

From SOPHIAHEMMET UNIVERSITY COLLEGE,  
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DRUG USE AMONG THE  
VERY OLD LIVING IN  
ORDINARY HOUSEHOLDS  
ASPECTS ON WELL-BEING, COGNITIVE  
AND FUNCTIONAL ABILITY

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**Karolinska  
Institutet**

Stockholm 2007

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Published and printed by Karolinska University Press

Box 200, SE-171 77 Stockholm, Sweden

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ISBN 91-7140-979-3

To my parents, Hans and Erna Westerbotn

*The best way to get rid of a problem  
is to hold it up to the bright light  
and look at it from all sides*

*Andy Rooney*



## ABSTRACT

## ENGLISH

**Background:** In Sweden today a major proportion of the population survive to old ages. To a large extent, the oldest old are capable of living longer in their own households; some of them are very healthy while others have multiple diagnoses or ailments caused by a normal ageing process. This means that many elderly persons receive their health care needs in their own home, and in the future this will be even more common. Drug use in the elderly is a complex field, and many drugs have side effects complicating the medical treatment and decreasing the quality of life.

**Aim:** This thesis aims to explore and describe the medicine use and the medical situation of very old persons ( $\geq 84$  years) living in ordinary households, and to obtain knowledge of their views on the use of drugs.

**Methods:** This thesis contains quantitative and qualitative research methods. The quantitative studies (**Study I, II and III**) were based on data from the Kungsholmen Project, a population based study of elderly people living in a district of the inner city of Stockholm, Sweden. Data collection for the present studies was carried out 1997-1998. The qualitative data (**Study IV**) was obtained 2005 through in-depth interviews with 25 elderly men and women, aged 85-97 years, living in ordinary households in Stockholm, Sweden. A pre-tested semi-structured questionnaire was used for the interviews.

**Results:** The findings in **Study I** demonstrated that cardiovascular (CV) diseases are very frequent in this population (62 %). Heart failure (47 %) and hypertension (37 %) were the most common conditions; and diuretics (69 %), nitrates (31 %) and cardiac glycosides (30 %) were the most commonly prescribed drugs. Multivariate regression analyses showed that while being affected by a CV disease did not affect the emotional well-being of the participants (PANAS-PA,  $p=0.171$ ; PANAS-NA,  $p=0.209$ ), the use of cardiac glycosides ( $p=0.006$ ) and nitrates ( $p=0.008$ ) was associated with increased negative feelings (NA). **Study II** revealed that 88 % of the population took medicines on a regular basis, and only 23 % of them received help with the handling of their medicines. Using logistic regression models controlling for sociodemographic variables, cognitive and functional status, female gender (OR: 2.8; 95 % CI: 1.2-6.5) was the only variable associated with regular use of medicines. The results also showed that older age and functional disability as measured by ADL, increased the risk of receiving help with medicines, while higher cognitive status decreased the odds of receiving help. Using multiple regression models, we found that the only factor related to not receiving help from a family member was living alone (OR:0.05; 95 % CI: 0.006-0.4). **Study III** showed that the prevalence of pain among very old persons was 46 %, and the prevalence of pain treatment was 71 %. Results from logistic regression analysis using all variables in the model indicated that pain reporting was not associated with age, gender or living conditions, but decreased with decreasing cognitive status and with increasing functional disability. Furthermore, pain treatment was not associated with age, gender, living conditions, cognitive and functional status. The qualitative data in **Study IV** indicated that most of the participants managed their medicines by themselves and were very content with this. Those older persons who received help with their medicines were also very pleased with this help. The findings also revealed that the most important components for older persons to be able to remain living in their homes and to handle their medicines by themselves were to have good cognitive ability, to be independent and to get support with their medicines from a close person as a back-up.

**Conclusions:** This study revealed that a large proportion of very old people ( $\geq 84$  years) were living in ordinary households and used medicines regularly. Being a woman and living alone were associated with receiving help with medicines from the community help services. Cognitive and functional ability were revealed to be significant factors in the management of medicines, but also to affect the pain reporting, and type of received pain treatment. Most of the older participants managed to handle their medicines by themselves, and were very pleased by doing this. However, most of them were concerned about the risk of losing their memory, as they are getting older, because they knew that they would not be able to manage themselves any more and therefore would have to move to an institution.

Three studies, included in this thesis, covered data collected from the third follow-up (phase V) of the Kungsholmen Project, with approval from the Ethics Committee of the Karolinska Institute (KI 95:101, 97:413). An ethical approval was also obtained for Study IV (EPN 04-916/5) from the Ethics Committee of the Karolinska Institutet.

**Keywords:** drug use, medicine management, very old, aged 84 and older, ordinary households, community, well-being, cognitive status, functional ability, population-based, in-depth-interviews, quantitative and qualitative methods, Sweden.

## SAMMANFATTNING

## SVENSKA

**Introduktion:** I Sverige idag, liksom i många andra länder runt om i världen, uppnår en stor del av de äldre en hög ålder, och de allra flesta klarar av att bo kvar i sina egna hem. En del av dem är friska medan andra lider av åldersrelaterade sjukdomar. Detta betyder att många äldre i vårt samhälle får hjälp med omvårdnad i deras egna hem, och i framtiden kommer denna andel att öka. De äldre som bor i ordinärt boende får hjälp med sin dagliga omvårdnad av personal anställda från kommunen. Men i detta ingår inte alltid hjälp med läkemedelshanteringen. De äldre som bor i ett ordinärt boende ansvarar själva för sina mediciner och de måste själva betala för dem, i motsats till de äldre som bor på sjukhem eller vårdas på sjukhus som har utbildad personal som hjälper till med medicinhanteringen. Läkemedelsbehandling av de allra äldsta är komplext. Syftet med varje läkemedelsbehandling är att lindra eller bota sjukdomar, öka den fysiska livskvaliteten och förlänga patientens liv. Många läkemedel har dock biverkningar som försvårar läkemedelsbehandlingen och därmed kan minska patientens livskvalitet.

**Syfte:** Denna avhandling syftar till att beskriva hur läkemedelsanvändningen och läkemedelshanteringen ser ut för de allra äldsta ( $\geq 84$  år) som bor i ett ordinärt boende, samt undersöka hur de äldre upplever sin läkemedelshantering, ur deras eget perspektiv.

**Metod:** Avhandlingen innehåller kvalitativa och kvantitativa forskningsmetoder. De kvantitativa studierna (**I**, **II** och **III**) baseras på data från Kungsholmsprojektet, en populationsbaserad studie bestående av äldre människor boende på Kungsholmen i Stockholms innerstad. Datainsamlingen genomfördes under åren 1997-1998. Den kvalitativa studien (**IV**) genomfördes 2005 genom djupintervjuer med 25 män och kvinnor i åldern 85-97, boendes i ett ordinärt boende i Stockholm. Ett förtestat semistrukturerat frågeformulär användes vid intervjuerna.

**Resultat:** Resultaten från **Studie I** visade att kardiovaskulära sjukdomar var vanliga (62 %) i denna undersökningsgrupp. Hjärtsvikt (47 %) och högt blodtryck (37 %) var de vanligaste sjukdomarna, och diuretika (69 %), nitrater (31 %) och digitalis (30 %) de mest använda läkemedlen. Att ha en hjärt-kärlsjukdom påverkade inte de äldres välbefinnande (PANAS-PA,  $p=0.171$ ; PANAS-NA,  $p=0.209$ ). Däremot var användningen av digitalis ( $p=0.006$ ) och nitrater ( $p=0.008$ ) associerade med negativa känslor (NA). I **Studie II** fann vi att 88 % av de allra äldsta som deltog använde läkemedel regelbundet, och endast 23 % av dem fick hjälp med sin läkemedelshantering. Att vara kvinna (OR: 2.8; 95 % CI: 1.2-6.5) var den enda variabel som var associerad med en regelbunden användning av läkemedel. Ålder och låg fysisk förmåga, mätt med ADL, ökade sannolikheten att få hjälp med läkemedelshanteringen, medan en högre kognitiv förmåga minskade sannolikheten att få hjälp. Den enda faktor som var associerad med att inte få hjälp med läkemedelshanteringen från en familjemedlem var att bo ensam (OR:0.05; 95 % CI: 0.006-0.4). **Studie III** visade att ha smärta var vanligt (46 %) bland de allra äldsta, och 71 % fick behandling mot smärta. Förekomst av självrapporterad smärta hade inget samband med ålder, kön eller levnadsstatus. Däremot visade det sig att sannolikheten att rapportera smärta ökade med en högre kognitiv förmåga och med lägre funktionell förmåga. Resultaten visade också att smärtbehandling inte hade något samband med vare sig ålder, kön, levnadsstatus, kognitiv eller funktionell förmåga. Kvalitativa data från **Studie IV** visade att de flesta äldre som deltog i intervjustudien klarade sin läkemedelshantering själva, och var nöjda med detta. Flertalet som fick hjälp med sin läkemedelshantering visade sig vara nöjda med denna hjälp.

De viktigaste förutsättningarna för att de äldre själva skulle klara av att hantera sina läkemedel och fortfarande bo i ett ordinärt boende, var att ha en god kognitiv förmåga, att vara oberoende, och/eller få hjälp med sin läkemedelshantering av en person och som stod dem nära.

**Sammanfattning:** Denna avhandling visar att många av de allra äldsta ( $\geq 84$  år) fortfarande bor i ett ordinärt boende och använder läkemedel regelbundet. Att vara äldre kvinna och bo ensam var associerat med att få hjälp med läkemedelshanteringen från kommunens hemsjukvård. Resultaten visade att kognitiv och fysisk förmåga har betydelse vid de äldres läkemedelshantering, men också vid rapportering av smärta och vilken typ av smärtlindring som ges. Vid intervjuer med äldre personer framkom att de allra flesta klarar sin läkemedelshantering själva och var nöjda med detta. Vidare framkom att flertalet äldre var oroliga över risken att förlora minnet i och med att de blir äldre. De förstod att de då inte längre skulle klara av sin läkemedelshantering själva och därmed skulle behöva flytta till någon form av äldreboende.

Studie I, II och III innehåller data ifrån Kungsholmsprojektets tredje uppföljningsstudie (FAS V) med tillstånd från Etiska Kommittén vid Karolinska Institutet (KI 95:101, 97:413). Ett etiskt tillstånd gavs också för Studie IV från Etiska Kommittén vid Karolinska Institutet (EPN 04-916/5).

**Nyckelord:** läkemedelsanvändning, läkemedelshantering, de allra äldsta, 84 år och äldre, ordinärt boende, kommuninvånare, välbefinnande, kognitiv status, funktionell förmåga, populationsbaserad, djupintervju, kvantitativa och kvalitativa metoder, Sverige.



## LIST OF ORIGINAL PAPERS

This thesis is based on the following original papers, referred to in the text by their Roman numerals (I-IV):

- I. Westerbotn, M., Agüero-Torres, H., Fastbom, J., & Hillerås, P. (2005).  
A population-based study on well-being in the very old: The role of cardiovascular diseases and drugs.  
*Archives of Gerontology and Geriatrics*, 40 (3), 287-297.
- II. Westerbotn, M., Hillerås, P., Fastbom, J., & Agüero-Torres, H. (2006).  
Factors influencing the handling of medicines among very old people living at home in an urban area.  
*Aging Clinical and Experimental Research*, 18 (6), 497-502.
- III. Westerbotn, M., Hillerås, P., Fastbom, J., & Agüero-Torres, H. Pain reporting by very old Swedish community dwellers: The role of cognition and function.  
*Aging Clinical and Experimental Research*, *In press*, 19, 2007.
- IV. Westerbotn, M., Fahlström, E., Fastbom, J., Agüero-Torres, H., & Hillerås, P.  
How do older people experience their management of medicines?  
(*Preliminary accepted*)

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## LIST OF ABBREVIATIONS

ADL	Activities of Daily Living
ADR	Adverse Drug Reaction
ATC	Anatomical Therapeutic Chemical classification system. In the ATC classification system, drugs are divided into different groups according to the organ or system on which they act and their chemical, pharmacological and therapeutic properties
CI	Confidence Interval
CV	Cardiovascular
CVD	Cardiovascular diseases
FASS	The Swedish drug compendium (Farmaceutiska Specialiteter i Sverige)
ICD-10	International Classification of Diseases – tenth edition
KP	Kungsholmen Project
MAS	A special nurse, responsible for the quality and safety in patient care and medical treatment, within the municipality. (Medicinskt Ansvarig Sjuksköterska)
MMSE	Mini-Mental State Examination
NVS	Department of Neurobiology, Caring Sciences and Society (Institutionen för Neurobiologi, Vårdvetenskap och Samhälle)
NSAID	Non-Steroidal Anti-Inflammatory Drugs
OTC	Over The Counter. Drugs sold without a prescription.
OR	Odds Ratio
PANAS	Positive and Negative Affect Schedule
PANAS -NA	Positive and Negative Affect Schedule-Negative Affect
PANAS-PA	Positive and Negative Affect Schedule-Positive Affect
QoL	Quality of Life
RN	Registered Nurse
SCB	The Swedish Bureau of Statistics (Statistiska Central Byrån)
SD	Standard Deviation
SNAC	Swedish National Study on Ageing and Care
TENS	Transcutaneous Electrical Nerve Stimulator
UN	United Nations
WHO	World Health Organization

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## INTRODUCTION

In Sweden today (Figure 1), as in many other countries worldwide, a major proportion of the population survive to old ages (Kalache, 1996; Jones & Poole, 1998; Raleigh, 1999; Statistics Sweden (SCB), 2005). To a large extent, they are capable of living longer in their own households (Sundström, 1987; Sundström, Larsson & Sjöstrand, 1994); some of them are very healthy while others have multiple diagnoses, or ailments caused by a normal ageing process (Tsujimoto, Hashimoto & Hoffman, 1989 a, b). This means that many elderly people get their health care needs in their home, and in the future more elderly will be cared for in their own homes (Berg & Sundström, 1999).



**Figure 1.** Map over the world (Sweden marked out) (United Nations (UN), 2006).

For those elderly living in ordinary households, i.e. in own homes, social service personnel employed by the municipality often provide everyday help and support with the basic activities of daily living (The Swedish National Board of Health and Welfare, 1997; Sandberg, Nolan & Lundh, 2002). However, this support does not always include help with medication. Elderly persons, living in ordinary households, are responsible for purchasing and handling their own medicines. In contrast, elderly persons staying in a hospital ward, in a geriatric ward or in a nursing home have trained healthcare personnel to help them with their medicines.

Drug use in the elderly is a complex field (Tsujimoto et al., 1989 a, b). The aim of any medical treatment is to decrease illness, to increase the quality of life (QoL), and to prolong the patient's life (The Swedish National Board of Health and Welfare, 1999). However, many drugs have side effects complicating the medical treatment and decreasing the QoL of the patients (Jones, Kallman & Revicki, 1987; Onder et al., 2002; Katz, 1989; Barabino, Galbariggi, Pizzorni & Lotti, 1991; Kiowski et al., 1991; Just et al., 1993; Lawson-Matthew, McLean, Dent, Austin & Channer, 1995).

Previous studies of drug use in the elderly have described the high number of drug use, inappropriate drug use, and hospitalisation related to adverse drug reactions (ADR); most of these studies have, however, been conducted in nursing homes or geriatric wards (Nikolaus, Kruse, Bach, Specht-Leible & Schlierf, 1996; Claesson & Schmidt, 1998; Furniss, Lloyd Craig & Burns, 1998; Schmidt, Claesson, Westerholm & Nilsson, 1998; Schmidt & Fastbom, 2000).

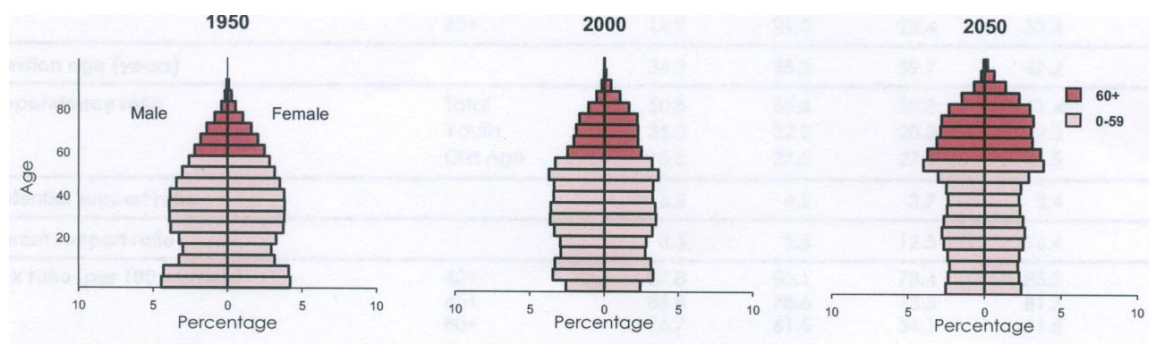
## The aging population

The elderly population is rapidly increasing in most parts of the world (Kalache, 1996; Kinsella, 1996; Jones & Poole, 1998; Raleigh, 1999; United Nations (UN), 2002; SCB, 2005). In developed countries this is mainly due to the increase in life expectancy due to improved health and health services, and better diagnosis and treatment of diseases earlier considered lethal (Raleigh, 1999). The developed countries have experienced this growing population group for decades, while for the developing countries, this is a rather new phenomenon. The world's population of persons aged 80 years and older is expected to increase from 70 million in 2000 to almost 400 million people in 2050. Seven out of ten are expected to live in developing countries (UN, 2002).

In Sweden, being old is defined as being 65 years or older, and this is also the general retirement age. The World Health Organization (WHO) (2006) defines 60 years as old and 80 years as oldest old, or very old. In this thesis the very old are defined as those aged 84 or older.

The fastest growing age segment in many countries is the “oldest old”, those persons who are 80 years and older (Kinsella, 1996; Jones & Poole, 1998). For example, in Sweden, persons 80 years and older, who constituted approximately 5 % of the elderly population in 2000, are expected to increase to 9.7 % by the year 2050 (UN, 2002; SCB, 2005) (Fig 2). Women (82 years) in Sweden have a longer life expectancy than men (78 years), so as the Swedish population ages, there will be an increasing proportion of women (SCB, 2005). Among persons 65 years and older in the year 2005, there were 76 men for every 100 women. In the age group 85 years and older, there were 47 men for every 100 women.

However, today it is difficult to exactly predict how the elderly population will develop in the future, when persons who have grown up under optimal conditions, i.e. those born in 1945 and later, reach late adulthood. Today's elderly were born in 1900-1930, when the mortality rate among young people was very high (nearly every fifth person died before the age of 20 years, in contrast with today when one in 20 die). Surely, in the future, there will be more people who are 100 years and older, but nobody knows if the elderly in the future will be healthier or less healthy than the elderly of today (Viidik, 2002).



**Figure 2.** Population age distribution in Sweden for 1950, 2000 and 2050 (source: UN, 2005).

## **Municipal care in Sweden**

When elderly people are in need of care, they are offered assistance in their own homes, or in special types of municipal resident homes, with different levels of care according to individual requirements (The Swedish National Board of Health and Welfare, 1996). Elderly care policy in Sweden has emphasized community and home-based services designed to keep older people out of institution (Hokenstad & Johansson, 1990), and since the Ädel-reform in 1992, the municipalities in Sweden have the responsibility for the service and care given to elderly people (The Swedish National Board of Health and Welfare, 1996; Sjölenius, 1997). The guiding principles of the reform focus on autonomy, privacy, safety and freedom of choice (The Swedish National Board of Health and Welfare, 1996).

In Sweden approximately 17 % of the people are 65 years or older. Five per cent are 80 years or older (SCB, 2005), and among them 40 % are in need of home service and nursing care. During the last five years, the number of beds in residential care facilities has decreased, while the number of elderly people receiving home care services in their own homes has increased. In December 2000, 127 000 residents in Sweden lived in residential homes, which was 10 000 less than in 1996 (The Swedish National Board of Health and Welfare, 2000). During that period, the number of elderly people in Sweden remained unchanged (SCB, 2005).

Accommodation in special types of residential homes includes service homes, retirement homes, group living for people with dementia disease, and nursing homes (Sjölenius, 1997). In service homes, the residents mostly have mild dysfunction and receive home help services and home medical care as required. In retirement homes, the residents need relatively extensive support, such as assistance with medicine management. Group-living is co-housing accommodation for approximately 8 to 10 residents with dementia disease. In nursing homes, the residents need extensive special care, since common diagnoses are stroke, malignancy, dementia and cardiovascular diseases (CVD). In order to decide the right level of residential home, the decision is made in accordance with the resident's wishes and ability to manage his or her daily life, together with the evaluation of a social worker (SFS 1982:763: Sjölund, 1999; SFS 2001:453).

In the late 1990s, the care of the elderly gradually changed. Short-term stay in a facility was established, as well as palliative care given to residents in the final stage of life. The aim of short-term stay is to offer elderly persons support during difficult periods so they can continue to live in their own homes as long as possible. In order to make it achievable for elderly people to continue living in their own homes, as long as possible, a temporary care can be given to elderly persons in need of further rehabilitation after hospital care, or if residents spouse need to receive a temporary support. However, when the elderly are in need of comprehensive day and night care, and their assistance offered in their own homes does not fulfil their needs, then they have to move to special types of housing (The Swedish National Board of Health and Welfare, 1996, 2000).

In residential homes, registered nurses (RN) are responsible for giving safe and appropriate nursing care of good quality (SOSFS 1997:10). The RN's working tasks include planning, implementing or delegating, leading, documenting, and evaluating nursing care. Medical needs are supplied by the resident's general practitioner, who is employed by the County Council (Sjölenius, 1997).

## **Drug use from a legal point of view**

In Sweden the Riksdagen (Parliament) institutes all laws, and this is where all decisions concerning law-changes or rescinding of special acts take place. All authorized health care personnel are under the supervision of the Swedish National Board of Health and Welfare (Socialstyrelsen). This board acts as the government's central advisory and supervisory agency for health and social services (SFS 1996:570). Other central agencies associated with the Swedish National Board of Health and Welfare, is the Swedish Medical Products Agency (Läkemedelsverket), controlling and evaluating the quality and safety of pharmaceuticals (SFS 1996:611), and the National Corporation of Swedish Pharmacies (Apoteket AB). This corporation is currently the sole retailer for drugs in Sweden and is owned by the state.

The most important law concerning drugs is the Medical Products Act (Läkemedelslagen) covering drugs for use in humans and animals, which are used with the purpose of preventing, indicating, relieving or curing illness or symptom of illness, or for similar purposes (SFS 1992:859). This law also contains regulations on drug preparation, quality control and clinical trials, information to patients and care providers as well as the sale of drugs. The Medical Products Act is the basis for all activities regarding pharmaceuticals and drug distribution in Sweden, and classifies pharmaceuticals into three categories: prescription drugs, over-the-counter (non-prescription) drugs (OTC), and drugs that can only be used in special clinics. The Swedish National Board of Health and Welfare publishes general advice for health care personnel, including the administration of drugs and delegation of work in connection with this (Raadu, 2006).

Nurses in Sweden are responsible for administering drugs to the patients in the health care system. The Swedish National Board of Health and Welfare has issued directives and general guidelines for drug handling within municipal health and medical care (SOSFS 2000:1). Drug handling is to be of a high quality, safety is to be guaranteed and the procedures of the health and medical services are to be reviewed continuously. The physician is responsible for prescribing drugs for each individual patient and for signing the entry in the patient's medical record (SFS 1985:562; SOSFS 2000:1). The nurse is responsible for the care and treatment provided in accordance with that prescribed by the physician (SOSFS 2000:1). However, if the nurse discovers that the prescription is not correct, it is her/his responsibility to question the prescription and to discuss it with the physician (SOSFS 2000:1).

In Sweden, the municipality is responsible for all the non-acute care for the elderly. Within the municipal area a special nurse (Medicinskt Ansvarig Sjuksköterska, MAS), has the responsibility for the quality and safety of patient care and medical treatment, but also that the routines for drug administration are well functioning and adapted (SFS 1982:763; SOSFS 1997:10). The physician is employed by the county council (Landstinget) and not by the municipality, and this gives the above mentioned nurse an over all responsibility for the community dwellers.



## **The ageing body and drugs**

Ageing is an ongoing process and affects all organs in the human body to a varying degree. An understanding of these changes is therefore required when planning and carrying out the treatment of elderly persons with medicines. Drug response in an individual is the result of many complex processes. These processes are divided into two major categories: pharmacokinetics and pharmacodynamics. Pharmacokinetics describes the absorption, distribution, metabolism and elimination of drugs, i.e. “what the body does to the drug”, while pharmacodynamics describes the time course of drug effects and relate concentrations of a drug at the site of action to the pharmacological effects, i.e. “what the drug does to the body” (Tsujimoto et al., 1989 a, pp.14).

Drugs can be administered in different ways and the most common is the oral route. The absorption of drugs taken orally depends on the function of the ventricle, intestines and the blood flow to the intestines. Another important factor affecting the amount of drug appearing in the blood is the so called first-pass metabolism, which refers to the hepatic or gut wall metabolism of a drug that occurs after absorption, but before the agent reaches the systemic circulation (Tsujimoto et al. 1989 a). The bioavailability is defined as the fraction of a drug reaching the circulation after administration, and for oral administration it depends on the amount of drug absorbed from the stomach or intestines and the extent of first-pass metabolism (Schwartz, 1999).

During the process of ageing, body composition undergoes different changes. For example, the amount of water in the body decreases and the proportion of body fat increases (Tsujimoto et al. 1989 a; Schwartz, 1999; Dehlin & Rundgren, 2000 b; Turnheim, 2003, 2004). According to a review by Bozzetti (2003), there is a gradual decrease in total body water from adulthood to old age, until it constitutes less than 50 % of bodyweight. These changes are important to take in consideration in medical treatment of elderly people, because some drugs, such as digoxin, dissolve in water (Tsujimoto et al., 1989 a) and others, e.g. benzodiazepines, dissolve in fat (Turnheim, 2003). Because of the higher proportion of fat, drugs that dissolve in fat (lipid soluble drugs) tend to accumulate in the body due to prolonged drug half-life (Turnheim, 2004). Moreover, the absorption of drugs administered by intramuscular and subcutaneous injections may be diminished in elderly because of reduced tissue blood flow. This is also true for transdermal administration of drugs (Turnheim, 2003).

Furthermore, as people age, the liver is less able to metabolise drugs, and the kidneys are less able to excrete drugs (Schwartz, 1999). The liver metabolises many drugs thereby prepares them to be excreted from the body (Dehlin & Rundgren, 2000 b). With the process of ageing the liver reduces in size by 25-35 %, and the liver blood flow declines by 40 %, and the metabolic capacity of some enzymes may also be reduced (Viidik, 2002; Turnheim, 2003, 2004). Drugs affected by a decreased liver function are for example benzodiazepines and opioides. Kidney function in elderly is about 50 % of that in young adults. This is a progressive decline in the renal filtration rate that starts after the age of 30 and continues throughout life (Viidik, 2002; Fastbom, 2006). Numerous drugs are affected by the decreased renal function, such as digoxin, diuretics, ACE-inhibitors and many antibiotics (Tsujimoto et al., 1989 a; Schwartz, 1999; Turnheim, 2003; Fastbom, 2006).

Another issue is the nutritional status of an elderly person, which also has an effect on the rate of drug metabolism (Turnheim, 2004). Very old individuals often lose weight according to anatomic and functional changes in the gastrointestinal system, e.g. atrophic gastritis, slow emptying time, decreased intestinal blood flow and motor dysfunction in the colon (Dehlin & Rundgren, 2000 b; Bozzetti, 2003). These changes may also affect the drug absorption. For example a reduction in intestinal blood flow could delay or reduce drug absorption (Tsujimoto et al., 1989 a; Dehlin & Rundgren, 2000 b). There is also a risk that older persons with a low weight receive higher doses per unit bodyweight than younger heavier persons (Turnheim, 2003, 2004).

The ageing process also affects the sensitivity to drugs in many organs, among others the central nervous system. Between the age of 20 and 80 years, brain weight is reduced by 20 %, and the grey matter decreases continuously in volume. The number of synapses also decreases (Dehlin & Rundgren, 2000 a; Viidik, 2002; Turnheim, 2003). These changes may explain why elderly persons are more sensitive to some centrally acting drugs than younger adults (Tsujimoto et al., 1989 b; Turnheim, 2003). In general this means an increased sensitivity to the unwanted effects of drugs. For example benzodiazepines and opiates, which are two of the most commonly used drugs in the elderly, carry an increased risk of adverse side effects such as sedation, confusion and loss of balance resulting in a falls (Fastbom, 2006).

The blood pressure regulation is also impaired with old age, thus increasing the risk of blood pressure falls with several drugs, including most CV drugs, antiparkinsonian drugs, neuroleptics and antidepressants (Tsujimoto et al., 1989 b; Fastbom, 2006). Moreover, older persons who take non-steroidal anti-inflammatory drugs (NSAID) runs a higher risk of developing gastric ulcers and bleedings (Ferrell, 1999). The reason for this is a thinner and weaker mucosa in the gastrointestinal system (Dehlin & Rundgren, 2000 b).

Ageing is recognized as a normal but an individual process, and old age is likely to be experienced and expressed in different ways by different persons in various ages, and there are also variations by gender (Tsujimoto et al., 1989 b; Sen, 1996; Schwartz, 1999; Bozzetti, 2003).

### **Drug use in the elderly**

When people get older, they tend to use more medicines (Giron et al., 1999; Beers, Jones, Berkwitz, Kaplan & Porter, 2005). Drug therapy is the most common and important form of medical treatment in the care of elderly people (Fastbom, 2006). Without proper medication, many older persons would function less well and therefore not be able to remain in their own homes (Beers et al., 2005). Most of the drugs used by older people are taken for many years, and usually to control chronic disorders such as diabetes and/or high blood pressure. However, drugs may also be used to prevent diseases or relieve symptoms and/or be taken for a short time, e.g. to treat infections or constipation.

The elderly population is a major recipient of drug therapy, using considerably more drugs than the younger population (Rumble & Morgan, 1994). In Sweden the age group 75 years and older constitutes 9 % of the population but receives approximately one fourth of all prescription drugs (The National Corporation of Swedish Pharmacies, 1999).

Medical treatment among the elderly is complicated because of the high number of taken drugs. This is often referred to as polypharmacy. One of several definitions of polypharmacy is “the use of more drugs than are clinically indicated” (Fastbom, 2006), another is the use of five or more drugs. Studies of elderly people aged 80 years and older, have shown that the number of drugs taken has increased during the last two decades; from (mean numbers) 3 to 5 among those living in the community (Österlind & Bucht, 1991; Giron et al., 1999), and from 3 to 10 among those living in institutions (Giron et al., 1999; Fastbom, 2006). One reason for this increased drug use is that new medicines have been introduced providing new possibilities to treat diseases (The Swedish National Board of Health and Welfare, 2005).

Studies have found several factors related to an increased drug use in the elderly. This includes an impaired physical function (Chrischilles et al., 1992), number of chronic diseases (Österlind & Bucht, 1991), poor self-rated health (Chrischilles et al., 1992), female gender (Chrischilles et al., 1992; Rumble & Morgan, 1994), poor QoL (Jensen, Dehlin, Hagberg, Samuelsson & Svensson, 1994), living alone, depressive symptoms, and former smokers (Chrischilles et al., 1992).

Drugs can have effects that are not intended or desired, i.e. side effects. Older people are more than twice as likely to have side effects from drugs than younger people (Beers et al., 2005). Moreover, in older people, side effects are more likely to be severe, to worsen the well-being and to require visits to the doctor or hospital stays. Digoxin is one example of such a drug that causes many problems among elderly persons, because of its narrow therapeutic index (Jones et al., 1987; Marcus, 1993; Lawson-Matthew et al., 1995; Fishkind, Paris & Aronow, 1997; Garg, Gorlin, Smith & Yusuf, 1997; Haas & Young, 1999; Rich, 1999; Hanratty, McGlinchey, Johnston & Passmore, 2000; Onder et al., 2002). Knowing which drugs are particularly likely to cause problems in older persons helps to avoid or flag for potential side effects (Beers et al., 2005).

An older person with multiple disorders or symptoms may take prescribed drugs from several physicians for acute or chronic ailments. The elderly may also self-medicate with OTC drugs to relieve common complaints, such as indigestion, dizziness, constipation, and insomnia. This multiple-drug use, polypharmacy, is a serious problem in geriatric care. Another problem in drug use among elderly persons may be the inappropriate use of drugs that may negatively affect the person’s well-being and even cause hospital care. Drugs can be harmful even when they are taken correctly but could be lethal when used inappropriately, such as benzodiazepines which are the dominant drug type used by elderly persons who committed suicide by drug poisoning in Sweden (Carlsten, Waern & Allebeck, 1999).

With the increasing aging population there is also a parallel increase in disease occurrence. Older people are particularly difficult to assess and to treat effectively, and are more vulnerable to therapeutic delays or errors. Therefore, to understand and to predict clinically age-related changes in drug disposition would help in designing medical treatment for elderly persons to avoid adverse drug reactions (Tsujimoto et al., 1989 a).

## **Functional ability**

Age-related loss in physiological capacity contributes to decline in physical function in the elderly (Cress et al., 1992). The functional ability of elderly persons is important for how well they cope with the activities of daily living, which in turn affects their QoL. Functional ability can be defined as a person's ability to perform activities, i.e. common everyday tasks, necessary to ensure well-being (Fillenbaum, 1996; WHO, 1998). Impairments, such as reduction in vision, hearing, understanding, or capacity to move, may result in increased difficulty in performing common tasks and therefore create problems for the elderly to remain living in their own homes (Fillenbaum, 1996). However, physical activity improves the QoL in many ways. Besides the physical benefits, physical activity has also been shown to improve mental health, motor control and cognitive function (WHO, 1998).

Physical capacity of elderly persons is also important for the administration of medicines. For example, in order to get the prescribed medicine, the elderly person may have to walk to the pharmacy. Moreover, to open packages of medicines requires functional ability of the hands. Without these skills the person would be dependent on others in helping them take their medicines. Hence, adequate health and functional ability are necessary for maintaining independence in later life because these characteristics relate to the capacity to meet the needs of daily living (Mutchler & Burr, 2003).

Among older adults functional ability varies considerably, and after the age of 85 the majority need some assistance with instrumental activities, and a portion of frail elderly are severely disabled (Spillman & Pezzin, 2000). Nurses have an important role to help elderly people with disabilities to improve the QoL, but also in the care of people with disabilities and in the prevention of disability. They also have a key-role in early detection and intervention, and therefore need to be involved in health promotion, prevention, teaching and counselling programmes for people with disabilities and their families.

Taking preventive measures, such as regular exercise, can help older people remain healthy, active, and able to function (Cress et al., 1992). Moreover, implementation of preventive actions can help older persons develop healthy habits and continue to participate in activities. However, the key to maintaining physical activity and functional ability lies within each individual, although immediate surroundings, important others such as family members, also have an important role in creating and maintaining an active approach to life.

## **Cognitive ability**

Older people may notice changes in brain function only when they try to learn new information, such as a new language or when trying to understand technical instruction books (Beers et al., 2005). In later life, there is a continuum from normal cognitive ageing to overt dementia. However, helping older persons to learn how to follow medication instructions can be a challenge. Older people may have many reasons for noncompliance, e.g. poor vision and/or hearing, physical disabilities, or failure to understand the importance of taking prescribed medications. The danger is that noncompliance may lead to unsuccessful treatment and a worsening condition. Furthermore, the physician may misinterpret the inadequate response and increase the drug dosage or prescribe a second drug, compounding the patient's problems.

Another important issue is misinterpretation of an elderly persons symptom, such as impaired cognition, confusion and delusion. These symptoms may be caused by ADR instead of cognitive decline attributable to “normal ageing”. For examples see Table 1. A physician who fails to detect the underlying cause of these symptoms might prescribe drug therapy when simply drug discontinuation or dose reductions would resolve the problem.

<b>Drugs with anticholinergic effects</b>	<b>Other drugs</b>
Drugs for incontinence	Benzodiazepines
Tricyclic antidepressant drugs	Opioids
Neuroleptic drugs of low potency type	Glucocorticoids for systemic use
Anticholinergic antiparkinsonian drugs	Dopaminergic antiparkinsonian drugs
Antihistamines (H <sub>1</sub> receptor antagonists), 1 <sup>st</sup> generation	Histamine H <sub>2</sub> receptor antagonists
	Cardiac glycosides
	Antibiotics of quinolone type

**Table 1.** *Example of drugs that may cause cognitive disturbances or delirium in the elderly.*

Mental disorders, such as dementia and depression are found in approximately 30 % of elderly people and have also been seen to increase with ageing (Skoog, 2004). According to results from the H70 study (or the Longitudinal Gerontological and Geriatric Population Studies in Gothenburg, Sweden) almost one-third of the participating 85-year-olds (n=100) had dementia (Skoog, 2004). Furthermore, another study from Gothenburg, Sweden, showed that among elderly (n=338) aged 95 years and older, 52 % had dementia (Börjesson-Hansson, Edin, Thorsteinn & Skoog, 2004). During ageing, the cognitive reserve declines and may result in a reduced capability in functions such as orientation, memory, abstract thought and perception (Cullum et al., 2000); all of which are significant functions needed in drug management. This means that elderly persons need more time to become acclimatised to new circumstances (Couture, Lariviere & Lefrancois, 2005). An example of a new circumstance could be the receipt of an unfamiliar medical treatment, to get a new medicine or a changed name on a long-term used drug.

### **Well-being**

In the developed world with the increasing longevity of populations, there is a general interest in knowledge about finding the “goodness” of life, so called well-being. However, there is no general agreement of what well-being is (Bowling, 1996; 2002 McDowell & Newell, 1996), and therefore it has been defined differently in different studies. Nevertheless, this is a subjective state that makes people validate their own feelings. Measurement scales in relation to the concept of well-being have been developed, some specifically for use in gerontology (Bowling, 2005).

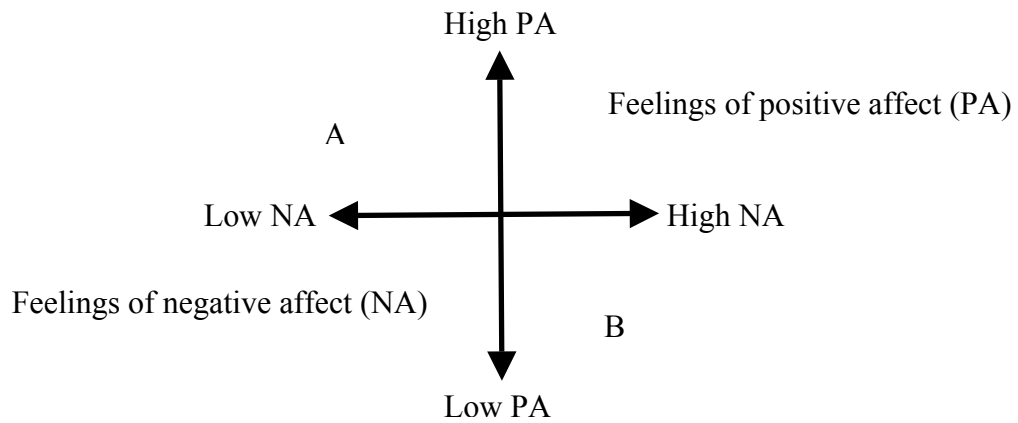
Commonly well-being is divided into three general dimensions; life satisfaction, positive affect (PA), and negative affect (NA) (Diener & Emmons 1985; Kercher 1992; Diener, Suh, Lucas & Smith 1999). Life satisfaction represents the cognitive component i.e. cognitive judgements of ones life, such as relationships and love. PA and NA represent the emotional components of well-being. PA refers to experiencing pleasant emotions, such as joy, while NA refers to experiencing unpleasant emotions, such as shame and depression. (Okun & Stock, 1987; Kercher 1992; Diener et al., 1999). However, the focus in this thesis has been on the emotional part of well-being.

Bradburn (1969) developed the affect scale in order to measure peoples' well-being, and in the field of ageing. He hypothesized that subjective well-being could be indicated by a person's position on two independent dimensions: positive affect (PA) and negative affect (NA). Well-being is expressed as the balance between these two dimensions. Thus, positive factors can compensate for negative feelings.

Bradburn's (1969) subscales are the most common measures of PA and NA, used in a vast number of gerontological studies that focus on QoL (Kercher, 1992). However, the Bradburn scales have been criticised on psychometric grounds, as it was found that they had both low validity and low reliability (Diener & Emmons, 1984; Kercher, 1992). Therefore, the 20-item Positive and Negative affect Schedule (PANAS) was developed by Watson and colleagues which replaced the Bradburn scales (Watson, Clark & Tellegen, 1988; Kercher, 1992; Watson & Clark, 1994). Later, Kercher (1992) has shortened the standard 20-item PANAS to a 10-item version, to assess subjective well-being in the very old. This shorter version of the PANAS has been shown to have an appropriate factor structure, high discriminant validity, and a reasonable reliability for its subscale. Moreover, it has also been found that the structural characteristics of positive and negative affect are robust to differences in age, sex and other demographic variables (Mackinnon et al., 1998). In addition it has been translated and validated in a Swedish very old population (Hillerås, Jorm, Herlitz & Winblad, 1998).

During the past decades, QoL and well-being have been emphasized as important aspects of medical treatment. These aspects are especially important in the very old, who are usually affected by many diseases and therefore require treatment with several drugs (The Swedish National Board of Health and Welfare, 1999). Therefore, medical treatment need to be evaluated in terms of whether medicines are more likely to lead to an outcome of a life worth living in social, psychological, and physical terms. However, most studies have focused on the physical QoL, meaning the extent side effects of these drugs on physical function (Jones et al., 1987; Katz, 1989; Barabino et al., 1991; Kiowski et al., 1991; Just et al., 1993; Lawson-Matthew et al., 1995; Rich, 1999).

Figure 3, illustrates the dynamic relation between positive affect (PA) and negative affect (NA). A person (A) can feel high well-being (PA) and at the same time be under medical treatment for a disease. The person's disease is well treated with the medications. On the other hand, another person (B), also receiving medical treatment for a disease, feels low well-being (NA) for other reasons, e.g. side effects from the medicines. This person may also get better from the disease, but this is outbalanced by the side effects of the medicines and makes the person not feel well. Therefore, an important goal for any medical treatment should be the right balance between desirable effects and side effects, resulting in the best possible well-being.



**Figure 3.** *Relation between positive affect (PA) and negative affect (NA).*

### **Nursing**

The increase in life expectancy results in a greater number of older persons in need of a wider range of health services, including health promotion, illness prevention, rehabilitation, acute/chronic care and palliative care. Therefore, the goal of nursing care in working with older persons is to achieve optimal health, well being, and QoL as determined by those receiving care or consistent with the values and wishes of the individual (ICN, 2006; Sjölenius, 1997).

Nursing services constitute the largest single element in providing care for the frail, sick and dying in all ages, while also contributing to health maintenance and disease prevention in all settings. Supporting self-care and the right of the older person to participate in decisions concerning life-style and treatment, are important aspects of the nurse's role. Nurses, as key care providers, have a responsibility to maintain their level of competence, plan and deliver quality care, delegate tasks safely and evaluate services provided (ICN, 2006; Sjölenius, 1997). Other important roles for nurses are advocacy, promotion of a safe environment, research in caring science, participation in shaping a health policy and health systems management and education.

In partnership with families and other health professionals, nurses have a key role to play in the care of older persons (ICN, 2006; Sjölenius, 1997), and this includes the use of drugs (SFS 1992:859). The nurses are responsible for the care and treatment provided in accordance with prescription by a physician. (SFS 1985:562). With an increasing age, multimorbidity becomes more frequent, leading to a high number of drugs. Therefore, many elderly persons may take drugs prescribed from several physicians, creating a situation in which the individual provider does not know about all drugs prescribed. Moreover, elderly persons are more likely to have cognitive disorders that increase the risk for mistakes in communication with their physicians about how to take the prescribed drug, and misunderstanding about correct doses. Physical disorders are also a risk for a non-adherence to medical treatment, e.g. difficulties in opening the packaging.

Therefore, nurses have an important role in coordinating the care the elderly receive from different providers and also in giving essential information to the patient. Through correct knowledge about their drugs, the elderly can themselves identify and report possible adverse drug reactions, and this may improve the adherence to drug treatment.

## SUMMARY

Elderly people in Sweden today not only survive to an old age (SCB, 2005), they are also living longer in their own households (Sundström, 1987; Sundström et al., 1994; Berg & Sundström, 1999). For those elderly living in ordinary households, social service personnel employed by the municipality often provide everyday help and support with the basic activities of daily living (The Swedish National Board of Health and Welfare, 1997; Sandberg et al., 2002) However, the elderly are responsible for their own medicines, and their everyday support does not always include help with medication. Therefore, there are older persons in our society that have to manage their medicines by themselves. Cognitive and functional ability are important for older persons to manage themselves in their own homes. If there is deficiency in one or both of these abilities this could lead to different problems in drug use, e.g. incorrect dosage, ADR and polypharmacy, and this may lead to a negative well-being for the older person and hospital admissions.

While there is extensive research on drug use in the elderly, there is scant literature relating to the very old. Most medical studies have generally not included the group of the oldest old, limiting the generalizability of the findings (Gambassi et al. 2000). Research on elderly people living in ordinary households is also sparse, and most studies have been conducted in nursing homes or geriatric wards (Furniss et al., 1998; Schmidt & Fastbom, 2000; Osborne, Hooper, Swift & Jackson, 2003). These studies have not taken into account the older person's point of view. To obtain older person's perspectives on their management of medicines is a necessary prerequisite for caregivers in planning and developing strategies allowing the elderly to remain in their own homes for as long as possible, or for as long as they wish (Townsend, Hunt & Wyke, 2003). To our knowledge, little is known about the medical situation among older people living at home. Therefore, obtaining more knowledge about the medical situation of the oldest old, living in ordinary households, and regularly taking medicines is the impetus of this study.



# **AIMS**

## **General aims**

The overall aim of this thesis is to explore and describe the medicine use and the medical situation of very old persons ( $\geq 84$  years) living in ordinary households, and to obtain knowledge of their views on the use of drugs.

## **Specific aims**

### **Study I**

to examine the association between cardiovascular diseases and their medical treatment on the emotional well-being of very old people

### **Study II**

to investigate factors influencing elderly people's ability to handle their medicines

### **Study III**

to report the prevalence of pain reporting and pain treatment, and their association with functional and cognitive status in a very old population

### **Study IV**

to describe how older people, living at home, experienced to manage their medication regime from their own perspective

## **MATERIAL AND METHODS**

This thesis is based on a multi-disciplinary collaboration and contains quantitative and qualitative research methods. Study I, II and III are based on quantitative data from the Kungsholmen Project (KP), phase V (Figure 4). The population is very old, and the majority is female. Study IV is based on qualitative data collected through in-depth interviews of 25 elderly people, aged 85-97 years, living in ordinary households. A pre-tested semi-structured questionnaire was used for the interviews.

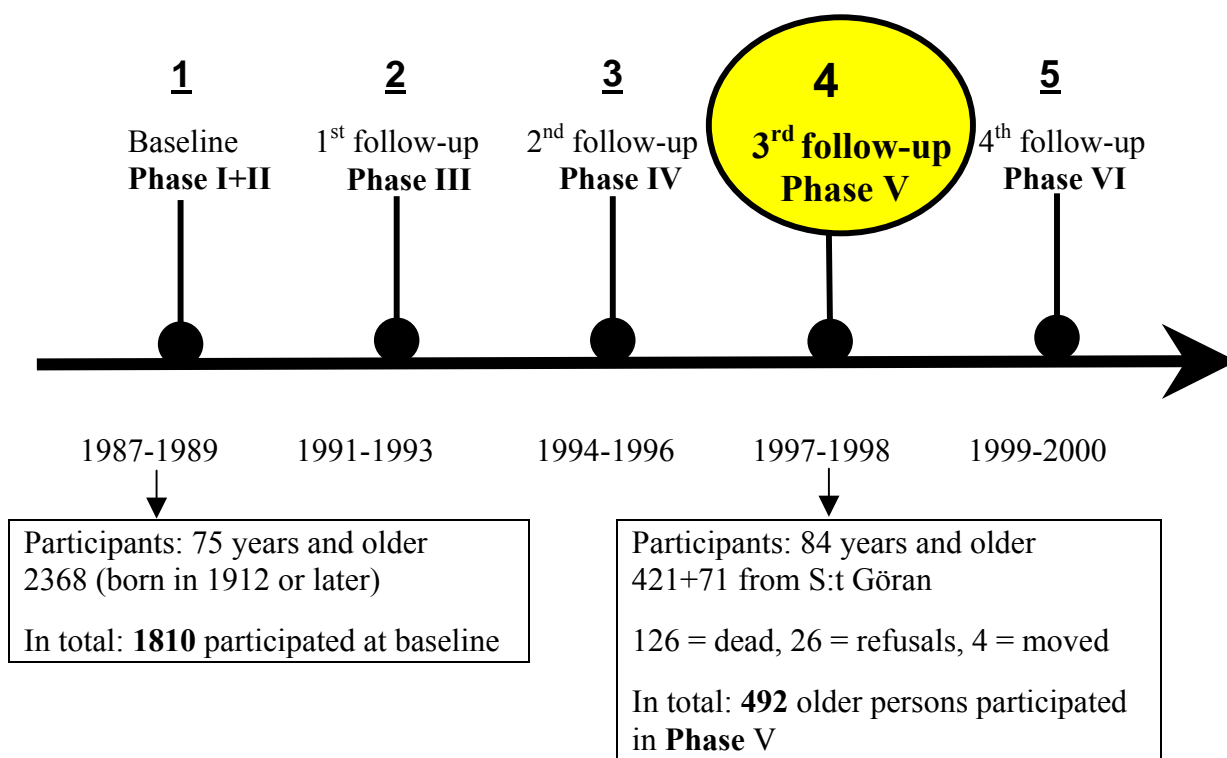
### **The Kungsholmen project and SNAC**

All data in Study I, II and III were obtained from the KP, a longitudinal, population-based study of elderly people living in Kungsholmen, a district of the inner city of Stockholm, Sweden. The study was initiated the 1<sup>st</sup> of October 1987 when all inhabitants that were born before 1913 (75 years and older) were invited to participate. A total of 2368 persons, including both community-dwelling and institutionalised persons, were eligible and 1810 (76 %) participated in the project (Fratiglioni, Viitanen, Bäckman, Sandman & Winblad, 1992). In 1991-93 the project included all persons aged 90 years and older, living in the St. Görans district, a nearby geographical area. The baseline phase (I and II) and four follow-ups (phase III to VI) have been completed, with the last phase (VI) concluded in the summer of 2000. The Division of Geriatric Epidemiology and Medicine at the Department of Neurobiology, Caring Sciences and Society (NVS) of the Karolinska Institutet and the Stockholm Gerontology Research Center conducted the project. The overall aim of the project is to study ageing from a medical, psychological and sociological perspective. The study population and data collection strategy are summarized in Figure 4.

In Study IV the participants names were obtained from the database of the Swedish National Study on Ageing and Care (SNAC). A longitudinal population-based study of persons 60 years and over, who live in the area of Kungsholmen/Essingeöarna, a district of the inner city of Stockholm, Sweden (Lagergren et al., 2004). In 1999 the Swedish Ministry for Social Affairs promoted and supported a national project aimed at monitoring and evaluating the care-of-the-elderly system in Sweden. To achieve these aims, SNAC, with four longitudinal individual-based data collections describing the ageing process and encompassing the care system as a whole, was initiated. The overall aim of the project is to understand the ageing process, and to identify possible preventive strategies to improve health and care in the elderly.

Further on, only aspects of the projects relevant to the present thesis are described. For a more detailed description of the design of the projects the reader is referred to the study by Fratiglioni and collaborators (1992) (KP), and Lagergren and collaborators (2004) (SNAC), or to the homepage of the KP; <http://www.aldrecentrum.se>, or homepage of the SNAC; <http://www.snac.org>.

# THE KUNGSHOLMEN PROJECT



**Figure 4.** *The Kungsholmen project. A schematic view over design and participants.*

## Study population

This thesis concerns the population of the Kungsholmen and St. Görän districts. Persons included in Study I-III were individuals who participated in the third follow-up of the population-based study of elderly people (n=492). Data collection was carried out from 1997 to 1998. The population was 84 years of age and older, and the majority was female (80 %). For the purpose of the studies we excluded persons who lived in institutions (n=157), and two persons that did not want to participate.

In Study I persons with visual and hearing problems and those with a Mini-Mental State Examination (Folstein, Folstein & McHugh, 1975; Grut, Fratiglioni, Viitanen & Winblad, 1993) (MMSE) score  $\leq 23$  were excluded. Therefore, the study population in this study included 235 persons.

In Study II and III the study population included all 333 persons, i.e. no further exclusions.

In Study IV, 25 elderly persons, 16 women and 9 men, aged 85 to 97, participated. Apart from age, the inclusion criteria were: MMSE  $\geq 24$ , living in ordinary households, and taking medicines regularly. Data collection was carried out from May to June in 2005.

## Methodological approach

In this thesis both quantitative (Study I, II and III) and qualitative (Study IV) methods were used (Table 2). This combination of methods gives the possibility for both an objective and a subjective approach to investigation of the management of medicines in old age. Quantitative data derived from large samples are often strong in terms of generalizability, while the strength of qualitative studies is the potential to yield insight into the nature of complex phenomena through in-depth information (Polit & Beck 2006). Studies I, II and III in this thesis were based on quantitative cross-sectional data, while Study IV had a qualitative approach based on in-depth interviews. The main focus of the studies was to explore and describe the medical situation of very old persons living in ordinary households, and to obtain knowledge of their views on the use of drugs.

Study	I	II	III	IV
<b>Aim</b>	- to examine the association between cardiovascular diseases and their medical treatment on the emotional well-being of very old persons	- to investigate factors influencing elderly persons' ability to handle their medicines	- to examine the prevalence of pain reporting and its association with functional and cognitive status in an elderly population	- to describe how older persons, living in ordinary households, manage their medication regime from their own perspective
<b>Context</b>	Urban area	Urban area	Urban area	Urban area
<b>The sample</b>	235 elderly people	333 elderly people	333 elderly people	25 elderly people
<b>Collection of data</b>	Structured interviews	Structured interviews	Structured interviews	In-depth interviews
<b>Analysis of data</b>	Descriptive and analytical (linear regression)	Descriptive and analytical (logistic regression)	Descriptive and analytical (logistic regression)	Content analysis

**Table 2.** Overview of research aims, context, samples, data collection and data analyses in the four studies.

## Questionnaires

In Study I, II and III the interviews were conducted using a semi-structured questionnaire from the KP, covering areas such as socio-demographic, health (including questions about pain), cognition, functional status and medicine use (Fratiglioni et al., 1992). The participants were personally interviewed in their place of living or at the Stockholm Gerontology Research Center. Trained nurses and physicians, experienced in working with elderly persons, conducted the data collection. Data on age (years), gender, marital status and place of residence was collected using the interview questionnaire. Participants' living arrangements were also recorded and in Study I, II and III they were classified as living together with someone else or living alone. Spouse or the elderly person's children were classified as family member, and community nurses/district nurses or other home care staffs, e.g. home help aides, delegated by district nurses, were classified as health staff.

To assess information on whether socio-demographic characteristics, cognitive and functional status influenced the help receiving with the handling of medicines, in Study II, the participants were asked, beside questions concerning prescription name, dose, dosage form, frequency, route of administration, and indication, questions about their medication handling and intake, for example if they received any form of help and by whom. The questions were closed-ended with several possible answers (Appendix 1).

To assess information on the elderly participants' subjective experience of pain, in Study III, the participants were asked about the presence of pain, duration, localization and treatment, by closed-ended questions with several possible answers. The questions about localization included the following locations: head; neck; back; joints; shoulders/extremities; legs; breast, abdomen and genitals; each localization of symptom to be answered with yes or no. When a person could not give the information, a relative or health care employee who knew the person well was asked (Appendix 2).

In Study IV an interview guide was used to identify the areas to be covered, i.e. the experience of medicine treatment and management of medicines (Appendix 3). An interview guide can be more or less detailed depending on the research question and aim of the interview, and therefore should be seen as an aid for the interviewer, though not a slavish contract, and the researcher can use a conversational interview style (Patton, 2002). In this study the interview guide contained open-ended questions such as "Will you tell me a little about your experience of your management of medicines?" Open-ended questions permitted the participants to talk freely about their medical situation and their experience of handling medicines (Polit & Beck, 2004). Test interviews with three older persons were performed in an open manner to find out whether the interview guide was suitable for those to be interviewed, and whether it actually covered different aspects of the aims of the study. However, since no modification of the interview guide was done because the questions worked out to be appropriate for the study and the participants, therefore, these three interviews were included to the study (n=25).

## **Positive Affect and Negative Affect**

In order to measure the emotional components of well-being in Study I, the 10-item short form of the Positive and Negative Affect Schedule (PANAS) was used (Kercher, 1992; Hillerås et al. 1998). PANAS positive affect (PANAS-PA) included the following five mood adjectives: active, enthusiastic, alert, inspired, determined. PANAS negative affect (PANAS-NA) included: distressed, upset, scared, nervous, afraid. The response options were: “not at all”, “a little”, “somewhat”, “quite a bit”, and “very much” (coded 1-5). The scores ranges from 5 to 25 indicating more positive (PANAS-PA) or more negative (PANAS-NA) affect, respectively. The respondents were asked to report their positive and negative affect during the last year. This time frame was chosen because it shows greater intra-individual stability than shorter time frames (Watson et al., 1988), but it still reflects affect experienced in the recent past.

## **Cognition**

In this thesis the Swedish version of the Mini-Mental State Examination (MMSE) (Folstein et al., 1975; Grut et al., 1993) was used to assess cognitive status. In Study I and IV the test was used to exclude persons with cognitive impairment (MMSE  $\leq$ 23 points) (Grut et al., 1993), i.e. those who may not give reliable information. The test takes about 10 minutes to administer by trained nurses and measures orientation, memory, attention and calculation, the ability to name, to follow verbal and written commands, to write a sentence spontaneously, and to copy a complex figure. The test score ranges, like the original American version, from 0 to 30 with the higher score being indicative of more intact cognitive functioning. In Study II and III cut-off points were used in the analyses to assess if there were any differences in cognition: scores  $\geq$ 24 indicated no cognitive impairment (Grut et al., 1993), while 20-23 indicated mild impairment, and 0-19 severe impairment (Folstein et al., 1975).

## **Functional status**

In Study II and III the participants functional status, i.e., their level of performance of basic activities of daily living (ADL), was measured using the Katz Index of Activities of Daily Living (Index of ADL) (Katz, Ford, Moskowitz, Jackson & Jaffe, 1963). A nurse questioning and observing the elderly person, collected the data. The Index of ADL is a scale from 0 to 6 with higher grades reflecting more dependence in function. To study if there were differences in physical function, the scale was divided as follows: independency (0), partial dependency (1-2), and moderate to severe dependency (3-6) (Katz et al., 1963; Agüero-Torres et al., 1998). The following six primary self-care functions are included in the scale: bathing, dressing, toileting, transferring, continence, feeding, with one point for each dependency (Katz et al., 1963; Fillenbaum, 1996).

## **Drug use**

In Study I, II and III the information on drug use was obtained from interviews with the participants. The data was obtained from the KP questionnaire in phase V. Actual prescriptions and drug containers were collected and inspected for confirmation. When persons could not give the information, a relative or health care employee was asked. The data on drug use contained information about the prescription name, dose, dosage form, frequency, route of administration, and indication.

Drug use was defined as the use of a drug on a “regular basis” at the time of interview and as drugs taken as “needed” at any time during the preceding two weeks of the interview. The questionnaire also included questions about factors involved in the drug intake process, e.g. if the participants were receiving any form of help with preparing doses of their medication, if they received any help with administering doses, and their ability to open different kinds of medicine containers.

In Study I, II and III all drugs used were classified according to the Anatomical, Therapeutic, and Chemical (ATC) classification system, a five-level coding system developed and recommended by the WHO (1999) (Table 3). This system classifies drugs into 14 main anatomical groups, each divided into therapeutic subgroups that are further subdivided according to chemical/therapeutic group and the particular chemical substance. For example, cardiovascular (CV) drugs were defined as those in ATC categories C01, C02, C03, C07, C08, and C09 (Table 4).

ATC-group	
A	Alimentary tract and metabolism
B	Blood and blood-forming organs
C	Cardiovascular system
D	Dermatologicals
G	Genito-urinary system and sex-hormones
H	Systemic hormonal preparation, excluding sex-hormones and insulin
J	Anti-infectives for systemic use
L	Antineoplastic and immuno-modulating agents
M	Musculo-skeletal system
N	Nervous system
P	Antiparasitic products, insecticides and repellents
R	Respiratory system
S	Sensory organs
V	Various

**Table 3.** *ATC-groups (Anatomical, Therapeutical, and Chemical classification) 1<sup>st</sup> level.*

ATC-sub group	
C01A	Cardiac glycosides
C01D	Vasodilators used in cardiac diseases
C02	Antihypertensive therapy
C03	Diuretics
C07	Beta blocking agents
C08	Calcium channel blockers
C09A	ACE-inhibitors
M01A B	NSAID (anti-inflammatory drugs), acetic acid derivates
M01A C	NSAID, oxicams
M01A E	NSAID, propion acid derivates
N02A A	Natural opioids
N02A C	Diphenylpropylamine derivatives
N02B A	Salicylic acid derivates (light analgesics)
N02B E	Anilides (paracetamol) (light analgesics)
N02C A	Antimigraines

**Table 4.** *ATC-sub groups used in the thesis.*

### **Medical diseases**

The information on diseases, in Study I, II and III, was based on the diagnoses recorded by the physician clinically examining the participants in KP, and from the Stockholm Computerized Inpatient Registry system. The clinical examination was similar to a normal physical examination in clinical practice. The diagnoses were classified according to the International Classification of Diseases-Tenth edition (ICD-10) (WHO, 1994).

### **Quantative methods- Statistical analyses**

The statistical methods used in the different papers applying quantative methods are presented in Table 5. In Study I, II and III, descriptive analyses were done to describe the study population, and chi-square statistics were used for test of significance (Bland, 2000).

To assess relationships between PANAS-PA and PANAS-NA and CVD, CV medicines, and sociodemographic characteristics in Study I, univariate and multivariate linear regression analyses were carried out (Vittinghoff, Glidden, Shiboski & McCulloch, 2005). The Cronbach's alpha coefficient was used to measure the internal consistency reliability of the PANAS measurement scale. This is a widely used measure of how strongly the items within the scale correlate with each other, and is indicative of the extent to which the items reflect the same, underlying phenomenon. As a rule of thumb, if  $\alpha \geq 0.8$  then the answers are considered reliable (Cronbach, 1951; Cortina, 1993; Leontitsis & Pagge, 2006).



To explore factors associated with using medicines, receiving help (Study II), and having pain (Study III), univariate and multivariate logistic regression analyses were conducted. Odds ratios (OR), and 95 % confidence intervals (CI) were calculated in both studies (Vittinghoff et al., 2005). P-values lower than 0.05 were considered statistically significant.

SPSS® computer software packages (version 10.1 and 12.1 for PC) were used for all the statistical analyses [SPSS®. (2004). *Statistical Products and Services Solutions (SPSS) for Windows*. Chicago (IL): SPSS Inc.].

<b>Paper</b>	<b>Background variables</b>	<b>Outcome variables</b>	<b>Statistical analyses</b>
<b>I</b>	Age, sex, marital status, living arrangement, cognitive status, functional status, having CVD and using CV medicines	PANAS-PA and PANAS-NA	Cross-tabulation, chi-square test, Cronbach alpha, and linear regression analyses
<b>II</b>	Age, sex, living arrangement, cognitive status and functional status	Use of medicines, help with medication and help providers	Cross-tabulation, chi-square test, and logistic regression analyses
<b>III</b>	Age, sex, living arrangement, cognitive status, functional status, and using medicines	Pain reporting and pain treatment	Cross-tabulation, chi-square test, and logistic regression analyses

**Table 5.** Summary of variables and statistical analyses used in studies I, II, and III.

### **A qualitative approach – Content analysis**

All the interviews in Study IV were transcribed verbatim by the first author (MW), which means that no interpretation was made during the transcription. This was done directly after each interview. Afterwards, the first author (MW) listened to all tapes simultaneously with reading the transcripts, and they were found to be of good quality.

In Study IV, the aim was to investigate and describe the medical situation of very old persons living in their own homes, and to acquire knowledge of their views on the use of drugs. The rationale for in-depth interviewing is to give participants the opportunity to describe their experiences with their own words (Cormack, 2000). The data, i.e. transcripts from twenty-five interviews were analysed by using qualitative content analysis (Graneheim & Lundman, 2004; Polit & Beck, 2004) in order to identify categories. The purposes of data analysis is to organize, provide structure to, and elicit meaning from large quantities of narrative text into fewer content categories, but also to identify salient categories and patterns (Polit & Beck, 2006).

In the current study, the method was used to give a systematic description of the manifest content of the interviews, i.e. an analysis of what the text said and describes the visible and obvious components (Graneheim & Lundman, 2004; Polit & Beck, 2006). According to Polit and Beck (2006) the interpretation and analysis of the data occurs almost at the same time. However, an inductive approach was used when analysing the current data. All the transcripts of this study were analysed individually by the first (MW) and the second author (EF). First, all the interviews were carefully read to gain an overall understanding. Thereafter, the text was re-read thoroughly, bearing the aims of the paper in mind. In total, each interview was read through several times, separately, in search for meaning and deeper understanding of the participant’s experience of medicine treatment and management of medicines as described by the participants. Meaning units focusing on treatment and management of medicines were identified (Table 6). These were then condensed and sorted into nine subcategories. Further, the subcategories were regrouped into three main categories on the basis of linkage among subcategories as found in the data. According to Graneheim & Lundman (2004), the manifest content analysis is often presented in categories, while themes are seen as expression of the latent analysis. The interview data were then re-read to refine and verify the categories and to achieve trustworthiness in the findings. Finally, the first and the second authors reviewed the fit of the categories to the participant’s responses that defined them to confirm the findings, and an agreement was considerably explicit.

<b>Data → Meaning units → Subcategories → Main categories</b>			
Older people, aged 85-97, living in ordinary households n=25	Experience of medicine treatment and management of medicines	<ul style="list-style-type: none"> <li>- Clear-headed</li> <li>- Lack of memory</li> <li>- Fear of losing memory</li> <li>- Dealing with short –term memory</li> </ul>	Cognitive ability
		<ul style="list-style-type: none"> <li>- Self-sufficiency</li> <li>- Back-up</li> </ul>	Independence/ Dependence
		<ul style="list-style-type: none"> <li>- Distrust of the medical service</li> <li>- To feel like a burden</li> <li>- To feel deserted</li> </ul>	Support

**Table 6.** Content analysis of interviews leading towards the main categories, i.e. cognitive ability, independence/dependence and support.

## ETHICAL CONSIDERATIONS

It is the ethical responsibility of the researcher to make sure that the patients involved in the study understand the nature of the research (risk-benefits), and that they are not exposed to more than a minor increase of any risk.

Therefore, at baseline, all eligible individuals living in the Kungsholmen district, Stockholm, Sweden, were first sent a personal letter explaining the nature of the health survey and presenting an invitation to participate, but clearly stating that participation was voluntary (von Strauss, 2000). Then, all participants were contacted by a telephone call in order to check their availability and to book their first visit. For all participants, informed consent was requested directly from the subject at the screening evaluation. If a subject had obvious cognitive impairment, a proxy, usually a next-of-kin or a close family member, was asked for consent. The aims of the project were explained and confidentiality of the information provided by the participants was stressed (Hermerén, 1996). However, a general rule was set that the examination or interview should be interrupted if the participant in any way expressed anguish or discomfort, regardless of whether the informed consent had been given by the participants themselves or by a proxy.

In addition, all researchers working with the KP database have followed the Swedish Research Council: Guidelines for ethical assessment of medical research on humans (2003). All phases of the KP received approval from the Ethics Committee of the Karolinska Institutet, Stockholm Sweden.

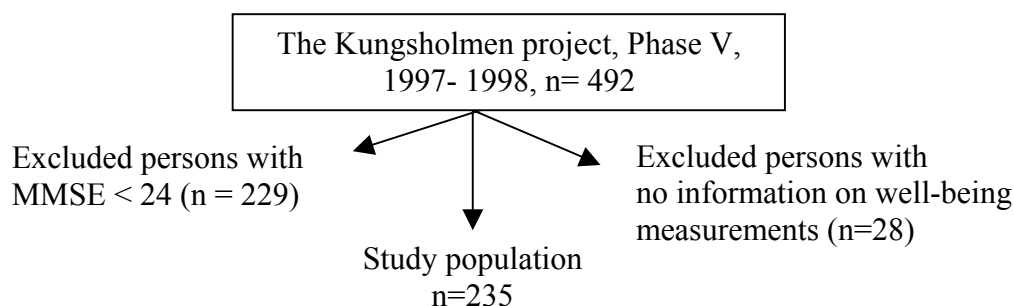
The three studies (Study I, II and III) included in this thesis covered the data collected from phase V (the third-follow up) of the project, and an approval from the Ethics Committee of the Karolinska Institutet, Stockholm, Sweden, was obtained (KI 95:101, 97:413).

In Study IV, the participants' names, addresses and telephone numbers were obtained from the database of the SNAC (Lagergren et al., 2004). First, all participants received a letter containing a full description and information about the aim of the study, stating that participation was voluntary and that data would be treated confidentially (Hermerén, 1996). Then, all participants were contacted by a telephone call in order to check their availability and to book a visit. The participants were once again informed (both by letter, by telephone and before the interview started) that participation was voluntary and that they had the right to refuse participation at any stage of the interview, without giving any reason (Hermerén, 1996). When reporting the findings, the confidentiality of the participants would be protected. During the interviews, the participants agreed to the use of direct quotations from the data collected and a written informed consent was obtained from the participants. All interviews were audiotaped with the participant's permission. In addition, all authors working with this data have followed the Swedish Research Council: Guidelines for ethical assessment of medical research on humans (2003). Approval from the Ethical Committee of the Karolinska Institutet, Stockholm, Sweden, was obtained (EPN 04-916/5).

## RESULTS

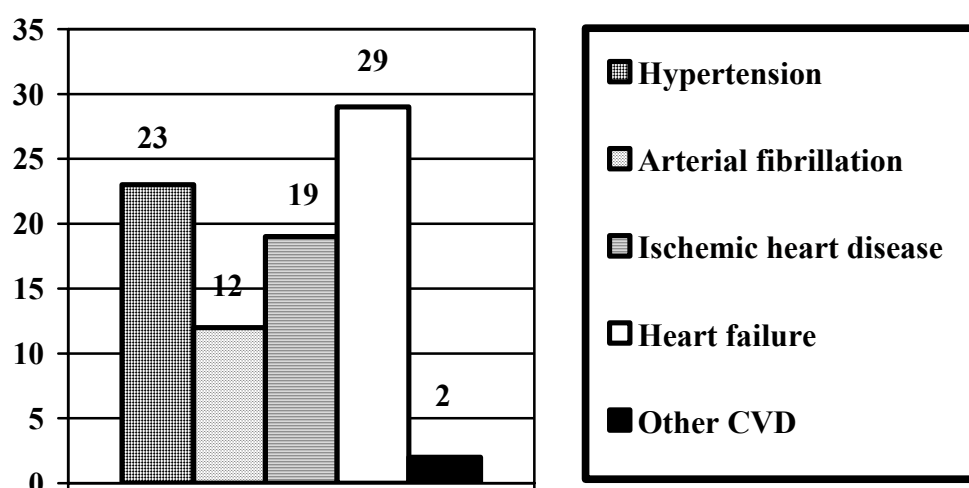
### Study I:

In this study 235 elderly persons participated (Figure 5), 83 % were women, mean age was 89 years ( $\pm 4$ ). Most of the participants were living in their own homes (94 %) and living alone (83 %). Furthermore, PANAS-NA/PA was normally distributed in this group (mean 10/16,  $\pm 4$ ).

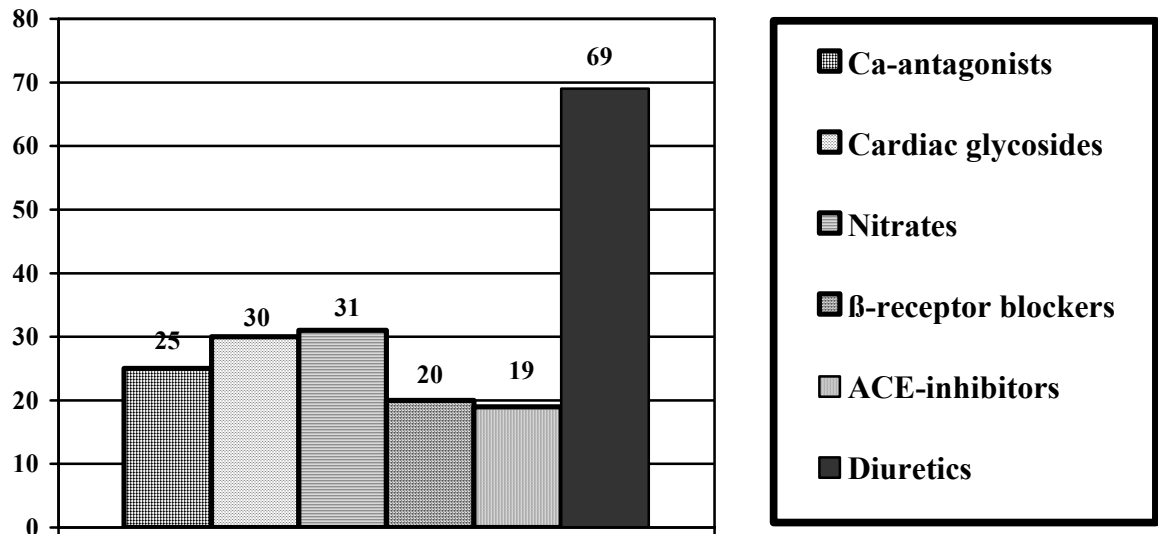


**Figure 5.** *The study population in Study I.*

The main purpose in this study was to examine the association between CVD and their medical treatment on the emotional well-being of very old people. The study showed that CVD was very frequent in this population (62 %) (Figure 6). Among participants with CVD (n=146), heart failure (47 %) and hypertension (37 %) were the most common conditions; and diuretics (69 %), nitrates (31 %) and cardiac glycosides (30 %) the most commonly prescribed drugs (Figure 7). Moreover, 58 % of the participants that were taking CV drugs used a combination of drugs, where the most common was cardiac glycosides and diuretics.



**Figure 6.** *The prevalence(%) of CVD (n=235).*

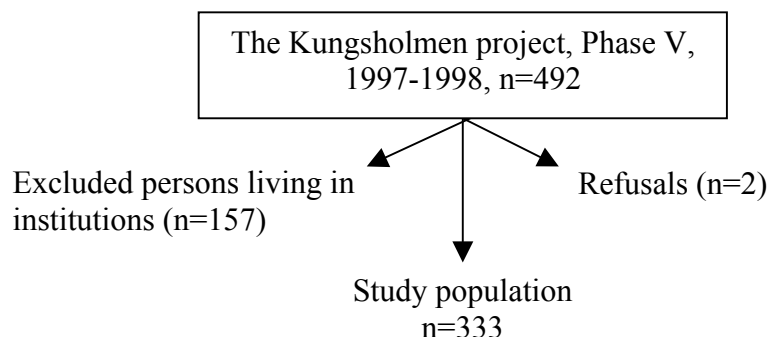


**Figure 7.** The use (%) of CV drugs (n=146).

Univariate linear regression analyses showed that being affected by a CVD did not affect the emotional well-being of the participants (PANAS-PA,  $p=0.171$ ; PANAS-NA,  $p=0.209$ ), whereas the use of some CV drugs (cardiac glycosides  $p=0.07$ , and nitrates  $p=0.017$ ) showed an association with well-being. To further explore the effect on the different CV drugs, multivariate linear regression analyses controlling for age, gender and CV diseases were done for both PANAS-PA and PANAS-NA. Among CV drugs, cardiac glycosides ( $p=0.006$ ) and nitrates ( $p=0.008$ ) were the only drugs that significantly affected well-being measurement in this population, specifically with increased negative feelings (PANAS-NA).

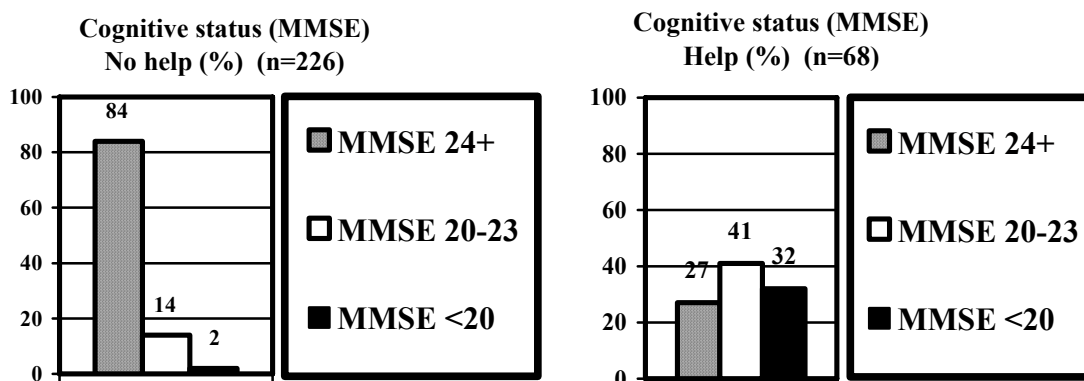
### Study II:

In this study we were interested in investigating factors influencing the participants' handling of medicines. Three hundred and thirty-three elderly persons participated in this study (Figure 8), 80 % were women, and mean age was 88 years ( $\pm 3$ ). Most of the participants were living alone (80 %). We found that 88 % in this population took medicines regularly and only 23 % of them received help with their medicines.

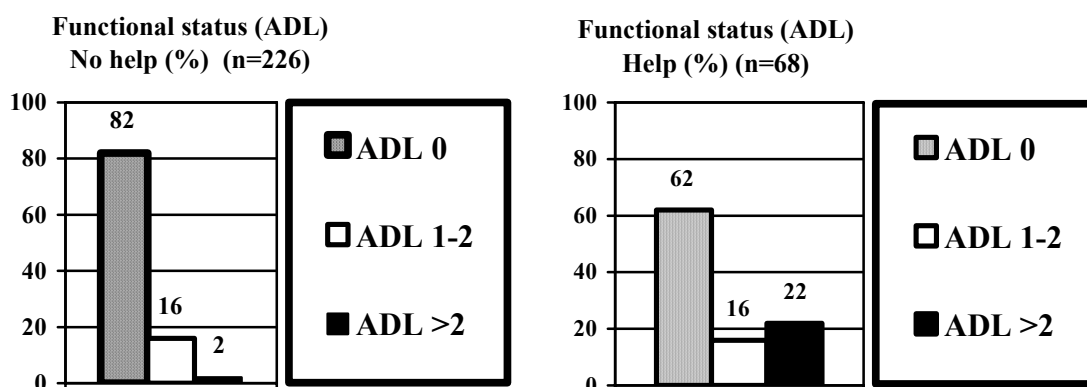


**Figure 8.** The study population in Study II and III.

The Katz Index of ADL was used to measure the participants' functional status (mean 0.54) and MMSE to measure their cognitive status (mean 25). Persons who did not have any help with their medication had a good cognitive and functional status, while persons who received help mostly had lower scores in MMSE, but still were mostly functionally independent (Figure 9 and 10). However, there were also participants (16 %) with low scores in the MMSE (<24) who did not receive any help with their medicines.



**Figure 9.** Description of cognitive status (prevalence in %) in elderly not receiving (left) and receiving (right) help with medication.



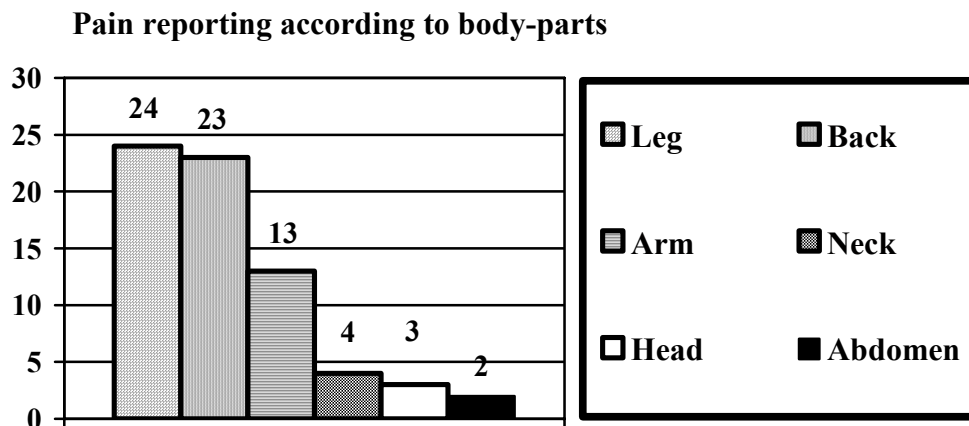
**Figure 10.** Description of functional status (prevalence in %) in not receiving (left) and receiving (right) help with medication.

In order to understand the relation between receiving help with the handling of medicines and sociodemographic characteristics, functional and cognitive status, further analyses were done. Using logistic regression models the results show that female gender and living alone was not associated with receiving help with medicines, while older age and functional disability increased the likelihood, and higher cognitive status decreased the odds of receiving help. When we controlled for sociodemographical variables and functional status, we found that having mild cognitive impairment (MMSE 20-23) increased the likelihood eight times for receiving help with medicines (OR 8.0, 95 % CI=3.0-17.6). We also found that, in comparison with those who had good cognition (MMSE 24+) having severe cognitive impairment (MMSE<20) increased the likelihood of receiving help 45 times (OR 45.0, 95 % CI=14.6-141.3).

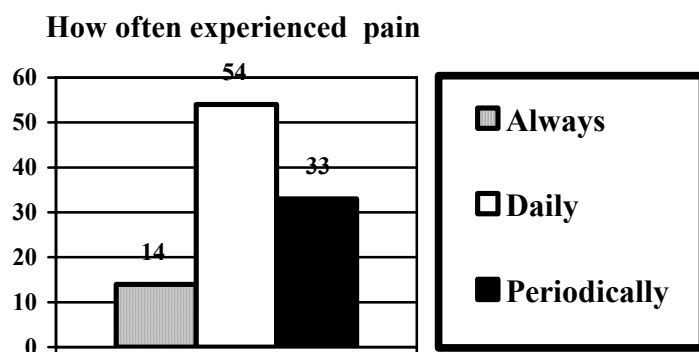
Controlling for sociodemographic variables and cognitive status, the results showed that being partially dependent in function (ADL 1-2) did not increase the likelihood for receiving help with medicines, while having moderate/severe functional dependence (ADL>2) increased the likelihood seven times (OR 7.0, 95 % CI=1.8-24.1) in comparison to those who were functionally independent (ADL=0). Further analyses were done to investigate help providers who assisted the participants with the handling of medicines. The results showed that the majority of the persons who helped the elderly were health staff (n=54). Among those who received help from a family member (n=14), the help mostly came from the wives (12/14). Persons who received help from health staff were mostly older females, living alone.

### Study III:

The aim of this study was to investigate the prevalence of pain reporting and pain treatment and their association with functional and cognitive status in a very old population. The study population is described in Figure 8. We found that the prevalence of pain among very old persons in this study was 46 % and females were reporting pain more often than males (49 % vs. 35 %), regardless of if they were living alone or not. The parts of the body that were most frequently reported as the location of the worst pain were from legs (24 %) and back (23 %) (Figure 11).

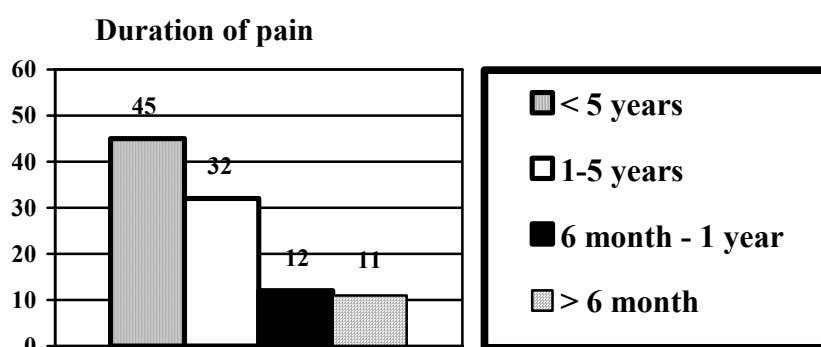


**Figure 11.** Location of reported worst pain (%).



**Figure 12.** Frequency of pain (prevalence in %).

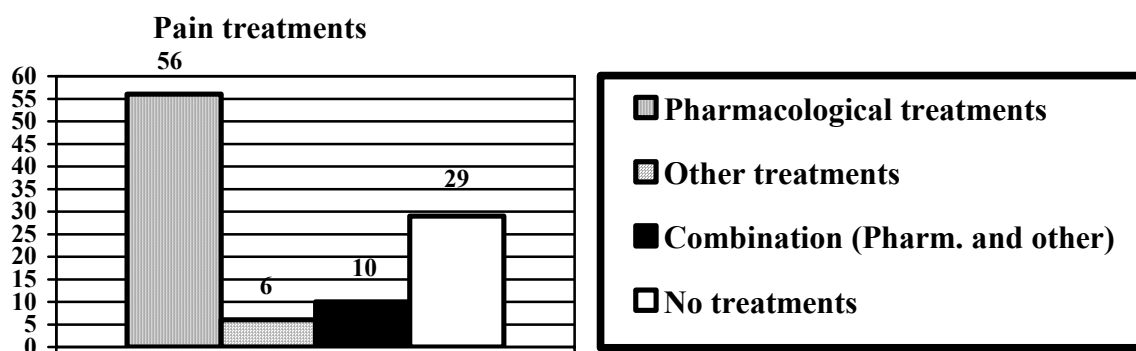
We also found that more than half of the participants experienced pain every day (Figure 12), and this pain was in more than half of the cases affecting them in their daily lives (54 %). Moreover, 77 % of the elderly had experienced pain for more than one year (Figure 13), and 46 % reported that this was their major problem. There was no difference found in age, gender or living condition.



**Figure 13.** Duration of experienced pain (presented in %).

To further understand the relationship between pain and demographic characteristics, functional and cognitive status, logistic regression models were constructed. The results indicated that pain reporting was not associated with age, gender or living condition. We found, however, that cognitive ( $p < 0.001$ ) and functional ( $p = 0.008$ ) status showed a significant association with reporting of pain. Each point increase in the MMSE increased the probability of reporting pain by 20 %, and each point increase in the ADL-scale increased the probability by 30 %. Further analyses were carried out to study the specific effects of functional and cognitive status respectively. Controlling for demographic variables and functional status, showed that having mild cognitive impairment (MMSE 20-23) increased the likelihood for reporting pain 2.5 times (OR 2.5, 95 % CI=0.8-7.8), and having good cognition (MMSE  $\geq 24$ ) increased the likelihood 8.3 times (OR 8.3, 95 % CI=2.9-23.9) in comparison to those who had poor cognition (MMSE  $\leq 23$ ). Controlling for demographic variables and cognitive status, showed that being partially dependent (ADL 1-2) increased the likelihood of reporting pain 1.4 times (OR 1.4, 95 % CI=0.7-2.7), and having moderate/severe functional dependence (ADL  $> 2$ ) increased the likelihood 4.2 times (OR 4.2, 95 % CI=1.4-12.3) in comparison to those who were functionally independent (ADL=0).





**Figure 14.** *The prevalence (%) of different pain treatments.*

As regards treatment, the results showed that 71 % of the participants had pain treatment, and the majority used only pharmacological treatment, mostly light analgesics (anilides, N02BE) against pain (Figure 14). However, 29 % did not receive any treatment at all. We also found that elderly with good cognition (MMSE scored  $\geq 24$ ) more frequently received pharmacological, combined treatment or other treatments ( $p=0.001$ ), i.e. TENS (Transcutaneous Electrical Nerve Stimulator), ultrasound and/or physiotherapy. Moreover, persons with  $ADL \geq 3$  received only pharmacological treatment, while persons with  $ADL=0-2$  received pharmacological, combined treatment or other treatments ( $p=0.065$ ). Persons with  $MMSE \leq 23$  received only pharmacological treatment, while persons with  $MMSE \geq 24$  received pharmacological, combined treatment or other treatments ( $p=0.345$ ). There was no difference found in treatment by age, gender, cognitive or functional status. However, living condition was found significant associated with treatment ( $p=0.031$ ). A logistic regression model was constructed to further understand the relationship between pain treatment and demographic characteristics, functional and cognitive status. The result showed that pain treatment was not associated with age, gender, living condition, functional and cognitive status.

#### **Study IV:**

The main focus of the study was to describe the medical situation of very old persons living in ordinary households, and to obtain knowledge of their views on the use of drugs. Twenty-five older persons, who took regular medications, participated in this study. Nine of them were men and 16 were women, mean age was 90 years ( $\pm 4$ ).

The interviews with the participants were directed to elucidate how they handled their management of medicines. Their responses were focused on three categories: having *cognitive ability*, to be *independent* or *dependent*, and *support*. All of these categories were reported as being of utmost importance in drug use among very old people living in ordinary households.

Cognitive ability was described as the most important factor for allowing the elderly to remain living in their homes. Therefore, there were participants in this study who expressed their concern about the risk for deterioration of their already short memory, as they continued to get older. They knew that lack of memory would mean they would have to move to an institution, because they would not be able to manage themselves any more. Dealing with loss of short-term memory was therefore described as a factor in maintaining their cognitive abilities. Hence, the participants had worked out different ways of remembering to take their daily medicines, e.g. using a pill dispenser, but generally a spouse or home care staffs was helping them.

“So far I am clear-headed and it works well. Then we’ll see what happens when I am not any more.” (Woman, 85 years old)

Independence was also described as an important factor for the elderly in this study. Some participants needed help occasionally and therefore were only partly dependent, while others had a special person as a back-up, i.e. in case of needing help with something, for example help with their medicine management. This back-up person was usually a spouse or their children, and in those cases where the participant did not have any close relatives this person was usually a neighbour.

“I think that is because one has been independent one’s whole life that you want to continue with that.” (Woman, 94 years old)

Lack of trust in the medical service, was also described by some of the elderly participants. This distrust lead them to not follow their medical treatments.

“In all her eagerness the district nurse wanted to help, but I had to change it because she did it wrong. ... Of course it is convenient when the nurse is preparing my pill dispenser, but I am a perfectionist, so it feels much safer when I am preparing it myself.” (Man, 89 years old)

Another issue described by the elderly participants in this study was their fear of being a burden for their relatives. These fears lead them to not ask for help with their medicines, despite their needs.

“I wish that I managed everything on my own. That is my greatest concern, to bother others. That’s my opinion, and I have done this since I started to take medicines, and I do not bother others without cause.” (Woman, 88 years old)

In addition, the results showed that most of the elderly participants were satisfied with their management of medicines, either with some help or managed it by themselves.

## DISCUSSION

Around the world, and in developing countries in particular, researchers try to find ways to help older persons remain healthy and active longer, but also to remain as independent as possible as they are getting older. In this thesis the main objective is to contribute with knowledge about the medical situation of very old persons ( $\geq 84$  years) living in ordinary households, as well as their views on the use of drugs. A large proportion of these very old participants were cognitively intact and functionally independent in spite of their advanced age, indicating that old age is not necessarily equivalent to cognitive or physical declines. In this section, the methods will be considered and main findings will be discussed. More detailed discussion of minor results is available in the discussion sections of the attached Studies I-IV.

### Methodological reflections

Some researchers argue that quantitative and qualitative research are based on totally incompatible paradigms, while others argues that some areas of research can be enriched through the blending of these two methods. By integrating different methods, the weakness of a single approach may be diminished and the value of using combined methods is increasingly accepted in research (Polit & Beck, 2004). In the present thesis, a quantitative design was used in Study I, II and III, followed by a qualitative design in Study IV. The usage of a multimethods approach has been helpful in coming closer to the understanding of the medical situation of the very old. By also using qualitative data, this study has been able to analyse from the individual's perspective, just how the very old experience their management of medicines in their own homes.

In Study I, II and III, the study design was cross-sectional, which are useful for descriptions or investigations of relationships (Bland, 2000; Polit & Beck, 2004). However, because data in cross-sectional studies are collected at the same point in time, the cross-sectional design has limitations concerning inferring changes over time. Therefore, causal conclusions should be avoided (Aronsson, 1999; Polit & Beck, 2004).

### Sample selection

The sample selected in this thesis has some minor problems regarding representativeness that are worth noting. We used a sample from the inner city of Stockholm, and, thus cannot generalise the findings to the population of elderly living in the rural areas (Fratiglioni et al., 1992). On the other hand, the studies in this thesis are all based on participants from the community, which could be a strength when results are to be generalized to the community population at large (von Strauss, 2000). In Study IV we interviewed very old persons and analysed the data using a qualitative method. In studies based on qualitative interviews the selection of appropriate participants is the focus (Patton, 2002; Graneheim & Lundman, 2004), and there is no attempt to stipulate statistical power, sample size, and generalisation of results (Krippendorff, 2004). Qualitative researchers uses the concept *transferability*, described as being similar to the concept of *generalizability*, and refers to the extent to which the findings can be transferred to other settings or groups (Graneheim & Lundman, 2004; Polit & Beck, 2006). Hence, the intention of the study was to provide adequate descriptive data to help readers to judge the applicability of the data in other contexts.

Another factor that may possibly be seen as a limitation is the exclusion of individuals with cognitive impairment, i.e.  $MMSE \leq 23$ , in Study I and IV. The reason for excluding these individuals is mostly ethical, but also practical. The cognitively impaired could have difficulties with comprehending parts of the questionnaire and it would have been wrong to ask them to try. The reliability of the answers for a cognitively impaired group could also be questioned. To study older persons with cognitive impairment may be problematic, but clearly worth attention.

### **Interviews**

In Study I, II and III, the elderly participants were personally interviewed in their place of residence or at the Stockholm Gerontology Research Center. They were given the opportunity to choose the place of the interviews, however, most of the participants wanted to come to the Stockholm Gerontology Research Center. The interviews in Study IV were carried out in the participant's own home and lasted about 1 hour. In this study the opportunity to choose the place for the interview was not given because of the researchers' interest in how the elderly managed their medicine used by themselves in their own homes. Therefore, the home-environment was of importance. However, all participants, when asked for permission for the interviews, expressed that they wanted the interview to take place in their own homes, and therefore this lack of choice would not have affected the results. Instead, the participants were given the opportunity to decide the date and time for the interview.

All interviews in Study IV were audiotaped to avoid loss of importance, details or meanings in the language. Using a tape-recorder could be seen as a strength of the study because actual things said by real people are recorded, and nothing can substitute these raw data (Patton, 2002). Moreover, it also permits the interviewer to be more attentive to the interviewee. However, according to Malterud (1998) using a tape-recorder may restrain the participants to enlighten on their experiences. To avoid these reactions the interviewer had informed the participants at three different occasions before the interviews took place, i.e. in the letter sent to them presenting the description of the study (i), when permission was asked by a telephone call (ii), and before the interview started (iii). The purpose with this procedure was to preclude that the participant would be taken by surprise. Thus, all participants gave permission to use a tape-recorder before the interviews were started. Notwithstanding this, we cannot exclude that the tape-recorder might have had some impact on the participants' answers and therefore affected the results.

Another methodological question concerning validity is that the tape-recorder should be of good quality. Therefore, all interviews in Study IV were made by using a tape-recorder of good quality, so that in transcribing the interview-text verbatim no problems occurred. Pauses/silences, laughter, and other intonations were noted to enrich the text, which is also important for validity.

Another common source for validating qualitative data is feedback from the participants. This method is based on the logic that it is the person who has experienced a setting and therefore is the expert and the owner of the experience as regards a second-order perspective, and that person is therefore able to give the best reflections on it (Patton, 2002). This type of validation can be used during the interview by asking similar questions, but expressing them differently (Kvale, 1996). Feedback from the participants is also a way to ensure the genuine conception of the participant.

In Study IV a dialogical validation was used (Malterud, 1998). After transcription of all the data, a dialogical intersubjectivity (Kvale, 1996) was used where two of the researchers (M. Westerbotn and E. Fahlström) analysed the interviews separately. In the next step all interview transcripts were worked through line by line by both researchers together, i.e. compared for differences and similarities. The material was discussed until agreement was reached.

### **The validity of used instruments**

Validity refers in general to ensure that a questionnaire measures what it is supposed to measure. There are different dimensions to the validity of a measure and two of the most common are content validity and construct validity (Cormack, 2000).

Content validity is concerned with the extent to which the questionnaire appears to measure what it is supposed to measure (Cormack, 2000). Therefore, in Study IV, to investigate elderly persons experience in handling of medicines, three pilot-interviews was performed to test the questionnaire design and attempt to establish content validity. However, no modification of the interview guide was done as the questionnaire seemed to be appropriate to its intended purposed, and therefore, these three interviews were included to the study.

Construct validity is the degree to which an instrument measures the construct under investigation (Polit & Beck, 2004). In Study I we used the 10-item version of Kercher's PANAS (1992) to assess subjective well-being in very old persons living in ordinary households. This shorter version of the PANAS has shown an appropriate factor structure, high discriminant validity, and a reasonable reliability for its subscale (Kercher, 1992). Furthermore, it has also been found that the structural characteristics of positive and negative affect are robust to differences in age, sex and other demographic variables (Mackinnon et al., 1998). Moreover, research on younger participants has not found any differences with respect to well-being between people in rural and urban areas (Veenhoven, 1984). The respondents were asked to report their positive and negative affect during the last year. This time frame was chosen because it shows greater intra-individual stability than shorter time frames (Watson et al., 1988), but it still reflects affect experienced in the recent past. The scale demonstrated acceptable reliability in the sample in Study I as shown by a Cronbach's alpha of 0.71 for PANAS-PA and 0.72 for PANAS-NA.

In all studies in this thesis we used the Swedish version of the MMSE (Grut et al., 1993) to assess cognitive status among the participants'. The test has been widely used by physicians throughout the world, often as a screening test in geriatric and neurological clinics. This is a brief psychometric test that takes about 10 minutes to administer by trained nurses (Grut et al., 1993), and it evaluates persons' cognitive aspects of mental functions (Folstein et al., 1975). To exclude persons with cognitive impairment, in Study I and IV, we used the MMSE  $\geq 24$  as a cut-off (Grut et al., 1993). According to Tombaugh & McIntyre's review (1992), the majority of previous studies using the 23/24+ cut-off points reported sensitivity for dementia in range from 80-90%. The reliability and construct validity of the test is considered good (Folstein et al., 1975; Tombaugh & McIntyre, 1992), and have shown high levels of sensitivity for moderate-to-severe cognitive impairment and lower levels for mild degrees of impairment (Tombaugh & McIntyre, 1992; Onishi et al., 2007). Therefore, the test fulfils its goal of providing a brief screening test (Tombaugh & McIntyre, 1992). The scale demonstrated acceptable reliability in the sample of Study II and III as shown by a Cronbach's alpha of 0.90.

In study II and III we used the Katz ADL-index to assess the functional status of the participants. The Katz Index is a widely used tool for evaluating a person's ability to perform daily personal care activities. The Katz index is a well-validated scale and has shown a good reliability and construct validity (Brorsson & Asberg, 1984). The levels reflect on service needs in terms of the type and amount of personal assistance. The index offers also a measure of objectivity, which has appealed to practitioners of medicine, nursing, and rehabilitation because of its relevance to patient problems (Katz & Akpom, 1976). The scale demonstrated acceptable reliability in the sample of Study II and III as shown by a Cronbach's alpha of 0.86.

### **The emic and etic perspectives**

The concept of emic and etic, influenced by ethnography, is useful to describe my own as well as other researchers' perspectives in this study, as we all want to capture and learn from the perspective of those studied, in this case the group of very old persons living in their own homes. An emic perspective is described as the way members of a particular setting picture their world, i.e. the insider's view (Study IV). In contrast, an etic perspective is described as the outsider's interpretation of the experiences of that setting, i.e. the outsider's view (Study II and III) (Patton, 2002; Polit & Beck, 2006). According to Bartunek and Louis (1996) people who are insiders to a setting and being studied have an own view of the setting that is quite different from the researchers', conducting the study and who are outside the setting. My own understanding in the current thesis was from an etic perspective when working with and interpreting data.

### **Reflections on main findings**

This thesis focused on drug use and the management of medicines in a group of very old persons living in ordinary households. Some of them handled their medicines by themselves while others needed help. Ageing is usually accompanied by age-related chronic conditions and multimorbidity, and therefore drugs have a considerable role in the treatment of diseases in the elderly. However, while medicines may treat diseases and symptoms, wrongly used they may lead to serious consequences such as dependency for the elderly, side effects and even hospitalisation. Although much research has been done on inappropriate drug use, polypharmacy, and hospitalisation related to ADR in the elderly, these problems still remain and the studies leave many questions unanswered. Hence, to improve the quality of drug therapy in this age group living in ordinary households, more studies about patterns of use and management of medicines, the reason for use, and the extent of potential problems with prescription drug use among the elderly community dwellers is needed.

Study I, II and III revealed that the prevalence of drug use was high among these very old participants. These results are in line with several other studies from all part of the world showing that drug use is extensive in the elderly (Chrischilles et al., 1992; Eggen, 1997; Giron et al., 1999), and especially the use of CV drugs (Study I) (Wills et al., 1996; Jones & Poole, 1998; Hanrattey et al., 2000; Giron et al., 2001; Westerbotn, Agüero-Torres, Fastbom & Hillerås, 2005) and analgesics (Study III) (Jones & Poole, 1998; Jørgensen, Johansson, Kennerfalk, Wallander & Svärdsudd, 2001). These patterns of prescribed drugs may reflect the epidemiology of disease in older adults (Jones & Poole, 1998). Studies have also shown different patterns of drug use in different settings, e.g. institutions (Furniss et al., 1998; Schmidt & Fastbom, 2000) and the community (Lindberg et al., 1994; Eggen, 1997).

While drugs often are helpful and necessary for treating the elderly, the use of drugs in this group is fraught with difficulties. The risk versus the benefit of each medication must be strongly considered (Kirkwood, 1998), and therefore the question is: is medical treatment worthwhile for very old individuals in cases where the outcomes do not include an improved well-being?

Good QoL is expected to be one important goal of medical treatment, especially in the very old who are usually afflicted with many diseases and therefore require treatment with several drugs (The Swedish National Board of Health and Welfare, 1999). The aim of any medical treatment is to decrease illness, to increase the QoL, and to prolong the patient's life (The Swedish National Board of Health and Welfare, 1999). Improving well-being and maintaining independence may be more important goals than increasing longevity from the perspective of an elderly individual.

In Study I we investigated if CVD and its medical treatment affected the emotional well-being in a group of very old participants. In spite of CVD being the most common diseases in this group, having a CVD did not affect the participants' well-being. The explanation for this could be due to the medical treatment that allowed these individuals to have a "well-adjusted" life resulting in an adequate emotional well-being for their age. However, the study showed that some CV drugs affected their well-being. More specifically, cardiac glycosides and nitrates were the only CV medicines that affected the participants' well-being negatively (PANAS-NA). This could be explained by ADR or disease severity. Cardiac glycosides have been used for the treatment of many different heart diseases for over 200 years and its role has been debated for the last centuries (Haas & Young, 1999). The discussions have mostly concerned ADR related to the narrow therapeutic index (Lawson-Matthew et al., 1995; Fishkind et al., 1997; Garg et al., 1997; Haas & Young, 1999; Rich, 1999; Hanratty et al., 2000; Onder et al., 2002; FASS, 2006), but also the fact that some of these reactions give diffuse symptoms and are therefore hard to identify, such as tiredness, reduced appetite, cognitive disturbance, or hazy visions (Haas & Young, 1999; Rich, 1999; FASS, 2006). Similar symptoms are commonly seen with "normal" ageing, and therefore mistakes about the elderly's symptoms are easily made. Nitrates have also been associated with several adverse side effects (Onder et al., 2002; FASS, 2006), the most frequently reported side effects being headache, skin reactions, and dizziness (Onder et al., 2002; FASS, 2006). Even though much research has been done on CV drugs in the elderly, knowledge on their effect on QoL in an elderly population is scarce. QoL is commonly seen as having two dimensions: the physical part and the emotional part (well-being), however, most medical studies usually focus on the physical QoL, i.e. side effects of a drug (Just et al., 1993; Lawson-Matthew et al., 1995; Rich, 1999), and therefore they are missing an important part in the comprehensive view of the patient in any medical treatment.

Adequate health, cognitive and functional abilities are necessary for maintaining independence in later life, because these characteristics relate to the capacity to meet the needs of daily living (Mutchler & Burr, 2003), including the ability to manage your own medical treatments. Taking medicines is a complex process that places both cognitive and physical demands on elderly people. Therefore, in Study II we investigated the role of cognitive and functional status among very old participants managing their own medicines. Among older adults both cognitive and functional status vary considerably, and other studies have shown that after the age of 85 years, the majority needs some assistance with basic daily activities, and a portion of frail elderly are severely disabled (Spillman & Pezzin, 2000).

In our study 23 % received help with their medicines, and most of them had lower cognitive status but were functionally independent. In Study IV we found that the elderly are aware of the fact that having a good cognitive ability is of importance to be able to remain longer in their own homes. Other studies have also reported that cognitive impairment is an important predictor for poor compliance with medicine intake in elderly people living in the community (Okuno et al, 2001).

According to Martin & George (1998) errors in drug taking is directly related to the degree of mental impairment, such as errors in drug dose, timing and sequence. Atkin, Finnegan, Ogle & Shenfield (1994) reported that opening a drug container could be a problem for elderly people with cognitive impairment. However, in our study (Study II) 16% of the participants had low cognitive status (MMSE<20) and still did not receive any help with their medicines. This is the group that creates concern, because they have low ability to follow prescriptions and therefore are at great risk for non-compliance. We do not know the reason for why persons with low cognitive status do not receive any help, however, identification of these persons is important to avoid the inappropriate use of medications.

The very old with cognitive impairment can also have physical disabilities, and our studies (II and IV) have shown that physical disability is also important for the ability to remain independent, and thereby may affect the medicine management. Findings from Study II revealed, however, that only persons with severe functional impairment were receiving help with their medicines. Functional status in the elderly is also an important dimension of health and illness, and may reflect on their needs for service assistance (Katz & Akpom, 1976). Therefore, health of an older person is best measured in terms of function rather than pathology, and good health and successful ageing could be defined in terms of the ability to function autonomously, within a given social setting. It is important to emphasise that this thesis is comprised of mostly cognitively intact and functionally independent elderly persons.

Advancing age is usually associated with a greater prevalence and expectation of pain. In an Australian survey of community-dwelling older people (mean age 79 years) 70% stated that they expected to have pain as they got older, although only 47% stated that they actually suffered from pain (Helme, Andrews & Allen, 1992). In Study III, the results indicate that pain is common among the very old participants, and these results are in line with other studies (Brattberg, Parker & Thorslund, 1996; Helme & Katz, 1998). Since only the individual can judge the severity and consequences of his/her pain, the results in prevalence studies are dependent on the questions asked (Helme & Gibson, 1999). Therefore, the prevalence of pain has been reported to be 25% to 50% among community dwellers (American Geriatrics Society (AGS), 1998; Gloth, 2000), depending on the definition of, and the methods used for quantifying the pain.

We found that the prevalence of pain was higher among women than men. Another Swedish study made by Brattberg et al. (1996) also found gender differences in pain reporting among the oldest old. However, in their study women reported more severe pain than men. Possible reasons for this, besides e.g. gender differences in cultural acceptance and behaviour (The Swedish National Board of Health and Welfare, 2004), could be different morbidity patterns. For instance, conditions such as rheumatoid arthritis, osteoarthritis, headache, and fibromyalgia are thought to be more common in women, while ankylosing spondylitis, and coronary heart disease are more common in men (Helme & Katz, 1998; Helme & Gibson, 1999).



According to LeResche (1999), men and women are exposed to different risk factors for pain due to their differing occupational and social roles. Other factors that may influence gender effects of pain reporting could be psychosocial support, education, and lifestyle factors (Unruh, 1996; Helme & Katz, 1998; Pickering, Jourdan, Eschalier & Dubray, 2002).

Most participants in Study III used pharmacological treatment from the ATC-group N (nervous system), especially anilides (N02BE). According to Helme & Katz (1998) anilides is preferred as pain reliever because it is relatively free from adverse effects when used in ordinary doses. The regular use of opioids was 13%, which is in concordance with a study by Jørgensen et al. (2001). According to Jørgensen and colleagues, one explanation for this high use (15%) in their study could be the differences between an urban and a rural community. The participants in our study, however, were living in an urban area, and, hence, have close proximity to physicians and pharmacies. The opposite was true for the rural participants in the study by Jørgensen (2001).

Findings from Study III showed that most of the participants reporting pain received some kind of pain treatment. They were using different methods, such as pharmacological treatments, TENS (Transcutaneous Electrical Nerve Stimulator), ultrasound, physiotherapy, or a combination of different methods, to relieve their pain. However, most participants used pharmacological treatment. Studies have shown that a combination of pharmacological and non-pharmacological treatment was the best method to relieve pain in elderly people, and should therefore always be used (Helme & Katz, 1998; Miaskowski, 2000). However, studies of non-pharmacological treatments in older people are sparse, and the effects are not clear (Sindhu, 1996; Helme & Katz, 1998). In our study combined treatment was seen only among those elderly without any cognitive impairment or any physical declines. In addition we found that 29 % of the population did not receive any treatment at all. We can only speculate about the reasons for this lack of treatment. One explanation could be that persons with cognitive impairment may have lower ability to report pain, which is discussed in the next section. Findings from other studies have shown that older persons might avoid medication because of fear of addiction, ADR or perception that medications are ineffective (Yates, Dewar & Fentiman, 1995; Helme & Katz, 1998; Lansbury, 2000). Fear of side effects from analgesics is reported as more common among older persons compared with younger adults (Miaskowski, 2000). Moreover, fear of side effects may result in under-treatment of pain that leaves persons suffering unnecessarily (Helme & Katz, 1998). Studies have also found that many elderly seem to have become resigned to their pain as a constant and unpleasant companion for the rest of their lives (Yates et al., 1995). Altogether these could be possible explanations to the fact that some of the population studied did not receive any treatment at all. However, we do not know the reason why persons with cognitive or physical impairment only received pharmacological treatments, despite the fact that studies have shown that a combined treatment is best when treating elderly persons with pain (Miaskowski, 2000).

Another, important factor in pain reporting, revealed from Study III, was the participants' cognitive and functional status. The study indicates that an increased MMSE and ADL-scores increases the probability of reporting pain. Most studies relating cognitive impairment and pain have shown a decreased pain with decreasing cognitive function. It has also been shown that patients' ability to report pain decreases with severity of dementia, and it has thus far been difficult to determine whether the decreased pain report is due to less pain or lower ability to report such pain (Huffman & Kunik, 2000; Gloth, 2000). As there are no objective biological markers of pain, the most accurate evidence of pain and its intensity is based on the patient's description and self-report. In patients with dementia and pain, the involvement of persons with a good acquaintance or familiarity with the individual is crucial for an adequate pain management. Furthermore, failure to identify, and /or treat pain may lead to functional disability and have dire consequences for older persons' general well-being.

To have good cognitive ability, to be independent and in some cases, to get support with handling medicines from a close back-up person, was the most important components for the elderly participants, to enable them to remain living in their own homes and to continue managing their medicines by themselves, as shown in Study IV. However, they were concerned about the risk of losing their memory as they are getting older.

“I dread the future, if you should end up in the situation where you can't take care of your own medication. You have seen on the TV from nursing homes how they help them putting a pill in some soup or in milk. But as long as you can manage it on your own you have to be happy and grateful for it.” (Man, 94 years old)

As a consequence to this concern, the elderly were also worried about becoming a burden for their relatives. Their concerns are not groundless. Results from Study II showed that older age, cognitive impairment, and functional disability were the only factors that were significantly associated with receiving help with their medicines, and the cognitive ability was the most important factor. Previous studies have shown that, besides polypharmacy (Gurwitz et al., 2003) and cost of medications (Wasserfallen, Bourgeois, Büla, Yersin & Buclin, 2003), older age, living alone, lack of knowledge or understanding, and cognitive status (Barat, Andreasen & Damsgaard, 2000), were prevalent risk factors in older people receiving home care services (Hall Ellenbecker, Frazier, & Verney, 2004).

As revealed in Study IV, most of the participants were very pleased with their medicine management, either they did it by themselves or they were getting some help.

“I like doing everything by myself and I'm proud of myself for doing that.” (Woman, 94 years old)

“So I can't complain because I get the help I ask for.”  
(Woman, 88 years)

According to Sundström (1995), most elderly in Sweden are satisfied with the help they get. Moreover, the help provided by families and by the state usually comes forth when needed. Therefore we have no reason to assume that the “real” opinion of the elderly may be one of dissatisfaction. However, we do have to correct what truly is unsatisfactory. Therefore, it is important to communicate with and listen to the very old individuals, and to take their concerns seriously.

When the very old in our study were treated with many different medicines they usually used different systems to organise their medicines, and most common among the participants was the use of a pill dispenser as an aid. However, the ability to take medications properly involves more than just remembering to take them. It also involves planning to ensure that medications are taken in the proper sequence, at the proper time, and under the proper circumstances, as well as understanding the relevance of the medication(s) to maintaining current health.

Study IV indicates that the elderly are very well aware of this process, and therefore most of them ask for help when they can not manage by themselves anymore.

“If I realise that I can’t manage then I will have to tell someone.”  
(Woman, 85 years old)

To optimise the effect of a drug, one central principle should be taken into account and that is that the drug therapy should be individualized. Therefore, it is important that the elderly in particular are aware of why they are taking their medications, as their drug treatment can be complex. If people understand why they are taking a drug they will not only be more likely to take the drug, but may also be more likely to report problems with the medication and to comply with follow-up investigations if required. To help a old person to understand the way a drug should be used will, in the long-term, pay off with fewer problems, i.e. polypharmacy, ADR and subsequent hospitalisations.

Another issue, revealed from the interviews with the elderly participants in Study IV, was the probability for the pharmacist changes the drug from the brand prescribed to a drug with lowest price, and for some of the elderly this was a source of confusion.

“ From the pharmacist you get new medicines that are cheaper,  
and with new names to learn, it’s hard for the elderly.”  
(Woman, 94 years old)

Furthermore, sometimes the pharmacist did not take into account the ability of opening the medicines when they changed the medicines based on lowest price. Studies have shown that bottles with small print or childproof caps can cause difficulties for the elderly, as well as drugs with similar names and components (Hall Ellenbecker et al., 2004; Beckman, Bernsten, Parker, Thorslund & Fastbom, 2005). Therefore, it is of importance to always inform and to involve the elderly in their own medical treatment, and to make sure that they understand and follow directions for the prescription.

In Study I and II we found gender differences in drug use. This have been described and analysed in several studies, and most of them showed higher drug use among women (Eggen, 1997; Jørgensen et al., 2001; The Swedish National Board of Health and Welfare, 2004). Furthermore, other studies have also showed gender-related differences in healthcare utilization, and other factor such as differences in behaviour, higher attendance rate at doctors visits, cultural acceptance of the sick role, and different prescribing patterns to women (The Swedish National Board of Health and Welfare, 2004). However, very little is known concerning these factors in the very old living in ordinary households.

Results from this thesis may, besides increasing our knowledge concerning subjective feelings of well-being and attitudes toward medication use and management, also contribute to the knowledge base and competence of those working with very old persons living in ordinary households, in other words, general practitioners, district nurses and other caring personnel. In addition, the findings may be useful for planning health strategies and finding more secure methods for facilitating the handling of medicines in this age group of persons who are able to remain living in ordinary households, with no help or only limited help from social service personnel or a family member. There is a need to even further our knowledge of the health care situation of the very old living in ordinary households.

The inevitability of ageing and its concurrent “problems” spurs us to find ways to measure up this need and studies on drug use are a means to achieve that goal. While there is extensive literature on drug use in the older population, there is scant literature in the very old, i.e. those who are 84 years or older. This thesis contributes to that knowledge and hopefully imparts valuable information to all health professionals involved in the care of very old persons.

## CONCLUSIONS

- √ A large proportion of the very old (84 years and older) were living in ordinary households and used medicines regularly. Most of them managed to handle their medicines by themselves, and were very pleased with this, either they did it by themselves or they were getting some help.
- √ CVD were one of the most common diseases in the very old participants investigated, and having a CVD did not specifically affect the persons' well-being. CV drugs were the most used medicines in this population, taken by 58 %. Cardiac glycoside and nitrates were the only CV medicines that significantly affected the participants' well-being, specifically with increased negative feelings (PANAS-NA).
- √ Among the very old participants investigated, older age, cognitive impairment, and functional disability were factors that were significantly associated with receiving help with the handling of medicines. However, the effect of cognition was stronger than the effect of function.
- √ Elderly women living alone were significantly more likely to receive help with their medicines from the community help services, and the only factor associated with receiving help from a family member was not living alone.
- √ Pain was common among the very old participants investigated (46%), and women reported pain more often than males, regardless of if they were living alone or not. Furthermore, more than half of the participants that reported having pain, experience pain every day that affect them in their daily lives, and 77 % of them experienced long-lasting pain (more than one year). The most commonly reported parts of the body affected were legs (24%) and back (23%).
- √ Cognitive and functional status was of significance for pain reporting in the very old participants investigated. Each point increase in the MMSE, and each point increase in the ADL-scale increased the probability of reporting pain.
- √ The most important components for the very old participants to be able to remain living in their own homes and to continue managing their medicines by themselves, was to have good cognitive ability, to be independent and in, some cases, to get support with their medicines from a close person as a back-up. Qualitative analysis showed that when the elderly were treated with many different medicines they used system to organise their medicines, most commonly a pill dispenser was used as an aid.
- √ Qualitative analysis showed that most of the elderly participants were concerned about the risk of losing their memory, as they are getting older. Consequently they were also concerned about becoming a burden for their relatives.

## **Generalizability**

The study population consisted of persons, 84 years and older, living in Kungsholmen, a district of Stockholm, Sweden. The age- and gender-distribution was comparable with other parts of the city. However, the population of Kungsholmen does differ from the rest of Sweden, in that there were higher proportions of females, highly educated people, and unmarried or divorced men and women (von Strauss, 2000). Thus, it is difficult to generalise our results to rural areas, as well as other cultures. We do believe that the results can be applied to other older urban population in western society.

In Study IV we interviewed very old people and analysed the data using a qualitative method. Through the concept of transferability (Polit & Beck, 2006), the intention in the present thesis has been to provide adequate descriptive data to help readers to judge the applicability of the data in other contexts.

## **Nursing implications**

Nurses, in almost all specialties and settings, come into contact with older persons on a regular basis in their work. Knowledge of the elderly's needs and ways to promote positive outcomes is therefore core knowledge for the profession, and not simply an area of specialty for a small subgroup of gerontological nurses. It is also my belief that nurses have the potential to improve the elderly's health across different settings, and, furthermore, to facilitate access to programmes and services, educating and empowering elderly individuals and their families to improve their health and thus, to manage chronic conditions. When either family caregivers or uneducated home care workers provide most of the direct care, nursing has a particular leadership role in working through others to promote an optimal clinical outcome, functional ability, and QoL. In addition, by building nursing research in gerontology, nurses can articulate best practices and subsequently improve care for older adults across settings.

## **Future perspectives**

The areas covered in this thesis raise further questions that are topical in ageing research and new knowledge is required to develop more secure methods and health strategies to facilitate the handling of medicines in this age group. Drug use by the elderly is a complex field that requires more attention, as the world population of the oldest old increases. The age-related changes and increased morbidity in the elderly put higher demands on physicians, nurses and other health care personnel, and their need to be aware of the variation in management of drugs in individuals, the adverse affects, and interactions, so that inappropriate drug use can be avoided. Moreover, the increased proportion of the oldest old in combination with a high level of drug consumption will result in an increased demand on the healthcare system during the next 10-20 years. There is thus a need for studies analysing the drug use among the oldest old, and additional studies are needed to find the right balance between "too few" and "too many" drugs. All together this will ensure an increased longevity, improved overall health, and enhanced function and well-being in the elderly.

Research has in different ways, together with physicians, nurses and other health care personnel, succeeded in adding years to life for elderly people around the world; but the question is if we have succeeded in adding life to years? How to add life to years could possibly be the next challenge to study, especially in different medical research.

## ACKNOWLEDGEMENTS

There are so many people who have contributed to this thesis in so many different ways that I would, truly, be able to write a separate thesis with acknowledgements if everyone was to be mentioned and thanked enough. However, I will do my best to be as brief as possible.

Firstly, to **ALL the participants** living in Kungsholmen, Stockholm, Sweden. Without you all there would not be any Kungsholmen Project. I am very grateful for the time and patience all of you have put into the KP. Furthermore, I had the privilege to meet some of you in my own interview study (Study IV). These meetings were very valuable and increased my knowledge. Therefore, thank you all for sharing your experiences with me.

**Pernilla Hillerås**, RN PhD, my main supervisor, for believing in me, for generously guiding me into the world of research, for constructive criticism, continuous encouragement, and for inspiring me to become a researcher. I also want to thank you for introducing me to all the fantastic researchers in the Ageing Research Centre (Äldrecentrum), Stockholm Sweden, for taking me to the Australian National University (ANU), Centre for Mental Health Research, Canberra, Australia, and for introducing me to professor **Anthony Jorm**, **Betty Kitchener**, and all the other fantastic colleagues at ANU.

**Hedda Agüero-Torres**, MD PhD, my co-supervisor, for excellent scientific guidance, especially methodological and statistical issues, for always giving me fruitful advice and creative inspiration, for continuous encouragement. Thank you for all the time you have given me to help me in my studies.

**Johan Fastbom**, MD Assoc. Professor, my co-supervisor, for excellent scientific, constructive and valuable advice in all my papers and in this thesis, and for your continuous encouragement. I am very proud to have been your doctoral student.

**Bengt Winblad**, Professor, my co-supervisor, for giving me the opportunity to do my PhD-work at the Department of Neurobiology, Caring Science and Society, Karolinska Institutet, Stockholm Sweden. But also for your continuous support and for inspiring me to become a researcher.

A special thanks to **Jan-Åke Lindgren**, Professor, my Superior and the Vice-Chancellor at Sophiahemmet University College. Thank you for your generosity, for providing support, for continuous encouragement and for believing in me.

To **all my colleagues and friends at Sophiahemmet University College**, Stockholm, thank you for all your support and encouragement during my doctoral studies. A special thanks to **Ulla Wissing**, vice principal at Sophiahemmet University College, and **Kerstin Berg**, Studierektor (assistance principal) at Sophiahemmet University College, I appreciate your encouragement and for always believe in me. Moreover, to **Åsa Craftman**, **Camilla Tomaschewski**, and **Catharina Gynäs** for a lot of laughs and reflections throughout all this time. To **Britten Jansson**, for commenting my paper IV, and to **Pelle Sandberg** for all technical support with my thesis.

I would also like to express my appreciation and thanks to the librarians at Sophiahemmet University College, Stockholm; the chief librarian **Eva Unemo-Walfridsson**, thank you for helping me with the reference list in my thesis, **Karin Gåård**, **Camilla Sandell-Persson**, and **Ylva Sundin**, many thanks for all valuable assistance with my references in all my papers.

**Gunnel Raadu**, thank you for valuable and excellent help with writing the part about medical laws in this thesis, and for your excellent revision on the English language. What you don't know about laws and regulations is not worth knowing. I am also very thankful and honored to be allowed to work with you, but also for your valuable friendship.

A special thank to **Anna Hansson**, my friend and my colleague as a PhD-student. Thank you for stimulating and constructive discussions, for reading and commenting my papers and thesis, and also for valuable friendships during our doctoral studies.

**Elin Fahlström**, RN MSc, “my” previous student at Sophiahemmet University College and “my” MSc-student at Karolinska Institutet, but also a valuable co-author in Study IV. Thank you for stimulating discussions.

To **all colleagues and friends at the Department of Neurobiology, Caring Science and Society (NVS)**, Karolinska Institutet, Stockholm, and **Stockholm Gerontology Research Center** (Stockholms Läns Äldrecentrum), Stockholm Sweden, thank you for all the knowledge you have shared with me, for all your support and friendship, but most of all for the great atmosphere. In particular **Sven-Erik Wånell**, Head of Stockholm Gerontology Research Center, and **Laura Fratiglioni**, Professor and Head of the Ageing Research Centre (ARC), Stockholm Sweden, for giving me the opportunity to do my PhD-studies at the Stockholm Gerontology Research Center, Stockholm Sweden, and also for excellent leadership that is the basis for creating such a great atmosphere. I am also grateful, for support, friendship, and constructive discussions, to **Eva von Strauss Gunilla Nordberg**, **Jan Nilsson**, **Weili Xu**, **Zarina Nahar Kabir**, **Marti Parker**, **Anita Karp**, **Neda Agahi** and **Maria Wahlberg**, for continuous help with the KP database and friendship. To **Cecilia Larsson**, **Sofia Österman**, **Britt-Marie Guldbrandsen**, and **Zoltan Pethö**, for administrative and technical help. To the members of the “drug-group”: **Inga Klarin**, **Christel Cornelius**, **Anna Beckman**, **Mats Thorslund**, **Cecilia Bernsten**, **Imran Syed** and **Kristina Johnell** for all interesting and stimulating discussions. I am looking forward to continue working with you all. To **Tina Kiderud**, at the Ageing Research Centre (ARC), Stockholm Sweden, for providing me with data and for generously sharing your valuable knowledge about the participants in KP with me. To **Sirkka-Liisa Ekman**, Professor and Head of Gerontological Caring Science, NVS, Karolinska Institutet, Stockholm, for all your kindness and valuable support.

**Susan Andersson**, thank you for your excellent revision of the English language in this thesis.

To **all my friends**, but especially to my oldest, very best and dearest friends; **Mikael Åslund**, **Carina & Peter Johansson**, **Agneta Westerlund**, **Rolf Malm**, **Gunilla Hansson**, **Sally Niva**, **Marie Långbacka**, and **Mats Freding**, who always believed in and encouraged me during all this time, but also had patience with me when I “was too tired to socialize”. Now, I do not have any more excuses...



To a very special person and a very dear friend, **Tomas Abrahamsson**. Thank you for always believing in me and for all encouragement, but also for reading and commenting my thesis. You will always have a special place in my heart.

Last but not least, to my parents, **Erna** and **Hans Westerbotn**. First, for giving me life, for all your great love, for always supporting and believing in me, but also for making me believe that I can do whatever I want. I love you both very much, and for me you are the “world’s best parents”.

“ Education is the only thing that no one can take away from you”, as my father has always told me.

To Sophiahemmet University College, Stockholm, Sweden, The Sophiahemmet Foundation for Clinical Research (Patientnära forskning), Stockholm, Sweden, and Stiftelsen Solstickan, Stockholm, Sweden, thank you for all financial support.

## REFERENCES

- Agüero-Torres, H., Fratiglioni, L., Guo, Z., Viitanen, M., von Strauss, E., & Winblad, B. (1998). Dementia is the major cause of functional dependence in the elderly: 3-year follow-up data from a population-based study. *American Journal of Public Health, 88*, 1452-1456.
- American Geriatrics Society (AGS). (1998). Clinical practice guidelines: The management of chronic pain in older persons. *Geriatrics, 53*, (Suppl 3),8-24.
- Aronsson, Å. (1999). *SPSS; en introduction till basmodulen*. Lund: Studentlitteratur (In Swedish).
- Atkin, P. A., Finnegan, T. P., Ogle, S. J. & Shenfield, G. M. (1994). Functional ability of patients to manage medication packaging: A survey of geriatric inpatients. *Age and Ageing, 23*, 113-116.
- Barabino, A., Galbariggi, G., Pizzorni, C., & Lotti, G. (1991). Comparative effects of long-term therapy with captopril and ibopamine in chronic congestive heart failure in older patients. *Cardiology, 78*, 243-256.
- Barat, I., Andreasen, F., & Damsgaard, E. M. (2000). The consumption of drugs by 74-year-old individuals living in their own homes. *European Journal of Clinical Pharmacology, 56*, 501-509.
- Bartunek, J. M., & Louis, M. R. (1996). *Insider/outsider team research* (Qualitative research methods series, 40). Thousand Oaks, CA: SAGE.
- Beckman, A., Bernsten, C., Parker, M. G., Thorslund, M., & Fastbom, J. (2005). The difficulty of opening medicine containers in old age: A population-based study. *Pharmacological World Science, 27*, 393-398.
- Beers, M. H., Jones, T. V., Berkwits, M., Kaplan, J. L., & Porter, R. (Eds.). (2005). *The Merck manual of health and aging*. New York: Ballantine Books.
- Berg, S., & Sundstöm, G. (1999). Sweden. In J. Schroots, B.R. Fernandez, & G. Rudinger (Eds.). *Aging in Europe*. (pp.123-130). Amsterdam: European Commission Directorate-General XII, Science, Research and Development, IOS Press.
- Bland, M. (2000). *An introduction to medical statistics*. (3<sup>th</sup> ed.). Oxford: University Press.
- Bowling, A. (1996). Quality of life. In S. Ebrahim, & A. Kalache (Eds.), *Epidemiology in Old Age* (pp. 221-227). London: BMJ Publishing Group.
- Bowling, A. (2002). *Research methods in health: Investigating health and health services* (2<sup>nd</sup> ed.). Buckingham: Open University Press.

- Bowling, A. (2005). *Measuring health: A review of quality of life measurement scales* (3<sup>rd</sup> ed.). Buckingham: Open University Press.
- Bozzetti, F. (2003). Nutritional issues in the care of the elderly patient. *Critical reviews in oncology/hematology*, 48, 113-121.
- Bradburn, N. M. (1969). *The structure of psychological well-being*. Chicago: Aldine.
- Brattberg, G., Parker, M.G., & Thorslund, M. (1996). The prevalence of pain among the oldest old in Sweden. *Pain*, 67, 29-34.
- Brorsson, B., & Asberg, K.H. (1984). Katz index of independence in ADL: reliability and validity in short-term care. *Scandinavian Journal of Rehabilitation Medicine*, 16, 125-132.
- Börjesson-Hansson, A., Edin, E., Thorsteinn, G., & Skoog, I. (2004). The prevalence of dementia in 95 year olds. *Neurology*, 63, 2436-2438.
- Carlsten, A., Waern, M., & Allebeck, P. (1999). Suicides by drug poisoning among the elderly in Sweden 1969-1996. *Social Psychiatry and Psychiatric Epidemiology*, 34, 609-614.
- Chrischilles, E. A., Foley, D. J., Wallace, R. B., Lemke, J. H., Semla, T. P., & Hanlon, J. T., et al. (1992). Use of medication by persons 65 and over: Data from the established populations for epidemiologic studies of the elderly. *Journal of Gerontology*, 47, M137-144.
- Claesson, B., & Schmidt, I. K. (1998). Drug Use in Swedish Nursing Homes. *Clinical Drug Investigation*, 16, 441-452.
- Cormack, D. F. (Ed.). (2000). *The research process in nursing* (4<sup>th</sup> ed.). Oxford: Blackwell science.
- Cortina, J. M. (1993). What is coefficient alpha?: An examination of theory and applications. *Journal of Applied Psychology*, 78, 98-104.
- Couture, M., Larivière, N., & Lefrancois, R. (2005). Psychological distress in older adults with low functional independence: A multidimensional perspective. *Archives of Gerontology and Geriatrics*, 41(1), 101-111.
- Cress, M. E., Buchner, D. M., Questad, K. A., Esselman, P. C., deLateur, B. J., & Schwartz, R. S. (1992). Exercise: Effects on physical functional performance in independent older adults. *Journal of Gerontology. Series A, Biological sciences and medical sciences*, 54, M242-248.
- Cronbach, L. (1951). Coefficient alpha and the internal structure of tests. *Psychometrika*, 16, 297-334.
- Cullum, S., Huppert, F. A., McGee, M., Denning, T., Ahmed, A., & Paykel, E. S., et al. (2000). Decline across different domains of cognitive function in normal ageing: Results of a longitudinal population-based study using CAMCOG. *International Journal of Geriatric Psychiatry*, 15, 853-862.

- Dehlin, O., & Rundgren, Å. (2000a). Biologiska åldersförändringar i nervsystem och sinnesorgan. In O. Dehlin, B. Hagberg, Å. Rundgren, G. Samuelsson, & B. Sjöbeck, *Gerontologi: Åldrandet i ett biologiskt, psykologiskt och socialt perspektiv* (pp. 76-91). Stockholm: Natur & Kultur. (In Swedish).
- Dehlin, O., & Rundgren, Å. (2000b). Biologiska åldersförändringar i matsmältningsorganen och urinvägarna. In O. Dehlin, B. Hagberg, Å. Rundgren, G. Samuelsson, & B. Sjöbeck, *Gerontologi: Åldrandet i ett biologiskt, psykologiskt och socialt perspektiv* (pp. 92-110). Stockholm: Natur & Kultur. (In Swedish).
- Diener, E., & Emmons, R. A. (1984). The independence of positive and negative affect. *Journal of Personality and Social Psychology*, *47*, 1105-1117.
- Eggen, A. E. (1997). Patterns of medicine use in a general population (0-80) years: The influence of age, gender, diseases and place of residence on drug use in Norway. *Pharmacoepidemiology and Drug Safe*, *6*, 179-187.
- FASS: Förteckning över humanmedicin* (2006). Stockholm: Läkemedelsindustriföreningen (LIF).
- Fastbom, J. (2006). Läkemedel och äldre. In L.-O. Wahlund. *Praktisk geriatrik* (pp. 90-114). Stockholm: Liber. (In Swedish).
- Ferrell, B. A. (1999). Pain management. In R.W. Hazzard, J. P. Blass, W. H. Ettinger, jr., J. B. Halter, & J. G. Ouslander (Eds.), *Principles of geriatric medicine and gerontology* (4<sup>th</sup> ed., pp. 413-433). New York: McGraw-Hill.
- Fillenbaum, G. G. (1996). Functional ability. In S. Ebrahim, & A. Kalache (Eds.), *Epidemiology in old Age* (pp. 228-235). London: BMJ Publishing Group.
- Fishkind, D., Paris, B. E. C., & Aronow, W. S. (1997). Use of digoxin, diuretics, beta blockers, angiotensin-converting enzyme inhibitors, and calcium channel blockers in older patients in an academic hospital-based geriatrics practice. *Journal of the American Geriatric Society*, *45*, 809-812.
- Folstein, M. F., Folstein, S. E., McHugh, P. R. (1975). Mini-mental state: A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, *12*, 189-198.
- Fratiglioni, L., Viitanen, M., Bäckman, L., Sandman, P. O., & Winblad, B. (1992). Occurrence of dementia in advanced age: The study design of the Kungsholmen project. *Neuroepidemiology*, *11*(Suppl.1), 29-36.
- Furniss, L., Lloyd Craig, S.K., & Burns, A. (1998). Medication use in nursing homes for elderly people. *International Journal of Geriatric Psychiatry*, *13*, 433-439.
- Gambassi, G., Lapane, K.L., Sgadari, A., Carbonin, P., Gatsonis, C., Lipsitz, L.A., Mor, V., & Bernabei, R. (2000). Effects of angiotensin-converting enzyme inhibitors and digoxin on health outcomes of very old patients with heart failure. *Archives of Internal Medicines* *160*, 53-60.

- Garg, R., Gorlin, R., Smith, T., & Yusuf, S., for the Digitalis Investigation group (DIG). (1997). The effect of digoxin on mortality and morbidity in patients with heart failure. *The New England Journal of Medicine*, 336, 525-533.
- Giron, M. S., Claesson, C., Thorslund, M., Oke, T., Winblad, B., & Fastbom, J. (1999). Drug use patterns in a very elderly population: A seven-year review. *Clinical Drug Investigation*, 17, 389-398.
- Giron, M. S., Wang, H.-X., Bernsten, C., Thorslund, M., Winblad, B., & Fastbom, J. (2001). The appropriateness of drug use in an older nondemented and demented population. *Journal of American Geriatric Society*, 49, 277-283.
- Gloth, F. M. 3<sup>rd</sup>. (2000). Geriatric pain: Factors that limit pain relief and increase complications. *Geriatrics*, 55(10), 46-48, 51-54.
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24, 105-112.
- Grut, M., Fratiglioni, L., Viitanen, M., & Winblad, B. (1993). Accuracy of the Mini-Mental Status Examination as a screening test for dementia in a Swedish elderly population. *Acta Neurologica Scandinavica*, 87, 312-317.
- Gurwitz, J. H., Field, T. S., Harrold, L. R., Rothschild, J., Debellis, K., & Seger, A. C., et al. (2003). Incidence and preventability of adverse drug events among older persons in the ambulatory setting. *JAMA: the Journal of the American Medical Association*, 289, 1107-1116.
- Haas, G. J., & Young, J. B. (1999). Inappropriate use of digoxin in the elderly. *Drug Safety*, 20, 223-230.
- Hall Ellenbecker, C., Frazier, S. C., & Verney, S. (2004). Nurses' observations and experiences of problems and adverse effects of medication management in home care. *Geriatric Nursing*, 25, 164-170.
- Hanratty, C. G., McGlinchey, P., Johnston, G. D., & Passmore, A. P. (2000). Differential pharmacokinetics of digoxin in elderly patients. *Drugs and Aging*, 17, 353-362.
- Helme, R.D., Andrews, P.V., & Allen, F. (1992). Medication use by elderly people resident in public housing in Melbourne. *Proceedings of the Australian Association of Gerontology*, 27, 30-33.
- Helme, R.D., & Gibson, S.J. (1999). Pain in older people. In I.K. Crombie, P.R. Croft, S.J. Linton, L. LeResche, & M. Von Korff (Eds.), *Epidemiology of pain* (pp. 103-112). Seattle: IASP Press.
- Helme, R.D., & Katz, B. (1998). Pain management. In C.F. George, K.W. Woodhouse, M.J. Denham, & W.J. MacLennan (Eds.), *Drug therapy in old age* (pp. 333-350). West Sussex: John Wiley & Sons Ltd.

- Hermerén, G. (1996). *Kunskapens pris: Forskningsetiska problem och principer i humaniora och samhällsvetenskap* [The price of knowledge: Ethical problems in research and principles in human and social sciences] (2<sup>nd</sup> ed.). Stockholm: Humanistisk-samhällsvetenskapliga forskningsrådet: Uppsala: Scandinavian Science Press. (In Swedish).
- Hillerås, P. K., Jorm, A. F., Herlitz, A., & Winblad, B. (1998). Negative and positive affect among the very old: A survey on a sample age 90 years or older. *Research on Ageing, 20*, 593-610.
- Hokenstad, M.C., & Johansson, L. (1990). Caregiving for the elderly in Sweden: program challenges and policy initiatives. In D. Biegel, & A. Blum (Eds.). *Ageing and Caregiving: Theory, Research and Policy*. (pp. 254-269). Newbury Park: Sage.
- Huffman, J. C., & Kunik, M. E. (2000). Assessment and understanding of pain in patients with dementia. *The Gerontologist, 40*, 574-581.
- ICN; International Council of Nurses. (2006). *Position statement: Nursing care of the older person*. Retrieved 30 August, 2006, from: <http://www.icn.ch/psolder.htm>.
- Jensen, E., Dehlin, O., Hagberg, B., Samuelsson, G., & Svensson, T. (1994). Medical, psychological, and sociological aspects of drug treatment in 80-year-olds. *The Gerontologist, 27*, 140-144.
- Jones, J. G., Kallman, H., & Revicki, D. A. (1987). Digitalis for congestive heart disease in elderly: A family practice view of the efficacy of long-term therapy. *Postgraduate Medicine, 81*, 141-142, 145-50.
- Jones, D., & Poole, C. (1998). Medicine taking by elderly people: an overview. In C.F. George, K.W. Woodhouse, M.J. Denham, & W.J. MacLennan (Eds.), *Drug therapy in old age* (pp. 1-22). West Sussex: John Wiley & Sons Ltd.
- Just, H., Drexler, H., Taylor, S. H., Siegrist, J., Schulgen, G., & Schumacher, M. (1993). Captopril versus digoxin in patients with coronary artery disease and mild heart failure: A prospective, double-blind, placebo-controlled multicenter study: The CADs study Group. *Herz, 18* (Suppl. 1), 436-443.
- Jørgensen, T., Johansson, S., Kennerfalk, A., Wallander, M.-A., & Svärdsudd, K. (2001). Prescription drug use, diagnoses, and healthcare utilization among the elderly. *The Annals of Pharmacotherapy, 35*, 1004-1009.
- Kalache, A. (1996). Functional ability. In S. Ebrahim, & A. Kalache (Eds.). *Epidemiology in old age* (pp. 153-161). London: BMJ Publishing Group.
- Katz, A. M. (1989). Changing strategies in the management of heart failure. *Journal of the American College of Cardiology, 13*, 513-523.
- Katz, S., & Akpom, C. A. (1976). Index of ADL. *Medical Care, 14* (Suppl. 5), 116-118.

- Katz, S., Ford, A.B., Moskowitz, R.W., Jackson, B.A., & Jaffe, M. W. (1963). Studies of illness in the aged: The index of ADL: A standardized measure of biological and psychosocial function. *JAMA: The Journal of the American Medical Association*, 185, 914-919.
- Kercher, K. (1992). Assessing subjective well-being in the old-old: The PANAS as a measure of orthogonal dimensions of positive and negative affect. *Research on Aging*, 14, 131-168.
- Kinsella, K. (1996). Demographic aspects. In S. Ebrahim, & A. Kalache (Eds.), *Epidemiology in old age* (pp. 32-40). London: BMJ Publishing Group.
- Kiowski, W., Drexler, H., Meinertz, T., Zuber, M., Ritz, R. & Burkart, F., et al. (1991). Cilazapril in congestive heart failure: A pilot study. *Drugs*, 41, (Suppl. 1), 54-61.
- Kirkwood, F. (1998). Clinical practice guidelines for heart failure. *The American Journal of Managed Care*, 4, (suppl.), S329-S337.
- Krippendorff, K. (2004). *Content analysis: an introduction to its methodology*. (2<sup>nd</sup> ed.). Thousand Oaks: SAGE.
- Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing*. London: SAGE.
- Lagergren, M., Fratiglioni, L., Hallberg, I. R., Berglund, J., Elmstahl, S., & Hagberg, B., et al. (2004). A longitudinal study integrating population, care and social services data: The Swedish National study on Aging and Care (SNAC). *Aging Clinical and Experimental Research*, 16(2), 158-168.
- Lansbury, G. (2000). Chronic pain management: A qualitative study of elderly people's preferred coping strategies and barriers to management. *Disability and rehabilitation*, 22(1-2), 2-14.
- Lawson-Matthew, P. J., McLean, K. A., Dent, M., Austin, C. A., & Channer, K. S. (1995). Xamoterol improves the control of chronic atrial fibrillation in elderly patients. *Age and Ageing*, 24, 321-325.
- Leontitsis, A., & Pagge, J. (2006). A simulation approach on Cronbach's alpha statistical significance. *Matematics and Computers in Simulation*. Advance access published on September 20, 2006 [doi:10.1016/j.matcom.2006.08.001](https://doi.org/10.1016/j.matcom.2006.08.001)
- LeResche, L. (1999). Gender considerations in the epidemiology of chronic pain. In I.K. Crombie, P.R. Croft, S.J. Linton, L. LeResche, & M. Von Korff (Eds.), *Epidemiology of pain* (pp. 43-52). Seattle: IASP Press.
- Lindberg, J., Claesson, C. B., Cornelius, C., Fratiglioni, L., Thorslund, M., & Winblad, B. (1994). Medicine use in the elderly: A population study in an urban area of Sweden. *Drug Investigation*, 8(4), 241-253.
- MacDowell, I., & Newell, C. (1996). *Measuring health: A guide to rating scales and questionnaires* (2<sup>nd</sup> ed.). New York: Oxford University Press.

- MacKinnon, A., Jorm, A., Christensen, H., Korten, A., Jacomb, P. A., & Rodgers, B. (1998). A short form of the positive and negative affect schedule: Evaluation of factorial validity and invariance across demographic variables in a community sample. *Personality and Individual Differences*, *27*, 405-416.
- Malterud, K. (1998). *Kvalitativa metoder i medicinsk forskning* [Qualitative methods in medical research]. Lund: Studentlitteratur (In Swedish).
- Marcus, F. I. (1993). Digoxin is effective, but is it safe? *Cardiovascular Drug Therapy*, *7*, 893-896.
- Martin, U., & George, C.F. (1998). Adverse drug reactions in the elderly. In C.F. George, K.W. Woodhouse, M.J. Denham, & W.J. MacLennan (Eds.), *Drug therapy in old age* (pp. 73-85). West Sussex: John Wiley & Sons Ltd.
- Miaskowski, C. (2000). The impact of age on a patient's perception of pain and ways it can be managed. *Pain Management Nursing*, *1*(3 Suppl. 1), 2-7.
- Mutchler, J. E., & Burr, J. A. (2003). Living arrangements among older persons: A multilevel analysis of housing market effects. *Research on Aging*, *25*, 531-558.
- The National Corporation of Swedish Pharmacies [Apoteksbolaget]. (1999). *Swedish drug statistics*. Stockholm: Apoteksbolaget. (In Swedish).
- Nikolaus, T., Kruse, M., Bach, N., Specht-Leible, P., Schlierf, G. (1996). Elderly patient's problems with medication: An in-hospital and follow-up study. *European Journal of Clinical Pharmacology*, *49*, 255-259.
- Osborne, A.C., Hooper, R., Swift, C.G., & Jackson, S.H.D. (2003). Explicit, evidence-based criteria to assess the quality of prescribing to elderly nursing home residents. *Age and Ageing*, *32*, 102-108.
- Okun, M. A., & Stock, W.A. (1987). Correlates and components of subjective well-being among the elderly. *Journal of Applied Gerontology*, *6*, 95-112.
- Okuno, J., Yanagi, H., & Tomura, S. (2001). Is cognitive impairment a risk factor for poor compliance among Japanese elderly in the community? *European Journal of Clinical Pharmacology*, *57*, 589-594.
- Onder, G., Pedone, C., Landi, F., Cesari, M., Della Vedova, C., & Bernabei, R., et al. (2002). Adverse drug reactions as cause of hospital admissions: Results from the Italian group of pharmacoepidemiology in the elderly (GIFA). *Journal of American Geriatric Society*, *50*, 1962-1968.
- Onishi, J., Suzuki, Y., Umegaki, H., Kawamura, T., Imaizumi, M., & Iguchi, A. (2007). Which two questions of mini-mental state examination (MMSE) should we start from? *Archives of Gerontology and Geriatrics*, *44*, 43-48.
- Patton, M.Q. (2002). *Qualitative research & evaluation methods* (3<sup>th</sup> ed.). London: SAGE.



- Pickering, G., Jourdan, D., Eschaliere, A., & Dubray, C. (2002). Impact of age, gender and cognitive functioning on pain perception. *Gerontology*, 48, 112-118.
- Polit, D. F., & Beck, C. T. (2004). *Nursing research: Principles and methods* (7<sup>th</sup> ed.). Philadelphia: Lippincott Williams & Wilkins.
- Polit, D. F., & Beck, C. T. (2006). *Essentials of nursing research: Methods, appraisal, and utilization* (6<sup>th</sup> ed.). Philadelphia: Lippincott Williams & Wilkins.
- Raadu, G. (Ed.). (2006). *Författningshandbok för personal inom hälso- och sjukvård* [Selection of statutes]. Stockholm: Liber. (In Swedish).
- Raleigh, V. S. (1999). World population and health in transition. *BMJ*, 9, 319, 981-984.
- Rich, M. W. (1999). Heart failure. *Cardiology Clinics*, 17, 123-135.
- Rumble, R.H., & Morgan, K. (1994). Longitudinal trends in prescribing for elderly patients: Two surveys four years apart. *British Journal of General Practice*, 44, 571-575.
- Sandberg, J., Nolan, M.R. & Lundh, U. (2002). The role of community staff in care home placement in Sweden. *Journal of Clinical Nursing*, 11, 488-497.
- Schmidt, I. K., & Fastbom, J. (2000). Quality of drug use in Swedish nursing homes: A follow-up study. *Clinical Drug Investigation*, 20, 433-466.
- Schmidt, I. K., Claesson, B.K., Westerholm, B., & Nilsson, L.G. (1998). Physician and staff assessments of drug interventions and outcomes in Swedish nursing homes. *The Annals of Pharmacotherapy*, 32, 27-31.
- Schwartz, J.B. (1999). Clinical Pharmacology. In R.W. Hazzard, J. P. Blass, W. H. Ettinger, jr., J. B. Halter, & J. G. Ouslander (Eds.), *Principles of geriatric medicine and gerontology* (4<sup>th</sup> ed., pp. 413-433). New York: McGraw-Hill.
- Sen, K. (1996). Gender. In S. Ebrahim, & A. Kalache (Eds.), *Epidemiology in old age* (pp. 32-40). London: BMJ Publishing Group.
- SFS 1982:763. *Hälso- och Sjukvårdslagen, HSL* [Health and Medical Care Act]. Stockholm: Riksdagen. (In Swedish).
- SFS 1985:562. *Patientjournallag*. Stockholm: Riksdagen. (In Swedish).
- SFS 1992:859. *Läkemedelslag*. Stockholm: Riksdagen. (In Swedish).
- SFS 1996:570. *Förordning med instruktion för Socialstyrelsen*. Stockholm: Riksdagen. (In Swedish).
- SFS 1996:611. *Förordning med vissa bemyndiganden för Socialstyrelsen för att meddela föreskrifter m.m.* Stockholm: Riksdagen. (In Swedish).

- SFS 2001:453. *Socialtjänstlagen*, SoL. Stockholm: Riksdagen. (In Swedish).
- Sindhu, F. (1996). Are non-pharmacological nursing interventions for the management of pain effective?: A meta-analysis. *Journal of Advanced Nursing*, 24, 1152-1159.
- Sjölund, C. (1999). *Socialtjänsten och lagen*. Lund: Anima Förlag. (In Swedish).
- Sjölenius, B. (1997). *Hälso- och sjukvård i kommunerna inför 2000-talet*. Stockholm: Kommentus. (In Swedish)
- Skoog, I. (2004). Psychiatric epidemiology of old age: The H70 study – the NAPE lecture 2003. *Acta Psychiatrica Scandinavica*, 109, 4-18.
- Spillman, B. C., & Pezzin, L. E. (2000). Potential and active family caregivers: Changing networks and the "Sandwich Generation". *The Milbank Quarterly*, 78(3), 347-374.
- SOSFS 1997:10. *Socialstyrelsens allmänna råd om medicinskt ansvarig sjuksköterska i kommunens hälso- och sjukvård* [General Guidelines for the medical responsible nurse within health and care in the municipalities]. Stockholm: Socialstyrelsen [The National Board of Health and Welfare]. (In Swedish).
- SOSFS 2000:1. *Socialstyrelsens föreskrifter och allmänna råd om läkemedelshantering i hälso- och sjukvård* [Regulations and general guidelines for the handling of medicines in the health- and care sectors]. Stockholm: Socialstyrelsen. [The National Board of Health and Welfare]. (In Swedish).
- Statistiska Centralbyrån [Statistics Sweden]. (2005). *Statistisk årsbok för Sverige 2005*. [Statistical yearbook of Sweden 2005]. Stockholm: SCB. (In Swedish).
- von Strauss, E. (2000). *Being old in our society: Health, functional status, and effects of research* (pp.1-51). Ph.D. thesis. Stockholm, Karolinska Institutet.
- Sundström, G. (1987). *Old care in Sweden: Yesterday, today... tomorrow?* Stockholm: Swedish Institute [Svenska institutet].
- Sundström, G., Larsson, B., & Sjöstrand, P. (1994). *Hemtjänst före och efter Ädel* (ÄDEL utvärderingen, 94:4). Stockholm: Socialstyrelsen (In Swedish).
- Sundström, G. (1995). Ageing is riskier than it looks. *Age and Ageing*, 24, 373-374.
- The Swedish National Board of Health and Welfare. (1996). *Ädelreformen: Slutrapport* [The Ädel-reform: Final report] (Socialstyrelsen följer upp och utvärderar, 1996:2). Stockholm: Socialstyrelsen. (In Swedish).
- The Swedish National Board of Health and Welfare. (1997). *Vård och omsorg om äldre personer och personer med funktionshinder: 1996* (Statistik. Socialtjänst, 1997:8). Stockholm: Socialstyrelsen. (In Swedish).

- The Swedish National Board of Health and Welfare. (1999). Diagnoser och förskrivning av läkemedel: En nationell kartläggning. Stockholm: Socialstyrelsen. (In Swedish).
- The Swedish National Board of Health and Welfare. (2000). Äldreuppsdraget: Slutrapport. (Socialstyrelsen följer upp och utvärderar, 2000:4). Stockholm: Socialstyrelsen. (In Swedish).
- The Swedish National Board of Health and Welfare. (2004). A gender perspective on Swedish health care: Conclusions and recommendations. Retrieved 2 December, 2004 from Socialstyrelsen: <http://www.socialstyrelsen.se/Publicerat/2004/5153/Summary.htm>
- The Swedish National Board of Health and Welfare. (2005). Uppföljning av äldres läkemedels användning (Uppföljningar och värderingar). Retrieved 8 August, 2006, from: <http://www.socialstyrelsen.se/publicerat/2005/8631/2004-103-19.htm>. (In Swedish)
- Swedish Research Council. (2003). *Riktlinjer för etisk värdering av medicinsk humanforskning: forskningsetisk policy och organisation i Sverige* [Guidelines for ethical assessment of medical research on humans: Policy and organisation of research ethics in Sweden.] (2<sup>nd</sup> ed.). Stockholm: Medicinska forskningsrådet (MFR). (In Swedish).
- Tombaugh, T.N., & McIntyre, N.J. (1992). The mini-mental state examination: a comprehensive review. *Journal of American Geriatric Society*, 40 (9), 922-935.
- Townsend, A., Hunt, K., & Wyke, S. (2003). Managing multiple morbidity in mid-life: a qualitative study of attitudes to drug use. *British Medical Journal* 327, 1-6. Retrieved 15 May, 2006, from: <http://bmj.com.2003;327:837>.
- Tsujimoto, G., Hashimoto, K., & Hoffman, B.B. (1989a). Pharmacokinetics and pharmacodynamics principles of drug therapy in old age: Part 1. *International Journal of Clinical Pharmacology*, 27, 13-26.
- Tsujimoto, G., Hashimoto, K., & Hoffman, B.B. (1989b). Pharmacokinetics and pharmacodynamics principles of drug therapy in old age: Part 2. *International Journal of Clinical Pharmacology*, 27, 102-116.
- Turnheim, K. (2003). When drug therapy gets old: Pharmacokinetics and pharmacodynamics in the elderly. *Experimental Gerontology*, 38, 843-853.
- Turnheim, K. (2004). Drug therapy in the elderly. *Experimental Gerontology*, 39, 1731-1738.
- United Nations. (2002). World population aging 1950-2050: Sweden. New York: UN. Population Division, DESA. Retrieved 15 September, 2006 from: <http://www.un.org/esa/population/publications/worldageing19502050/pdf/191swede.pdf>
- United Nations (2005). The UN millennium development goals. New York: UN. Retrieved 15 September, 2006, from: <http://www.un.org/millenniumgoals/>.

- Unruh, A.M. (1996) Gender variations in clinical pain experience. *Pain*, 65, 123-167.
- Veenhoven, R. (1984). *Conditions of happiness*. Dordrecht: D. Riedel Publishing Company.
- Viidik, A. (2002). *Boken om kroppens åldrande*. Stockholm: Liber. (In Swedish).
- Vittinghoff, E., Glidden, D. V., Shiboski, S. C., & McCulloch, C. E. (2005). *Regression methods in biostatistics: Linear, logistic, survival and repeated measures*. New York: Springer.
- Wasserfallen, J.-B., Bourgeois, R., Büla, C., Yersin, B., & Buclin, T. (2003). Composition and costs of drugs stored at home by elderly patients. *The Annals of Pharmacotherapy*, 37, 731-737.
- Watson, D., Clark, L.A., & Tellegen, A. (1988). Development and validation of brief measures of positive and negative affect: The PANAS scales. *Journal of Personality and Social Psychology*, 54, 1063-1070.
- Watson, D., & Clark, L.A. (1994). *The PANAS-X: Manual for the positive and negative affect schedule: Expanded form*. City of Iowa: The University of Iowa.
- Westerbotn, M., Agüero-Torres, H., Fastbom, J., & Hillerås, P. (2005). A population-based study on well-being in the very old: The role of cardiovascular diseases and drugs. *Archives of Gerontology and Geriatrics*, 40, 287-297.
- Wills, P., Fastbom, J., Claesson, C. B., Cornelius, C., Thorslund, M., & Winblad, B. (1996). Use of cardiovascular drugs in an older Swedish population. *Journal of the American Geriatric Society*, 44, 54-60.
- World Health Organization (1994). *International classification of diseases, injuries and Causes of Death (ICD-10)*. (10<sup>th</sup> Revision). Geneva: WHO. Retrieved 30 August, 2006, from: <http://www3.who.int/icd/currentversion/fr-icd.htm>.
- World Health Organization (1998). *Growing older-Staying well: Ageing and physical activity in every day life*. Geneva: WHO. Retrieved 30 August, 2006, from: [http://whqlibdoc.who.int/hq/1998/WHO\\_HPR\\_AHE\\_98.1.pdf](http://whqlibdoc.who.int/hq/1998/WHO_HPR_AHE_98.1.pdf).
- World Health Organization Collaborating Centre for Drug Statistics and Methodology. (1999). *Guidelines for ATC classifications*. Oslo: The Centre.
- World Health Organization (2006). *Ageing and Life Course*. Geneva: WHO. Retrieved 30 August, 2006, from: <http://who.int/ageing/en/>.
- Yates, P., Dewar, A., & Fentiman, B. (1995). Pain: The views of elderly people living in long-term residential care settings. *Journal of Advanced Nursing*, 21, 667-674.
- Österlind, P. O., & Bucht, G. (1991). Drug consumption during the last decade among persons born in 1902 in Umeå, Sweden: A longitudinal population study. *Drugs and Ageing*, 1, 477-486

**Appendix 1.** *The questionnaire on handling of medicines from the Kungsholmen Project used in Study II.*

<p>In which way have you got information about the elderly's medicines?</p>	<ul style="list-style-type: none"> <li>- The elderly has no medicine</li> <li>- The elderly has shown prescription</li> <li>- The has shown packages</li> <li>- The elderly has shown prescription and packages</li> <li>- Medicine list, Cardex or the like,</li> <li>- The elderly took the information from memory</li> <li>- The elderly has shown prescription and took the information from memory</li> <li>- The elderly has shown packages and took the information from memory</li> <li>- The elderly has shown prescription, packages and took the information from memory</li> <li>- Medicine list, Cardex or the like and the elderly took the information from memory</li> </ul>
<p>Does anyone help to divide the medicine into doses?</p>	<ul style="list-style-type: none"> <li>- The elderly has no medicine</li> <li>- The elderly handles his/her medicine completely by him-/herself</li> <li>- The medicine is divided in Dosett by... (state who, for example the home-help service, husband/wife etc.)</li> <li>- The medicine is divided by the pharmacy in Apodos</li> <li>- The elderly gets help from other to divide his/her medicine, state who ...</li> </ul>
<p>The medicine is divided by...</p>	<p>Open question</p>
<p>The elderly receives help from other to divide his/her medicine, state who...</p>	<p>Open question</p>
<p>Does anyone help giving the medicine to the elderly?</p>	<ul style="list-style-type: none"> <li>- The elderly has no medicine</li> <li>- The elderly takes his/her medicine completely by him-/herself</li> <li>- The elderly gets help from other to take his/her medicine, state who...</li> </ul>
<p>The elderly receives help from other to take his/her medicine, state who...</p>	<p>Open question</p>

**Appendix 2.** *The questionnaire on pain from the Kungsholmen Project used in Study III.*

Do you have ache/pain?	No / Yes
In what part of the body do you have pain?	<ol style="list-style-type: none"> <li>1. Head, face, mouth</li> <li>2. Back of the head, neck</li> <li>3. Back (breast back, loin back, pelvis)</li> <li>4. Joints</li> <li>5. Shoulders, arms, hands</li> <li>6. Leg, knee, foot</li> <li>7. Breast</li> <li>8. Abdomen</li> <li>9. Lower abdomen</li> </ol>
In which body part is the ache/pain most severe?	<ol style="list-style-type: none"> <li>1. Head, face, mouth</li> <li>2. Back of the head, neck</li> <li>3. Back (breast back, loin back, pelvis)</li> <li>4. Joints</li> <li>5. Shoulders, arms, hands</li> <li>6. Leg, knee, foot</li> <li>7. Breast</li> <li>8. Abdomen</li> <li>9. Lower abdomen</li> </ol>
How often do you have ache/pain?	<p>Always</p> <p>Daily or almost daily</p> <p>Periodically</p>
For how long have you had ache/pain?	<p>Less than 1 month</p> <p>1 month - 6 months</p> <p>6 months - 1 year</p> <p>1-5 years</p> <p>More than 5 years</p>
Are you prevented by the ache/pain in your daily life?	No / Yes
Is the ache/pain one of your biggest problems?	No / Yes
Do you get any treatment of the ache/pain?	<p>None</p> <p>Medicines only</p> <p>Other treatment (e.g. physiotherapy, TENS, ultrasound)</p> <p>Both medicine and other treatment</p>
Does the treatment alleviate the pain?	No / Yes

**Appendix 3. Interview guide used in Study IV.**

**INTERVIEW GUIDE**

Ref. No.:

Sex:

Age:

Are you married, single, divorced, or widow/widower?

For how many years (as married, single, divorced, or widow/widower)?

Do you have any children?

What type of housing do you live in?

Do you live alone or together with someone?

What was your profession or main duty before retirement?

What is your first language?

Will you tell me a little about your experience of your management of medicines?

Will you tell me a little about which medicines you take?

Do you know why you take these medicines?

Do you manage to purchase your medical treatment, to prepare the medication dosage, and to take the medicines by yourself? If not, who helps?

Please, tell me about your experience of manage yourself with your medicines?

(If the respondent manages the medication administration by him/herself)

Please, tell me about your experience of receiving help with your medicines?

(If the respondent is not managing the medication administration by him/herself)

Do you consider that you get enough help managing your medication?

If not, what do you feel that you need help with, and why?

Will you, please, describe your routine of preparing medication dosage and intake to me?

## Appendix 4.

### List of dissertations from the Stockholm Gerontology Center and Aging Research Center 1991-2006

#### 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, Swede

**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 Wahlén 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.