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# **Formal and Informal Care in an Urban and a Rural Elderly Population**

**Who? When? What?**

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Institutet**

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*To my children:  
Jacob, Camilla, Sofia and Marcus*



## ABSTRACT

## ENGLISH

This thesis explored informal and formal care in relation to physical and mental functioning in an urban and a rural setting in Sweden. Three different study populations were used: eight cohabiting couples where one of the spouses was the primary caregiver for a partner with dementia; an urban and a rural elderly population (75+ years) participating in the Kungsholmen Project in central Stockholm; or in the Kungsholmen-Nordanstig Project in the county of Hälsingland. Both projects are longitudinal, population-based studies on aging and dementia, using the same standardized protocols in both areas.

**Study I.** A qualitative approach, following spouses who were primary caregivers for a demented partner, was chosen to describe types and patterns of caring activities. The findings demonstrate the intricacy and multidimensionality of the caregiving situation, as well as the varied time-consuming caring activities and tasks performed by informal carers. Spouses found the caregiving role rewarding in terms of experiencing nearness and a feeling of *togetherness*.

**Study II.** In a rural elderly population, the amount of informal in-home care was much greater than formal in-home care, and also greater among demented than non-demented persons. We found an association between the severity of cognitive decline and the amount (hours per day) of informal care, while this pattern was weaker regarding formal care.

**Study III.** A study of all institutionalized elderly inhabitants in a rural community showed that having dementia increased the amount of total care time (hours per day). The presence of dementia added more than nine hours, while each loss of one ADL function added 2.9 hours. The estimated cost for institutional ADL-care time increased with more than 85% for people being dependent in 5-6 ADL activities, compared to persons with no functional dependency, and with 30% for persons with dementia compared to the non-demented.

**Study IV.** We found geographical differences in two elderly populations living at home. The rural elderly residents were almost three times more likely to receive informal care. Living alone was strongly associated with receiving formal care in both areas, but it was the women with high education in the urban area who received more formal care. There were no area differences in physical functioning, whereas rural elderly were more cognitively impaired.

**Summary.** Elderly cohabiting caregivers were engaged in demanding time-consuming care, from supervision to heavy physical responsibility. The amount of informal in-home care was much greater than in-home formal care. Our findings indicate that informal care substitutes rather than complements formal care. There was a variation in time use of care in institutional settings due to differences in ADL dependency, but also whether dementia was present or not. These variations have implications for cost of institutional care. The rural elderly population received significantly more informal care, and was more cognitively impaired.

**Key words:** ADL, aging, caregiving, cost of care, dementia, disability, formal care, functional status, informal care, in-home care, observational study, population-based, RUD, rural, spouses, urban

Det övergripande syftet med denna avhandling var att studera informell och formell vård i förhållande till fysisk och mental funktionsförmåga i en stads- och en landsortsbefolkning. Tre olika studiepopulationer användes: åtta sammanboende par där den ena partnern var vårdgivare till sin demente make/maka; en stads- och en landsbygdsbefolkning (75+ år) och deltagare i Kungsholmsprojektet i centrala Stockholm eller i Kungsholmen-Nordanstig Projektet i Hälsingland. Båda är longitudinella befolkningsbaserade studier om åldrande och demens och använder samma standardiserade protokoll.

**Studie I.** Denna studie med en kvalitativ ansats och med syfte att beskriva olika aktiviteter och mönster i vårdandet, följde sammanboende par där den ena partnern var primär vårdgivare åt sin demente make/maka. Resultaten belyser den svåra och mångfasetterade situation som vårdgivare till dementa personer har. Den beskriver även de olikartade och tidskrävande uppgifter som utförs av de informella vårdgivarna. De vårdgivande makarna fann sin roll som vårdare belönande, de beskrev också närhet och en känsla av *togetherness* (samhörighet).

**Studie II.** I en äldre landsortsbefolkning, var mängden hembaserad informell vård större än den formella hembaserade vården och också större hos dementa än icke-dementa personer. Vi fann också ett samband mellan graden av kognitionsnedsättning och mängden (timmar per dag) av informell vård, medan det sambandet var svagare beträffande nedsatt kognition och formell vård.

**Studie III.** En studie bestående av samtliga institutionsboende äldre personer i en landsortskommun fann att demens ökade mängden vård (timmar per dag). Att ha demens ökade mängden formell vård med nio timmar medan varje förlorad ADL-förmåga adderade 2,9 timmar. Den uppskattade kostnaden för institutionsbaserad ADL-vård ökade med mer än 85% för personer som var beroende i 5-6 ADL-aktiviteter jämfört med fysiskt oberoende personer och med 30% för dementa personer jämfört med icke-dementa personer.

**Studie IV.** Sannolikheten för äldre boende på landsbygd att ha informell vård var nästan tre gånger större jämfört med äldre boende i storstad. Ensamboende var starkt associerat till att ha formell vård i båda områdena, dock var det kvinnor med hög utbildning i stadsbefolkningen som i större utsträckning fick formell vård. Vi fann inga geografiska skillnader vad gällde fysisk funktionsförmåga, medan äldre boende på landsbygden var mer kognitivt nedsatta.

**Slutsatser.** Äldre sammanboende vårdgivare var involverade i tidskrävande vård, allt från övervakning till tungt fysiskt ansvar. Mängden informell vård i hemmet var mycket större än den formella hembaserade vården. Resultaten indikerar att informell vård snarare ersätter än kompletterar den formella vården. Vi fann tidsskillnader i institutionsbaserad vård p.g.a. ADL-beroende, men också beroende på demensgrad. Dessa variationer kan få implikationer på kostnaderna för institutionsvård. Den äldre befolkningen på landsbygden hade signifikant mer informell vård och var mer kognitivt nedsatta.

## LIST OF ORIGINAL PUBLICATIONS

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

- I. Jansson W, Nordberg G, Grafström M. Patterns of elderly spousal caregiving in dementia care: an observational study. *Journal of Advanced Nursing* 2001; 34: 804-812.
- II. Nordberg G, von Strauss E, Kåreholt I, Johansson L, Wimo A. The amount of informal and formal care among non-demented and demented elderly persons - results from a Swedish population-based study. *International Journal of Geriatric Psychiatry* 2005; 20: 862-871.
- III. Nordberg G, Wimo A, Jönsson L, Kåreholt I, Sjölund BM, Lagergren M, von Strauss E. Time use and costs of institutionalised elderly persons with or without dementia: results from the Nordanstig cohort in the Kungsholmen Project -a population based study in Sweden. *International Journal of Geriatric Psychiatry* 2007; 22:639-648.
- IV. Nordberg G, Sjölund BM, Wimo A, von Strauss E. Home care in relation to physical and mental functioning: comparison of an urban and rural elderly population. Manuscript submitted for publication.

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## LIST OF ABBREVIATIONS

ADL	Activities of Daily Living
aOR	adjusted Odds Ratio
CDR	Washington University Clinical Dementia Rating Scale
CI	Confidence Intervals
DSM-III-R	Diagnostic and Statistical Manual of Mental Disorder, Third Edition, Revised
IADL	Instrumental Activities of Daily Living
MMSE	Mini-Mental State Examination
MoVies	Monongahela Valley Independent Elders Survey
OR	Odds Ratio
Ref	Reference category
RIS MRC CFAS	Resource Implications Study of Medical Research Council Cognitive Functioning and Ageing Study
RUD	Resource Utilization in Dementia instrument
SEK	Swedish krona

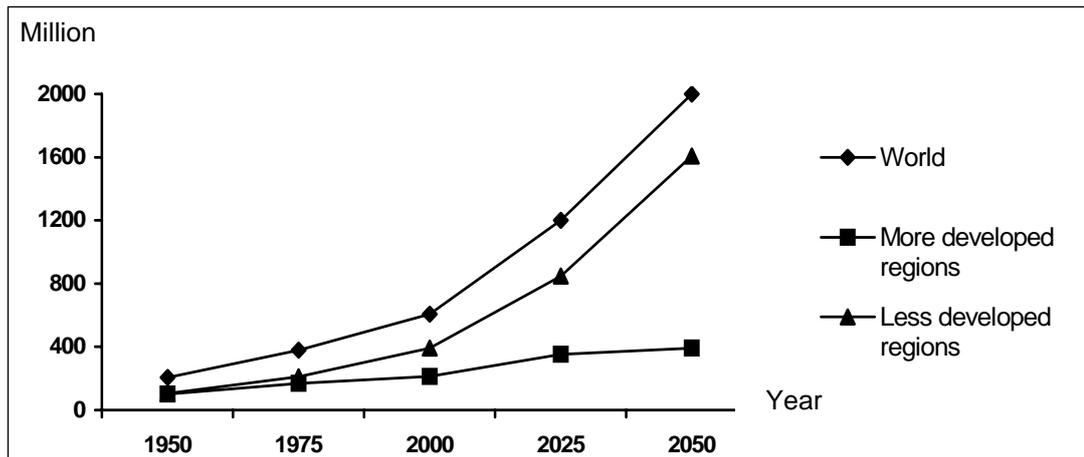
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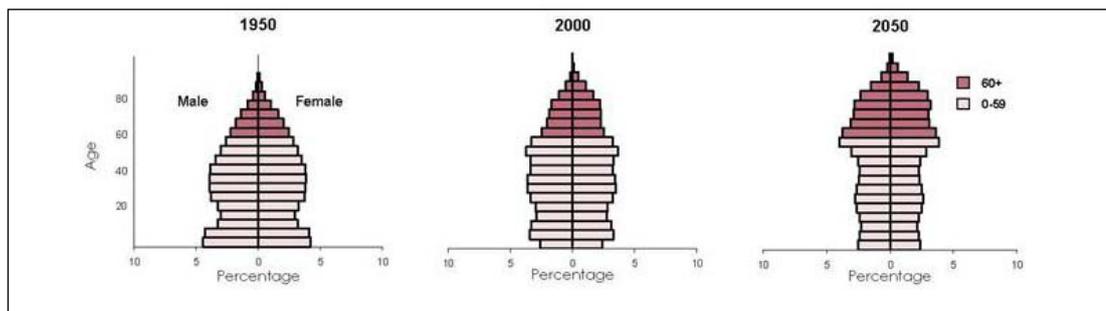
# 1 INTRODUCTION

During the past few decades, the aging of the population has become a worldwide phenomenon, occurring both in the developed and the developing countries (Kalache 1996). The proportion of elderly in the world wide population is expected to double over the next half century (United Nations 2002). In absolute numbers, persons aged 60 and over are projected to expand from 606 million year 2000 to nearly 2 billion by the year 2050, see Figure 1 (United Nations 2004).



**Figure 1.** Population aged 60 or over: world and development regions 1950-2050 (United Nations. 2004).

The developed countries are also facing a progressive aging of the elderly population itself (United Nations 2002; Statistics Sweden 2003). In Sweden, it is estimated that the number of people aged 65 and over will be 2.2 million by year 2025, a rise from today by 700.000. The number of people aged 80 and over is expected to increase by 180.000 to 640.000 by year 2025, which means that 32% of elderly people will be over 80 years of age (Statistics Sweden 2005; The Swedish Institute 2003) (Figure 2). These demographic changes will have a great influence on public health and are expected to lead to an increasing demand for elderly care.



**Figure 2.** Population age distribution for 1950, 2000, and 2050 in Sweden (United Nations 2002).

## 1.1 ELDERLY CARE

Care of the elderly, the development of geriatric home care and a combination of informal and formal care have become one of the most important issues in society today. While those in need of care are not exclusively older people, and certainly not all elderly are in need of care, there is little doubt that, in numerical terms, that the greatest need for care exists within this group.

In most countries, the amount of formal services provided to elderly people is well known in terms of aggregated data, concerning e.g., the number of social services hours produced or similar. More rarely, such data disaggregated to the individual level are combined with data on e.g., functional or cognitive capacity (RIS MRC CFAS et al. 1998; Wimo et al. 2002), giving opportunities to analyse the patterns of how resources are utilized. Often these data are derived from research projects.

Although there are several studies describing the amount of formal and informal care, most of these studies are made on selected populations, such as clinical or convenient samples (Schneider et al. 2002; Wimo et al. 2002). A Canadian study by Penning, 2002 examined the relationship between the extent of formal in-home care and level of informal care, and found no support for the substitution hypothesis that an increased use of formal care will tend to erode levels of informal care. Similar results were found in a study consisting of a nationwide sample of non institutionalized elderly in Sweden. The researchers found an estimated ratio between informal and formal care of two to one, and that formal care had only a complementary role (Johansson and Thorslund 1992). Others have found similar relationships that informal care is two or three times as extensive as formal care (Sundstrom et al. 2002; Szebehely 2005).

A national population-based study on elderly conducted in the United States by Langa and co-authors, found that informal caregiving, covering Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) increased dramatically for elderly persons with dementia. Non demented persons received almost five hours per week, and it increased to 13 hours in mild dementia and to more than 46 hours per week for severe dementia (Langa et al. 2001).

In spite of the relevance, the knowledge regarding the amount of formal and informal care and its interaction on a population-based level is still limited (OECD 2002). A

study comparing the 80+ populations in Canada and Sweden (Miedema and de Jong 2005), found that Canadians reported far more informal and formal supports compared to Swedes, despite the fact that Swedish elderly citizens in general have more funded support compared to Canadian citizens. The authors, therefore, speculate that the concept of support has different meanings, and raise concerns about cross-cultural comparisons within these types of research questions. Others have posed similar questions regarding; the diversity of dependency level for those cared for at home, levels of formal care, and informal caregiver burden (Carpenter 2005; Carpenter et al. 2004; Davey et al. 2005; Shea et al. 2003; Wimo et al. 2007b).

Due to the demographic changes, the developed countries are forced to implement policies of community care in order to achieve more cost-effective use of the relatively limited resources. Increasing interest has therefore been placed on the role of informal carers, mainly family members (Nolan et al. 1996).

#### *Urban versus Rural*

Most research projects concerning aging and health related problems are carried out on urban populations, while rural elderly are less frequently studied. The few studies on rural populations, e.g., the Monongahela Valley Independent Elders Survey (MoVies) (Ganguli et al. 1993b), do not have the possibility to directly compare rural with urban populations. Studies that have included elderly from both rural and urban areas have not focused on area differences (Canadian study of health and aging 1994; Cornoni-Huntley et al. 1993; Dartigues et al. 1992), with few exceptions (Klarin et al. 2003; RIS MRC CFAS 1998; Wackerbarth et al. 2001).

One exception is the Resource Implications Study of Medical Research Council Cognitive Functioning and Ageing Study, which included both rural and urban areas in United Kingdom (RIS MRC CFAS 1998). No regional differences in the occurrence of dementia and cognitive impairment were detected (RIS MRC CFAS 1998). A high frequency of disability was present amongst the oldest old, and physical ability varied by age, gender and other socio-demographic variables, but not by geographical area (McGee et al. 1998). However, the rural areas reported healthier diets than urban regions (Morgan et al. 2000). A study from the United States by Wackerbarth and co-authors on first time visitors to a memory clinic found that urban patients were more educated, and urban family members reported more memory

problems and personality changes. They found no area differences in age- and education-adjusted Mini-Mental State Examination (MMSE) or raw ADL/IADL (Wackerbarth et al. 2001).

A study from the United States, using data from the longitudinal National Long-Term Care Survey, found that non-institutionalized urban disabled older persons were more likely to receive formal care than their rural counterparts, but rural disabled were more likely to receive informal care than urban residents (Clark 1992).

Some Asian studies have examined rural and urban differences in dementia (Liu et al. 2003), functional disability (Tang et al. 1999), and health status (Kabir et al. 2003), showing that the rural areas more affected by diseases. Other reports from developing countries concern only rural populations, e.g. studies from India (Rajkumar et al. 1997), Korea (Suh et al. 2003), and the Indo-US Cross-National Dementia Epidemiology Study (Ganguli et al. 1993a), which is a cross national comparison between rural areas in India and the United States.

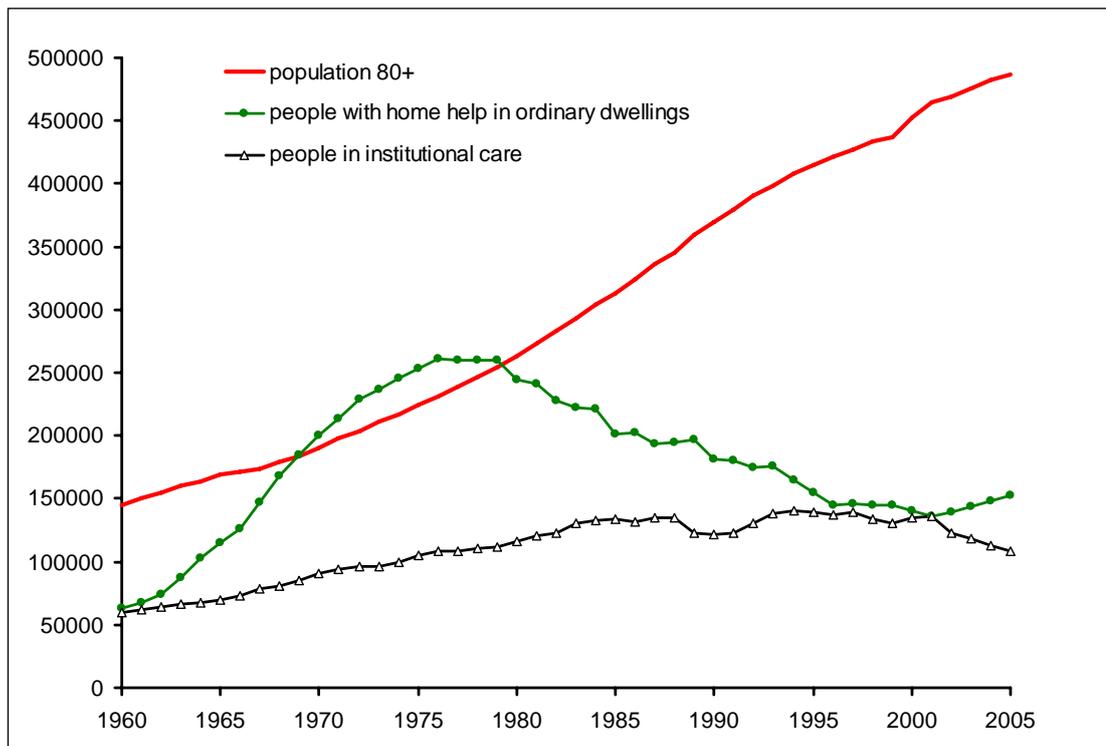
## **1.2 ELDERLY CARE IN SWEDEN**

### **1.2.1 Formal care and its development**

In Sweden, institutional care dominated the elderly care system in the first half of the 20<sup>th</sup> century, as it was strongly believed that this was the most suitable way to solve the need of care to the frail elderly in the society (Larsson 2004). At the beginning of the 1950s an intensive public debate regarding the future direction of old age care took place (Lo-Johansson 1952). Following this debate, the municipalities in Sweden gradually started to offer support to dependent elderly persons in their own homes (Trydegård 2000). In 1956 a new law was passed, where children's responsibility to care for their parents was abolished (Thorslund and Parker 1994), and gradually the care of the elderly shifted from the family towards the publicly funded sector.

The Social Service Act (Socialtjänstlagen, SFS, 1980:620) states that individuals in Sweden have the right to receive publicly funded service and help in everyday life. The municipalities' have the responsibility to provide such service. In addition, the Health and Medical Service Act (Hälsa- och sjukvårdslagen, SFS, 1982:763) confirmed that healthcare should be offered to all and on equal terms (Willow 2005). The number of beds in nursing homes doubled between 1960 and 1980 (Larsson

2005; Thorslund and Parker 1994) (see Figure 3). At the same time, the home help services and medical home care also developed dramatically (Szebehely 1995), and reached their peak in 1978 (Larsson 2004; Szebehely 1998). During the 1980s, economic recession and the increasing number of elderly people in the population put pressure on publicly funded elderly care. Institutional care was questioned from both an economic as well as a human perspective. The quality of life in institutional care was questioned and it was thought to be inhuman to move elderly persons from their homes unless it was absolutely necessary. The care of the elderly shifted towards a community-based care so that society would better able to meet the needs of an aging population and reduce the expensive institutional care (Jansson et al. 2001; Thorslund and Parker 1994). After the millennium shift there has been a decrease in the number of beds in institutional settings (from 120,000 to 100,000).



**Figure 3.** Old-age care in Sweden 1960-2005 (Larsson 2007).

In 1992, the responsibility for care of the elderly, including nursing home residents and patients who were still in need of care after being discharged from hospital, shifted from the county council to the municipalities. Thereafter, the municipalities had the responsibilities, not only for housing and social services, but also for long-term medical care, both institutional and in-home care. This reform of elderly care was named the ÄDEL- reform (The National Board of Health and Welfare 1998).

Due to further economic recession in the beginning of the 1990s the public funds suffered from substantial cutbacks. The municipalities were forced to concentrate their resources on those who were in need of extensive care, which led to a reduction of elderly persons receiving home help services during the first half of the 1990s (Ministry of Health and Social Affairs 2003; Thorslund et al. 1997). The number of people receiving home help did not decline after the mid 1990s.

However, a study using the information from the 1994 and 2000 National Survey of Home Living, including 75 years and older persons in Sweden, estimated that approximately 40% of the total amount of care was provided by the public sector in 1994, and that this amount had decreased to 30% by the year 2000 (Sundstrom et al. 2002). Municipalities today provide formal support only to people with heavy care needs or with poor informal support. Home help services have changed to a more medical type of care (Larsson 2004), while other needs are left to informal sources (Andersson 1996 ).

In conclusion, during the last decades a gap has emerged between number of elderly persons and limited financial resources available for publicly funded home care (Daatland 1997), this gap will increase in the future. In addition, people with less extensive needs will have to rely on informal care sources to a greater extent (Szebehely 2003).

### **1.2.2 Informal care**

It is a well known fact that the extensive care to frail elderly people is provided mostly by the immediate family, and that informal caregivers represent a large, but hidden, part of support to elderly persons (Haley 1997; Max et al. 1995; Ostwald 1997). Several studies have demonstrated that the major providers of home-based care for elderly in Sweden are informal caregivers (Jeppson Grassman 2001;

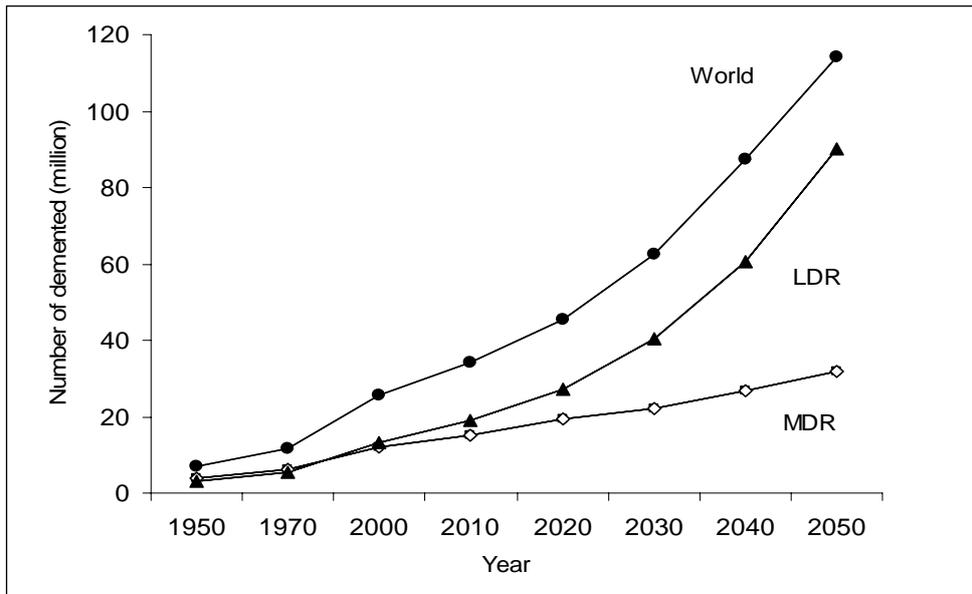
Johansson and Sundström 2002; Johansson and Thorslund 1992; Larsson 2004; Larsson et al. 2006; Thorslund et al. 1997; Wimo et al. 2002), as well as in other countries (Cavallo and Fattore 1997; Clipp and Moore 1995; Rice et al. 2001; RIS MRC CFAS et al. 1998; Schneider et al. 2002).

In the past, relatives have had the responsibility to provide in-home care for the elderly. In Sweden, as well as in other Nordic countries, laws have regulated children's obligation to provide care for their parents (Andersson 1992). Due to the financial cutbacks during the 1980's and 1990's, the informal care came back as a major topic of discussion for policy-makers. The municipalities have the responsibility to detect and recognise the citizens' needs for medical and social services, and to provide support and relief for informal caregivers. This obligation is stated in the revised Social Services Act (Socialtjänstlagen, SFS, 1980:620; Government Bill, 1996/97:124).

The increase of elderly people in the future will increase the demands on informal caregivers even more. It will also put an increasing demand on the public elderly care (Nordberg et al. 2007). Neither formal care nor informal care can take care of the needs of a growing elderly population alone. Society must find alternative solutions and make efforts to improve collaboration between providers of formal care and informal caregivers (Jansson 2001; Larsson 2004; Lyons and Zarit 1999).

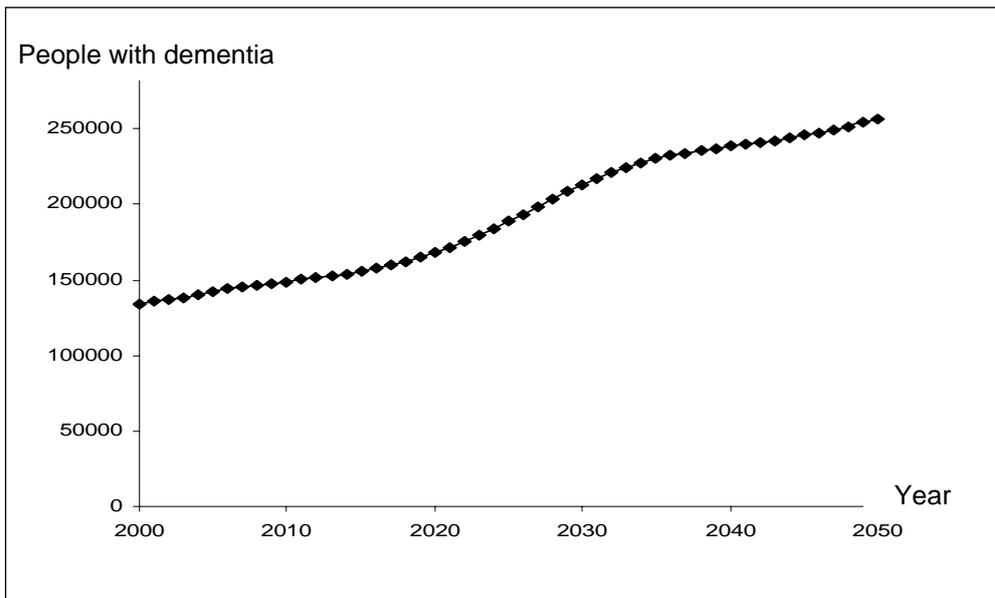
### **1.3 COGNITION**

The relationship between increasing age and cognitive impairment is well known and explored (Fratiglioni et al. 2000; von Strauss et al. 1999). Cognitive impairment is associated with increased use of both health and social services (Ganguli et al. 1993b). People diagnosed with dementia have considerably more care needs than non-demented people (Philp et al. 1995). Due to the aging of the population, the actual number of persons with dementia will increase. Estimations have been made that the number of people with dementia in the world will increase from 2.5 million in 2000, to 63 million in 2030, and to 114 million in 2050 (see Figure 4, Wimo et al. 2003).



**Figure 4.** Dementia occurrence (millions) and forecast of dementia occurrence in the world, and divided in less developed regions (LDR) and, more developed regions (MDR), 1950–2050 (Wimo et al. 2003).

In the year 2000, the occurrence of dementia in Sweden was approximately 133 000 (Wimo and Jonsson 2001). In a recent report from the National Board of Health and Welfare this number had increased to 142 200 by the year 2005, and is estimated to increase dramatically over the coming decades (Figure 5).

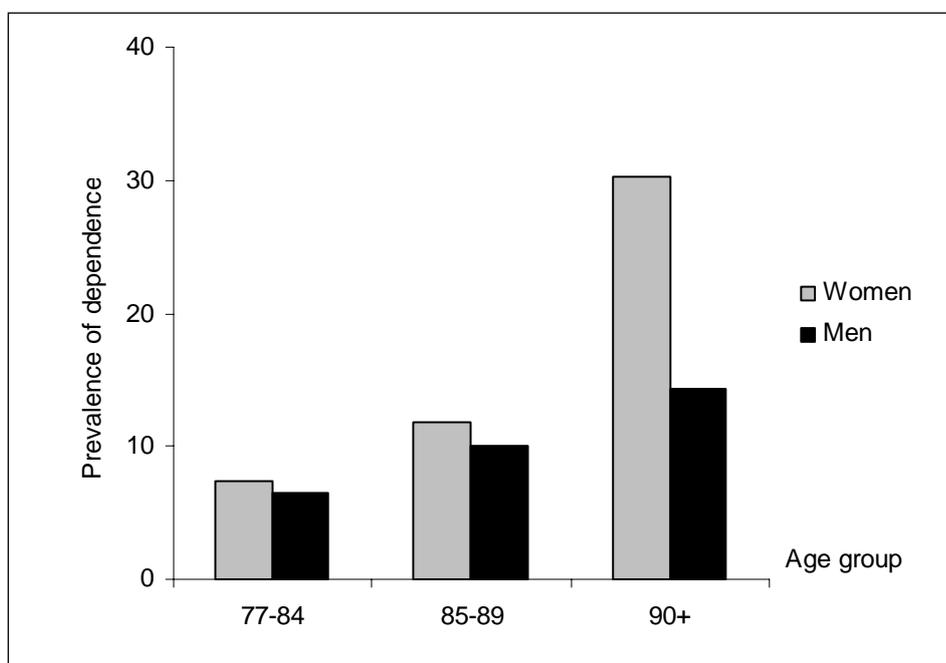


**Figure 5.** Estimations of the number of people with dementia 2000-2050 in Sweden (Wimo et al. 2007a).

## 1.4 PHYSICAL FUNCTIONING

Functional dependency is an age related condition, affecting approximately one third of 75+ years old people (Aguero-Torres et al. 1998; von Strauss et al. 2003; von Strauss et al. 2000) (Figure 6). The most common way to assess functional ability is to measure ADL tasks, a concept that was introduced in 1963 by Katz et al (Katz et al. 1963). This hierarchical scale consist of six activities that measures level of dependency in basic self-care essential to daily living, such as bathing, dressing, going to the toilet, transferring, continence and feeding. Since then, a number of ADL instruments have been developed e.g., the index of Barthel (Mahoney and Barthel 1965) but also more complex scales, which also aim to measure Instrumental ADLs (IADL; cooking, cleaning, shopping, using transportation, handling finances etc) (George and Fillenbaum 1985; Lawton and Brody 1969).

Several studies have shown that limitations in physical functioning are reliable predictors of formal and informal care (Larsson et al. 2006; Miller and Weissert 2000; Nordberg et al. 2007; Nordberg et al. 2005; Thorslund et al. 1991).



**Figure 6.** Prevalence of functional dependence in at least to ADL-activities. Divided by age and gender (von Strauss et al. 2003).

## 2 AIMS

### 2.1 GENERAL AIMS

This thesis has two general aims:

- To study formal and informal care in relation to dementia
- To study the use of home care in an urban and a rural elderly population

### 2.2 SPECIFIC AIMS

The specific aims in the four different studies (papers I-IV) can be summarized as follows:

**Study I.** To describe the type of activities carried out by spouses when caring for a partner with dementia.

**Study II.** To describe the amount and type of informal and formal care among elderly non-demented and demented persons living at home.

**Study III.** To analyse time use and costs of institutional care for elderly persons in relation to different levels of cognitive and functional capacity.

**Study IV.** To describe physical and mental functioning and use of home care in two elderly populations: one living in an urban area and one living in a rural area.

To detect geographical differences in physical and mental functioning as well as in-home care.

## **3 MATERIAL AND METHODS**

Three populations were used for this thesis. For the first study, eight cohabiting couples recruited from an eldercare clinic were included. In Studies II-IV data derived from the Kungsholmen-Nordanstig Project. In Study IV data from both the Kungsholmen Project and the Kungsholmen-Nordanstig Project were used in order to fulfil the aims.

### **3.1 THE OBSERVATIONAL STUDY (STUDY I)**

#### **3.1.1 Description of the population**

The sample consisted of eight cohabiting couples, where one of the spouses was the primary caregiver for a partner suffering from a demanding disorder. A further criterion for participation was that the spouse had total responsibility for the provision of care and support with no assistance from formal services. The care-receivers consisted of six men and two women with a mean age of 75 years (range 71-85). Participants were at different stages of the disease and, thus, dependent upon their spouses for managing their daily living in varying degrees. The couples had all been married for more than 40 years.

#### **3.1.2 Recruitment of participants**

The subjects in this observational study were recruited from an eldercare clinic at a hospital in Stockholm where one partner in each couple had been examined and classified as having Alzheimer's disease or another form of dementia. Permission to contact the spouses was obtained through a senior nurse at the clinic. The caregivers were first contacted by one of the two observers through telephone to make appointment for a first visit.

#### **3.1.3 Data collection**

The participants were first visited by the observer in their home to obtain a broad view of their situation, to get to know each other and develop trust. The observations were conducted by two researchers (first two authors in the paper). During this first meeting the caregivers and the care-receivers were given detailed information

regarding the nature of the study and its purpose. This information was given both verbally and in writing. Informed consent was obtained. The participants were all informed of their right to withdraw at any point from the study without pressure or sanctions (Grafstrom et al. 1995; von Strauss et al. 1998). To avoid disturbing the daily routines, as well as not changing anything in the environment or the behaviour, the importance of the observer staying in the background and not interfering was emphasized (Polit and Beck 2006; Polit 2007).

Data was gathered both through observations and conversations. Open ended informal interviews to get additional information about the care activities and to obtain details of situations not possible to witness were also carried out (Bailey 1996; Polit 2007). These interviews were mutual since both researchers and the couples observed were engaged in dialogues where feelings, impressions etc., were shared (Bailey 1996; Trochim 2006).

To cover a whole day, the observations were performed during two consecutive days; one morning and one afternoon. The two observers simultaneously and independently performed the first two observations. The third author assessed the comparability of these observations. Thereafter, the two observers performed three observations each. The attention during these observations was directed towards the caring activities performed, but also to the interaction between spouses. The observers did not participate in the daily activities but did respond if spoken to.

Field notes were made after the first visit. During the observation activities, behaviours and interactions were discretely noted as word/short sentences and mental notes. However, no notes were written during informal interviews or conversations but as soon as an opportunity occurred. Immediately after each observation, all the notes about observed events, interactions and informal interviews were completed and transcribed, as well as notes regarding physical environment and other impressions. This was made to provide a transcription for data analysis.

#### **3.1.4 Qualitative analysis**

A qualitative approach was chosen to describe patterns of spousal caregiving in dementia care. The transcribed text was content-analysed, where the analysis focused on both manifest and latent content. This method was used to give a systematic

description of the observations. Manifest content can be described as “what the text says”, and latent content as “what the text talks about”. Latent content can therefore be seen as the deeper meaning expressed in the message. (Berg 2004; Graneheim and Lundman 2004; Polit and Hungler 1999). When subcategories were created these grouped the content that shared commonality. This refers mainly to a descriptive level of content and could, therefore, be seen as the manifest content of the text.

Combining subcategories into categories and themes was a way to link underlying meanings together, which could be seen as the latent content of the text (Graneheim and Lundman 2004). Polit and Beck (2006) claims that in qualitative studies, analysis and interpretation of data occur almost simultaneously, and that the interpretation of the data starts when researchers categorize and combine data into categories and themes.

The multi-step data analysis started with several readings of the transcribed text in order to search for meaning and deeper understanding of the content of the caregiving situations for each couple. The reading was followed by a process of open coding where the text was examined sentence by sentence. Meaning units focusing on the caregiving situation were identified. To ensure that texts with similar content were placed in the same meaning unit, comparisons of differences and similarities were made continuously.

The second step of the analysis involved condensing and grouping the meaning units into nine subcategories. The subcategories were given names that were most logical to the data they represented. In the third step, the nine subcategories were combined into four categories, which in the final step of the analysis yielded two broad themes.

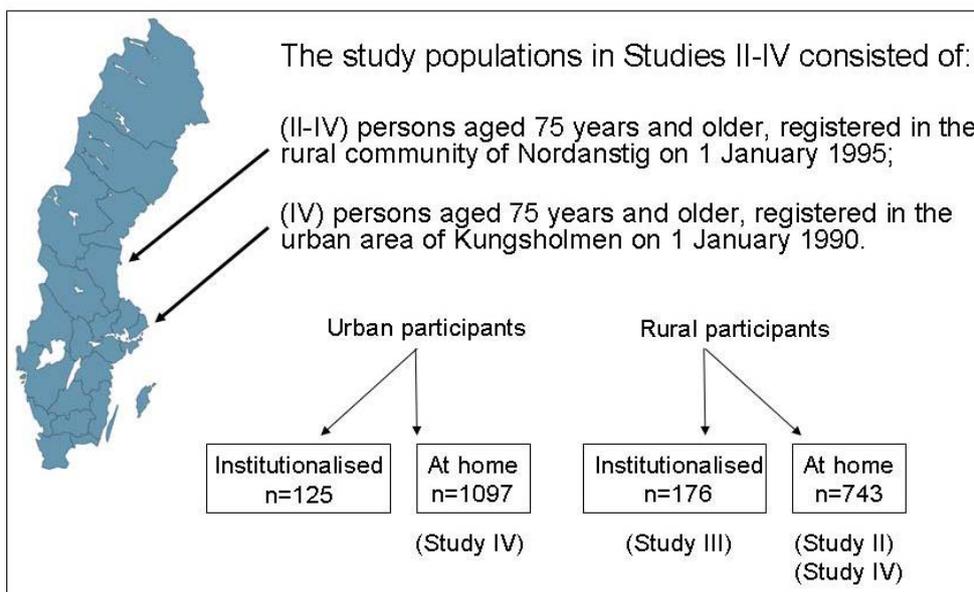
### **3.2 THE KUNGSHOLMEN PROJECT (STUDIES II-IV)**

Data for Studies II-IV were collected from a longitudinal, population-based study on aging and dementia ongoing in the central part of Stockholm between the years of 1987 to 2000 (Fratiglioni et al. 1991; Fratiglioni et al. 1992b). The name of the project, the Kungsholmen Project, is derived from the area in the city where the study population was originally located. In 1995, the rural area of the municipality of Nordanstig was included and, thus, this part of the project was named the Kungsholmen-Nordanstig Project (Klarin et al. 2003; Nordberg et al. 2005), see Figure 7.

### 3.2.1 Description of the population

At the time of the study, the city of Stockholm had 674,000 inhabitants, and 15,000 of them lived in the area of Kungsholmen. The rural municipality of Nordanstig, located in the Hälsingland County 330 km north of Stockholm, had approximately 11,000 inhabitants. This coastal district has no city or central areas- instead there are several small villages- and covers an area of 1,463 square kilometres. The largest village is Bergsjö with approximately 3,100 inhabitants.

Studies II and III used data from the Kungsholmen-Nordanstig Project only and study IV used data from both cohorts using the first follow-up of the urban population as baseline.



**Figure 7.** The study populations of the Kungsholmen and Kungsholmen-Nordanstig Projects in Studies II-IV.

### 3.2.2 Recruitment of participants

Both the urban and rural areas used the same procedure in their recruitment of participants. All inhabitants in Sweden are registered and identified according to their residency, and lists of all inhabitants in the studied areas were obtained from the local authorities. All inhabitants, aged 75 years and older, were invited to participate in the project through a personal letter describing the outline and purpose of the study. In this letter the importance of participation was explained, but it was also clearly stated that participation was voluntary and that they could discontinue at any time. A nurse

contacted the potential participants by telephone, to check their availability. At their first appointment written informed consent was obtained.

All inhabitants in the two areas were included, whether living at home or in an institution. The examination took place either at the research center or in the subject's home (apartment, service building, house or nursing home, depending on their living place).

### **3.2.3 Data collection**

All participants, whether living at home or in an institution, were examined using the same standardized protocols in both living areas. At each contact, nurses measured functional status and assessed cognitive status with brief cognitive tasks (Folstein et al. 1975; Katz et al. 1963). This assessment also included a social interview and laboratory tests. In addition, all persons were clinically examined by a physician, and in the urban part of the study population trained psychologists examined the participants with a neuropsychological battery. No psychologists were available in the rural Nordanstig, so the psychological testing was restricted to basic diagnostic tests performed by nurses.

The clinical examination was similar to a comprehensive physical, neurological and psychiatric examination usually performed in clinical practice, but was structured and defined with scoring criteria. At the end of the examination, the physician made diagnoses of current diseases according to standardized criteria. All diagnoses were reviewed by two senior clinicians (Fratiglioni et al. 1992a).

In addition, a proxy interview with a next-of-kin or other close person was carried out. Information on specific topics, such as detailed occupational life history, caregiver burden and information on home help and home services were collected. The family interview also concerned past and current health status of the subjects, as well as selective risk factors of the most common diseases. If the subject's answers were incomplete or if s/he was diagnosed with dementia, information was obtained from the proxy interview.

### **3.2.4 Study variables**

All variables were collected during the examination and/or through an interview with a proxy.

#### *Socio-demographic variables*

The socio-demographic variables used in these studies were age, gender, marital status, education and living situation. Education was assessed as the highest educational level achieved.

Living situation included living at home or in institution, alone or together with someone (cohabitation). The participants in both areas either lived at home (apartment or house), in sheltered accommodation (service building), or in an institution (nursing home). The setting “service building” was slightly different in the two areas. In the urban area, living in a service building meant having your own apartment in a block of flats. In the rural community of Nordanstig there was no difference between a service building and an institution, and they were both staffed around the clock. People in the rural population living in either place were dependent. This was not the case for people living in a service building in the urban population where the dependency level was lower. Due to these setting differences, participants living in service buildings were regarded as living at home in the urban population, and as living in institution in the rural population.

#### *Physical functioning*

Physical functioning was measured with the Katz ADL index (Katz et al. 1963). This measure is based on a hierarchical scale formed by six activities: dependency in bathing, dressing, going to toilet, transferring, continence, and feeding. Level of dependency was expressed in grades, 0 being the most independent (requiring no personal assistance in any of the six activities) and 6 being the most dependent grade (requiring assistance in all six activities). Good reliability and construct validity of this scale, when administered by nurses, have been previously reported (Brorsson and Asberg 1984). In the Kungsholmen Project, as well as in the Kungsholmen-Nordanstig Project, nurses collected the data by questioning and by observing the subjects or by asking an informant.

### *Mental functioning*

Mental health included assessment of cognitive function, dementia diagnosis, and evaluation of dementia severity.

*Cognitive function* was measured by the MMSE (Folstein et al. 1975) and was administered by nurses. The MMSE is a brief psychometric test that takes approximately ten minutes to administer and test various cognitive domains, such as memory, orientation, attention and calculation, as well as the ability to name and to follow verbal and written instructions, to write a sentence spontaneously and to copy a complex figure. The test ranges from 0 to 30, with the highest score being indicative of intact cognitive functioning. If a question could not be completed due to physical disability, or if a subject refused to answer a question, a score of zero was given. It is widely used internationally and is frequently used as a screening test in neurological and geriatric clinics. The Swedish version of this psychometric test (Grut et al. 1993) was used, with a score <24 indicating cognitive impairment.

*Dementia diagnoses* were made according to the Diagnostic and Statistical Manual of Mental Disorder, Third Edition, Revised (DSM-III-R) including a combination of findings from the medical examination, cognitive testing, patient history as well as information from the proxy, and followed a three-step diagnostic procedure (Fratiglioni et al. 1992a; Fratiglioni et al. 1997): (1) the examining physician made a first preliminary diagnosis; (2) all cases were then independently reviewed by a specialist who made a second diagnosis, and (3) in case of disagreement, a third opinion was requested from a senior physician before the final diagnosis was accepted.

*Dementia severity* was measured according to the Washington University Clinical Dementia Rating Scale (CDR) (Berg 1988; Hughes et al. 1982). In this scale, cognitive impairment is rated in six categories: memory, orientation, judgment, and problem solving, community affairs, home and hobbies, and personal care. From the ratings of these categories the global CDR was established following an algorithm that results in five different levels: CDR=0 (not demented), CDR=0.5 (questionable dementia), CDR=1 (mild dementia), CDR=2 (moderate dementia) and CDR=3 (severe dementia). The staging of the CDR was completed by a physician.

### ***Physical health***

Physical health was assessed by the physician during the clinical examination and, if necessary, with the support of an informant. In the studies reported here (Studies II & III) only current diseases were included. Diagnoses were made according to the International Classification of Diseases – Ninth Revision (ICD-9) (World Health Organization, 1987). A modification of the Charlson co-morbidity index was used to measure co-morbidity (Charlson et al. 1987; Klarin et al. 2005), including eight diagnoses; myocardial infarction, congestive heart failure, cerebrovascular disease, chronic pulmonary disease, connective tissue disease, diabetes mellitus, renal disease and malignancy, but excluding dementia.

### ***Formal and informal care***

Three concepts need to be addressed under this paragraph: *formal care*, *informal care* and *private services*.

The term *formal care* in this thesis refers to care provided on an organised basis, either home-based care or institutional care by professionals from social and/or health organizations, and usually received for pay. The care can be both personal and instrumental.

*Informal care* refers to care provided by someone close to the elderly person, usually a husband/wife or a child, but this care provider can also be another family member, or a friend. This care is usually provided without financial payment, also in-home or in an institution.

Finally *private services*, e.g., cleaning, were included in formal care as it was received for pay, and few of the elderly used this type of service.

The information on use of home care was obtained by the nurse asking the person or a proxy the following question: “Do you receive any practical assistance at home from: 1) a co-resider; 2) a next-of-kin or a friend outside the household; 3) a voluntary organization; 4) a privately paid service; 5) community home help services.

Alternatives 1 to 3 were considered as informal care and, consequently, alternatives 4 and 5 were considered as formal care. Studies II and IV included only in-home care, whereas Study III included care giving in institutions.

Furthermore, in Studies II and III number of hours spent on formal and informal care was examined by the Resource Utilization in Dementia instrument (RUD) (Wimo 1998). This instrument is focused on time spent on the basic components of care in terms of support in ADL, IADL (i.e., complex activities such as meal preparation, shopping, laundry, etc.) and supervision/surveillance. The risk of dangerous events such as risk of fire, risk of losing one's way, nocturnal anxiety, and risk of falling or other accidents is related to the supervision/surveillance part of this instrument. The subjects as well as the next-of kin were asked about the situation during the past four weeks. Some caregivers stated that the need for supervision/surveillance constituted the whole period even if they also supported the patients in ADL/IADL activities. In these cases, the ADL/IADL figures were subtracted from the figures of supervision/surveillance, because the total figure would otherwise extend to 24 h. As a consequence of this correction, the need for supervision/surveillance may be underestimated. In the RUD instrument, assumptions are made that all caregiving activities can be described in the three main categories: ADL, IADL and supervision (Wimo et al. 2000; Wimo et al. 2002), regardless of whether these activities are performed by professional staff or informal caregivers.

### **3.2.5 Statistical analysis**

#### **Study II**

Only subjects living at home were included in the data analysis. Gender specific prevalence figures for socio-demographic data, mental health and disability were calculated, as well as mean values for the number of hours of formal and informal care received.

Tobit regression analyses, with age as a covariate, were carried out to identify different aspects of dementia care (Breen 1996; Kmenta 1986). The dependent variables were the amount of formal and informal care and the independent variables were various aspects potentially influencing dementia care such as gender, age, dementia severity (CDR) (Berg 1988; Hughes et al. 1982), cognition (MMSE) (Folstein et al. 1975), physical functioning (Katz index of ADL) (Katz et al. 1963), co-morbidity and co-habitation. Due to the fact that many participants were not in need of any support in order to manage their daily lives, the amount of formal and

informal care were not normally distributed and extremely skewed. With such a distribution it was not appropriate to use ordinary linear regression. The zero censored observations were treated as if they had been at risk for receiving formal or informal care but it did not take place, and the values censored at 24 as if they, hypothetically, had been at risk of receiving more than 24 h of care. However, the results from a Tobit analysis are interpreted in the same way as an ordinary linear regression (Breen 1996; Kmenta 1986).

### **Study III**

Mean values and 95% Confidence Intervals (CI) for the number of hours of formal and informal care received by participants living in institutions were calculated. Due to the similar skewed distribution as described in Study II, Tobit regression analyses were used to identify determinants of the amount of formal support received by the institutionalized subjects (Breen 1996; Kmenta 1986). In these analyses, the dependent variable was the amount of formal care, separately for ADL time, IADL time and on the total amount of formal care including supervision. Dementia and physical functioning were used as independent variables. Finally, a cost model was constructed to calculate the costs corresponding to the use of care. In this model assumptions were made that the average number of hours in support of ADL and IADL functions is directly correlated to the average cost per day of institutional care in the area where the study was conducted i.e., 1200 Swedish kronor (SEK) (equal to €130 or US\$ 150, as of December 2005).

### **Study IV**

Age and gender specific prevalence figures for socio-demographic characteristics, functional status and use of formal and informal care were calculated. Age and gender distributions of the studied variables were tested with chi-square tests. Logistic regression analyses were used to verify possible area differences in use of home care, and physical and mental functioning. Finally, to detect factors that could explain area differences in use of informal and formal care, univariate and multivariate multinomial logistic regressions analyses were conducted. Odds ratios (OR) and 95% CI were calculated based on the normal distribution (Rothman and Greenland 1998). To explore the association with use of formal care and living area age, gender, education, cognition, disability and use of informal care were introduced as covariates. Factors associated with use of in-home care were analyzed using a four-

class dependent variable; having informal care only, having formal care only, or having both informal and formal care as dependent categories, with no use of in-home care as the reference category. To verify differences in use of formal care, analyses using a three-class dependent variable were performed; use of formal care weekly or a few times per week, and use of formal care daily were the dependent categories, whereas use of no formal care or less than weekly was the reference category.

## 4 ETHICAL CONSIDERATIONS

When conducting research involving humans it is of utter importance to make careful ethical considerations. This is even more important when the research involves elderly with a fair proportion of frail and/or cognitively impaired persons (Barron et al. 2004; Locher et al. 2006; McGloin and Ostfeld 1996). Further more, in Studies II-IV, the persons invited to participate were part of the general population as opposed to e.g., healthy volunteers. It is, therefore, important to consider how these elderly persons were approached and how they consented to participate. All potential participants for all studies included in this thesis were sent a personal letter of invitation, explaining the content, duration and aim for of the project. This letter clearly stated that participation was voluntary and that they could withdraw from the project at any time. The potential participants were then contacted via telephone by a nurse and asked whether or not they agreed to participate. Written informed consent was obtained during the first visit, including consent to interview a next-of-kin or other close person. One of the more difficult issues regarding research on elderly concerns how to receive informed consent from persons with cognitive impairment (Berghmans and ter Meulen 1995; Bowsher et al. 1993; Grafstrom et al. 1995; McGloin and Ostfeld 1996). If s/he was severely cognitive impaired, a proxy was asked for consent (usually a close family member). It was agreed that the examination or interview should be interrupted if the person in any way expressed anguish or discomfort, regardless of whether informed consent had been given by the person her/himself or by a proxy.

In the observational study, Study I, the research method used required special ethical considerations. Using observations to collect data, the researchers conducting the observations come into close contact with the participant. There is always a risk that personal and private boundaries are crossed (Dickson-Swift et al. 2006; Sixsmith et al. 2003). In this study the researchers acted carefully to ensure integrity and to maintain respect for the participants, the caregiving spouses as well as the care-receiving spouses, was high. In addition, the participants were visited for a further interview where they were asked about lifetime history and motives for taking the responsibility to care for their spouse. When performing observations such as these it is important to exit the field with care, something that may be more difficult than entering (Merriam 1998). After the observations were finished, the researchers also

contacted the participants by telephone in order to follow-up on how the couples were getting on.

All studies included in this thesis have been approved by the ethics committee of Karolinska Institutet, Stockholm, Sweden; Study I Dnr: 97-070, Study II and Study III Dnr: 94-122 and Study IV Dnrs: 90-251 and 94-122. In addition, all researchers working with the Kungsholmen Project and the Kungsholmen-Nordanstig Project databases follow the guidelines of the Swedish Council for Research in the Humanities and Social Sciences (HSFR): the principles of autonomy and integrity, the rule of consent and the demand for research (HSFR 1991).

## 5 RESULTS

The general aim of this thesis was to describe the use of formal and informal care in the elderly population (75+ years), whether living at home or in institutions, in an urban or a rural habitat. Below the main results will be presented separately for each study included in this thesis.

### 5.1 STUDY I: Patterns of Elderly Spousal Caregiving in Dementia Care: an Observational Study

The aim of Study I was to describe and understand caring activities performed by cohabiting caregivers when caring for a partner with dementia, and to describe how these activities were carried out. In Table 1 the characteristics of the eight couples (family caregivers as well as the persons with dementia) participating in Study I are presented.

**Table 1.** Characteristics of the participating couples in Study I.

	Caregivers	Care receivers
<b>Number of participants</b>	8	8
<b>Age (years)</b>		
Mean (Range)	74 (69-81)	75 (71-85)
<b>Female gender (%)</b>	75.0	25.0
<b>Length of marriage (years)</b>		
Mean (Range)	46 (40-54)	46 (40-54)
<b>MMSE</b>		
Mean (Range)	-*	14 (0-24)

\* MMSE was not tested in caregivers

The content analysis resulted in four categories, which included nine subcategories. Finally, two broad themes emerged from the analysis, Spousal caregiving and Togetherness (Table 2). All spouses performed demanding every day caregiving tasks, both personal and instrumental. Simultaneously they supervised and interacted with their demented spouse. During all these caring activities, a clear sense of togetherness appeared.

**Table 2.** Content analysis of the observations leading to the themes of spousal caregiving and togetherness.

Meaning units	Subcategories	Categories	Themes
Caregiving activities and interactions	Hygiene/dressing-undressing	Activities of daily living (ADL)	Spousal caregiving
	Meals/medicine		Togetherness
	Communication/interaction	Communication	
	Empathy/thoughtfulness		
	Nearness		
	Supervision	Supervision/surveillance	
Reminders			
	Physical activity	Activity/stimulation	
	Mental stimulation		

### 1. Activities of daily living (ADL)

The demented elderly in this study were all in need of help with their personal hygiene. Caregivers addressed this in various ways e.g., one couple found it natural to shower together. Some of the care receivers could manage to wash and get dressed if their spouses guided them through the procedures, while others needed help with most tasks. All meals observed during the study were prepared by the caregivers as who also took care of medications. All but one could manage eating by themselves, if reminded at regular intervals. The caregivers were all anxious to do their very best.

*For supper Mr A serves yoghurt, sandwiches and fruit. He is very anxious that they get a lot of vitamins, and earlier he and his wife went to the woods to pick a herb that he has read about and says is good for the memory. Mr A rinses them, slices them and puts them on the bread. 'We shall make you well' he says, and pats his wife on the shoulder. Mrs A has diabetes and her husband is careful that she does not get food that is too fat or sweet. With the meal, he also gives the prescribed medication.*

### 2. Communication

This second category, communication, also included empathy and nearness. None of the participants with dementia could take part in continuous conversations anymore, but their spouses kept talking and answering even though the same questions were repeated over and over, and despite not receiving an answer.

*Mr B does a crossword in the newspaper. Sometimes he asks his wife about some words. Even if Mrs B does not know and cannot be helpful any longer, it seems that she is participating and enjoys it.*

### **3. Supervision/surveillance**

The caregivers in this study needed to ensure the safety of their spouses. They were constantly worried that their partners would get lost. Supervision covered most of the day for several of the participating couples. Another way to ensure safety was to rearrange the environment; to take away carpets to avoid potential falling and to remove objects that could cause injury. All demented elderly had lost their capacity of taking initiative. Thus, their spouses needed to support them by reminding and guiding them in all activities. This repetition of directions required the caregivers' attention most of the day.

*Mrs D gets a telephone call. When finished, she immediately wonders where her husband is and walks around to find him. He has previously, on several occasions, left the house and not found his way back. Mrs D worries that it will happen again.*

### **4. Activity/stimulation**

The final category was activity/stimulation. Caregivers were concerned that their partners should be active and get stimulation both physically and mentally in order to have as normal life as possible. After a long life together, caregivers were aware of their partner's needs and interests, and were able to choose activities that they knew would please them.

*In order to keep Mr H's motor ability intact as long as possible, the couple goes for a walk almost every day, also at the time of the observation. Mrs H places her husband on the bed so that she can dress him. This is quite hard work as Mr H is stiff and unable to cooperate. The procedure must be repeated, as the husband stands up and walks away when his wife leaves him for a moment to pick up clothes. During the last part of the walk, Mr H is pushed in a wheel-chair because he must have enough energy to walk up the three flights of stairs to their apartment, as their block of flats lacks an elevator.*

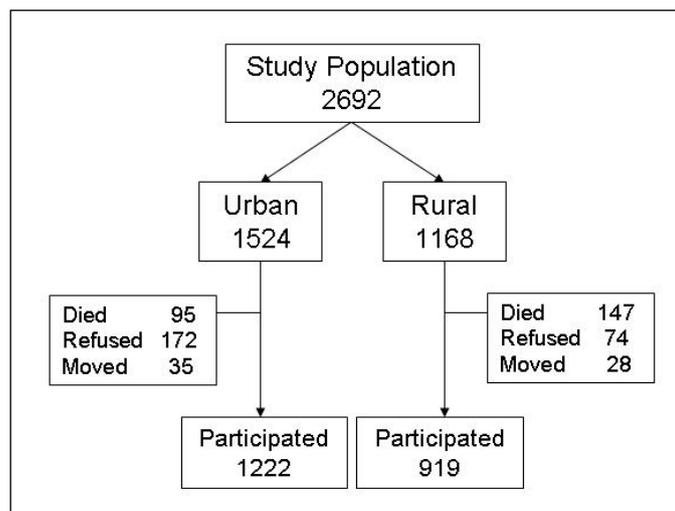
Each caring situation was unique and dependent on the dementia severity.

Nevertheless, all caregivers shared noteworthy similarities in their caring role: a) their

lives had changed and they had given up most of their own lives; b) they had assumed a new role in the marriage as they changed from being an equal partner to becoming a caregiver; and c) caregiving entitled a fulltime responsibility for planning, decisions and assignments in the home, responsibilities that had previously been shared with the partner. No difference was observed between husbands and wives in the pattern of caregiving.

## 5.2 STUDIES II-IV: The Kungsholmen and Kungsholmen-Nordanstig Projects

Eighty percent of the invited 2692 inhabitants in the urban Kungsholmen parish and the rural community of Nordanstig participated in the data collection. Nine percent had died, 2.3% had moved from the areas before examination, and 9.1% refused to participate. There were no significant differences in reasons for dropping out between the areas concerning moving, whereas almost reverse figures appeared for refusal and death (11.3% and 6.2% in the urban area, and 6.3% and 12.6% in the rural area). There were no significant age- or gender differences between participants and non-participants. Rural participants were more often living in institutions compared to urban participants, 19.2% and 10.2% respectively ( $p < 0.001$ ), and this pattern was evident for both genders and in all age groups (Figure 8).



**Figure 8.** The study populations of the Kungsholmen Project and the Kungsholmen-Nordanstig Project in Studies II-IV, drop-outs by causes, and number of participants.

Table 3 shows the socio-demographic characteristics, and physical and mental functioning of the participants in Studies II, III and IV.

**Table 3.** Socio-demographic characteristics, physical and mental functioning of the study populations for Studies II-IV.

	<b>Study II</b> Rural pop At home		<b>Study III</b> Rural pop Institution		<b>Study IV</b> Rural & Urban All	
<b>Number of participants</b>	740		176		1840	
<b>Age (years)</b>						
Mean $\pm$ SD	81.8 $\pm$ 4.2		84.6 $\pm$ 5.6		82.6 $\pm$	
Range	75-98		75-98		75-100	
	n	%	n	%	n	%
<b>Female gender</b>	433	58.5	107	60.8	1265	68.7
<b>Marital status</b>						
Married	297	40.2	36	20.8	570	31.0
Unmarried/divorced	66	8.9	31	17.9	339	18.4
Widowed	376	50.9	106	61.3	930	50.6
<b>Education</b>						
Elementary (2-7 yrs)	673	92.4	155	93.4	1208	65.8
High school/vocational (8-14 yrs)	51	7.1	10	6.0	544	29.6
University/adv studies (15+ yrs)	4	0.5	1	0.6	85	4.6
<b>Disability (Katz index)</b>						
No disability (0-1)	702	95.0	59	33.7	1758	95.8
Partial disability (2-4)	31	4.2	54	30.9	60	3.3
Disability (5+6)	6	0.8	62	35.4	17	0.9
<b>MMSE Mean (<math>\pm</math>SD)</b>	25.2	( $\pm$ 4.8)	13.9	( $\pm$ 9.3)	25.4	( $\pm$ 4.8)

### 5.3 STUDY II: The Amount of Informal and Formal Care Among Non-Demented and Demented Elderly Persons - Results from a Swedish Population-Based Study

This study aimed to describe the amount of formal and informal care given to non-demented and demented elderly persons. Data derived from 740 participants living at home in the rural population-based sample.

The overall dementia prevalence was 9.9% (CDR 1-3) while 7.6% were classified as having questionable dementia (CDR 0.5). Most people had no functional disability,

95% had 0 or 1 on the Katz ADL scale. There was no gender difference in disability or in dementia prevalence.

The amount of informal care was much greater than the amount of formal care, and also greater among demented compared to non-demented. For non-demented subjects, the relation between informal versus formal care was 4:1 (0.4:0.1) and almost 6:1 (5.8:1.0) for subjects with dementia. A relation was found between the severity of cognitive decline and informal care, while this pattern was weaker regarding formal care (Table 4).

**Table 4.** Number of subjects and the amount of formal and informal care among non-demented and demented subjects according to CDR.

	Formal care		Informal care	
	n	h/d*	n	h/d*
<b>CDR</b>				
0	601	0.1	600	0.4
0.5	55	0.5	55	1.1
1	38	0.7	38	2.0
2	27	1.2	27	8.3
3	7	1.5	7	16.1
1-3	72	1.0	72	5.8

\* hours per day

To investigate the relation between cognitive decline and informal and formal care Tobit regression analyses, with age as a covariate, were carried out. The results revealed a clear association between the number of hours of informal care and cognitive decline. For example, people with mild dementia (CDR=1) had 3.8 hours per day more informal care than non-demented people (CDR=0). The corresponding figure for people with moderate dementia (CDR=2) was 11.6 hours. Although not significant, the same tendency was found for formal care, where people with mild dementia (CDR=1) received 1.7 hours more care per day and people with moderate dementia (CDR=2) received 2.8 hours more care per day when compared to the non-demented group (Table 5).

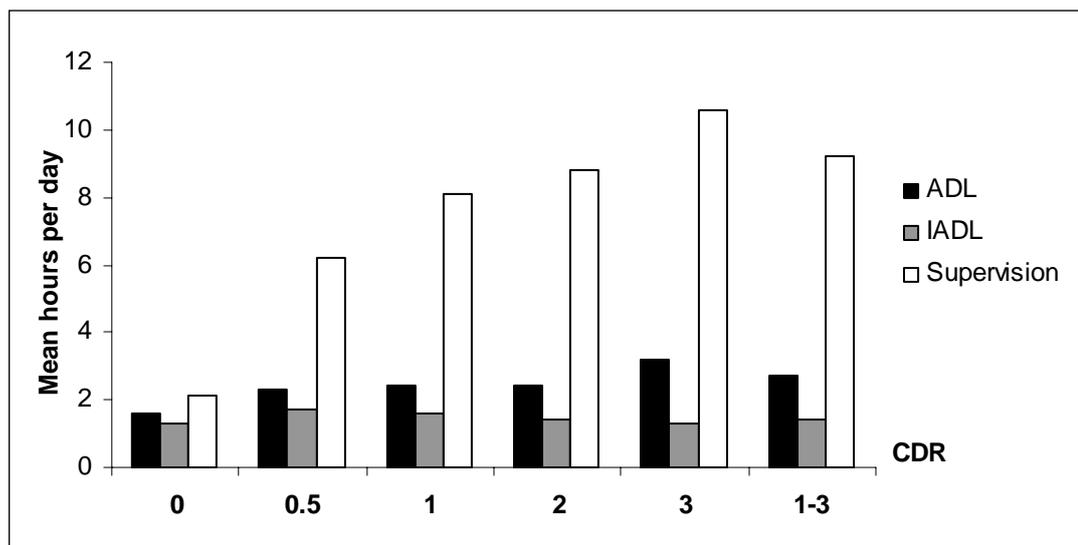
**Table 5.** Informal and formal care in relation to cognitive decline according to CDR for people living at home. Results derived from Tobit regression models adjusted for age. Reference category marked with “Ref”, expressed as hours per day (h/d) and 95% confidence intervals (95% CI).

CDR	Informal care		Formal care	
	h/d	95% CI	h/d	95% CI
0	-	Ref	-	Ref
0.5	2.5	0.9-4.1	1.8	1.0-2.5
1	3.8	1.9-5.6	1.7	0.9-2.6
2	11.6	9.5-13.6	2.8	1.9-3.8
3	19.5	16.3-22.8	3.6	1.9-5.4

#### 5.4 STUDY III: Time Use and Costs of Institutionalised Elderly Persons with or without Dementia: Results from the Nordanstig Cohort in the Kungsholmen Project -a Population-Based Study in Sweden

The aim for Study III was to analyse time use and costs in institutional care in relation to different levels of cognitive and functional capacity. Data were derived from a population-based sample consisting of all institutional inhabitants, 75+years old, living in a rural community (n=176). Sixty-two percent of the subjects living in institutions were demented. There were no significant differences between women when compared to men, even though the dementia prevalence was higher in women.

The amount of formal care for support in ADL was significantly higher among people with dementia (CDR=1-3) compared to non-demented people (CDR=0), 2.7 h/d versus 1.6 h/d. Although there was a tendency of a higher amount of formal ADL care at higher CDR stages, this was not statistically significant (Figure 9). When IADL and supervision were included, the total amount of formal care for people with dementia increased almost five times (13.3:2.7), whereas the ratio for non-demented people was approximately three times (5.1:1.6).



**Figure 9.** The crude amount of formal care, expressed in hours per day (h/d), among non-demented and demented subjects according to CDR. Distribution among ADL, IADL, and supervision.

There was also a significant association between functional disability and use of formal care time for ADL with an increased use of formal care with more than 1 h for each level of disability. Moreover, the results revealed some contributions from informal care givers, although the level was low and had no correlation to severity of ADL dependency level.

To reveal the determinants of care time, Tobit regression analyses were performed. These analyses showed that having dementia increased the amount of formal ADL care time by 0.9 h/d when compared to non-demented people. Each loss of an ADL function (0-6) added 0.6 h/d of ADL care time. When the total care time (ADL, IADL and supervision) was introduced, the presence of dementia among people being dependent in one ADL activity added more than 9 h/d compared to non-demented people with the same level of ADL. For people without dementia, each loss of one ADL function added 2.9 h/d of formal care time.

Finally, a cost model was used to explore the costs of institutional care, with the assumption that the average number of hours in support of ADL and IADL functions (not supervision) is directly correlated to the average cost per day of institutional care. In this model, the estimated cost for formal care increased for persons being functional dependent in 5-6 ADL domains by 85% compared to persons with no functional dependency (relative cost 0.71 to 1.32), and by approximately 30% for

demented persons compared to those without dementia (relative cost 0.84 to 1.08) (Table 6).

**Table 6.** Costs in Swedish kronor (SEK) in institutional care\* by functional dependency and dementia diagnosis.

	n	ADL+IADL (hours)	Cost per day (SEK)	Cost per year (SEK)	Relative cost
<b>ADL dependency</b>					
No disability (0+1)	58	2.7	853	311 211	0.71
Partial disability (2-4)	54	3.6	1 137	414 947	0.95
Disability (5+6)	60	5.0	1 579	576 316	1.32
<b>Cognition (CDR)</b>					
Non demented (0+0.5)	65	3.2	1 011	368 842	0.84
Demented (1-3)	107	4.1	1 295	472 579	1.08
<b>All</b>	172	3.8	1 200	438 000	1.00

\* Missing formal care on 4 persons

\* Average number of hours of care in correlation to average cost per day of institutional care

## 5.5 STUDY IV: Home Care in Relation to Physical and Mental Functioning: Comparison of an Urban and Rural Elderly Population

Study IV aimed to describe mental and physical functioning and use of home care in an urban and a rural elderly population (75+ years), and to explore possible geographical differences in physical and mental functioning, and in-home care.

The rural population received significantly more informal care compared to the urban elderly population. An opposite direction was found for formal care, where more elderly in the urban population had formal care. There were no area differences in physical functioning whereas rural elderly were more cognitively impaired after adjustment for age and gender (aOR 1.5, CI 1.2-1.9). This was confirmed by split analyses where both rural men and rural women were more cognitively impaired compared to their urban counterparts (Table 7). Living alone was strongly associated with having informal care, independently of living area, age, gender, education, and physical and mental functioning.

**Table 7.** Home care, physical and mental functioning of the study population in Study IV. Percent distribution divided by living area.

	Urban area n=1097		Rural area n=743	
	n	%	n	%
<b>Home care*</b>				
No help	583	53.6	326	43.9
Informal care	160	14.7	265	35.8
Formal care	243	22.4	81	10.9
Formal and informal care	101	9.3	70	9.4
<b>Physical functioning**</b>				
Independent (0)	995	91.0	672	90.6
Partially dependent (1+2)	75	6.9	50	6.7
Dependent (3-6)	23	2.1	20	2.7
<b>Mental functioning</b>				
Cognitive impairment***	216	19.7	173	23.3

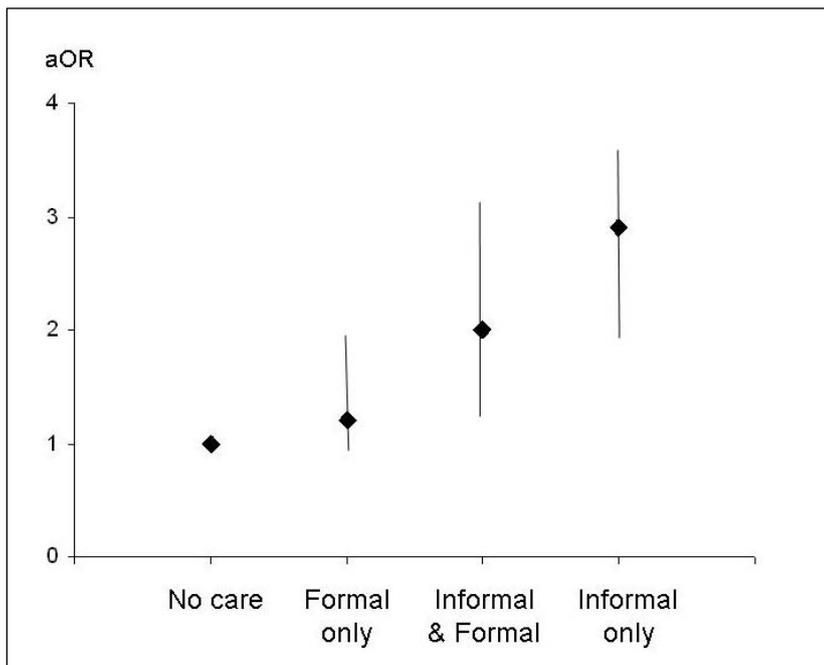
\* Missing data on home care for 10 persons in the urban area and for 1 person in the rural area

\*\* Missing data on physical functioning for 4 persons in the urban area and for 1 person in the rural area

\*\*\* MMSE below 24

Multinomial logistic regression analyses showed that, compared to those with no home care, rural elderly were almost three times more likely to receive informal care (aOR 2.9, 95% CI 2.2-3.8), and two times as likely to receive both informal and formal care (aOR 2.0, 95% CI 1.3-3.1) compared to urban elderly (Figure 10). Multivariate analysis revealed that older age, being disabled and being cognitively impaired were significantly associated with all different care conditions.

Compared to those receiving no formal care, participants in the urban area received more formal care on a weekly basis than the rural elderly population (crude OR 0.4, 95% CI 0.3-0.7), whereas rural participants tended to receive formal care on a daily basis, although not statistically significant. Being physically disabled was the strongest single predictor of receiving formal care daily (aOR 32.6, 95% CI 19.9-53.3). Living alone and having low cognition were also strongly related to daily care (aOR 6.3, 95% CI 3.4-11.8 and aOR 5.5, 95% CI 3.6-8.4 respectively).

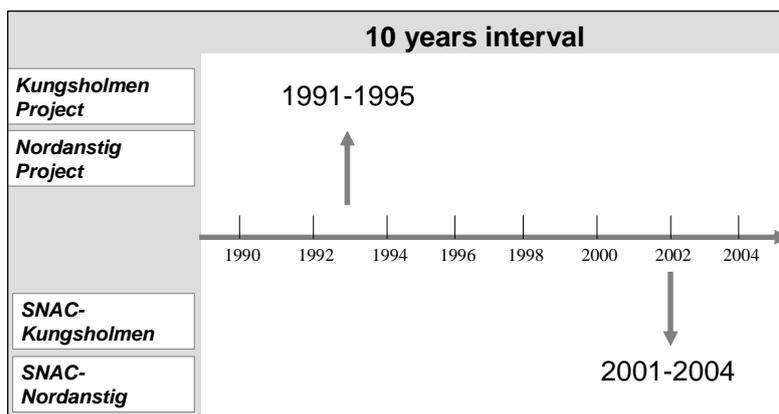


**Figure 10.** Adjusted\* Odds Ratio (aOR) and 95% CI of living in the rural area in relation to use of in-home care. Data derived from multinomial logistic regression analyses using no care as the reference category.

\*Adjusted for age, gender, education, cohabitation, and physical and mental functioning.

## 5.6 FORMAL AND INFORMAL CARE TEN YEARS LATER – Data from the Swedish National study on Aging and Care (SNAC) in Kungsholmen and Nordanstig

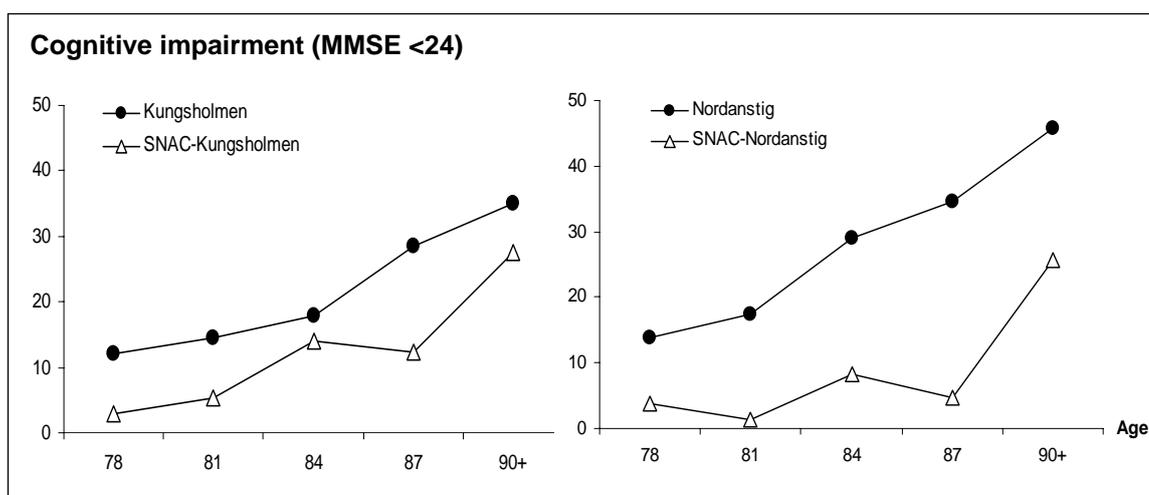
The results in this thesis are based on data from the 1990-ies. In the year 2000 a large, national, long-term, multipurpose study was launched in Sweden – the Swedish National Study on Aging and Care (SNAC) (Lagergren et al. 2004). The study involves four research centers collecting data in four different areas in Sweden, two of these are SNAC-Kungsholmen and SNAC-Nordanstig. Here will be presented unpublished data on physical and mental functioning, and use of formal and informal care at two points in time. Data collection is carried out in the same areas as in the previous Kungsholmen and Nordanstig Projects, and the same research leaders, study design and outline of protocol has been used (Figure 11). This provides a unique possibility to study temporal variations in physical and mental health, as well as use of formal and informal care.



**Figure 11.** Data collection 10 years interval: Kungsholmen and Kungsholmen Nordanstig Projects in 1991-1995, and SNAC-Kungsholmen and SNAC-Nordanstig in 2001-2004.

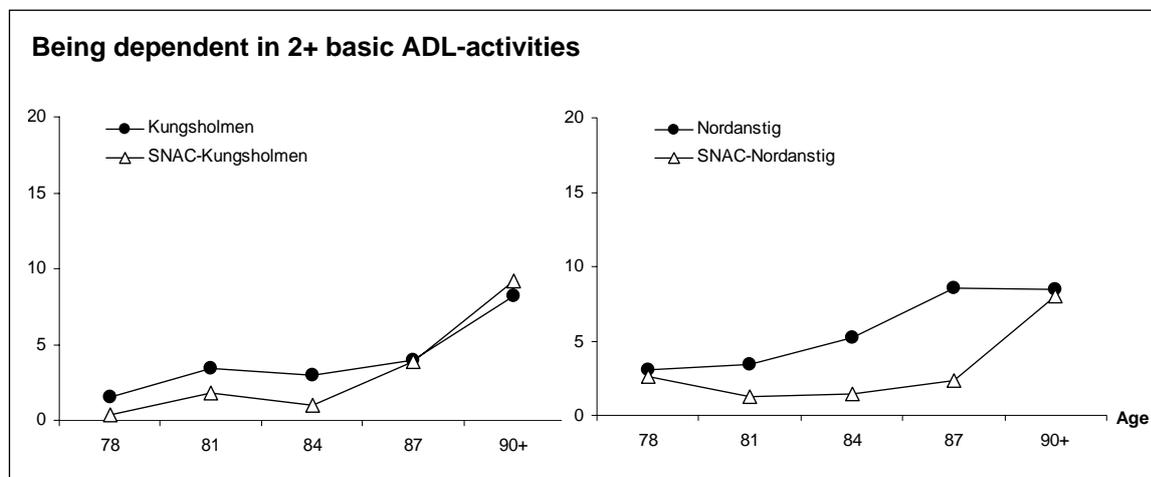
**Data from the Kungsholmen and Nordanstig Projects 1991-1995, and from the SNAC-Kungsholmen and SNAC-Nordanstig ten years later 2001-2004.**

The mental functioning (as measured by the MMSE score) has improved in the population 78+ years who live at home, today compared to ten years ago (see Figure 12). This is especially evident in the rural population, and is probably due to differences in the educational level. In 2001-2004, 17% of the rural elderly population had more than elementary schooling, compared to only 7% ten years earlier. The corresponding figures for the urban area are 70% and 51% respectively.



**Figure 12.** Percentage of persons living at home and having an MMSE-score below 24 at two points in time in the urban (Kungsholmen) and rural (Nordanstig) areas. Distribution by age.

Physical functioning - how one manages basic ADL, has improved in the elderly population 78+ years today compared to ten years ago. This is especially evident in the rural population (see Figure 13).



**Figure 13.** Percentage of persons living at home and being dependent in two or more basic ADL activities at two points in time in the urban (Kungsholmen) and rural (Nordanstig) areas. Distribution by age.

Use of in-home care has decreased from 1991-1995 to 2001-2004. This is especially evident in use of formal care only. Use of both informal and formal care has increased in both areas. The area differences remain as the rural elderly population receives more informal care, and the urban elderly receive more formal care, especially in the older ages (see Table 8).

**Table 8.** Use of in-home care in an urban an rural elderly population at two points in time; 1991-1995 and 2001-2004.

		HOME CARE*							
		1991-1995				2001-2004			
		No care	Informal only	Formal only	Informal and formal	No care	Informal only	Formal only	Informal and formal
		%	%	%	%	%	%	%	%
<b>Urban area</b>									
<b>Age</b>									
	78	72.7	10.6	14.4	2.3	79.2	9.4	7.8	3.6
	81	61.9	16.8	17.2	4.1	69.1	14.8	7.6	8.5
	84	52.1	20.9	20.5	6.5	62.9	14.6	12.3	10.2
	87	37.0	12.2	33.5	17.3	44.8	15.6	24.0	15.6
	90+	22.3	17.8	34.4	25.5	24.5	18.7	23.2	33.6
<b>Rural area</b>									
<b>Age</b>									
	78	60.1	31.4	4.9	3.6	66.7	25.6	2.6	5.1
	81	50.0	33.7	9.6	6.7	60.3	33.3	2.6	3.8
	84	32.3	38.7	14.8	14.2	46.5	32.9	5.5	15.1
	87	30.9	29.6	23.5	16.0	23.3	46.5	0.0	30.2
	90+	13.6	50.8	15.3	20.3	12.8	46.2	7.7	33.3

\*Missing data in the urban area 10 (1991-1995), and 15 (2001-2004); in the rural area 1 (1991-1995).

## 6 DISCUSSION

The four studies included in this thesis aimed to describe formal and informal care given to elderly people (75+ years), but also to detect geographical differences in care received, and physical and mental functioning. Data were derived from an urban and a rural setting. Efforts were also made to gain a deeper understanding of the caring activities performed by cohabiting caregivers. For this purpose, both qualitative and quantitative data were collected. In the following section, the main findings from the four studies will be discussed as well as some relevant methodological issues.

### 6.1 FORMAL AND INFORMAL CARE

There is an ongoing debate whether the formal care system would be able take over the enormous amount of services and care provided by the informal caregivers to elderly living at home. In this thesis we describe the relationship between the formal and informal care received. The results show that the informal caregivers provide the major part of the care for the elderly living at home. In all four studies the impact of disability and dementia on care was heavy. There was a strong association between dementia severity and number of daily hours of both informal and formal care. This thesis also shed light on geographical differences in regard to in-home care, revealing that the rural elderly population received significantly more informal care. There were no area differences in physical functioning, whereas rural elderly were more cognitively impaired.

#### *Caregiving by spouses*

The observational study revealed the enormous amount and complexity of care that is performed by informal caregivers. Although this study did not specifically measure the number of hours spent by a caregiver in taking care of his/her relative, it was evident that the workload for the informal carers was extensive. A qualitative, inductive approach was chosen to describe patterns and to evaluate the quality of spousal caregiving in dementia care. The findings demonstrate the intricacy and multidimensionality of the caregiving situation, as well as the varied time-consuming caring activities and tasks performed by informal carers. The study suggests that it seems difficult, if not almost impossible, that the formal care sector may replace the type and amount of informal care, particularly where there is need for essentially continuous supervision and surveillance.

Caring for a person suffering from dementia involves much more than support in ADL and IADL. This became clear during the observations in the study. A large part of the care consisted of supervision, which covered most of the day for the caregivers and most of them were not able to leave their spouse alone in their home. They were constantly “attached” to their demented spouse. The caregivers also tried to provide care so that their spouses could have as normal life as possible. They worked hard to protect their spouses from feeling as if they were only a care recipient. Having lived a long life together, the carers knew what interests and needs their spouse had before developing dementia, and could therefore choose activities that they knew their spouse would enjoy. They provided dignified care at a very highly individualized level.

Previous research on informal caregiving to cognitively impaired elderly have mostly focused on negative outcomes, such as burden and stress (Almberg et al. 1998; Chappell and Reid 2002; Gaugler et al. 2007; Hebert et al. 2001; Meiland et al. 2001; Navaie-Waliser et al. 2002). Others have reported an increased mortality associated with caregiving (Schulz and Beach 1999). In contrast, a clear theme emerged from the content analysis of the current study. Despite the intense spousal caregiving, the caregivers clearly expressed a sense of *togetherness*. They found the caregiving role rewarding in terms of experiencing nearness, and a feeling of belonging together. The couples had all been married for long time and had built up a relation that was still very much alive. This nearness has been described by others as mutuality; the ability to find gratification and meaning in caregiving (Grafstrom 1994). Both burden and great satisfaction can coexist in the caregivers’ situation (Andren and Elmstahl 2005). The satisfaction of being together and having the strength to maintain the care recipient’s dignity and self-esteem was of high importance to the caregivers. Family caregivers were caring *for* as well as *about* their spouses.

In summery, this study contributes in reinforcing the opinion that a strong positive component is present in providing care to a demented spouse, in spite of the tremendous amount of time and energy devoted to this constant activity. Although it may not be possible to measure all kinds of care provided to a demented person, the study shed light on the quantity and quality of the care provided by informal carer.

### *In-home care*

Informal care constitutes a large part of the total care provided to elderly people who live at home. This thesis reports that the amount of informal care given to cognitively impaired elderly persons is high, ranging from 0.4 hours to 24 hours per day. Further, the main part of this care is supervision. The reported quantity of informal care varies in the literature, which may be due to difficulties in measuring supervision in quantitative terms (Albert et al. 1998; Chappell and Reid 2002; McDauid 2001; Schneider et al. 2002). The ongoing debate concerning whether informal care complements or substitutes formal care is complex. Due to the cross-sectional design of Studies II and IV, it was not possible to verify whether informal care substitute's formal care, but the data support previous findings that informal care substitutes, rather than complements, formal care (Penning 2002; Sundstrom et al. 2002; Szebehely 2005), especially for persons with dementia. Given the fact that living alone is a strong predictor for receiving formal care, one might speculate that if a person has access to informal care, s/he is less likely to receive formal care.

Longitudinal studies, which follow non-dependent individuals to the time of disability development and monitor the changes in care needs over time, are necessary in order to reveal the underlying factors that influence provision of different types of care.

There may be time differences in the pattern of care provisions between demented and non demented persons. In a progressive disorder, such as dementia, it is logical to consider that informal care is provided first, initially at a lower level, but then increases as the disease progresses until a point when formal care needs to be added. In disorders with a more sudden onset, such as a stroke in a previously healthy person, formal care may be introduced first or at the same time as informal care. In the case of multimorbidity, where progressive disorders may be present in addition to sudden onset events, there may be a mixed and complex situation.

The amount of informal care, reported as hours per day, was much greater than formal care, especially for elderly persons with dementia. There was a clear association between the number of hours of informal care and cognitive decline according to the CDR, while this pattern was less clear for formal care. The amount of informal care was much greater than formal care among demented than non-demented persons; twice as much when caring for non-demented persons and six times more when caring for people suffering from dementia.

### *Institutional care*

A clear correlation was found between the amount of formal caregiving time and personal ADL in institutional long-term care. In addition, having dementia was also significantly related to the time devoted by staff to provide care in ADL. However, the amount of time devoted to help persons with their IADL was equal at all stages of functional disability, as well as for people with or without dementia. Dependency in ADL had a more straightforward relation to time devoted to care than cognition had, although both aspects (they were also highly intercorrelated) had a strong correlation to time use. This relation has also been reported by others (Kavanagh and Knapp 2002).

When time used for supervision was included, the amount of time spent on caregiving (hours per day) was much higher. However, in institutions supervision care includes components of “group supervision”. Thus, it is difficult to separate these aspects of care at an individual level, as supervision can be combined with other caring tasks and provided to several patients simultaneously. Nevertheless, it is of high importance to highlight this part of caregiving in institutions, as a large proportion of residents in nursing homes have dementia.

The estimated cost of care for persons with dementia was much higher than for non-demented persons. Similarly, the care costs for people with functional dependency were higher than the care costs for persons without functional limitations. Due to the large variation between demented and non-demented, and physically dependent and non-dependent persons, it is not sufficient to use average cost for all residents when analyzing costs of care in institutions. Tools to enable measuring institutional care on an individual level are needed to guide the location of resources.

An interesting finding of Study III was the detection of some informal care contributions even for elderly persons living in institutions. This level was much lower compared to in-home care and had no correlations with ADL dependency or cognitive performances. Nevertheless, it was obvious that care in institutions came, to a certain extent, from informal sources, which has also been reported by others (Chappell et al. 2004; Gaugler et al. 2004; Lyons and Zarit 1999; Paulus et al. 2005). Even after institutionalization, informal carers play a role in caregiving. This fact may have importance for the public sector’s long-term care planning. The support of

informal caregivers to institutionalized elderly may have an impact on both quality of life but also on the costs of institutional care.

## **6.2 GEOGRAPHICAL DIFFERENCES**

There are area differences in use of in-home care. It was more common among urban elderly to receive formal care, whereas the rural elderly residents were almost three times likely to receive informal care. Living alone was strongly associated with receiving formal care in both areas, and as more women lived alone in the urban area this might also explain the higher use of formal care. However, it was the urban women with higher education who received more formal care. This is in agreement with other studies reporting that people with higher education are more likely obtain formal in-home care (Dunlop et al. 2002; Portrait et al. 2000). Rural home care users have also been found to have a higher level of education (Forbes and Janzen 2004). They may be more aware of their rights and possibilities, and may have better knowledge on how to get access to the formal resources available.

Use of formal home care is more frequent in urban compared to rural elderly. The higher use of formal care in the urban area could not be explained by greater disability or impaired cognition, as we found no area differences in disability and the urban elderly population was less cognitively impaired than the rural elderly. It may be more difficult to provide care to rural compared to urban elderly people due to geographical factors, personnel shortages and other factors. Similar results have been reported by others (Bedard et al. 2004; Forbes and Janzen 2004; Schlenker et al. 2002), while other studies that have found contrasting results that older people residing in rural areas were more likely to use formal care than elderly in urban areas (McAuley et al. 2004).

The rural population was more likely to receive informal care. This could be explained by area differences in civil status. However, multinomial regression analyses showed that compared to those with no home care, and after adjusting for age, gender, education, living alone, and physical and cognitive status, rural elderly were still almost three times more likely to receive informal care. Furthermore, the distance to formal services may be greater and the supply and type of formal home care may differ. That may have an effect on the likelihood of receiving more informal support. However, in Study II there were no significant differences in the amount of

formal care received between those close to and those far away from formal services. Other researchers have reported that transportation is not a barrier for receiving health care in rural areas compared to urban areas (Blazer et al. 1995). On the other hand this could be due to other factors such as family structure. The rural population may have better social networks, know their neighbours and may have a tradition of helping each other out.

Limitations in ADL have shown to be consistent predictors of receiving formal care (Larsson et al. 2006; Liu et al. 2000), and this was confirmed also in our study. Being disabled was the strongest single predictor of receiving formal care daily even after adjusting for other factors (age, gender, education, cognition and living alone). No area differences in disability were found for elderly persons living at home.

Rural elderly are more affected by cognitive impairment. One explanation of this finding may be the lower educational level among the rural elderly. It has been reported that low education increases the risk of impaired cognition in old age (Karp et al. 2004). Cognition is known to be a strong indicator of informal support (Langa et al. 2001; Wenger et al. 1998), and this was confirmed also in Study IV as well as in Study II. In both living areas, being cognitively impaired was associated with receiving in-home care.

### ***Ten years later***

We had the opportunity to study temporal variation in physical and mental functioning, and use of in-home care by analyzing data collected ten years later in both the urban and rural areas. Physical functioning (measured by dependency in basic ADL) and mental functioning (measured by the MMSE) had improved in both areas. The improvement was more evident in the rural elderly population. The non-users of in-home care had increased in both areas. One may speculate if this might be due to the improved physical and mental functioning. Elderly persons receiving only formal care had decreased; however, the elderly persons using both informal and formal care had increased. The area differences remained, and the urban elderly received more formal care, and the rural elderly population received more informal care.

### **6.3 METHODOLOGICAL CONSIDERATIONS**

Using mixed research methods is increasingly accepted in health services research (Johnstone 2004). In the current thesis, a qualitative design was used for Study I, followed by quantitative designs in Studies II-IV. In Study IV, the use of populations from two different settings, rural and urban, made it possible to make comparisons between two geographical areas. A strength of using a multi-method approach is that it provides the opportunity for method triangulation. Method triangulation can be described as a form of comparative analysis, where each type of analysis could lead to more understanding of the research area (Patton 2002). Findings from the observational study were used in the development of the RUD instrument used in Studies II and III (Wimo et al. 2000). Adapting different research methods gave a deeper understanding of how extensive caregiving to elderly persons can be, both from a quantitative and a qualitative point of view. The use of multi-methods made it possible to illustrate different aspects of caring for elderly persons with dementia (Polit and Beck 2006).

#### **6.3.1 The qualitative approach (Study I)**

When using an observational research method there are several difficulties to consider. However, the method also offers opportunities to collect data that would be otherwise difficult to capture. The population in the observational study may not be representative of the total group of persons who provide informal care to demented elderly. However, the aim of qualitative research is not to make generalizations, but rather to give detailed descriptions and deeper understanding (Patton 2002). All research findings should be as trustworthy as possible, whether qualitative or quantitative. Concepts such as validity, reliability and generalizability are related to trustworthiness in quantitative research. In qualitative research the concepts of credibility and transferability have been used to describe different aspects of trustworthiness (Graneheim and Lundman 2004; Polit and Hungler 1999). The term *transferability* refers to whether findings from a study can be transferred to other settings (Polit and Beck 2006). The intention of including a qualitative study design in this thesis was to provide a deeper understanding and knowledge of the caring situation for elderly people, both of caregivers and care receivers. Although the results may not be transferable to all persons who give informal care to people with dementia, the current thesis provides an insight on informal dementia care. The

*credibility* of a study refers to interpretation and confidence in the truth of the data (Polit and Beck 2006). To ensure the credibility of the content analysis, the emerging findings were read and validated by another researcher, and when disagreement concerning the findings emerged, the text was reread and discussed until agreement was reached. Other considerations regarding the use of observational methods are that any group being studied may alter to some degree as a result of the presence of the researcher. The participants may behave differently than they do otherwise, due to observational situation. It also takes time to build a level of trust with participants that facilitates full and honest self-representation (Patton 2002). To minimise this influence, the researchers who carried out the observations made a preliminary visit prior to the actual data collection day, to give information concerning observation and its purpose, as well as to get to know the couples.

There are advantages of including a qualitative study. The observations revealed the complexity of caring for a demented person and the interactions between the caregiver and the care receiver, and allowed the researchers to identify recurring patterns of behaviour that participants may have been unable to recognize themselves.

### **6.3.2 The quantitative approach (Studies II-IV)**

The design of the Kungsholmen Project has been thoroughly discussed by others (Fratiglioni et al. 1992a; Fratiglioni et al. 1992b; Klarin et al. 2003; von Strauss et al. 1999). The dropout rate in Studies II-IV was quite low (below 20%). However, there were great area differences in cause of dropout, as contrasting patterns concerning the number of persons who died or refused to participate were seen between areas (6.2% and 11.3% in the urban area, and 12.6% and 6.3% in the rural area). It took two years to examine the population in the urban area compared to three years in the rural area. This could explain the higher percentage of deaths in the rural area among this elderly population. One might also speculate that those who died were more disabled and in greater need of care. However, we have insufficient knowledge whether those who died lived at home or in institutions, nor if they had any in-home care. The subjects who refused to participate had an age- and gender distribution similar to that of the participants in both areas. Thus, it is unlikely that the results were affected by the refusals. Furthermore, all participants, whether living at home or in institutions in the urban or rural areas, were clinically examined for disability using a direct assessment

with the same standardized protocols, providing the possibility of reliable comparisons.

Expressing care in quantitative terms is difficult, particularly when measuring care devoted to supervision and IADL, as this can be combined with other caring tasks and, in institutional care it can be combined with caring activities to other patients. One explanation of the large differences reported in the literature regarding quantity of informal caregiving time (Cavallo and Fattore 1997; McDaid 2001; Rice et al. 1993; Smith and Wright 1994; Winblad et al. 1997), may be due to these difficulties. In the RUD instrument, different caring tasks are specified in: ADL care; IADL care and; supervision/surveillance care. This provides the caregivers, whether informal or formal, the opportunity to reflect on the different parts separately. An advantage of the RUD instrument is that it can be used in institutional care and in in-home care, which makes it possible to compare different care settings. RUD has been validated for use in institutional settings (Wimo and Nordberg 2007).

In Studies II-III, the aims were to describe the amount of informal and formal care in a population consisting of all inhabitants aged 75 and over in a municipality in northern Sweden. Study II included people living at home and Study III people living in institutions. Study IV focused on rural versus urban differences in physical and mental functioning and in-home care. Of course, while the configuration of formal and informal care received by the study population may be illustrative of those in other rural and urban parts of Sweden, it may differ for people in other regions such as semi-rural or small town settlements. It is also possible that people in rural areas have a closer relationship with their neighbours and relatives, and, therefore, have easier access to informal care. The population may also differ from people in other countries with other service contexts. Despite this element of selectivity, the results highlight the proportion and the amount of formal and informal care given to elderly people in both in-home and institutional care, especially in relation to cognitive decline and functional capacity.

Another methodological consideration was that some of the subgroup analyses in Studies II and II suffered from low statistical power and that data were skewed and not normally distributed. Efforts were made to solve this through the use of Tobit analysis, which takes this into account when calculating the proportion of care in relation to cognitive decline (Breen 1996).

Information on in-home care in Study IV was restricted to whether or not the participants received in-home care (informal or formal) and how often (daily, a few times a week or weekly). The amount of time was not investigated in the urban part of the study population. Thus, it was not possible to detect factors influencing the amount of care received, only whether there were differences in the odds of receiving in-home care.

There were area differences regarding age, gender and education. The rural elderly population was younger than the urban elderly population. There were more women in the urban area. Only 0.5% in the rural area had studied at university compared to 7.4% in the urban area. These regional differences could, to some extent, limit the possibility to generalize to other populations. However, in most western societies the population composition would be similar, and the results of the present study may therefore be applicable elsewhere.

## **6.4 CONCLUSIONS**

Describing who receives care, what care is given and when different sources of care are provided to older adults, is important in order to understand the serious challenges that already exist and will increase dramatically in the coming future. Today, more elderly people receive support in their daily living at home instead of being cared for in institutions, and the responsibility for this support has shifted more and more to informal carers. Formal care is targeted toward elderly living alone with great need of service and care (National Board of Health and Welfare 2002).

The demand for long-term formal care will continue to rise during the coming decades as the 'greying' of the population continues and will force public health decision makers around the world to take action in order to take care of the elderly and their needs (Karlsson et al. 2006). The lion's share of services and care to home dwelling elderly, many of them affected by cognitive impairment, is provided by the family and the next of kin. Substituting this to any major extent with formal service provisions would be impossible, both on economic and humanitarian grounds (Wimo et al. 2002). To take on the responsibility to care for a husband/wife/parent/friend is a matter of course for most people. Many informal caregivers have a strong wish to

continue to care for their next-of-kin as long as they possibly can. However, the majority of informal carers to elderly persons are old themselves.

Interventions aimed at supporting family members in caring for their elderly relatives could prevent early institutionalization and make it possible for the family to remain in the caregiver roles (Mittelman et al. 1996; Mittelman et al. 2006). It is necessary that support programs are developed to relieve family caregivers from the physically and mentally demanding tasks they perform. These interventions should aim both to communicate knowledge and techniques in caregiving to the informal caregivers, but also to provide respite and relief services to this group. A formal sector that is able to provide care and services with high quality will make caregiving easier for informal carers and will strengthen their wish to help. Building a support strategy to relieve caregivers from physical and mental stress will be necessary, and decision makers should focus, not only to the needs of the disabled elderly people, but also to their informal caregivers. This will enhance the public sector's possibilities to use our limited resources in the most efficient way.

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## 9 APPENDIX

### List of dissertations from Stockholm Gerontology Research Center and Aging Research Center 1991-2007

**1991**

**Herlitz Agneta.** Remembering in Alzheimer's disease. Utilization of cognitive support. (Umeå University and Karolinska Institutet).

**1992**

**Borell Lena.** The activity life of persons with a dementia disease.

**1993**

**Fratiglioni Laura.** Epidemiology of Alzheimer's disease. Issues of etiology and validity.

**Almkvist Ove.** Alzheimer's disease and related dementia disorders: Neuropsychological identification, differentiation, and progression.

**Basun Hans.** Biological markers in Alzheimer's disease. Diagnostic implications.

**1994**

**Grafström Margareta.** The experience of burden in care of elderly persons with dementia. (Karolinska Institutet and Umeå University).

**Holmén Karin.** Loneliness among elderly - Implications for those with cognitive impairment.

**Josephsson Staffan.** Everyday activities as meeting-places in dementia.

**Stigsdotter-Neely Anna.** Memory training in late adulthood: Issues of maintenance, transfer and individual differences.

**Forsell Yvonne.** Depression and dementia in the elderly.

**1995**

**Mattiasson Anne-Cathrine.** Autonomy in nursing home settings.

**Grut Michaela.** Clinical aspects of cognitive functioning in aging and dementia: Data from a population-based study of very old adults.

**1996**

**Wahlin Åke.** Episodic memory functioning in very old age: Individual differences and utilization of cognitive support.

**Wills Philippa.** Drug use in the elderly: Who? What? & Why? (Licentiate thesis).

**Lipinska Terzis Beata.** Memory and knowledge in mild Alzheimer's disease.

## 1997

**Larsson Maria.** Odor and source remembering in adulthood and aging: Influences of semantic activation and item richness.

**Almberg Britt.** Family caregivers experiences of strain in caring for a demented elderly person. (Licentiate thesis).

## 1998

**Agüero-Eklund Hedda.** Natural history of Alzheimer's disease and other dementias. Findings from a population survey.

**Guo Zhenchao.** Blood pressure and dementia in the very old. An epidemiologic study.

**Björk Hassing Linda.** Episodic memory functioning in nonagenarians. Effects of demographic factors, vitamin status, depression and dementia. (In collaboration with the Department of Psychology, University of Gothenburg, Sweden).

**Hillerås Pernilla.** Well-being among the very old. A survey on a sample aged 90 years and above. (Licentiate thesis).

## 1999

**Almberg Britt.** Family caregivers caring for relatives with dementia – Pre- and post-death experiences.

**Robins Wahlin Tarja-Brita.** Cognitive functioning in late senescence. Influences of age and health.

**Zhu Li.** Cerebrovascular disease and dementia. A population-based study.

## 2000

**Hillerås Pernilla.** Well-being among the very old. A survey on a sample aged 90 years and above. (In collaboration with H. M. Queen Sophia University College of Nursing, Stockholm, Sweden).

**von Strauss Eva.** Being old in our society: Health, functional status, and effects of research.

## 2001

**Jansson Wallis.** Family-based dementia care. Experiences from the perspective of spouses and adult children.

**Kabir Nahar Zarina.** The emerging elderly population in Bangladesh: Aspects of their health and social situation.

**Wang Hui-Xin.** The impact of lifestyles on the occurrence of dementia.

## 2002

**Fahlander Kjell.** Cognitive functioning in aging and dementia: The role of psychiatric and somatic factors.

**Giron Maria Stella T.** The rational use of drugs in a population of very old persons.

## 2003

**Jönsson Linus.** Economic evaluation of treatments for Alzheimer's disease.

## 2004

**Berger Anna-Karin.** Old age depression: Occurrence and influence on cognitive functioning in aging and Alzheimer's disease

**Cornelius Christel.** Drug use in the elderly - Risk or protection? Findings from the Kungsholmen project

**Qiu Chengxuan.** The relation of blood pressure to dementia in the elderly: A community-based longitudinal study

**Palmer Katie.** Early detection of Alzheimer's disease and dementia in the general population. Results from the Kungsholmen Project.

**Larsson Kristina.** According to need? Predicting use of formal and informal care in a Swedish urban elderly population. (Stockholm University)

## 2005

**Derwinger Anna.** Develop your memory strategies! Self-generated versus Mnemonic strategy training in old age: Maintenance, forgetting, transfer, and age differences.

**De Ronchi Diana.** Education and dementing disorders. The role of schooling in dementia and cognitive impairment.

**Passare Galina.** Drug use and side effects in the elderly. Findings from the Kungsholmen Project.

**Jones Sari.** Cognitive functioning in the preclinical stages of Alzheimer's disease and vascular dementia.

**Karp Anita.** Psychosocial factors in relation to development of dementia in late-life: a life course approach within the Kungsholmen Project.

**Nilsson Jan.** Understanding health-related quality of life in old age. A cross-sectional study of elderly people in rural Bangladesh.

## 2006

**Klarin Inga.** Drug use in the elderly – are quantity and quality compatible.

**Nilsson Erik.** Diabetes and cognitive functioning: The role of age and comorbidity.

**Ngandu Tiia.** Lifestyle-related risk factors in dementia and mild cognitive impairment: A population-based study.

**Erika Jonsson Laukka.** Cognitive functioning during the transition from normal aging to dementia.

**2007**

**Ferdous Tamanna.** Prevalence of malnutrition and determinants of nutritional status among elderly people. A population-based study of rural Bangladesh. (Licentiate thesis).

**Westerbotn Margareta.** Drug use among the very old living in ordinary households- Aspects on well-being, cognitive and functional ability.

**Rehman Jenny.** The role of gender in face recognition. (Stockholm University)

**Beckman Gyllenstrand Anna.** Medication management and patient compliance in old age.