	7 798 (17)	449 (17)	943 (16)	11 769 (17)	251 645 (16)

<sup>a</sup>Estimation of home nursing care, no official statistics available.

## Design

In this thesis, a cross-sectional design has been used (Study I-IV). In addition, designs including comparison (Study I-IV), correlation (Study I, II and IV) and agreement (Study III) were used.

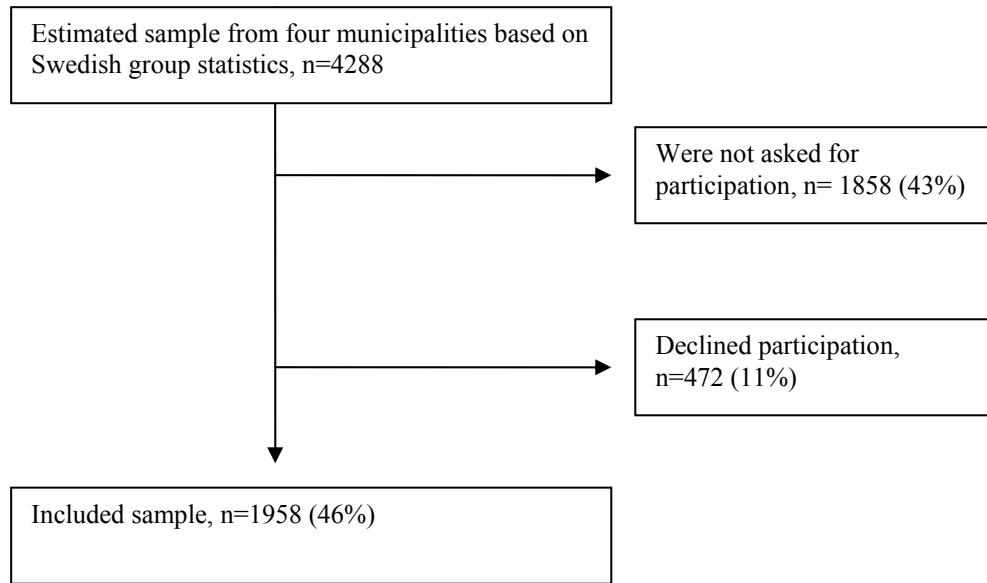
**Table 4.** Design and samples in Studies I-IV.

Study	I	II	III	IV
<b>Design</b>	Cross-sectional Comparative		Cross-sectional Agreement	Cross-sectional Comparative
<b>Sample</b>				
n	1958		152	166
Women, %	69		63	63
Age, m (sd)	84.4 (7.15)		84.3 (7.06)	84.5 (7.01)
Special accommodation, %	49		45	46
<b>Data collection</b>	Questionnaire	Questionnaire Register	Standardised interview Questionnaire	Standardised interview
<b>Analysis</b>	Chi-square test (Fisher's exact test) Logistic regression Multinomial logistic regression	Chi-square test (Fisher's exact test) Kruskal-Wallis test Mann-Whitney <i>U</i> -test Multiple linear regression	Chi-square test Cohen's Kappa Cohen's weighted Kappa Spearman's rank order correlation	Chi-square test (Fisher's exact test) Mann-Whitney <i>U</i> -test Spearman's rank-order correlation Multiple linear regression

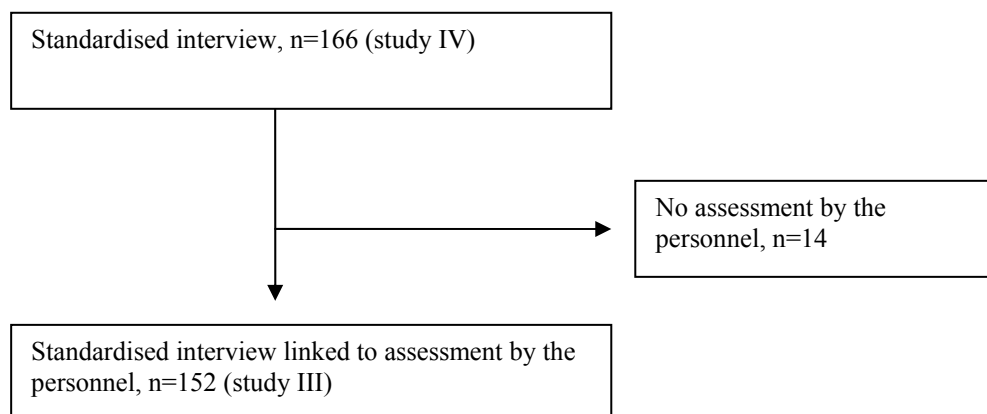
## Sample

A total of 1958 people, all of whom received long-term care and service from the municipality, either at home or in special accommodation, were included in study I and study II (Figure 2). All persons (65+) receiving care and service in four municipalities, who had been granted public care and services at home, or care in special accommodation, or who received at least four home nursing or rehabilitation visits per month, were regarded eligible for inclusion in the study. Persons with only safety alarms, meals on wheels or transport services were excluded.

Study IV included 166 individuals who received public care and services in five municipalities in southern Sweden (Figure 3). Persons 65 years or older with a decision for public care and service at home, who were living in special accommodation or had at least two visits per month from home nursing care or rehabilitation were consecutively selected for the study. Data were collected in personal interviews. Of those in the sample from study IV, 152 individuals were included in study III (Figure 3).



**Figure 2.** Description of the sample in studies I and II.



**Figure 3.** Description of the sample in studies III and IV.

This study is a part of a larger national longitudinal study, the Swedish National Study of Aging and Care (SNAC) (Lagergren et al., 2004). SNAC includes four areas in Sweden (Skåne, Blekinge, Nordanstig and the district of Kungsholmen in Stockholm) and has two parts: the care and services part, which focuses on aspects related to older people with municipal care and services, and the population part, which focuses on different aspects of the ageing process in a randomly selected sample of older people in general (Lagergren et al., 2004). The two samples were drawn from the care and services part, in one of the four involved areas (the region of Skåne in southern Sweden) including five municipalities representing both rural and urban areas. This particular sub-study of SNAC is called Good Ageing in Skåne (GAS). The criteria for participation was that the person should be aged 65 and above and receive long-term

municipal care either at home or in special accommodation. Those who only had safety alarms, meals on wheels or transport services were excluded. The sample in paper I and II consisted of the baseline data from four municipalities and for paper III and IV data was drawn from the continuous data collection in the five municipalities.

## Measurement

### *Needs assessment in municipal care and service*

For assessment, a questionnaire built up around validated measures was developed covering demographic data, functional ability, health complaints, adaptation and standard of accommodation, as well as public and informal care (Studies I-III). Demographic data included age, gender, marital status and type of accommodation. The questionnaire was based on existing literature regarding issues of importance for older people receiving care and services. In addition, it was based on consultation with a national expert group, including researchers in geriatrics, gerontology, nursing science and social science (Jakobsson & Hallberg, 2006).

Physical functional ability for PADL was measured by Katz' ADL index and consisted of hygiene, dressing and undressing, ability to go to the bathroom, mobility, ability to control bowel and bladder, and food intake (Katz, 1963). Variables for IADL included ability to clean, buy food, manage transportation and cook (Åsberg & Sonn, 1989). One variable related to doing laundry was added, after consultation with the expert group. Each variable had the following response alternatives: independent, partly dependent or dependent. The Berger scale was used to measure cognitive ability and was assessed by seven predefined alternatives, ranging from no cognitive dependency to bedridden and mutistic (Berger, 1980). For taking walks outside the response alternatives were: no walks outside, less than once a week, more than once a week and daily walks outside. For social contacts the response alternatives were: no contacts, less than once a week, more than once a week and daily contacts. A developed index for ADL was used (Study II). The index had been calculated by means of factor analysis, which resulted in three components: Personal Activities of Daily Living (SNAC-PADL index), Instrumental ADL (SNAC-IADL index) and Psychosocial Needs (SNAC-Psychosocial index) (Hallberg et al., 2002). The SNAC-PADL included transfer, going to the bathroom, faecal incontinence, urinary incontinence, mobility, dressing, eating and cognitive ability (Cronbach's alpha 0.91). The SNAC-IADL included washing, shopping, cooking, bathing, transportation, cleaning and going outdoors (Cronbach's alpha 0.86). The SNAC-Psychosocial Needs included anxiety, depressed mood, difficult behaviour, need for supervision and special care needs (Cronbach's alpha 0.72).

In the section covering public care and services, decisions related to the Social Services Act (SFS, 2001) and the Health and Medical Services Act (SFS, 1982) were recorded. The Social Services Act regulates care and services at home, including day, evening and night care as well as care in special accommodation, and the response alternatives were: no, yes and don't know. The questions concerning care and service

at home were specified with regard to care in the areas of IADL and PADL, and by hours per week. Home nursing care, as regulated by the Health and Medical Services Act, included day, evening and night time care, and response alternatives in each section were: no, yes and don't know. The frequency of home nursing care was specified by visits per month from a nurse, assistant nurse or other staff, while the extent of home nursing care was calculated by hours per month with respect to all staff. The use of aid equipment included aid for transfer (supporting stick and wheelchair), aid for sitting in a chair, aid for personal care, sickbed, hearing aid, vision aid (not glasses) and protective aid for incontinence, with the response alternatives: no, yes and don't know. Adaptation in housing at home included doorsteps removed, bathroom available for wheelchair and bathtub replaced by shower, with response alternatives: no, yes or don't know. The questionnaire also included items about informal care, which were divided into help with IADL and help with PADL and who provided it: spouse, child, brother or sister, grandchild, other relative, neighbour/friend, privately financed care or care from associations/voluntary organisations. The response alternatives for each helper were: not applicable, no care, care less than once a week, more than once a week, daily care and don't know (Jakobsson & Hallberg, 2006). The interviews (Study III) included the same questions as in the standardised needs assessment, but the variables were reformulated into questions to the respondent. Items for informal care in hours per week for each provider were added to the standardised needs assessment.

### ***Medical health care***

Data concerning medical health care provided by the county council (Study II) were collected from the county council administrative register (PASiS) (Condelius et al., 2008; Kristensson et al., 2007), which contains information on hospital care and outpatient care for each individual in the county and is recorded by the staff. This is a routine procedure and the data forms the basis for subsidies to each unit/department. The data used in this study comprised number of admissions and days in hospital. The outpatient care data concerned contacts with primary health care, psychiatric care and specialist care other than psychiatric care. Contact with outpatient care included face-to-face as well as telephone contact with a physician.

### ***Health-related quality of life (HRQoL)***

The Short Form Health Survey, SF-12, was used to measure health-related quality of life (HRQoL) (Study IV). The instrument is a shorter version of the SF-36 and is well documented as a HRQoL instrument validated for Swedish conditions (Ware & Sherbourne, 1992; Sullivan et al., 1997). The SF-12 is preferable in contrast to the longer version for use among older people since it includes fewer questions, which makes it easier to answer. Also, questions about work are excluded (Resnick & Nahm, 2001). SF-12 covers a Physical Component Summary Scale (PCS) including general health, physical function, physical role limitation and bodily pain. Another section of the instrument covers a Mental Component Summary Scale (MCS) including vitality, social function, role-emotional and mental health (Ware et al., 1996). Each score

includes a standardised range from 0 (poorest well being) to 100 (highest well being). In a general population, the SF-12 has shown to be psychometrically valid and reliable, and Test-retest showed correlations of 0.89 for PCS and 0.76 for MCS (Ware et al., 1996). The relationship between the summary scores for SF-12 and SF-36 has also been found to be high. More than 90% of the variance in SF-36 PCS and MCS measure was found to be reproduced in SF-12 (Ware et al., 1996). Reliability in one study among older people (age 75-105) showed in terms of Cronbach's alpha 0.73-0.86 (Jakobsson, 2007).

### ***Care satisfaction***

Care satisfaction was measured with an instrument including different perceived quality attributes in home help services for older people, 65+ (Study IV). The instrument was developed by Samuelsson et al. (1993) using the Multiattribute Utility Technology (MAUT) (Edwards & Newman, 1982). The quality attributes perceived to be important to consumers receiving care and service has been examined with the MAUT scale procedure by half-structured interviews. The procedure organised the quality attributes in a tree diagram to rank them into three levels of factors. The instrument covered areas of continuity, suitability, availability/times, influence and personal relations. Continuity included staff as well as care continuity. Suitability covered personal qualities and professional competence. Questions concerning personal qualities included friendly and cheerful, respectful and considerate, quiet, reliable, and careful and orderly. Professional competence concerned household jobs, giving personal care and giving social care. Available/time included when the home care provider comes, how times are kept and whether there is plenty of time is available for care. Finally, influence over home care and personal relations with the provider were covered. Each quality attribute was ranked on a 7-grade scale (1=very dissatisfied to 7=very satisfied) and was used to measure the evaluation of received care and service (Samuelsson et al., 1993). An overall assessment of the home help and/or home nursing care, and the number of persons visiting per week/month were also ranked on a 7-grade scale and added to the instrument. There was also an added question about how many providers from home help/home nursing care the older person had met during the last week or month. The questionnaire was originally developed to be used for older people receiving care and service at home only (Samuelsson, 2000). For this thesis it was modified to make it suitable for those receiving home nursing care and those living in special accommodation. For those receiving home nursing care, questions concerning giving medical service and how many providers from home nursing care the person had met during the last week or month was added to the instrument. For those living in special accommodation, the question about professional competence concerning household jobs was deleted and the questions about overall assessment of care and service at home and home nursing care were replaced with an overall assessment of care and service in special accommodation.

## Procedure

The data collection procedures in the municipalities were first tested in a pilot study that resulted in minor adjustments (Karlsson et al., 2003). The staff received information and instructions before the study commenced (Study I, II and III). The subjects gave informed consent before the start of the data collection. In cases where the individual was incapable of giving his/her consent, the next of kin gave it. In the municipalities, the registered nurses represented care and service in special accommodation and home nursing care, home help officers represented home help, and occupational therapists and physiotherapists represented rehabilitation. The instruction to the staff was to collect current data about the older people receiving care and service. In cases with a recent assessment or frequent contact, data was collected through personal information and documentation. In other cases a new assessment was made. The data from the municipalities was individually linked, through a 10 digit personal number, to the PASiS data about hospital and outpatient care during 2001 (Study II).

Standardised needs assessments were performed by home help officers (n=27), registered nurses (n=124), physiotherapist (n=1) concerning older person's needs, care and services. The personnel who performed the needs assessment did not know in advance that their assessment would be compared with the interview of the older person (Study III). The older person's view was collected in personal interviews within a month after the home help officer/registered nurse did the needs assessment. Trained registered nurses with no link to care and service performed the interviews in the respondents' housing, special accommodation or at home. The registered nurses had extensive experience in elderly care and the interviews were performed during their specialist education within the area of elderly care (Study III and IV). When the respondent had impaired communicative or cognitive ability the next of kin or contact person was interviewed instead, so called proxy (Study III, n=8 and Study IV n=9). Instruments measuring care satisfaction (Samuelsson et al. 1993) and health-related quality of life (SF-12) were used for those respondents answering by themselves only (Study IV).

## Data analysis

### *Group comparisons*

Non-parametric statistics were used for comparisons between age groups and types of accommodation (at home or in special accommodation). For categorical variables, the Kruskal-Wallis test was used to compare three independent groups and the Mann-Whitney U-test between two independent groups. The chi-square test (Fisher's exact test when applicable) was applied to the analysis of differences between two and three independent groups measured on a nominal scale. A p-value below 0.05 was considered significant. When multiple comparisons were made, a reduced p-value of <0.017 was used to avoid the risk of mass significance (Polit & Beck, 2004).

## ***Regression analysis***

Logistic regression analyses were carried out in study I using the Backward Likelihood Ratio method. Informal and municipal care (1) and municipal care only (0) at home were used as dependent variables (Study I). Independent variables were SNAC-PADL, SNAC-IADL, SNAC-Psychosocial dependency and cognitive ability. For those variables, dummies were created with the lowest value as reference. Age and gender were entered as independent variables in each analysis. Confidence intervals (CI) of 95% were calculated for the odds ratios (OR). The model fit was measured with the Hosmer and Lemeshow goodness-of-fit test. The good model fit is specified by a non-significant chi-square value, which means no differences between actual and predicted dependent values (Hair et al., 1998). A multinomial logistic regression analysis was performed (Hosmer & Lemeshow, 2000) with the response alternatives: receiving municipal care only at home, receiving a combination of municipal and informal care at home and care in special accommodation as the dependent variable (Study I). Independent variables were age, gender, cohabitation, the Katz' PADL-index, the Hultner-Åsberg IADL-index, SNAC-Psychosocial dependency, cognitive ability, hearing, vision, slow healing wound, pressure ulcer, pain and dizziness.

In study II, multiple linear regression analyses (Altman, 1991) were performed with medical health care consumption regarding outpatient care by physician and hospital care as the dependent variables. The forward method was employed and the following independent variables were entered: gender, type of accommodation, informal care, the SNAC-IADL and the SNAC-Psychosocial indexes. Age and the SNAC-PADL index were additional independent variables which were held constant, by means of the enter method. For SNAC-IADL, SNAC-PADL and SNAC-Psychosocial indexes, dummy variables were created with the lowest value as reference. The quality of the regression models was tested with adjusted  $R^2$ . For analysis of residuals, the Kolmogorov-Smirnov test and histogram were applied (Chakavarti 1967). All models were normally distributed, except the model using outpatient specialist care other than psychiatry as the dependent variable.

In study IV, a multiple linear regression analysis (Altman, 1991) was performed with care satisfaction as the dependent variable. The stepwise method and the following independent variables were used: gender, housing, cohabitation, walking ability, dizziness, urinary incontinence, faeces incontinence, pressure ulcer, slow healing wound, vision, hearing, anxiety, depressed mood, cognitive ability, pain and HRQoL. Another regression analysis was also performed using independent variables: care and service with IADL, care and service with PADL, home nursing care from registered nurse, home nursing care from assistant nurse, informal care with IADL from spouse, informal care with IADL from children, informal care with PADL from spouse, informal care with PADL from children. Age, IADL-sum and PADL-sum were held constant, by means of the enter method in both analyses. For walking ability, dizziness, urinary incontinence, faeces incontinence, vision, hearing, anxiety, depressed mood, cognitive ability and pain, dummy variables were made with the lowest value as reference. Adjusted  $R^2$  tested the quality of the models. For analysis of



residuals, the Kolmogorov-Smirnov test and histogram were used (Chakavarti 1967). The analysis showed normal distribution in both models.

### ***Agreement***

Interrater reliability between the needs assessment of the personnel and the interviews by the elderly was analysed using Cohen's Kappa for variables in the nominal scale and Cohen's weighted Kappa for variables in the ordinal scale (Study III). Results were interpreted as follows: below 0.20 was regarded as poor, 0.21-0.40 as fair, 0.41-0.60 as moderate, 0.61-0.80 as good and above 0.80 as very good agreement (Altman, 1991). Spearman's rank order correlation was used for analysis of continuous variables. Values below 0.20 were regarded as poor correlations (Fowler et al., 1998). Comparisons were conducted between the higher and lower estimation compared to an expected evenly distributed difference in rating. A univariate chi-square test was used to identify if the personnel systematically assessed more or less presence than the older persons reported in ADL-dependency, health complaints, provided care and use of aid equipment.

The SPSS version 11.5 was used for all statistical analyses.

### **Dropout analysis**

The exact number of people receiving municipal care and services is not available, as there are only official statistics on a group level. Based on Swedish group statistics (National Board of Health and Welfare, 2002), it was estimated that a total of 4288 older people received public long-term care in the municipalities concerned. Calculations on this estimate indicated that 1958 (46%) (Study I and II) had been asked and agreed to participate, thus about 1858 (43%) had not been invited to participate while 472 (11%) declined participation. The mean age of those who declined was 85 (SD 7.0) with 12% in the 65–74 age group, 36% in the 75–84 age group and 52% aged 85+. Among those who declined participation, 71% were women and 46% received care and service in special accommodation.

A special file including all care and service recipients, in accordance with the inclusion criteria of this study, was linked to the county council administrative register (PASiS). This allowed for comparisons of the medical health care received from the county council between the study group and those who had declined or had not been invited to participate. No differences between the study group and the dropout group were found concerning contact with a physician in primary health care or in specialist care, except when it came to psychiatric care. The study group had more contact with psychiatric outpatient care (median=1, range 1–8) compared to the dropouts (median 1, range 1–6) ( $p=0.031$ ). The number of days in hospital and days per hospital stay was lower among those in the study group (median=10, range 1–100, and median=6, range 1–57, respectively) than those in the dropout group (median=13, range 1–172, and median=7, range 1–165, respectively) ( $p<0.001$ ). The effect from internal dropout (i.e.

no response to an individual item) was analysed in terms of the SNAC-IADL, the SNAC-PADL and the SNAC-Psychosocial indexes. When those with complete indexes were compared with the missing data it was found that the missing data mainly derived from those with public care at home regarding the SNAC-PADL and Psychosocial index (p-value <0.001 and 0.004 respectively), while missing data regarding the SNAC-IADL index derived from those in special accommodation (p-value <0.001).

In calculation of the SNAC-IADL index (Study II, Table 5), those included were more often receiving care at home,

**Table 5.** Comparisons between included and dropouts in SNAC-IADL index

	Included n=1365	Dropout n=563	P-value
<b>Gender, %</b>			0.439 <sup>a</sup>
Women	69	69	
Men	31	31	
<b>Age</b>			0.974 <sup>b</sup>
Mean (sd)	84 (7.2)	84 (6.9)	
<b>Housing, %</b>			<0.001 <sup>a</sup>
At home	43	30	
Special accommodation	57	70	
<b>Admissions in hospital</b>			0.349 <sup>c</sup>
Median (range)	1 (1-12)	2 (1-11)	
<b>Cooking (n=1365/484)<sup>1</sup>, %</b>			<0.001 <sup>c</sup>
Independent	19	28	
Partly independent	8	18	
Dependent	73	54	
<b>Washing (n=1365/455)<sup>1</sup>, %</b>			<0.001 <sup>c</sup>
Independent	12	17	
Partly independent	7	12	
Dependent	81	71	
<b>Transportation (n=1365/378)<sup>1</sup>, %</b>			0.021 <sup>c</sup>
Independent	13	9	
Partly independent	14	11	
Dependent	73	80	
<b>Bathing (n=1365/484)<sup>1</sup>, %</b>			<0.001 <sup>c</sup>
Independent	21	30	
Partly independent	7	7	
Dependent	72	63	
<b>Shopping (n=1365/471)<sup>1</sup>, %</b>			0.003 <sup>c</sup>
Independent	12	20	
Partly independent	8	6	
Dependent	80	74	
<b>Walking outdoors (n=1365/368)<sup>1</sup>, %</b>			0.009 <sup>c</sup>
Daily	25	36	
Once a week	35	29	
More seldom than once a month	34	29	
Never	5	6	

<sup>a</sup>Chi-square test, <sup>b</sup>Students T-test, <sup>c</sup> Mann-Whitney U-test

<sup>1</sup> First number = included, second number = dropout.

more dependent in cooking, washing, bathing and shopping, while they were more seldom walking outdoors and less dependent in transportation compared to those in the dropout group.

Those included were more often living in special accommodation, more dependent in feeding, more cognitively impaired and had fewer complaints for urinary incontinence compared to the dropout in the SNAC-PADL index (Study II, Table 6).

**Table 6.** Comparisons between included and dropouts in the SNAC-PADL index

	Included n=1467	Dropout n=491	P-value
<b>Gender, %</b>			0.113 <sup>a</sup>
Women	70	67	
Men	30	33	
<b>Age</b>			0.111 <sup>b</sup>
Mean (sd)	84 (7.2)	84 (6.8)	
<b>Housing, %</b>			<0.001 <sup>a</sup>
At home	45	67	
Special accommodation	55	33	
<b>Admissions in hospital</b>			0.257 <sup>c</sup>
Median (range)	1 (1-11)	2 (1-12)	
<b>Feeding (n=1467/457)<sup>1</sup>, %</b>			<0.001 <sup>c</sup>
Independent	76	85	
partly independent	14	10	
Dependent	10	5	
<b>Urinary incontinence (n=1467/288)<sup>1</sup>, %</b>			<0.001 <sup>c</sup>
Continent	52	39	
Partly incontinent	25	32	
Severe incontinent	7	10	
Total incontinent	16	19	
<b>Cognitive ability (n=1467/386)<sup>1</sup>, %</b>			0.009 <sup>c</sup>
No dependency	46	54	
Mild dependency	21	17	
Severe dependency	22	22	
Total dependency	10	7	

<sup>a</sup>Chi-square test, <sup>b</sup>Student's T-test, <sup>c</sup> Mann-Whitney U-test

<sup>1</sup> First number = included, second number = dropout.

Those included in the SNAC-Psychosocial index more often were living in special accommodation and needed less extra supervision and special care compared to dropout (Study II, Table 7).

**Table 7.** Comparisons between included and dropouts in the SNAC-Psychosocial index

	Included n=1467	Dropout n=491	P-value
<b>Gender, %</b>			0.227 <sup>a</sup>
Women	69	71	
Men	31	29	
<b>Age</b>			0.171 <sup>b</sup>
Mean (sd)	84 (7.2)	84 (7.0)	
<b>Housing, %</b>			<b>0.004 <sup>a</sup></b>
At home	49	58	
Special accommodation	51	42	
<b>Admissions in hospital</b>			0.540 <sup>c</sup>
Median (range)	2 (1-12)	1 (1-6)	
<b>Extra supervision (n=1603/279)<sup>1</sup>, %</b>			<b>&lt;0.001 <sup>c</sup></b>
No	86	76	
Yes	14	24	
<b>Special care needs (n=1603/277)<sup>1</sup>, %</b>			<b>&lt;0.001 <sup>c</sup></b>
No	88	83	
Yes	12	17	

<sup>a</sup>Chi-square test, <sup>b</sup> Student's T-test, <sup>c</sup> Mann-Whitney U-test

<sup>1</sup> First number = included, second number = dropout

## ETHICAL CONSIDERATIONS

Special ethical considerations must be taken into account when doing research on a group, particularly when including vulnerable people. The studies in this thesis followed the ethical principles of autonomy, non-maleficence, beneficence and justice (Beauchamp & Childress, 2001).

Autonomy concerns the respondent's right to make a decision about participation based on knowledge. It includes informed consent and the option to refuse participation or to interrupt participation in a study (Beauchamp & Childress, 2001). In all of the studies, informed consent was obtained and the respondents received information about the study, written as well as verbal. In Studies I, II and III written informed consent was obtained by the data-collecting staff. The staff gave written information comprising the aim of the study and what involvement implied. The same information was also given verbally. In those cases where the respondent was incapable of giving informed consent due to cognitive decline, the next of kin gave it. In Study III and IV the trained registered nurses obtained verbal informed consent connected to the interviews. Information was provided on three occasions: the respondents received a letter including written information, and verbal information was given by telephone when they were asked for participation and then again before

the interview started. The respondents themselves decided the place and time for the interviews and it was emphasised that they could decline or stop the interview with no further consequences. Most of the interviews were performed in the respondent's home, which required a careful approach in order not to disturb their activities and privacy.

The principles of beneficence and non-maleficence refer to the value of the research and the risks of doing harm (Beauchamp & Childress, 2001). It is important to balance the risk for the respondents with the benefits for health and welfare. The benefit of a research project may, however, be clinical and/or theoretical. The clinical benefit could imply improvement of treatment and health care. The theoretical benefit may be described in terms of how much the research contributes to the development of new methods or adds new knowledge to the already existing base of knowledge (MFR, 2000). Results from the studies in this thesis contribute with knowledge which hopefully may improve care and service to older people. To secure confidentiality the research data was kept separate from personal data and was only available to the research team. In study II, the respondents were assigned coded numbers which meant that it was not possible to track information to any person in the files. However, merging the different files provided unique results.

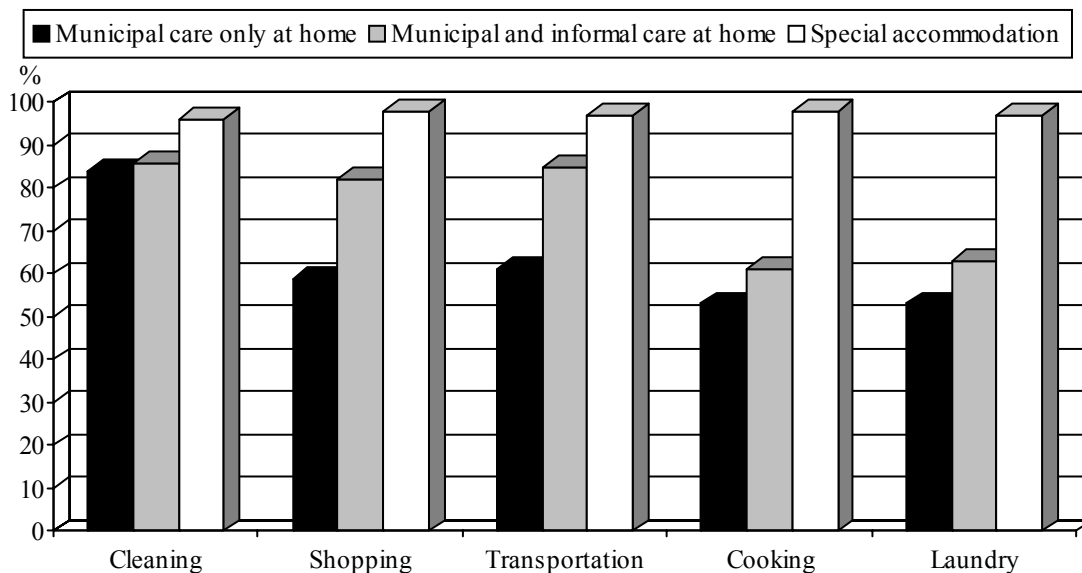
The principle of justice refers to official justice regarding people's rights to be treated with fairness. It also includes aspects of discrimination of any groups and aims to defend vulnerable groups against being exposed (Beauchamp & Childress, 2001). In this thesis the principle of justice was taken into consideration when selecting respondents for the studies. Respondents were selected without any restrictions regarding social levels, race, gender, religion, native language or political views. Also persons with cognitive impairment were included in all studies and proxy was used when applicable.

The studies were approved by the Ethics Committee of the Medical Faculty of Lund University (LU 744-00 and LU 650-00).

## RESULTS

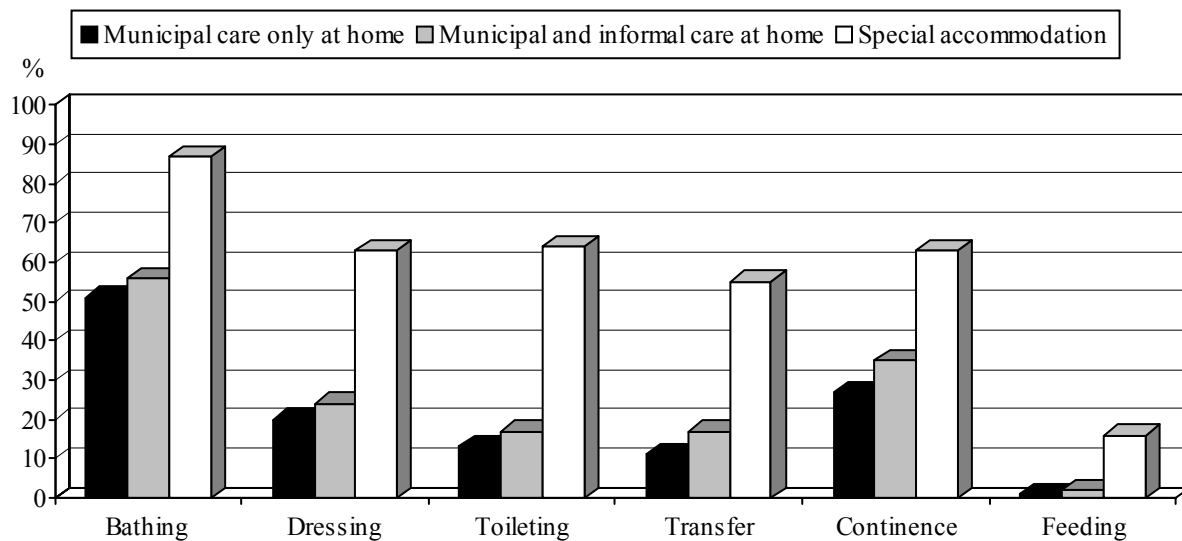
49% of those receiving public care and services lived in special accommodation and they were significantly older (mean 85 years) than those living at home (mean 82 years) ( $p<0.001$ ), more often women and less likely to be married (17% compared to 24%) ( $p<0.001$ ) or cohabiting (5% compared to 25%) ( $p<0.001$ ) (Study I and II). Persons receiving care at home were taking more walks outside (80% vs. 44%) and had more social contacts (89% vs. 75%), once a week or more, compared to those in special accommodation ( $p<0.001$ ). Further, those in special accommodation were more dependent on assistance with IADL (Instrumental Activities of Daily Living) compared to those at home ( $p<0.001$ ) (Figure 4).

Persons living at home receiving both informal and municipal care were more dependent with regard to shopping (82% vs. 59%), transportation (85% vs. 61%), cooking (61% vs. 53%) and laundry (63% vs. 53%) compared to those with municipal care only at home ( $p<0.001$ ) (Study I and II).



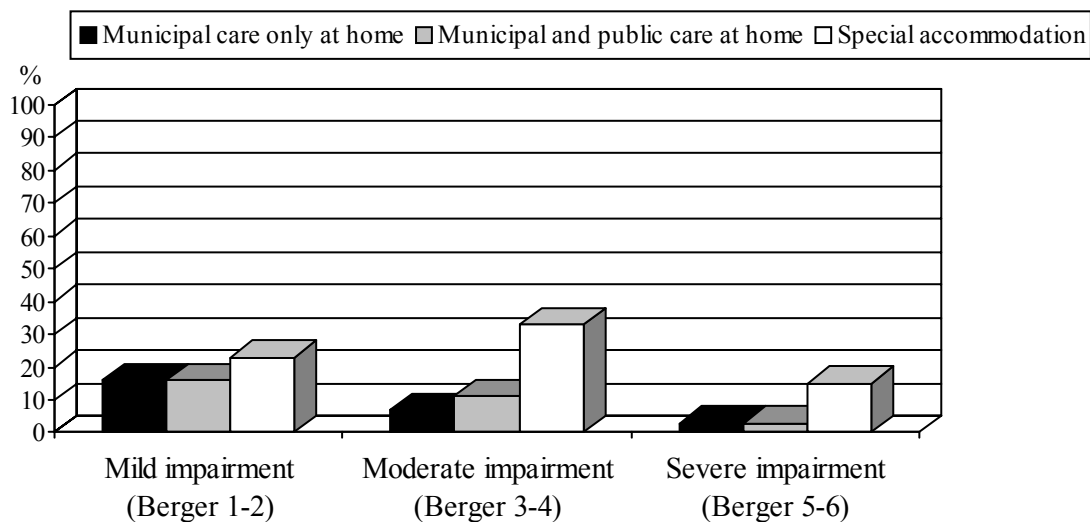
**Figure 4.** Dependency in IADL among those receiving municipal care only vs. a combination of municipal and informal care at home and care in special accommodation.

Those in special accommodation were more dependent on assistance with PADL (Personal Activities of Daily Living) compared to those receiving care at home. ( $p<0.001$ ) (Figure 5). In addition, those receiving both municipal and informal care were significantly more dependent with regard to dressing (24% vs. 20%,  $p=0.020$ ), toileting (19% vs. 13%,  $p=0.043$ ), transportation (17% vs. 11%,  $p=0.026$ ) and continence (35% vs. 27%,  $p=0.040$ ) compared to those receiving municipal care only at home.



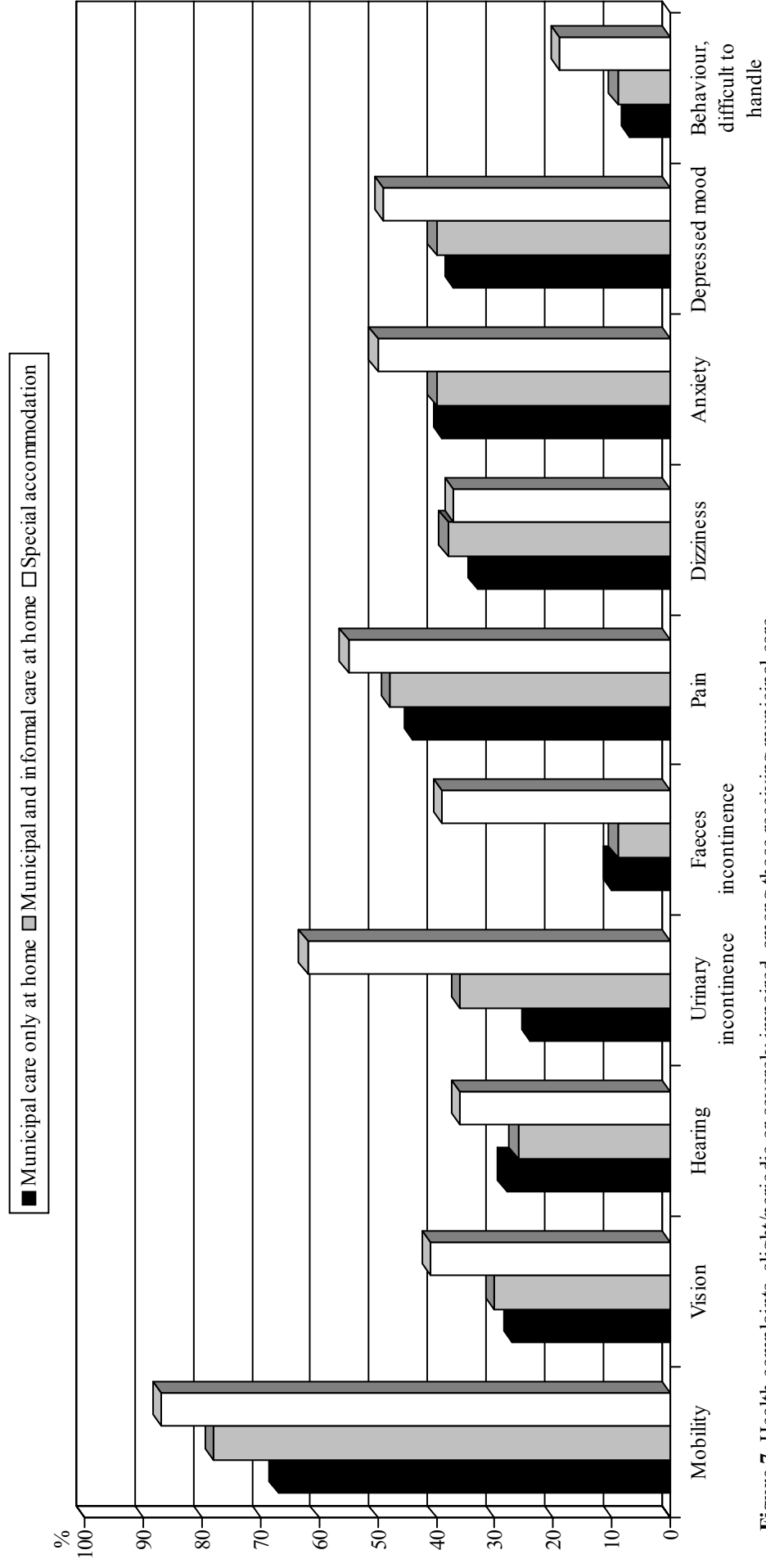
**Figure 5.** Dependency in PADL among those receiving municipal care only vs. a combination of municipal and informal care at home and care in special accommodation.

Persons living in special accommodation were more often cognitively impaired, 49% had moderate/severe impairment compared to 13% among those receiving care and service at home ( $p < 0.001$ ) (Figure 6) (Study I and II).



**Figure 6.** Cognitive impairment among those receiving municipal care only vs. a combination of municipal and informal care at home and care in special accommodation.

Those in special accommodation had a higher level of mobility problems (87% vs. 74%), impaired vision (41% vs. 29%), urinary incontinence (62% vs. 30%), faeces incontinence (39% vs. 9%), anxiety (50% vs. 39%), depressed mood (49% vs. 37%) and behaviours difficult to handle (19% vs. 8%) compared to those at home ( $p < 0.001$ ) (Figure 7, Study I).

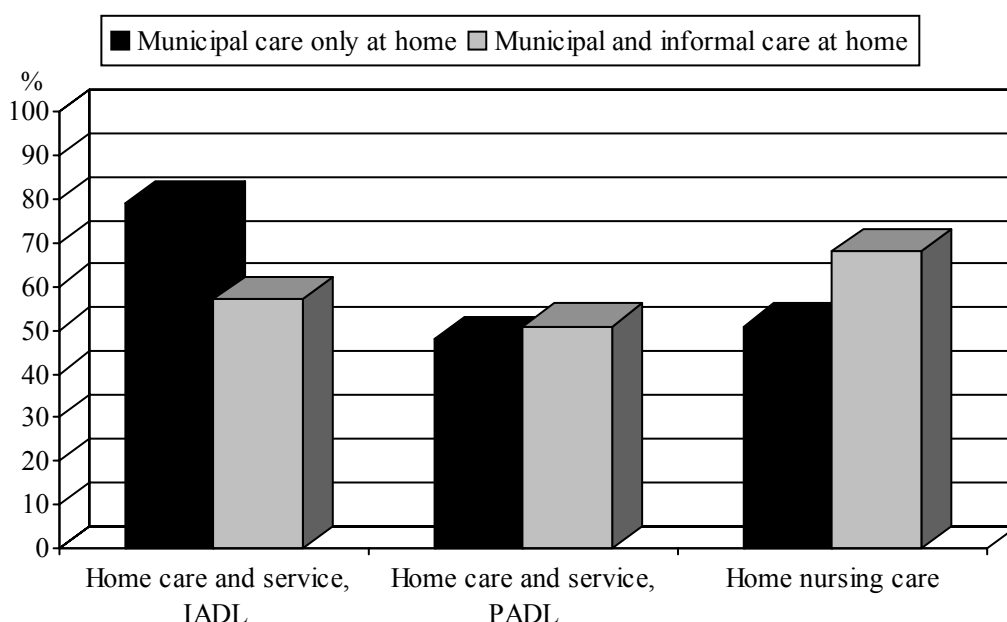


**Figure 7.** Health complaints, slight/periodic or severely impaired, among those receiving municipal care only vs. a combination of municipal and informal care at home and care in special accommodation.



Those living at home receiving a combination of informal and municipal care had higher level of impaired mobility (78% vs. 67%) and urinary incontinence (36% vs. 24%) compared to those with municipal care only ( $p<0.001$ ). Those living in special accommodation had a higher level of impaired hearing (36% vs. 26%) compared to those with a combination of municipal and informal care at home ( $p<0.001$ ).

The results showed that those with only municipal care at home received more home care and services (84%) ( $p=0.002$ ) compared to those who received a combination of municipal and informal care (73%) (Figure 8, Study I). Help with IADL was more common (79%) ( $p<0.001$ ) among those who received municipal care only compared to those who received a combination of municipal and informal care (57%). Those with only municipal care received less help with PADL (48% vs. 51%,  $p=0.002$ ) and home nursing care (51% vs. 68%,  $p<0.001$ ) compared to those who also received informal care.



**Figure 8.** Municipal care at home among those receiving municipal care only vs. a combination of municipal and informal care at home

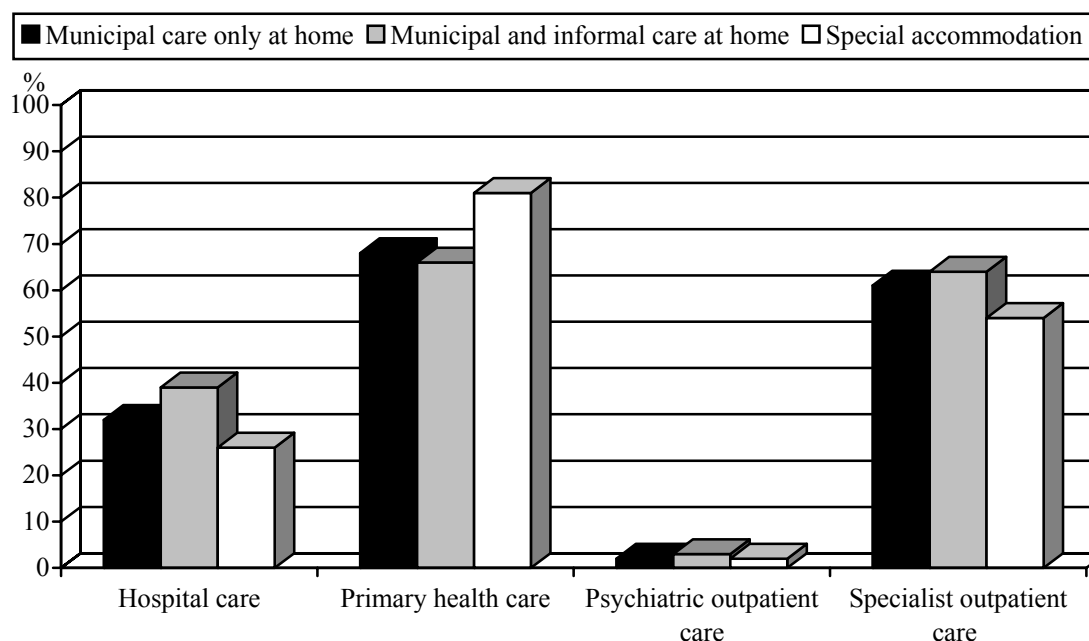
Adaptations in housing were made in terms of doorsteps removed in 45%, bathroom available for wheelchair in 45% and bathtub replaced by shower in 53% among those receiving care and service at home. Those at home used a supporting stick or walking frame (79% vs. 60%) and aid for sitting in chair (42% vs. 35%) significantly more often than those in special accommodation (Table 8). Persons at home used a wheelchair (21% vs. 54%), sickbed (32% vs. 81%) and protective aid for incontinence (51% vs. 77%) significantly less often than those in special accommodation.

**Table 8.** Use of aid equipment, at home and in special accommodation

	At home n=989	Special accommodation n=969	P-value	Total n=1958
<b>Use of aid equipment, %</b>				
Aid for transfer: supporting stick, walking frame	79	60	<0.001	69
Aid for transfer: wheelchair <sup>a, c</sup>	21	54	<0.001	
Aid for personal care <sup>a, c</sup>	58	63	0.061	61
Aid for sitting in chair <sup>a, c</sup>	42	35	0.004	39
Sickbed <sup>a, c</sup>	32	81	<0.001	59
Vision aid (not glasses) <sup>a, c</sup>	47	47	0.966	47
Hearing aid <sup>a, c</sup>	20	19	0.797	20
Protective aid for incontinence <sup>a, c</sup>	51	77	<0.001	66

Chi-Square Test (Fisher's Exact Test).

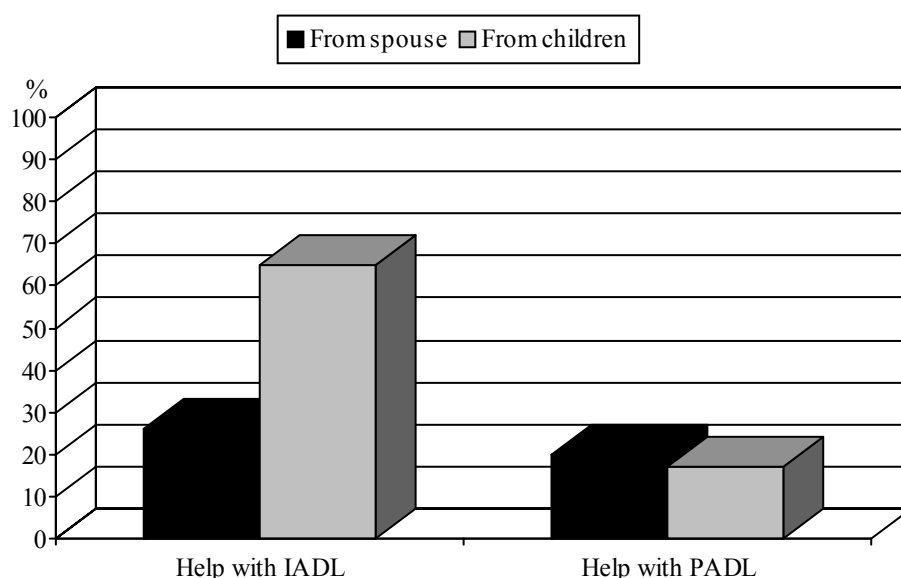
In the course of twelve months, 598 persons (31%) from the study group were admitted to hospital. Hospital care was significantly more common among persons receiving both public and informal care at home (39% vs. 26%) compared to those living in special accommodation ( $p<0.001$ ) (Figure 9, Study II).



**Figure 9.** Received care from county council: hospital care and outpatient care by physician in primary health care, psychiatry and specialist care other than psychiatric care among those receiving municipal care only vs. a combination of municipal and informal care at home and care in special accommodation.

Outpatient health care provided by primary health care (PHC) physicians was received by 73%, specialist care other than psychiatric care by 58% and psychiatric outpatient care by 2%. Contact with a physician in outpatient care in general (87% vs. 76%) and with primary health care physician (81% vs. 67%) was more common among those in special accommodation than among those at home with public care and service ( $p<0.001$ ). Specialist outpatient contact with a physician was more common among those receiving both public and informal care at home (64% vs. 54%) compared to those in special accommodation ( $p<0.001$ ).

Among those living at home who received municipal care and service care 64% received informal care in addition, which was distributed as help with IADL in 64% and with PADL in 48%. Help with IADL was provided by children in 65%, while help with PADL was provided by a spouse in 20%. The spouse provided help daily and children at least once a week (Figure 10, Study II).



**Figure 10.** Informal care among those receiving municipal care and service at home

Cohabitation was a predictor of a combination of municipal and informal care in the home (OR 5.935), while assistance with IADL provided by municipal home care and services predicted municipal care only (OR 0.344). Care in special accommodation was predicted by advanced age (OR 1.051), dependency in IADL (OR 19.883) and PADL (OR 2.695), and impaired cognitive ability (OR 3.849) with receiving municipal care only as a reference. Living alone (OR 0.106), dependency in IADL (OR 11.348) and PADL (OR 2.506), impaired cognitive ability (OR 3.448), impaired vision or blindness (OR 1.812) and the absence of slow healing wounds (OR 0.407) were predictors of special accommodation with a combination of informal and municipal care at home as a reference (Study I).

Dependency on help to perform PADL was associated with fewer specialist care contacts with the exception of psychiatric care (B varied between -1.673 and -0.773), while living in special accommodation was associated with more primary care contacts (B=0.713), fewer specialist care contacts, with the exception of psychiatric care (B=-0.734), and fewer days in hospital (B=-2.798) (Study II).

Moderate correlations were found between the SNAC-IADL index and living in special accommodation ( $r_s=0.565$ ) and between the SNAC-PADL index and living in special accommodation ( $r_s=0.511$ ). The SNAC-IADL index and the SNAC-PADL index also correlated moderately to having home service help in PADL ( $r_s=0.471$  and  $r_s=0.486$  respectively). A modest correlation was found between the SNAC-Psychosocial index and outpatient care by a physician in psychiatry ( $r_s=0.335$ ) (Table 9).

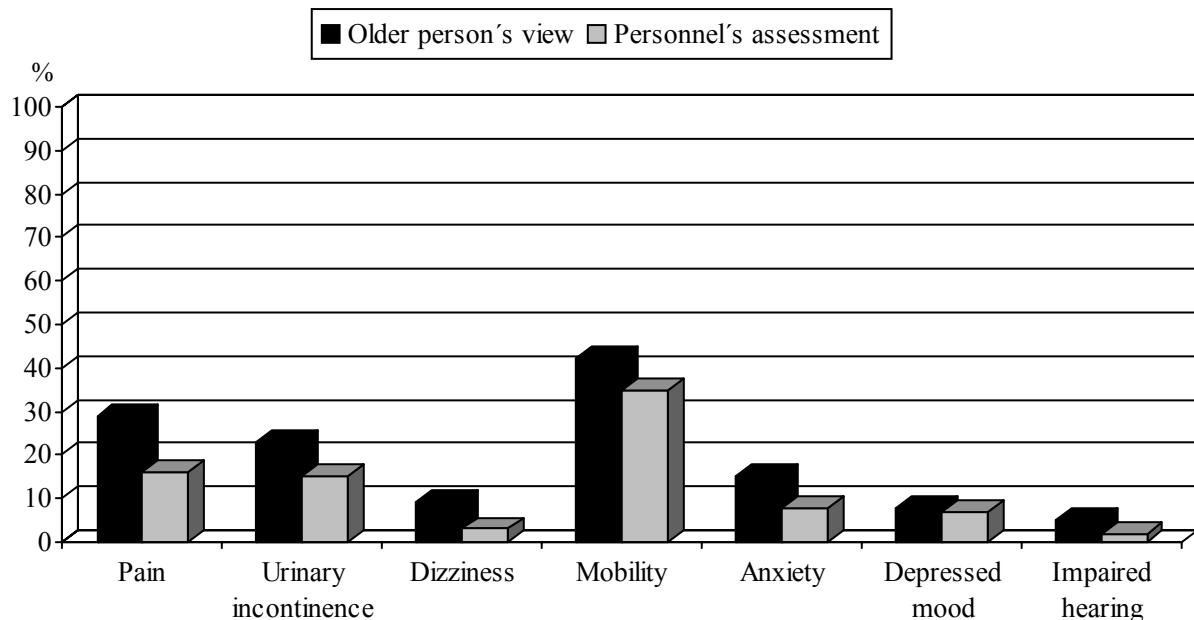
**Table 9.** Correlations between SNAC-index and care and service from municipality, county council and informal caregivers.

	SNAC-IADL index	SNAC-PADL index	SNAC-Psychosocial index
<b>Municipality</b>			
Living at home or in special accommodation <sup>a</sup>	0.565***	0.511***	0.199***
Home care and service <sup>b</sup>			
Help in IADL, hours/week	0.193**	0.278**	0.077
Help in PADL, hours/week	0.471**	0.486**	0.168**
Home nursing care <sup>b</sup>			
Visits/month by nurse	0.021	0.005	0.061
Visits/month by assistant nurse	0.094	0.123	0.016
<b>County council</b>			
Outpatient care by physician <sup>b</sup>			
Psychiatry	0.049	-0.037	0.335*
<b>Informal care at home</b>			
Help in IADL <sup>b</sup>			
From spouse	-0.195**	-0.238**	-0.038
From children	-0.057	0.014	-0.072
Help in PADL <sup>b</sup>			
From spouse	-0.253**	-0.342**	-0.062
From children	-0.091	0.009	-0.156*

\* $p<0.05$ , \*\* $p<0.01$ , \*\*\* $p<0.001$ , <sup>a</sup>Phi and Cramér's V correlation, <sup>b</sup>Spearman's Rho correlation ( $r_s$ )

Agreement between the older person and personnel regarding dependency in Instrumental Activities of Daily Living (IADL) and Personal Activities of Daily Living (PADL) varied between good ( $\kappa=0.78$ ) and moderate ( $\kappa=0.43$ ) (Study III). Poor agreement was found for presence of dizziness ( $\kappa_w=0.17$ ) and fair agreement for presence of impaired hearing ( $\kappa_w=0.27$ ), urinary incontinence ( $\kappa_w=0.38$ ), pain ( $\kappa_w=0.21$ ), anxiety ( $\kappa_w=0.37$ ) and depressed mood ( $\kappa_w=0.37$ ). Older persons more often reported health complaints compared to the personnel's assessment. Agreement for provided public care at home was poor ( $r_s=0.14$ ), while it for informal care varied between very good ( $\kappa=1.00$ ) and moderate ( $\kappa=0.52$ ), except help with PADL from

children ( $\kappa_w=0.26$ ). The personnel as compared with the elderly less often reported presence of pain (16% vs. 29%), urinary incontinence (15% vs. 23%), dizziness (3% vs. 9%), mobility (35% vs. 42%), anxiety (8% vs. 15%) and depressed mood (7% vs. 8%) (Figure 11), and also concerning need of extra care (7% vs. 11%). In other instances the differences seemed to be more at random than systematic.



**Figure 11.** Older people's view compared to personnel's assessment regarding health complaints.

Those receiving care and service at home were more satisfied with care continuity (87% vs. 77%,  $p=0.027$ ), personal relations (91% vs. 84%,  $p=0.036$ ) and that staff had plenty of time (72% vs. 46%,  $p=0.012$ ), were respectful (91% vs. 78%,  $p=0.006$ ) and quiet (91% vs. 78%,  $p=0.002$ ), compared to those in special accommodation (Study IV). Low care satisfaction was associated with dependency in IADL ( $B=-1.338$  and  $B=-1.630$ ), impaired mobility ( $B=-12.579$ ), blindness ( $B=-26.143$ ), faeces incontinence ( $B=-11.898$  and  $B=-17.529$ ) and anxiety ( $B=-6.105$  and  $B=-27.197$ ), while high care satisfaction was associated with dependency in PADL ( $B=2.109$ ) and receiving informal care with IADL from spouse ( $B=8.738$ ). In special accommodation, low care satisfaction had to do with continuity, timing, the staff's personal characteristics and with their ability to give service. At home, the older people were the least satisfied with the staff's ability to do housework and to give medical care, with the staff's amount of time and with their own influence over their care.

Low HRQoL in the physical component was associated with dependency in IADL (B=-2.686), slight to constant severe pain (B varied between -7.583 and -4.571) and constant severe dizziness (B=-14.856) (Table 10). A low level in the mental component was associated with living alone (B=-4.496), mild and moderate cognitive impairment (B=-5.343 and -19.531 respectively) and periodic to constant severe depression (B varied between -32.480 and -8.796). The regression model showed adjusted R<sup>2</sup> between 37.0% and 33.1% (Table 10).

**Table 10.** ADL dependency and health complaints associated with HRQoL, SF-12.

Independent variables	Adjusted R <sup>2</sup>	B	95 % confidence interval		p-value
<b>PCS (physical component score)</b>	0.353				
Age		0.081	-0.140	0.302	0.468
IADL-sum		-2.686	-3.830	-1.542	<b>&lt;0.001</b>
PADL-sum		-0.550	-1.902	0.802	0.422
Slight pain		-4.571	-8.525	-0.617	<b>0.024</b>
Periodic severe pain		-7.583	-12.366	-2.801	<b>0.002</b>
Constant severe pain		-7.374	-12.357	-2.390	<b>0.004</b>
Constant severe dizziness		-14.856	-27.117	-2.595	<b>0.018</b>
<b>MCS (mental component score)</b>	0.370				
Age		-0.075	-0.296	0.146	0.503
IADL-sum		-0.367	-1.437	0.703	0.498
PADL-sum		0.134	-1.418	1.151	0.837
Cohabit		-4.496	-8.440	-0.552	<b>0.026</b>
Mild cognitive impairment (Berger 1)		-5.343	-10.658	-0.028	<b>0.049</b>
Moderate cognitive impairment (Berger 4)		-18.148	-34.629	-1.667	<b>0.031</b>
Periodic depression		-8.796	-11.895	-5.696	<b>&lt;0.001</b>
Periodic severe depression		-18.803	-25.832	-10.755	<b>&lt;0.001</b>
Constant severe depression		-32.480	-48.577	-16.382	<b>&lt;0.001</b>

Variables entered in the regression analysis: age, gender, housing, cohabit, IADL-sum, PADL-sum, walking ability, dizziness, urinary incontinence, faeces incontinence, pressure ulcer, slow healing wound, vision, hearing, anxiety, depressed mood, cognitive ability, pain. Age, IADL-sum and PADL-sum were held constant during all analyses.

Low HRQoL in the physical component was associated with dependency in IADL and PADL (B=-3.166 and -1.659 respectively), care and service in special accommodation (B=-5.488) and home nursing care from registered nurse (B=-0.563) (Table 11). A high level in the physical component was associated with informal care with IADL and PADL from children (B=2.584 and 2.331 respectively). The regression model showed adjusted R2 between 37.3% and 3.2%, and p-value between <0.001 and 0.050 (Table 11).

**Table 11.** Type of care and services associated with HRQoL, SF-12.

Independent variables	Adjusted R <sup>2</sup>	B	95 % confidence interval		p-value
<b>PCS (physical component score)</b>	0.373				
Age		0.072	-0.166	0.311	0.548
IADL-sum		-3.166	-4.499	-1.833	<b>&lt;0.001</b>
PADL-sum		-1.659	-2.890	-0.429	<b>0.009</b>
Care and service in special accommodation		-5.488	-1.612	-9.365	<b>0.006</b>
Home nursing care from registered nurse		-0.563	-0.886	-0.240	<b>&lt;0.001</b>
Informal care with IADL from children		2.584	0.773	4.395	<b>0.006</b>
Informal care with PADL from children		2.331	0.760	3.903	<b>0.004</b>
<b>MCS (mental component score)</b>	0.032				
Age		-0.162	-0.122	0.446	0.261
IADL-sum		-0.797	-2.292	0.698	0.293
PADL-sum		-0.506	-1.938	0.925	0.485

Variables entered in the regression analysis: age, IADL-sum, PADL-sum, housing, care and service with IADL, care and service with PADL, home nursing care from registered nurse, home nursing care from assistant nurse, informal care with IADL from spouse, informal care with IADL from children, informal care with PADL from spouse, informal care with PADL from children. Age, IADL-sum and PADL-sum were held constant during all analyses.

## DISCUSSION

### Methodological considerations

The intentions of empirical research are to uncover relations between variables that otherwise may not be detected and to confirm relationships that have been hypothesised (Kazdin, 2003). From a methodological view, the better the design of the research, the more it excludes competing explanations of the results. Methodology in research refers to different principles, procedures and practices and may be viewed as a decision-making process. The way a study is carried out, the used measures and how data are analysed will consequently influence the results and the explanations that can be made on the basis of the results. The aim is to attain justifiable conclusions about relationships between variables. However, several threats may occur that have an impact on the validity of a study and by that interfere with the conclusions of the results. Study validity can be expressed in terms of internal, external, construct and statistical conclusion validity. These types of validity provide a useful approach to convey several aspects of validity in research, to justify methodological practices and to outline the types of problems that may emerge in designing and interpreting a study (Kazdin, 2003).

#### *Internal validity*

Internal validity refers to the extent to which a study rules out alternative explanations of the results. Extraneous factors or influences other than the independent variable which could explain the results will provide threats to internal validity. In cross-sectional designs (as in this thesis) with comparisons and correlations, a strong internal validity can seldom be obtained due to the lack of control over the independent variable. The strength in those designs is more related to external validity (Kazdin, 2003). Cross-sectional designs provide information concerning occurring phenomena in nature, without any manipulation of the independent variable during the study. In this thesis no causal relationships can be established, due to that the effect on the dependent variable cannot be predicted. However, the relationships found implies probable predictors that may be confirmed and generate new hypotheses that can be tested in research with longitudinal or experimental design (Polit & Beck, 2004).

Instrumentation refers to variations in measuring instruments or measurement procedures (Kazdin, 2003). In this thesis, data was based on information collected by the staff (Study I, II and III), which could be a threat to the internal validity since different personnel might make assessments in different ways. Moreover, there could be a risk of bias in the measurement, which would affect the validity and reliability of the collected data (Kazdin, 2003). The interrater reliability of the questionnaire was not tested as a whole. However, the questionnaire and the procedure were tested in a pilot study (Karlsson et al., 2003) and it included reliable and valid instruments (Berger, 1980; Katz, 1963; Åsberg & Sonn, 1989). In addition, there was an instruction about how to fill in the questionnaire.



In study II SNAC-indexes were used; SNAC-IADL, SNAC-PADL and SNAC-Psychosocial index. The internal dropout in the SNAC-indexes was mainly among those in special accommodation. The explanation for that may be that help with IADL is included in the care and social services provided in special accommodation. Thus, that variable may not be valid to assess for those living in special accommodation. Dropout associated with PADL and psychosocial dependency was higher among those living at home and could be due to insufficient knowledge among the staff concerning these needs. The internal dropout may affect the results in different directions if it is systematic. It should be taken into account in the interpretation of the results regarding the SNAC-index at home and in special accommodation.

Maturation refers to variations over time and may come from specific events as well as from processes related to the subjects (Kazdin, 2003). A threat to internal validity is maturation due to the time between the assessments and the interviews (Study III). The time between the needs assessment by the personnel and the interview with the older person was in mean 15.3 days (sd 5.3). Thus, the time between the needs assessment and the interview was considerably shorter than a month, which was the limit chosen for the study. Two weeks for the logistics of collecting needs assessments and arranging interviews was considered reasonable. Changes in the older person's conditions were assumed to be minor during a two week period in most cases.

History refers to external events that take place concurrently with the independent variable and that may have an impact on the dependent variables (Polit & Beck, 2004). In study III, data from the personnel needs assessment could be influenced by the older person's dependency, since the personnel was also in charge of care and service. However, the personnel did not know in advance that their needs assessment would be compared with the interview of the older person, a factor which may have reduced such influence. During the interviews, the older person may be freer to express health complaints since there was no connection between the older person and the interviewer, regarding the care and service they received.

For collecting data about medical health care, the PASiS register was used (Study II). No control for validity and reliability was performed on the county council (PASI) register. The PASiS register has, however, been in operation since the early 1990s and is a well-established routine among the staff as well as connected to payment in the county council. These circumstances most likely increased the reliability of the data collected. Although the register has been in operation for a long time and is well-established, some confounders may still be possible. The older persons received medical health care mainly in four hospitals and routines for documentation may differ between hospitals, but also within a hospital between different clinics or departments. For example, the number of days in hospital may be affected by available places over time, not only the needs in the individual case. In addition, the availability of care and service in the municipality can have an impact on the number of days spent in hospital. For example, a lack of vacancies in special accommodation can delay discharge. Another example may be that not all contacts with a physician for persons in special accommodation were registered in PASiS. The physician may have had contacts

regarding the person's medical care in special accommodation without any subsequent registration in PASiS. Those contacts that did not generate payment were not registered. For example, what a physician's suggests or prescribes to a registered nurse regarding an older patient was probably not registered in PASiS. Thus, there seems to be an underestimation of the number of contacts with physician for those in special accommodation.

### ***Construct validity***

Construct validity refers to the conceptual source underlying the effect. In assessments construct validity refers to the explanation of the measure, while in experiments and investigations it refers to the explanation of the results. Given that the intervention or the variable under study was responsible for the change, the question is which particular aspects of the intervention or variable caused the change (Kazdin, 2003).

The questionnaire measuring municipal care and service was developed by a Swedish research group for assessing older people's functional ability and provision of municipal care and services (Lagergren et al., 2004). Variables included were based on the literature and on consultation with an expert group of researchers in geriatrics, gerontology, nursing science and social science. The questionnaire was not tested as a whole but included reliable and valid instruments such as the Berger scale (Berger, 1980), the Katz ADL index (Katz et al., 1963) and the Hulter-Åsberg index for IADL (Åsberg & Sonn, 1989). The Berger scale correlates well with the typical clinical course of Alzheimer's disease and clinical experience has revealed it to be a valid and reliable means of obtaining an overview of cognitive status (Berger, 1980). For Katz' ADL index, validity and reliability tests has been conducted by means of a comparison with the Activity Index (n=131) and showed a correlation coefficient of 0.93 and a Cronbach's alpha of 0.94 (Hamrin & Lindmark, 1988). The combined, IADL and PADL variables are commonly known as "the ADL-staircase" (Åsberg & Sonn, 1989). The ADL-staircase has shown good validity and reliability, inter-observer reliability  $r=0.81-0.88$  (Brorsson & Åsberg, 1984) and Cronbach's alpha 0.88 (Jakobsson, 2008). In addition, it has been found to be suitable for older people (ibid.).

The used SNAC index developed for IADL and PADL has shown high correlation with Katz' ADL index for PADL and the Hulter-Åsberg index for IADL (Cronbach's alpha 0.91 and 0.86 respectively) (Hallberg et al., 2002). Furthermore, the SNAC-PADL index and SNAC-IADL index had a stronger relation to the care and services provided ( $r_s=0.68$ , and  $r_s=0.46$ ) than either the Katz ADL index ( $r_s=0.25$ ) or the Hulter-Åsberg IADL index ( $r_s=0.65$ ), which indicates that the summarised SNAC index better explains care needs than separate use of the scales (Hallberg et al., 2002). Calculation of the factor analysis was performed repeatedly in another sample with the same results as previous SNAC-PADL and SNAC-IADL (Cronbach's alpha 0.92 and 0.88 respectively) (Lagergren et al., 2003). Thus, by that the factor solution may be regarded as stable.

HRQoL was measured with SF-12, which is a well known instrument and also tested for reliability as well as for validity. Correlations between the physical component summary score (PCS) and the mental component summary score (MCS) have shown acceptable convergent and discriminant validity. Correlations between PCS and MCS have been found moderate ( $r_s=0.34$ ) and Cronbach's alpha was 0.85 for PCS and 0.76 for MCS. The instrument has been used in previous studies and is particularly suitable in settings including older people (Jakobsson, 2007).

The instrument measuring care satisfaction was developed for use for older people receiving home help (Samuelsson et al., 1993). In this study it was used also for home nursing care, for a combination of home help and home nursing care and for those living in special accommodation. Questions were added or deleted to adapt the questionnaire to the received care in the individual case. These modifications should not affect the results, since only a few questions were changed and the total score was standardised. One drawback of these modifications is that they make it difficult to compare the results with those of other studies, but at the same time, the modifications made the study applicable to a wider sample of older people. The dichotomising of the 7-graded scale in the analysis could be questioned. The scale was dichotomised into grades 1-5 for not satisfied versus 6-7 for satisfied. The high breakpoint for satisfaction was applied in order to discriminate possible differences and since previous studies indicate a high level of care satisfaction in general among older people receiving care and services (Chen, 2001; Chesterman et al., 2001; Helset, 1998; Kane et al., 1997). The instrument has not been tested for validity and reliability. However, methods have been used to achieve face and content validity by means of a literature review and interviews with older people about qualities regarded as important (Samuelsson et al., 1993).

### ***Statistical conclusion validity***

Statistical conclusion validity refers to the extent to which statistical relations can be disclosed and how well the study can identify existing relations. It relates to aspects that have an impact on the quantitative evaluation, which in turn influence the conclusions of the results that can be reached (Kazdin, 2003). This kind of validity is referred to as a Type I error ( $\alpha$ ) and a Type II error ( $\beta$ ). Firstly, if the null hypothesis is rejected due to a significant result when the null hypothesis is in fact true a "false positive finding" is prevented. Thus, the Type I error is the risk of reaching false conclusions about significant differences, and such a risk is given by the p-value and usually set below 5%. To reduce the risk of mass significance in multiple comparisons, a reduced p-value must be calculated (Altman, 1991). When a no significant result is obtained, the null hypothesis is not true; a "false negative finding" or a Type II error occurs. A Type II error depends on the size of effect and the sample size (Altman, 1991).

When comparisons between two groups were carried out in this thesis (Study I, II and IV) a p-value below 0.05 was set for significant differences to avoid Type I errors. In comparisons between three groups (Study I and II), a reduced p-value was used to

avoid mass significance. However, no power analysis was applied to avoid Type II errors. The samples were regarded as large with  $n=1958$  for study I and II,  $n=152$  for study III and  $n=166$  for study IV. The samples were assumed to be large enough to detect statistical significance between groups.

The goodness of fit of a statistical model illustrates how well it fits a set of observations. Measures of the goodness of fit usually summarises the difference between observed values and the values expected for the model in question. Such measures can be used in statistical hypothesis testing, e.g. to test for normality of residuals (Chakravarti, 1967). In logistic regression analysis (Study I), the model fit was measured with the Hosmer and Lemeshow goodness-of-fit test. The test of the analysis indicated 7.813 for Chi-square and 0.452 for significance. In linear regressions (Study II and IV), for analysis of residuals the Kolmogorov-Smirnov test and histogram was used to investigate the goodness of fit. Data sets were normally distributed in all analyses, despite in one analysis in study II.

Cohen's Kappa was used in the analysis of agreement between the personnel and the older persons (Study III). The advantage of Cohen's Kappa is that it also accounts for agreement by chance. One limitation of Cohen's Kappa is that it takes no account of the degree of disagreement. Cohen's Weighted Kappa was used in variables with ordered categories, which gives weight to disagreement according to the degree of discrepancy (Altman, 1991). In order to measure agreement in variables on a continuous scale, Spearman's rank order correlation was used. A non-parametric method was appropriate since the data was not normally distributed. Also, this method reduces influence from possible outliers (Altman, 1991).

### ***Reliability***

Reliability refers to the level of consistency or dependability with which an instrument measures the attribute it is intended for (Polit & Beck, 2004). It could be regarded either within the measure or over time (Streiner & Norman, 1995).

A weakness is that the questionnaire measuring municipal care and service was not tested for interrater reliability. Many persons performed the assessments and that is a shortcoming (Study I-IV). The high extent of "don't know" regarding health complaints concerning older people receiving care and service at home compared to those in special accommodation (Study I) indicated a scarcity in interrater reliability. In addition, the results showed low agreement for health complaints (Study III). However, the agreement for ADL, cognitive ability and informal care was good (Study III). Previous research has reported the interrater reliability as high ( $r_s=0.81-0.88$ ) for the "ADL-staircase" when nurses assessed older persons (Jakobsson 2008). One strength of the study was that personnel received instructions before they used the questionnaire, from members in the research group and the contact persons in each municipality. Also, the personnel received written instructions including explanations of how to use the questionnaire.

All older persons receiving care and services were meant to be consecutively included, also those with impaired communicative ability. In study III 152 were included and in study IV 166 were included, of which eight and nine respectively were communicatively impaired. For eight persons in study III and for nine persons in study IV proxy answered the questionnaire regarding municipal care and services, while they were excluded from the HRQoL and care satisfaction assessment (Study IV). Thus, answers from proxy probably do not affect the results, but rather give a more comprehensive view of older people receiving care and service. Persons with impaired communicative ability are otherwise commonly excluded in studies of this kind.

Registered nurses performed the data collection after receiving training on how to use the instruments during the interviews (Study III and IV). The older people's dependency on care and services may have influenced their responses. However, in order to minimise such influence, the interviews were not carried out as a part of the older person's care and services. The personal interviews implied a strength regarding low dropout. In study III, those personnel who assessed the elderly were separated from the personnel who performed the interviews. It avoided influences between the assessments and the interviews. The results could be regarded as reliable taken into account the considerable numbers (n=152) of assessments by the personnel that were linked to interviews of older persons.

In study III, not all questions were responded to by both personnel and older persons, so a matched pair could not be formed. Internal dropouts came mostly from personnel. It is recognised that missing data can lead to bias in the analysis. However, there were only four variables where the internal dropout was more than 20 respondents among the study group (n=152). In six variables there were more than 10 dropouts among those living at home (n=84). Questions with a higher dropout included those about for example social contacts, dizziness and informal care. The dropout may indicate that these were sensitive issues for the personnel to ask the older persons. In addition, it may indicate that issues are difficult to capture or are not regarded as important by personnel.

### ***External validity***

External validity refers to the extent to which the results can be generalised beyond the samples, settings and conditions where the study was carried out. The aim of research is normally to reveal stable relationships and thereby obtain an understanding that may be used to improve people's health and well being. A study is externally valid to the extent that the sample is representative of the broader population and the study setting is representative of other environments. Threats to external validity could be generalised across subjects and across settings, which refer to the degree to which the results can be extended to other populations outside the study group (Kazdin, 2003). External validity is usually strong in non-experimental designs, due to the fact that there is no manipulation of the variables and no special arrangements. The variables are rather "manipulated by nature". Several characteristics can thereby be described and numerous of patterns of associations be identified (Brink & Wood, 1998).

In this thesis the response rate was estimated to be low (46%) (Study I and II), which is a threat to external validity, thus limiting the extent to which the results can be generalised (Kazdin, 2003). However, the exact number of older people receiving municipal care and services cannot be obtained, as there are no exact official statistics. The reports from municipalities have been found to be unstable, as the numbers of people receiving care vary extensively from one year to another (See table 3, National Board of Health and Welfare, 2001; 2002; 2003 & 2004). The official statistics on a group level have wider criteria for inclusion, ie. all people 65+ receiving home nursing care are included, while in this thesis, only those who had at least four home nursing or rehabilitation visits per month were regarded eligible for inclusion. The issue, however, depends more on whether the dropout is systematic than on its size (Altman, 1991). Of the dropouts, approximately 11% declined to participate in the study, while approximately 43% had not been invited. The reason why they were not invited to take part in the study was reported to be due to heavy staff workload and was therefore unlikely to be systematic. The distribution of age and gender among the dropouts resembled those who participated, although a higher proportion of the latter lived in special accommodation ( $p < 0.001$ ), which indicates that more people with reduced functional ability were included. In this thesis, 49% (Study I and II) versus 45% and 46% (Study III and IV respectively) lived in special accommodation while in Sweden as a whole in 2006, 39% of those receiving municipal care and service lived in special accommodation (National Board of Health and Welfare, 2007). Thus, non-participants in this thesis were most likely the youngest old living at home and those with less frailty, and therefore the results may present a skewed negative view of older persons receiving municipal care and service. Further, the results may limit generalising to the group of older people receiving care and service at home.

The distribution of care and service to older people in the included municipalities vary (See table 2). Each municipality has its own policy regarding the proportion of care and service at home or in special accommodation. One strength in this thesis is that data was collected from more than one municipality, which implies that the results may be suitable for generalisation to the group of older people receiving municipal care and service. Most of the data was collected in 2001 and changes in distribution in care and service over time may affect a generalisation applied to the current circumstances. In the municipalities, changes were found regarding the proportion of persons 65+ receiving care (Table 12) and the distribution of care at home compared to care in special accommodation. The proportion receiving care at home increased between 2001 and 2006 in the five municipalities in total and in the country as a whole. Local variations within the municipalities were found between 2001 and 2006. The proportion of persons 65+ receiving care and service decreased in municipality 1, 2 and 5, while it increased in municipality 3 and 4. In municipality 2, 3 and 4 the distribution of care at home increased and care in special accommodation decreased, while the reversed pattern was seen in municipality 1 and 5.

**Table 12.** People 65+ receiving care and service during 2001 and 2006 in 5 municipalities as well as in the country as a whole (National Board of Health and Welfare 2002 and 2007)

	Municipality 1	Municipality 2	Municipality 3	Municipality 4	Municipality 5	Total	Sweden
<b>2001-10-01</b>							
Care and service at home	507 (63)	1 253 (59)	4 633 <sup>a</sup> (60)	246 (52)	863 (77)	7 502 (61)	139 661 (54)
Special accommodation	296 (37)	879 (41)	3 043 (40)	225 (48)	263 (23)	4 706 (39)	118 621 (46)
Care and service, total (part of the population 65+)	803 (17)	2 132 (22)	7 676 (16)	471 (17)	1 126 (20)	12 208 (18)	258 282 (17)
<b>2006-10-01</b>							
Care and service at home	425 (59)	1 307 (66)	6 446(73)	306 (64)	599 (68)	9 083 (71)	154 445 (61)
Special accommodation	292 (41)	662 (34)	2 376 (27)	171 (36)	284 (32)	3 785 (29)	98 619 (39)
Care and service, total (part of the population 65+)	717 (14)	1 969 (20)	8 822 (19)	477 (18)	883 (14)	12 868 (18)	253 064 (16)

<sup>a</sup>Estimation of home nursing care, no official statistics available

In this thesis, both the external and the internal dropout were considered large and in certain aspects systematic. The skewed distribution between persons receiving care at home and in special accommodation and the internal dropout in the SNAC-index should be taken into account in the interpretation of the results. The acceptable agreements in study III strengthen the reliability in collected data, also for study I and II. Furthermore, the pilot study, consultations with the expert group and the review of literature strengthen the reliability of the studies. Only a few studies have previously connected data from municipal care and service with medical health care, which provides a unique comprehensive view of older people's medical health care and social services.

## Discussion of the results

### *Health Related Quality of Life*

Health Related Quality of Life (HRQoL) seems to be lower in the older population and especially for those receiving care and service. In this thesis (Study IV) the physical component score (PCS) was below the mean for a general Swedish population (n=647) in the same age group (34.2 versus 44.4), while the mental component score (MCS) was above the mean (54.8 versus 53.7) (Sullivan et al., 1997). In two studies including a population 75 years and above showed a similar pattern, PCS mean 37.5 and MCS mean 50.3 (Jakobsson, 2007, n=4278) and PCS mean 38.9 and MCS mean 52.3 (Borglin et al., 2005, n=469) Another study found that PCS was significantly lower among those with IADL help (27.6 vs. 41.2) and PADL help (26.9 vs. 39.7) compared

to those without help (Stenzelius et al., 2005). However, only a small group of those older people included in the study received care and service. A study including people 75 and above and receiving help (public and/or informal care,  $n=1247$ ) showed PCS mean 27.9 and MCS mean 41.9, and frequently help in IADL and PADL was associated with low PCS and self reported diseases (Hellström et al., 2004b). In this thesis low HRQoL in PCS was associated with dependency in IADL ( $B=-2.686$ ), pain ( $B$  varied between  $-7.583$  and  $-4.571$ ) and dizziness ( $B=-14.856$ ), while a low level in MCS was associated with living alone ( $B=-4.496$ ), cognitive impairment ( $B=-5.343$  and  $-19.531$ ) and depression ( $B$  varied between  $-32.480$  and  $-8.796$ ). A previous study found that the strongest predictors for low PCS were mobility problems, advanced age, digestion-related problems, and female gender. Predictors for low MCS were psychosocial problems, digestion-related problems, and mobility problems (Stenzelius et al., 2005). Another study showed that low HRQoL PCS was associated with urinary incontinence, breathlessness, pain and mobility problems, while MCS was associated with pain, urinary incontinence, nervous/worried, fatigue and sleep problems (Borglin et al., 2005). Thus, HRQoL for the person's was in this thesis overall lower for the physical component score, which makes sense since this sample consists of people with high dependency whilst the other samples referred to are mixed in terms of dependency on care. The overall higher score in MCS may be related to the fact that persons cognitively impaired and with mental problems declined participation in this study. Further, it is worth noting that there was no difference in HRQoL for those receiving care and service at home as compared to those in special accommodation (Study IV). A previous study showed the same pattern when controlling for functional ability (Hellström et al., 2004b). Thus, this thesis as well as previous research indicates that health complaints and ADL dependency is important to take into consideration in care and service to older people and to include in needs assessments to provide appropriate interventions for improvement of older people's HRQoL.

### ***Care satisfaction***

Care satisfaction is seemingly complex among older people receiving care and service, at home versus in special accommodation. The findings indicated that those receiving care and service in special accommodation perceived lower care satisfaction compared to those receiving care at home. This was shown in aspects regarding care continuity, personal relations, staff's amount of time, and the staff's being respectful and quiet (Study IV). Previous studies have shown a high level of care satisfaction in care and service at home (Helset, 1998; Martin-Mathews, 1995) as well as in special accommodation (Kane et al., 1997; Chen, 2001; Chesterman, 2001). However, previous studies looked only at care in nursing homes or only at care and service at home, without comparisons. In this thesis, there was no relationship between care satisfaction and receiving care at home or in special accommodation. Persons in special accommodation were more functionally impaired and thus more dependent on help, and low care satisfaction was associated with dependency for IADL, impaired mobility and vision (Study IV). Thus, care satisfaction seems to be associated more with functional impairment and health complaints than with whether care is received at home or in special accommodation. Several aspects of care were rated as less



satisfactory by one fifth of the respondents or more and differed between those living at home and those living in special accommodation. Influence over care and service stood out as insufficient among the respondents, at home (30 %) and in special accommodation (52 %) (Study IV). A previous study by Hellström & Sarvmäki (2007) showed that being dependent on care and services in special accommodation implied feelings of resignation, not being valued and having no influence. Another study regarding home care showed that receiving care and service could imply feelings that things were out of control, as well as resigning and adapting when the care was dissatisfactory (Aronsson, 2002). Thus, in order to improve care satisfaction, older people dependent on help need to be supported and empowered by the care system. Also, the older persons reported dissatisfaction related to lack of time among the staff when providing care, 54 % in special accommodation and 28 % at home (Study IV). This may be due to a shortage of resources, but could also be related to how the staff members prioritise their tasks when providing care. In home care, a previous study reported that the lowest level of satisfaction was reported for time and availability (Samuelsson & Wister, 2000). However, another study showed that increased care hours were associated with only a small improvement in care satisfaction in special accommodation (Chou et al., 2003). Regarding personal qualities and skills among the staff, 22 % of those living in special accommodation reported that the staff was not respectful and quiet enough (Study IV). This cannot be considered acceptable, as previous studies have shown that the staff's attitudes and respect plays a central role in determining other aspects of satisfaction in special accommodation (Chou et al., 2002; Bostick et al., 2006). Those living in special accommodation were also dissatisfied with the staff's ability to give medical (33 %) and social service (30 %). Of those receiving care at home, 32 % were not satisfied with the staff's ability to do housework. At the same time, dependency in IADL was associated with decreased care satisfaction (Study IV). These issues are crucial when older persons have been granted care and service, and the staff has been trained and instructed to perform such tasks. Earlier studies have shown that people receiving care at home highly value care which corresponds to their needs and is delivered by staff with suitable knowledge, skills and competence (Woodward et al., 2004; Raynes et al., 2001). Improved competence by the staff seems to be required in order to provide care and service matching the older people's needs. While the findings point at more dissatisfaction among those in special accommodation, dissatisfaction is not explained by where care and service is provided, but rather by how dependent the elderly are on the staff and their skills.

### *Informal care versus municipal care*

Although Sweden is supposed to have a public care and service system, care and service to older people rely heavily on informal care. In this thesis, 64% (Study I and II) versus 68 % (Study III and IV) of those receiving care and service at home had informal care in addition. Among those who received informal care, children were the most common helpers with IADL (65 %) and spouses with PADL (20 %) (Study II). The distribution of informal care can be considered to belong to the complementary model. The complementary model presumes that informal care is the basis for care and

services to older people and that public care is a supplement when the needs exceed what the family members are able to provide (Attias-Donfut & Wolff 2000). Officially, informal care is associated with the substitution model in the Nordic countries, while in reality it seems to be provided more along the lines of the complementary model (Ministry of Health and Social Affairs, 2007). The frailest older people at home with more dependency in IADL and PADL received care from a combination of caregivers, while those in less need received municipal care only and without any family member available to provide care. Further, they received less home care and services pertaining to IADL, but more home care and service for PADL and home nursing care compared to those receiving municipal care only (Study I). This is in line with a previous study showing that older persons receiving help from a combination of municipal and informal care had more help with IADL and PADL compared to those receiving help from municipal care only (Hellström & Hallberg, 2004). Results in this thesis showed that help with IADL was largely covered by informal caregivers and that dependency in IADL predicted receiving informal care (Study I). More help with PADL was provided by municipal care, while help with IADL seems to have been transferred to informal caregivers, as has also been found in another study (Johansson et al., 2003). Thus, the policy of providing more care and service to older people at home and reducing places in special accommodation implies that informal caregivers are increasingly involved in the provision of care.

Family members play an important role in care and service to older people, but it is unclear how they are approached by public care. The results in this thesis showed that informal care was associated with HRQoL as well as with care satisfaction in older people. Informal care from children was associated with a high level of HRQoL, while informal care from a spouse was associated with high care satisfaction (Study IV). Thus, findings indicate that family involvement may be beneficial for the elderly. Previous studies have shown that social support from the family has a positive impact on older people's QoL (Tseng & Wang, 2001; Cummings, 2002). However, another study indicated that who provided the help had no impact on older people's QoL (Hellström et al., 2004b). The importance of family involvement suggests that collaboration between informal and public care is essential for the older person receiving care and service. The results indicated that agreement between the personnel and the older persons was very good and good for most of the variables regarding informal care (Study III). This implies that the personnel was seemingly well informed about the amount of informal care and about who was performing it. Those findings may be an indicator of good collaboration between informal and public care. However, previous research focusing on the relation between informal and public care has identified poor collaboration (Andersson, 2004; Ingvad, 2003) and that family members have felt excluded when needs are assessed as a basis for a decision about public care (Janlöv et al., 2006; Walker & Dewar, 2001). Further, the legislation that regulates needs assessments focuses on the person in need of care (SFS, 2001; SFS 1986) and does not take the family into account. On the other hand, there are indications that public care providers do indeed consider access to family care in the needs assessment as a basis for the provision of care and service (Johansson et al., 2003). This may be interpreted as an adjustment of public care by taking informal care

into account. Further results in this thesis have shown that receiving informal care was associated with more consumption of medical health care, outpatient care as well as hospital care (Study II). This may indicate that the informal carer feels insecure in providing sufficient care or is more prone to turn to the hospital when problems occur. More contacts with registered nurses for those cared for at home may be a useful preventive intervention to support the family as well as the person receiving care. As the pressure on the informal caregivers increases, the health care and social services probably need to develop a more structured way of supporting and collaborating with informal caregivers and sharing the knowledge needed to provide care. More emphasis on the family seems to be required when providing care and services, and may benefit informal caregivers as well as the older persons. Increased family involvement highlights a need of attention paid to the family as a whole when providing municipal care and service. The Family Systems Illness model is grounded in a strength-oriented perspective and views family relationships as a potential resource (Rolland, 1994). Such an approach may be helpful.

It has been found that informal care is an important environmental factor (ICF, WHO, 2001) for older people's care and service. The policy with less care in special accommodation and more care at home has implied changes in the influence of functioning and disability. Public care seems to mostly focus on activities regarding PADL, while activities regarding IADL are transferred to informal care. The increased pressure on informal caregivers calls for facilitators as structured support, transfer of knowledge and more skilled staff in public care and service for older people. The contribution from informal care seems to be taken into account in the planning of public care, but informal caregivers may be neglected in practice as well as in legislations. A more comprehensive view focused on the family, like the Family Illness model, may be suitable in planning and providing care for older people. A needs assessment including the family may detect problems and needs regarding the older person. Also, family members will give more appropriate interventions benefiting QoL and care satisfaction for the family as a whole.

### ***Needs assessment as a basis for care and service***

The user's perspective should be given high priority in needs assessment and guide care providers in their provision of care and services. Care and service according to what the older persons themselves perceive as important, beneficial and acceptable (Hancock et al., 2003) requires knowledge of the older persons' views. The results in this thesis showed good agreement for most of the variables in IADL and PADL (Study III). Functional ability in terms of IADL, PADL and cognition could be measured as actual performance or as self reports, which may affect the agreement between personnel and older persons (Kane & Kane, 2000). A previous study showed that self-reported ADL was influenced by emotional function and personality, while performance measures were not (Kempen et al., 1996). Self-reported functional abilities in IADL may also be influenced by gender roles, skills, physical environment and interest (Larsson, 2006; Avlund, 1997) and by the fact that individuals are not fully aware of their deficit (Paulman et al., 1996). The variation between good and

moderate agreement in IADL and PADL (Study III) may be acceptable; however, a more systematic approach may improve the assessment and thus the care and service provided may be more in accordance with the older person's needs. The results showed that care and service to older people seems mainly to be based on the person's physical and cognitive ability, and in addition on access to informal care. This has been reported in earlier studies, for instance that the personnel assessed physical impairment and mobility more carefully than health complaints and psychological distress (Walters et al., 2000). Also, a review indicated that needs assessments of older people as a basis for receiving care and service was standardised and detailed regarding ADL (Challis & Hughes, 2002). This thesis included well known and validated instruments for measuring ADL and cognitive ability: the ADL-staircase and the Berger scale respectively. The use of instruments may have influenced the agreement in a positive direction, as shown in a study using standardised instruments (Dalby et al., 1999). Thus, needs requiring the provision of practical care and service were well known by the personnel. Also, informal care appears to be included in older people's care and services and influence decisions about public care. Thus, in general the findings indicated that other resources than public care and practical issues needed to handle daily living seem to be in focus in needs assessments.

Health complaints from older people receiving public care appeared to be mainly undetected and estimated lower by the personnel. In the collected data, a number of questions covering health complaints were answered with 'Don't know' by the personnel. These answers were more common for older people receiving care at home, which indicated that the staff members providing care at home seem to have poorer knowledge about their care clients' health complaints than their colleagues in special accommodation (Study I). Furthermore, the results showed that the personnel less often assessed severe health complaints compared to the reports from the older persons. Compared to the older persons, the personnel tended to rate less pain, urinary incontinence, dizziness, mobility and mental problems (Study III). The differences in ratings were mostly randomly lower or higher estimations, rather than indicating a systematic over- or underestimation. The insufficient agreement may be detrimental to the older persons, since health complaints are known to be common among older people. Low agreement and underestimation regarding health complaints indicates that older people are left to themselves with their suffering and probably reduced quality of life. Previous studies have shown that older people suffered from in mean 6 to 10 health complaints. The most common were mental problems, pain, impaired mobility, vision and hearing problems, dizziness, malnutrition, constipation and memory loss (Hellström & Hallberg, 2001; Visentin et al., 1998). Thus, in accordance with previous research this study indicates that health complaints are common. However, these problems were not systematically assessed by the personnel in the need assessment procedure and especially not when older persons received care at home. The personnel's needs assessment may not include taking health complaints into account. It may well be that the personnel does not view these health problems as part of their assignment. The responsibility of the municipalities may be understood to be only to compensate for ADL problems and not to deal with the older person's health and

wellbeing from a more comprehensive view. If this is so, there will be detrimental consequences for the older person's quality of life.

Related to ICF, needs assessments belong to the environmental factors that influence functioning and disability (WHO, 2001). A needs assessment may be regarded as a guide for the subsequent provided care and services. As an environmental factor, a needs assessment can either facilitate or hinder a person's functioning and disability (WHO, 2001). The results indicate that needs assessments facilitate the detection of older persons' cognitive functions and activities in daily living (ADL). The standardised instruments used to measure cognitive ability and ADL may be of help in this detection, which in turn affects the type and amount of received care and services. Informal care may be regarded as a competing environmental factor which also influences functioning and disability. Regarding health complaints, needs assessments seem to prevent the detection of those problems. Possible hindrances may be a lack of systematic assessment and an infrequent use of standardised instruments measuring health complaints. Hindrance may well be associated with inadequate competence by the personnel or that the personnel does not view these health complaints as part of their responsibility. The current approach in needs assessment for older people as a basis for the provision of care and service seems to be focused on compensating for decreased physical and cognitive functions, while health complaints and social needs are given less attention. For a more comprehensive view, an approach which is preventive and palliative while also compensating for decreased functional ability may be helpful. The use of a preventive approach means early detection of symptoms and subsequent interventions, medication and adjustment to chronic illness (Hallberg & Kristensson, 2004). Palliative care is defined as an approach that intends to improve the quality of life for patients facing problems associated with chronic illness and their families (WHO, 1990). Recently, palliative care has been expanded to emphasise its incorporation throughout chronic illness (Zwerdling et al., 2005). Palliative care with a focus on the relief of health complaints, psychosocial and existential issues is argued to be an appropriate approach for older people's care and services (Hallberg, 2006). The needs assessment is aimed to obtain a person's status in functioning and disability and to be a guide towards suitable interventions in care and service (environmental factors) which in turn affect the person's QoL and care satisfaction. In practice, standardised instruments for need assessment are not often used. Previous studies, not using instruments, have shown a high variability in the detection of needs and decisions regarding the type and amount of care in comparable cases (Challis & Hughes 2002; Lagergren, 1998). Agreement between patients and health professionals has been found to be poor ( $k < 0.4$ ) (Walters et al. 2000) and one study indicated that professionals rated the need of care to a lower level than the older care recipients did (Morrow-Howell et al. 2001). In this thesis (Study III), a standardised instrument was used in needs assessments and even so, there was poor agreement regarding important issues, especially health complaints and social needs. The results indicate that needs assessments as a basis for the provision of public care requires a comprehensive view for improvements of interventions which may increase QoL and care satisfaction for older people receiving care and service. A model that could be useful is the comprehensive geriatric assessment (CGA), a validated and multidisciplinary process

for defining the person's functional, social and psychological problems. Commonly included components are a functional assessment of instrumental IADL and PADL. The medical assessment concerns the presence of comorbidity and cognition and mental status, such as depression. The social assessment estimates the amount of informal care and care resources needed, and the environmental assessment evaluates home safety and transportation (Wieland & Hirth, 2003).

### ***Municipal care and service at home or in special accommodation***

The results showed a clear distinction between those receiving care at home and those cared for in special accommodation. The latter were significantly older, less likely to be cohabitating, more often women, more dependent in IADL and PADL and more frequently reported as having health complaints (Study I). Previous studies have shown a similar pattern (Laukkanen, 2001; Trydegård, 1998). Results in this thesis indicated that dependency in IADL and PADL and impaired cognition predicted receiving care in special accommodation, whether the person had informal care in addition or not. Further, living alone predicted being cared for in special accommodation (Study I). Beside dependency in IADL and PADL, previous studies have indicated that cognitive impairment is a strong predictor of care in special accommodation (Aguero-Torres et al., 2001). This suggests that the oldest and most frail persons, who live alone, probably with some form of cognitive impairment, receive care in special accommodation. However, there is a group of older people with extensive health complaints, including psychosocial problems and dependency in ADL, who live at home, and those persons may have limited freedom of choice between receiving care at home or in special accommodation. In Sweden, the number of places in special accommodation has decreased by 11% between 2000 and 2004, while care and services at home have increased by 9 % (National Board of Health and Welfare, 2005). This is in line with the Swedish policy that assumes that it is best for older people to remain at home for as long as possible (Ministry of Health and Social Affairs 2007). The trend with more care at home and less care in institutions has also been shown in other European countries (European Foundation for the Improvement of Living and Working Conditions, 2004). This increased care of older people at home applies to the complementary model, i.e. public care being a complement to family care. The educational level among the staff in care and service is low, out of those about 255 000 employed 35% had no nursing education (SALAR, 2007). The increasing number of frail older people being cared for at home demands higher nursing competence and availability to support and monitor the care and in addition to transfer knowledge and give support to the family caregivers. Psychosocial dependency was no predictor of receiving care at home or in special accommodation (Study I). A previous study of older people receiving care (mean age 79) showed that the presence of depression or anxiety was associated with less help in ADL and had a negative impact on wellbeing (Smalbrugge, et al., 2006). Apart from the policy that older people should remain in their own home for as long as possible, frailty and cohabitation have a strong impact on the distribution of municipal care, while psychosocial needs seemed to be less important.

## ***Medical health care***

The trend towards more elderly people being cared for at home may mean more hospital and outpatient care by physicians, thus handing over responsibility to the medical health care system provided by the county councils. The findings in this thesis showed that people living at home had more frequent hospital admissions than those living in special accommodation; 35 % (median=2) of those living at home were admitted to hospital compared to 26 % (median=1) of those living in special accommodation. Care and service at home as compared with care in special accommodation was also associated with less contact with primary health care and more contact with specialist outpatient care (Study II). One reason may be that hospitals are accessible around-the-clock, while primary health care may be less available in an emergency situation. In addition, it could be that older persons living at home to a higher degree decide for themselves, or together with the family, when they are to seek help at a hospital. The current policy is that long-term care and service for older people should preferably be provided at home, which as indicated by the findings may increase the pressure on medical health care. The range of hospital admissions were large, ranging from one to twelve hospital admissions per person during one year, and the admission could in total mean up to 100 days spent in hospital during one year (Study II). The higher medical health care consumption of those living at home highlights a need for more accessible medical health care at the primary health level for those living at home. Also, the competence of the personnel providing home care to fulfil the older people's needs may be a problem. The results showed that those receiving care at home had less visits per month by a registered nurse (7 visits in mean) and more visits by an assistant nurse (36 visits in mean) (Study II, inclusion criteria was 4 or more visits by home nursing care per month). Home nursing care provided by less skilled staff may hinder early detection of emerging health problems. Thus, more people cared for at home may result in older people being more frequently admitted to hospital, resulting in higher costs in another organisation.

Persons living in special accommodation may be interpreted as being at risk of being marginalised, since they receive less specialised medical health care than those living at home. Those living in special accommodation were significantly older, more psychosocially and cognitively dependent in IADL and PADL, and had more health complaints than those living at home (Study I and II). This indicates that they may have had more severe health problems than those living at home. The results showed that persons who were totally dependent in PADL had fewer contacts with outpatient specialist care (Study II). Other studies also showed decreased consumption of medical health care in the older age groups (Levinsky et al., 2001; McGrail et al., 2000), while nursing and social care increased with age (Long & Marshall, 2000). This thesis showed that fewer days in hospital were related to living in special accommodation (Study II), even though it means receiving more medical care at a lower professional level. Fewer days in hospital among those in special accommodation may mean that the responsibility for completing the medical treatment was handed over to the staff in special accommodation in collaboration with a physician in primary health care. The findings indicated that about 80 % of those living in special accommodation had contact with a primary health care physician during the year of study II. In the Swedish

context, all persons living in special accommodation are supposed to have an assigned primary health care physician (general practitioner). It could be expected that 100 % in special accommodation should have had at least one contact with a physician in primary health care for the period of one year. Another interpretation may be that registered nurses provide the necessary medical health care after a first contact with the physician. However, their skills are not on the same level as physicians specialised in, for instance, geriatrics. Those living in special accommodation had more severe health problems and were more physically, mentally and cognitively dependent than those living at home. Despite that, they received less medical health care and on a lower professional level than those living at home.

Municipal care serves as a base for continuous care and service at home or in special accommodation, while medical health care in addition includes incidental care in hospital and/or visits in outpatient clinics. Collaboration between municipal care and service and medical health care is highly important in order to provide appropriate interventions influencing older people's functioning and disability. Those at home seem to require facilitators for transferring the high consumption of specialist and hospital care to a primary health care level. Possible facilitators may be increased accessibility in primary health care, outpatient care as well as regular home visits. In addition, higher competence among the staff close to older people at home may be a facilitator that makes it possible to solve more cases of health problems at home. Older persons in special accommodation were frailer, but despite that they received less specialist and hospital care. On the other hand they received more primary health care. Those results do not make it clear if the environmental factors (medical health care) sufficiently fulfil the needs regarding functioning and disability for those in special accommodation. The findings indicate that health conditions require interventions including medical health care on a more adequate level which improve body functions, activities and participation, and in turn may improve QoL and care satisfaction for older people.

## **CONCLUSIONS AND CLINICAL IMPLICATIONS**

Related to ICF, the thesis showed a clear distinction between those receiving care at home and those in special accommodation. Regarding functioning, those in special accommodation were more impaired in body functions; they had more health complaints and more impaired cognitive ability, and had more activity limitations in ADL compared to those receiving care and service at home. Care in special accommodation was determined by physical and cognitive dependency, while psychosocial dependency seemed to have less impact. Needs assessments as a basis for the provision of care and service seem to be valid in the focus on older persons' ADL capacity, cognitive ability and informal care, while health complaints and social needs seem to be less systematically detected. In addition, the limited reporting of health complaints by health care staff, especially in the case of those at home, indicated an inadequate needs assessment. The sparse knowledge of, and the risk of not detecting



and intervening in the case of, health complaints by the personnel may be related to the fact that their task is narrowed down to practical issues, such as compensating for ADL, when decisions are made about providing care and services. Along with compensative care, a preventive and palliative approach may be useful and improve the quality of life for older people receiving care and service.

The most important environmental factor in care and service for older people seems to be informal care. Care and services for older people living at home rely heavily on the family. The frailest persons at home were cohabitants and were cared for by a combination of municipal and informal caregivers, while those in need of less care received municipal care only. The extensive amount of informal care requires more family orientation in municipal care with organised support and knowledge transfer for informal caregivers, as well as effective collaboration between municipal and informal care. The attitude to care and services for older people and their families may have shifted, so that municipal care will become a complement to informal care, in contrast to the officially recognised substitution model. Housing seems to divide the distribution of medical health care in different directions. The high consumption of hospital care among those receiving care and service at home indicates an increased need for preventive interventions regarding medical health problems. Home nursing care provided by less skilled staff may hinder early detection of emerging medical health problems. Higher competence with registered nurses more frequently close to older people receiving care may make it possible to solve health problems at home instead of in the hospital.

Care satisfaction was rated higher among older people receiving care and service at home than among those in special accommodation. The lower care satisfaction in special accommodation was concerning continuity, timing, the staff's personal characteristics and ability to give service, and at home the staff's ability to do housework and to give medical care, the staff's amount of time and the older persons' influence over their care. A staff more sensitive to older persons' needs and integrity may improve the care quality in special accommodation. HRQoL was related to the older persons' functional ability and did not take into account whether the person was receiving care at home or in special accommodation. An approach using interventions focused on functional ability and health complaints is needed for improved HRQoL and care satisfaction for older people receiving care and service.

## **FURTHER RESEARCH**

The poor agreement regarding health complaints and social needs between the older person's reports and the assessments by the personnel requires further interventions. Research is needed in order to develop instruments and routines with a more comprehensive approach that could be used by the professionals involved in older people's care and services.

The policy of providing more public care and service at home implies that the family is increasingly involved in the provision of care. Further research is needed in order to develop models with a more comprehensive view with a focus on the family and to develop interventions for improvement of the support for and collaboration with informal caregivers.

Those living in special accommodation had more severe health problems and were more physically, mentally and cognitively dependent than those living at home. Despite this, they received less medical health care than those living at home. More research is required for investigating how their medical needs are fulfilled. It is also important to validate the registration in PASiS concerning medical health care in special accommodation.

The high consumption of hospital care among those receiving care and service at home indicates an increased need for preventive interventions, but also improved access to medical competence at home. Research is needed in order to develop appropriate preventive interventions, including improvement in the collaboration between municipal care and service at home and hospital care.

## SUMMARY IN SWEDISH

### Svensk sammanfattning

Hög ålder medför en ökad risk för sjuklighet och nedsatt funktionell förmåga vilket kan innebära en komplex situation för äldre personer. Eftersom andelen äldre i befolkningen ökar kommer det också att medföra ökade påfrestningar på kommunal vård och omsorg, och hälso- och sjukvård, men även på vårdtagarens familj. Det behövs kunskap om i vilken omfattning vårdbehov blir tillgodosett inom kommunal vård och omsorg och informell vård (främst make/maka och barn). Vidare är det viktigt att få kännedom om vilka faktorer som bestämmer om äldre vårdas hemma eller i särskilt boende. Liksom i många andra länder delas ansvaret för vård och omsorg i Sverige mellan två huvudmän, kommunen och landstinget. Med en delad ansvarsfördelning blir det problematiskt att få en helhetssyn över vårdutnyttjande i de enskilda fallen. Det föreligger en risk att äldre ”faller mellan stolarna” eller att en vårdgivare försöker förskjuta ansvaret till en annan vårdgivare. Få studier har tidigare sammanfört data från de båda huvudmännen, samt integrerat informell vård, när utnyttjande av hälso- och sjukvård har undersökts. Sådan kunskap krävs för att vidareutveckla hälso- och sjukvården och vården och omsorgen om de äldre, samt för kunskap om hur den offentliga vården fungerar på individnivå.

Vårdpersonalens bedömning av vårdbehov är avgörande för vilken vård och omsorg som den äldre erbjuds. Tidigare studier har visat betydande skillnader i bedömningen av vårdbehov mellan kommuner, men också mellan personal inom en kommun. Det finns begränsad kunskap om hur personalens biståndsbedömning överensstämmer med den äldres uppfattning. Bristande överensstämmelse kan få konsekvenser för vårdtagaren genom att vården och omsorgen inte motsvarar den äldres behov. Vidare kan tilldelningen av resurser för vård och omsorg, men även vårdtagarens tillfredsställelse med vården och livskvalitet, bli påverkad. För att få kunskap om hur den kommunala vården identifierar äldres behov är det värdefullt att undersöka överensstämmelsen mellan personalens och den äldres bedömning. Det är vidare viktigt att undersöka familjens vårdinsatser och deras samverkan med personalen. Genom sådan kunskap kan biståndsbedömningen förbättras och möjligheterna till ett mer effektivt utnyttjande av resurserna inom vård och omsorg ökas, vilket kan leda till förbättrad vårdkvalitet med mer fokus på den äldres behov.

Vårdtagarens tillfredsställelse med vården betraktas som en viktig aspekt när vårdkvalitet definieras. Den aspekten kan vara särskilt angelägen för äldre vårdtagare med tanke på deras nedsatta hälsa. Det kan förmodas att funktionsnedsättningar och hälsoproblem påverkat äldres tillfredsställelse med vården. Äldre med vård och omsorg har visat sig ha sämre hälsorelaterad livskvalitet jämfört med äldre som inte behöver vård. Tidigare studier visar att hälsorelaterad livskvalitet påverkas negativt av funktionsnedsättning och hälsoproblem. Däremot har det inte undersökts om funktionsnedsättning, hälsoproblem och hälsorelaterad livskvalitet kan relateras till tillfredsställelse med vården. Vidare, behövs det mer kunskap om hur dessa aspekter är relaterade till vård i ordinärt boende jämfört med vård i särskilt boende. För att kunna

förbättra äldres vård och omsorg behövs det således även ökad kunskap om faktorer som är avgörande för tillfredsställelsen med vården.

Avhandlingen omfattar fyra delstudier som hade ett övergripande syfte att beskriva och jämföra funktionell förmåga och hälsoproblem hos äldre med kommunal vård och omsorg i relation till boende och informell vård, samt att undersöka faktorer förknippade med hälso- och sjukvård, kommunal vård och informell vård. Vidare var syftet att undersöka överensstämmelse i behovsbedömning mellan personal och vårdtagare, samt att undersöka tillfredsställelse med vård och hälsorelaterad livskvalitet (HRQoL) bland äldre vårdtagare inom kommunal vård och omsorg.

I delstudie I var syftet att beskriva och jämföra funktionell förmåga och hälsoproblem bland äldre vårdtagare i särskilt boende och vårdtagare med kommunal vård eller kombinerad kommunal och informell vård i ordinärt boende. Syftet var också att identifiera faktorer som predicerade för kommunal och/eller informell vård i ordinärt boende jämfört med särskilt boende. Urvalet bestod av 1958 personer, 65 år och äldre, med varaktig kommunal vård i fyra kommuner i södra Sverige. Biståndshandläggare, sjuksköterskor, arbetsterapeuter och sjukgymnaster genomförde bedömningar med hjälp av ett formulär som behandlade demografi, funktionell förmåga och hälsoproblem, samt omfattning av kommunal och informell vård. Resultatet visade att vårdtagare i särskilt boende var äldre (medelålder 85 år) än de i ordinärt boende (medelålder 82 år) och mer sällan gifta (17 % jämfört med 24 %) eller sammanboende (5 % jämfört med 25 %). De i särskilt boende var mer beroende i instrumentella aktiviteter för dagligt liv (IADL) (91 % jämfört med 43 % med stort beroende) och personliga aktiviteter för dagligt liv (PADL) (30 % jämfört med 6 % med stort beroende), samt hade fler hälsoproblem jämfört med de i ordinärt boende. Personer med enbart kommunal vård i ordinärt boende fick mer hemtjänst för IADL, medan de med en kombination av kommunal och informell vård fick mer hemtjänst för PADL och hemsjukvård. När vårdtagaren var sammanboende var det relaterat till en kombination av kommunal och informell vård, medan hjälp med IADL från hemtjänst var förknippat med vård enbart från kommunen. Vård i särskilt boende var relaterat till hög ålder, ensamboende, beroende i IADL och PADL, nedsatt kognitiv funktion, nedsatt synförmåga och frånvaro av kroniska sår.

I delstudie II var syftet att undersöka äldre med vård och omsorg, antingen i ordinärt boende eller i särskilt boende, i relation till konsumtion av hälso- och sjukvård och informell vård, samt att undersöka faktorer som är relaterade till konsumtion av hälso- och sjukvård. Urvalet och datainsamlingen avseende kommunal vård var samma som i studie I. Data om den kommunala vården kopplades samman med landstingets (Region Skåne) patientadministrativa system (PASiS) avseende sjukhusvård och öppen sjukvård under ett år. Det var 49 % som vårdades i särskilt boende. Personer i ordinärt boende hade förutom kommunal vård även omfattande informell vård, 64 % fick hjälp med IADL och 23 % fick hjälp med PADL. Det var vanligast att vårdtagarens barn hjälpte till med IADL (42 %), medan vårdtagarens make/maka oftast hjälpte till med PADL (13 %). Make/maka gav i genomsnitt hjälp dagligen, medan barnen i genomsnitt gav hjälp en eller flera gånger per vecka. Fler personer (35 %) i ordinärt

boende konsumerade sjukhusvård, och hade dessutom högre frekvens inläggningar (i genomsnitt 2 inläggningar jämfört med 1 inläggning) och fler vård dagar (i genomsnitt 11 dagar jämfört med 8 dagar), jämfört med dem som bodde i särskilt boende (26 %). En större andel i ordinärt boende konsumerade öppen specialistvård med fler läkarkontakter (62 %, i genomsnitt 3 läkarkontakter) jämfört med dem i särskilt boende (54 %, i genomsnitt 2 läkarkontakter), medan fler i särskilt boende konsumerade öppen primärvård (81 %) jämfört med dem i ordinärt boende (66 %). Enbart 2 % av de äldre hade kontakt med den öppna psykiatriska vården. Inläggning på sjukhus var förknippat med att ha informell vård. Stora psykosociala behov och lågt beroende i PADL var associerat till fler vård dagar på sjukhus, medan manligt kön och totalt beroende i PADL var associerat med färre vård dagar på sjukhus. Ett ökat antal läkarkontakter inom primärvården var relaterat till vistelse i särskilt boende och informell vård, samtidigt som totalt beroende i PADL var relaterat till färre kontakter inom primärvården. Läkarkontakter inom psykiatrisk öppen vård relaterades till omfattande psykosociala behov. Kontakter inom öppen specialistvård var relaterat till informell vård, medan vistelse i särskilt boende och stort eller totalt beroende i PADL var relaterat till färre läkarkontakter inom öppen specialistvård.

I delstudie III var syftet att undersöka överensstämmelse mellan biståndsbedömningen av biståndshandläggare eller sjuksköterska och vårdtagarens uppfattning om sin funktionsförmåga, hälsoproblem, omfattningen av vård- och omsorgsinsatser, samt insatser från informell vård. Studien inkluderade 152 personer, 65 år och äldre, med kommunal vård och omsorg och boende i fem kommuner i södra Sverige. Biståndshandläggare och sjuksköterskor samt en sjukgymnast genomförde standardiserade behovsbedömningar utifrån ett formulär som behandlade personuppgifter, funktionell förmåga, hälsoproblem, bostadsanpassning, kommunal och informell vård. I nära anslutning till behovsbedömningen genomförde sjuksköterskor under specialistutbildning personliga intervjuer med de äldre utifrån samma formulär, men som anpassats för intervju. Överensstämmelsen mellan behovsbedömningar och intervjuer analyserades statistiskt. De äldre var i genomsnitt 84 år, varav 63 % var kvinnor och 45 % vårdades i särskilt boende. Av de med kommunal vård i ordinärt boende, hade 68 % dessutom informell vård. Överensstämmelsen mellan personalens bedömning och de äldres uppfattning avseende beroende i IADL och PADL varierade mellan god och måttlig. Förekomst av yrsel visade på låg överensstämmelse, medan en viss överensstämmelse förekom avseende hörselnedsättning, urininkontinens, smärta, oro och depressiva besvär. De äldre rapporterade oftare hälsoproblem jämfört med personalens bedömning. Beträffande omfattning av kommunal vård i ordinärt boende var överensstämmelsen låg, medan omfattning av informell vård varierade mellan mycket god och måttlig överensstämmelse. Personalen, till skillnad från de äldre, rapporterade mer sällan förekomst av smärta, urininkontinens, yrsel, nedsatt rörelseförmåga, oro och depressiva besvär. Personalen rapporterade även mer sällan behov av särskilda vårdinsatser och kommunal vård i ordinärt boende, jämfört med de äldre. I de flesta fallen föreföll skillnaderna vara mer slumpartade än systematiska.

I delstudie IV var syftet att undersöka tillfredsställelse med vården i förhållande till hälsorelaterad livskvalitet, funktionsnedsättning och hälsoproblem hos personer, 65 år och äldre, med kommunal vård och omsorg i ordinärt och särskilt boende. Studien omfattade 166 personer som intervjuades av sjuksköterskor utifrån ett formulär som innehöll frågor avseende funktionell förmåga, hälsoproblem, kommunal och informell vård. Vidare användes en enkät med livskvalitetsfrågor (SF-12) och en enkät med frågor om tillfredsställelse med vården, i samband med intervjun. Vårdtagarna i ordinärt boende var mindre beroende i IADL och PADL, var i lägre grad kognitivt nedsatta och hade färre hälsoproblem avseende nedsatt rörlighet, avföringsinkontinens och trycksår, jämfört med dem som vistades i särskilt boende. De i ordinärt boende var generellt mer tillfredsställda med vården än de i särskilt boende. Vårdtagare i ordinärt boende var mer tillfredsställda med kontinuiteten i vården och relationen med personalen, samt uppfattade att personalen hade gott om tid, visade respekt och hänsyn, och var lugn och trygg, jämfört med de i särskilt boende. Låg tillfredsställelse med vården var relaterat till beroende i IADL, nedsatt rörelseförmåga, blindhet, avföringsinkontinens och oro. Hög tillfredsställelse med vården var däremot relaterat till beroende i PADL och informell hjälp med IADL från make/maka. Det fanns ingen skillnad i hälsorelaterad livskvalitet (HRQoL) mellan vårdtagare i ordinärt boende och vårdtagare i särskilt boende.

Distributionen av kommunal vård och omsorg delade in de äldre i tre väl avgränsade grupper. De sköraste äldre som var ensamboende fick vård i särskilt boende som främst baserades på deras grad av fysiska och kognitiva funktionsnedsättning. De sköraste äldre i ordinärt boende var sammanboende och fick kommunal vård kombinerat med informell vård, medan de med enbart kommunal vård hade en bättre funktionell förmåga och främst hade hjälp med IADL. Distributionen av kommunal vård och omsorg ger begränsad frihet och möjlighet för äldre vårdtagare att välja vård i ordinärt boende eller flytta till särskilt boende. Resultaten indikerade ett systemskifte inom vården och omsorgen om de äldre, från att kommunal vård har varit ett substitut för informell vård till att kommunal vård mer blivit ett komplement till informell vård. Sådana förhållanden kan orsaka press på familjer och därför behöver informella vårdgivares situation uppmärksammas inom vården och omsorgen till äldre. Den höga konsumtionen av vård på sjukhus, hos de med kommunal vård i hemmet, betonar ett behov av förebyggande insatser för denna grupp. Som kontrast konsumerade de sköraste äldre i särskilt boende sjukvård på en lägre nivå och kan riskera att bli marginaliserade.

Biståndsbedömningar var fokuserade på de äldres ADL, kognitiva funktionsförmåga och insatser från informell vård, medan hälsoproblem och sociala behov var mindre uppmärksammade. Överensstämmelsen var acceptabel mellan personalen och de äldre avseende ADL, kognitiv förmåga och informell vård, medan överensstämmelsen var bristfällig avseende hälsoproblem och sociala behov. De äldre rapporterade oftare hälsoproblem jämfört med personalen. Personalens under- och överskattningar av behov verkade vara mer slumpmässiga än systematiska, vilket visar på en brist på systematisk bedömning snarare än reducering av problem. En mer omfattande biståndsbedömning utifrån en helhetssyn, som även inkluderar hälsoproblem som kan

förebyggas eller lindras, ger en möjlighet att förbättra livskvaliteten för äldre personer med vård och omsorg.

Lägre tillfredsställelse med vården i särskilt boende i jämförelse med ordinärt boende kan förklaras med att de i särskilt boende var mer funktionsnedsatta vilket påverkar tillfredsställelse med vården negativt, men det kan också förklaras med att vården bedrivs i olika kontexter, i det egna hemmet respektive på institution. Däremot konstaterades ingen skillnad avseende hälsorelaterad livskvalitet (HRQoL), vilket inte heller var relaterat till tillfredsställelse med vården. Behovet av personlig vård (PADL) verkade vara väl tillfredsställt, vilket också visades med att beroende i PADL predicerade god tillfredsställelse med vården. Äldre i ordinärt boende var tillfredsställda med de personliga egenskaperna hos personalen, medan 22 % i särskilt boende ansåg att personalen inte visade tillräcklig respekt och hänsyn och inte uppfattades som lugn och trygg. Resultatet från särskilt boende kan inte betraktas som acceptabelt, i synnerhet inte när personliga egenskaper hos personalen i tidigare studier har graderats som den viktigaste faktorn för tillfredsställelse med vården. Vårdtagarna var missnöjda med personalens yrkeskicklighet avseende hushållarbete (32 %) och sjukvård (19 %) i ordinärt boende, samt sjukvård (33 %) och social umgänge i särskilt boende (30 %). Detta är områden som ingår i personalens åtagande och resultaten kan tolkas som bristande kompetens bland personalen. En betydande andel av vårdtagarna ansåg att personalen hade tidsbrist (28 % i ordinärt och 54 % i särskilt boende) och ansåg att de själva hade otillräckligt inflytande över sin vård (30 % i ordinärt och 52 % i särskilt boende). Tidsbrist kan vara en fråga om tilldelning av resurser, medan inflytande på vården mer kan bero på kunskap hos personalen.

Vården och omsorgen om de äldre verkar främst vara relaterad till personers fysiska funktioner, framför allt IADL och PADL, och kognitiva funktioner. ADL-förmåga och kognition är avgörande för om vård erbjuds hemma eller i särskilt boende, men påverkar också i vilken omfattning och på vilken nivå sjukvård konsumeras. Personalen genomförde omsorgsfulla bedömningar om vårdtagarnas fysiska och kognitiva funktioner. Vidare verkar vårdtagarna vara tillfredsställda med vården avseende PADL. Detta kan tolkas som att vården och omsorgen främst är inriktad mot att kompensera äldre vårdtagares nedsatta fysiska och kognitiva funktioner. Vårdtagarnas hälsoproblem visade sig vara av mindre betydelse i beslut om kommunal vård och omsorg. Personalens bedömning av hälsoproblem var ofta bristfällig med låg överensstämmelse med vårdtagarnas uppfattning. Vårdtagarna rapporterade ofta fler hälsoproblem jämfört med personalens bedömning. Hälsoproblem påverkade också tillfredsställelse med vården och HRQoL negativt. En större uppmärksamhet på äldres hälsoproblem i biståndsbedömning och en mer preventiv och palliativ inriktning på vården skulle kunna ge ökad livskvalitet hos den äldre vårdtagaren. Förutom kommunal vård hade en stor andel även informell vård i ordinärt boende. Vårdtagarna med de största behoven i ordinärt boende hade både kommunal och informell vård. Personalens bedömning av omfattning och vem som gav informell vård stämde väl överens med den äldre vårdtagarens uppfattning. Informell vård visade sig också påverka tillfredsställelse med vården positivt. Den offentliga vården har formellt betraktats som substitut för informell vård, men det verkar numera som att den är ett komplement till informell vård.

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