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PHYSICAL FUNCTIONING IN OLD AGE:

Temporal trends and geographical variation in Sweden

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PHYSICAL FUNCTIONING IN OLD AGE: Temporal trends and geographical variation in Sweden.

THESIS FOR DOCTORAL DEGREE (Ph.D.)

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ABSTRACT

ENGLISH

ADL disability is an age-related condition that leads to poor quality of life, increased health-related care costs, and increased mortality. The proportion of older adults are increasing worldwide, and it is therefore important both for society and the individual that research provide us with information about the process leading to ADL disability and how to identify persons at risk. The most effective design for following the aging process is found in population-based studies that include all older persons, both those living at home and those in residential care. This thesis uses data from three population-based studies: the Kungsholmen Project (KP), the Nordanstig Project (NP) and the SNAC-N study. The aims of the thesis was to examine temporal changes in physical functioning in older adults, to identify underlying development of new disability and functional decline, as well as to explore geographical variation in physical functioning between urban and rural elderly habitats. We also wanted to describe the amount of informal and formal care in relation to levels of ADL disability. The ultimate aim was to identify factors suitable for prevention.

Study I: We compared two populations of older adults, 75 years and older (the KP and the NP) from different living areas (urban and rural) and found differences in ADL disability, morbidity and disease patterns. The most common health problem in both areas was cardiovascular diseases (39.9% in the urban area and 45.2% in the rural area). There were great differences, urban vs rural, in the prevalence of stroke (7.4% vs 14.0%), diabetes mellitus (6.3% vs 16.1%), and Parkinson's disease (1.0% vs 3.7%). Having two or more diseases vs. no disease was more common in the rural area than in the urban area, odds ratio (OR) = 1.9, 95% confidence interval (CI) = 1.4-2.4. Living area differences (urban vs rural) were found in population attributable risk (PAR) for disability due to stroke (5.6 vs 32.2), diabetes mellitus (1.2 vs 6.1), fractures (1.4 vs 10.7), and hearing impairment (8.7 vs 22.0).

Study II: Data were gathered from a population-based study of adults 60 years and older, the SNAC-Nordanstig (SNAC-N), and the study explored the association between ADL disability, muscle strength, disease severity and mortality. Upper and lower muscle strength decreased with increasing age, with a tendency for lower performance in women than in men. A significant association was found between ADL disability and having reduced lower muscle strength. Having an increased number of diseases increased the risk of being ADL disabled. Diseases with the greatest impact on ADL disability were musculoskeletal diseases, hypertension and dementia. ADL disability and being unable to perform the gait speed test were factors that increased the risk of death. Inability to perform the chair stand test or weaker grip strength increased the risk of death for men.

Study III: Data from two populations, 78 years and older, the NP (1995-1998) and the SNAC-N study (2001-2003), were used to study time trends in the prevalence of ADL disability and survival, comparing two cohorts. The prevalence of ADL disability was stable from 1995-1998 to 2001-2002 for men, while women became more disabled in ADL over the time period, (OR 2.36; CI 1.12-4.94). No significant difference was

found in survival time between the cohorts in either ADL-disabled or non-disabled persons. There was a tendency for increased survival for non-disabled persons in the SNAC-N study compared with the NP, although it was not significant; this was particularly true for women. In general, women survived longer than men did regardless of whether they were ADL disabled or not.

Study IV: The aims were to examine the incidence of ADL disability, to explore whether being physically active earlier in life is a significant predictor of being disability free at follow-up, and to describe the amount of informal and formal care received in relation to ADL disability. Data were gathered from persons 78 years and older in the SNAC-N study. The incidence rates for men were almost the same in the age group 78-81 compared with the age group 84 years and older, 42.3 vs. 42.5/1000 person-years. For women the incidence rate for ADL disability increased significantly from the age group 78-81 to the age group 84 years and older, 20.8 vs. 118.3/1000 person-years. In the age group 78-81 years, being physically active earlier (aOR 6.2) and during the past 12 months before the baseline examination (aOR 2.9) were both significant preventive factors for ADL disability. The amount of both informal and formal care increased with the number of ADL activities the persons were dependent on and the amount of informal care was greater than the amount of formal care.

Conclusions: This thesis shows an increase in ADL disability due to increased age, and that women are more ADL disabled than men, but also shows how diseases affect ADL disability. The diseases that negatively affect ADL are often due to unhealthy lifestyle, e.g. physical inactivity, obesity and smoking, etc. The results show the importance of prevention of the factors that cause ADL disability, preferably already in midlife. The amount of both informal and formal care increased significantly with the number of ADL activities the persons required help with. Regarding prevention of becoming ADL disabled, it is of importance to find ways to postpone the onset of ADL disability so that we can live longer without disability.

Key words: ADL disability, informal and formal care, morbidity, mortality, older adults, physical activity, population-based, rural vs urban, time trends

Funktionsnedsättning i aktiviteter i dagliga livet (ADL) är ett åldersrelaterat tillstånd som leder till försämrad livskvalité, ökade hälsorelaterade vårdkostnader och ökad dödlighet. Andelen äldre vuxna (60 år och äldre) ökar i hela världen, och därför är det viktigt både för samhället och för den enskilde individen med forskning om processen som leder till funktionsnedsättning i ADL och hur personer som är under risk att drabbas kan identifieras. Populationsbaserade studier, som inkluderar alla äldre personer, dels de som bor hemma men även de som bor på särskilt boende, är den mest lämpade designen för att följa åldrandeprocessen. Denna avhandling använder data från tre populationsbaserade studier: Kungsholmsprojektet (KP), Nordanstigsprojektet (NP) och SNAC-Nordanstig (SNAC-N). Syftet med avhandlingen var att undersöka förändringar över tid i fysisk funktionsförmåga hos äldre vuxna, att identifiera utvecklingen av nya funktionshinder och funktionsnedsättning samt att undersöka geografiska variationer i fysisk funktion mellan äldre vuxna boende i stad- och landsbygd. Vi ville också beskriva mängden informell och formell omsorg i förhållande till olika nivåer av funktionsnedsättning i ADL. Det yttersta målet var att identifiera faktorer som är lämpliga för förebyggande arbete.

Studie I: Vi jämförde två populationer med äldre vuxna, 75 år och äldre (KP och NP) från olika miljöer, stad och landsbygd, och fann skillnader i ADL nedsättning, sjuklighet och sjukdomsmönster. Det vanligaste hälsoproblemet i båda områdena var hjärtkärlsjukdomar (39,9% i stad och 45,2% på landsbygden). Skillnaderna var stora, mellan stad och landsbygd, i förekomst av stroke (7,4 % vs 14,0%), diabetes mellitus (6,3% vs 16,1%) och Parkinsons sjukdom (1,0 % vs 3,7%). Att ha två eller fler sjukdomar jämfört med att inte ha någon sjukdom var mer förekommande på landsbygden än i staden, odds ratio (OR) = 1,9; 95 % konfidens intervall (CI) = 1,4–2,4. Skillnader mellan stad och landsbygd hittades också i population attributable risk (PAR) för funktionsnedsättning i ADL på grund av stroke (5,6 vs. 32,2), diabetes mellitus (1,2 vs 6,1), frakturer (1,4 vs 10,7) och hörselnedsättning (8,7 vs 22,0).

Studie II: Data samlades in från en populationsbaserad studie med vuxna 60 år och äldre, i SNAC-Nordanstig (SNAC-N), och studien undersökte sambandet mellan funktionsnedsättning i ADL, muskelstyrka, sjukdomens svårighetsgrad och dödlighet. Övre och nedre muskelstyrka minskade med stigande ålder, med en tendens till lägre prestationsförmåga hos kvinnor än hos män. Ett signifikant samband hittades mellan funktionsnedsättning i ADL och att ha lägre muskelstyrka. Att ha flera sjukdomar ökade risken för att bli funktionsnedsatt i ADL. Sjukdomar med störst påverkan på ADL nedsättning var muskuloskeletala sjukdomar, högt blodtryck och demens. Funktionsnedsättning i ADL och att inte kunna utföra gånghastighetstest var faktorer som ökade risken för dödsfall. Oförmåga att utföra stol-stå-test eller svagare greppstyrka ökade risken för dödsfall hos män.

Studie III: Data från två populationer, 78 år och äldre, NP (1995-1998) och SNAC-N (2001-2003), användes för att studera tidstrender i förekomsten av ADL funktionsnedsättning och överlevnad. Prevalensen av funktionsnedsättning i ADL var

stabil från 1995-1998 till 2001-2002 för män, medan kvinnorna blev mer funktionsnedsatta i ADL under tidsperioden, (OR 2,36; CI 1,12–4,94). Ingen signifikant skillnad fanns i levnadstid mellan kohorterna i antingen ADL-nedsatta och icke-nedsatta. Det fanns en tendens till ökad överlevnad för icke-funktionshindrade personer i SNAC-N studie jämfört med NP, även om det inte var signifikant, detta gällde särskilt för kvinnor. I allmänhet levde kvinnor längre än män oavsett om de var funktionsnedsatta i ADL eller inte.

Studie IV: Syftet var att undersöka incidensen av funktionsnedsättning i ADL, undersöka om att vara fysisk aktiv tidigare i livet är en signifikant prediktor för att inte vara funktionsnedsatt i ADL vid uppföljningarna, och att beskriva mängden av informell och formell vård i förhållande till funktionsnedsättning i ADL. Data samlades in från de deltagare i SNAC-N studien som var 78 år och äldre. Incidensen för funktionsnedsättning i ADL hos män var nästan densamma i åldersgruppen 78-81 jämfört med åldersgruppen 84 år och äldre, 42,3 vs 42,5/1000 personår. För kvinnor ökade incidensen av funktionsnedsättning i ADL signifikant för åldersgruppen 78-81 till åldersgruppen 84 år och äldre, 20,8 vs 118,3/1000 personår. Att ha varit fysiskt aktiv tidigare i livet (aOR 6,2) och/eller under de sista 12 månaderna före baslinjeundersökningen (aOR 2,9) var båda signifikant förebyggande faktorer för att inte bli funktionsnedsatt i ADL i åldersgruppen 78-81 år. Summan av både informell och formell vård ökade med antalet ADL aktiviteter som personen var beroende i och summan av den informella vården var större än summan av den formella vården.

Slutsatser: Denna avhandling visar på en ökning av funktionsnedsättning i ADL beroende på stigande ålder och att kvinnor är mer funktionsnedsatta i ADL än män, men visar också hur sjukdomar påverkar ADL förmågan. De sjukdomar som påverkar ADL förmågan negativt beror ofta på ohälsosam livsstil, t.ex. fysisk inaktivitet, fetma och rökning etc. Resultaten visar på vikten av förebyggande arbete för de faktorer som orsakar funktionsnedsättning i ADL, helst redan i medelåldern. Mängden informell och formell vård ökade markant med antalet ADL aktiviteter de äldre personerna behövde hjälp med. När det gäller att förebygga funktionsnedsättning i ADL är det av betydelse att hitta vägar för att skjuta upp uppkomsten, så att vi kan leva längre utan funktionsnedsättning i ADL.

Nyckelord: dödlighet, funktionsnedsättning i ADL, fysisk aktivitet, informell och formell vård, landsbygd vs stad, populationsbaserad, sjuklighet, tids trender, äldre vuxna

LIST OF PUBLICATIONS

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

- I. **Sjölund BM**, Nordberg G, Wimo A, von Strauss E. Morbidity and physical functioning in old age: Differences according to living area. *J Am Geriatr Soc* 2010;58:1855-1862.
- II. **Sjölund BM**, Wimo A, Lagergren M, Sköldunger A, von Strauss E. The association between ADL disability, muscle strength, disease severity and mortality: data from a longitudinal population-based study on rural elderly (60+years) in Sweden (the SNAC-N study). Submitted.
- III. **Sjölund BM**, Wimo A, Qiu C, Engström M, von Strauss E. Time trends in prevalence of activities of daily living (ADL) disability and survival: Comparing two populations (aged 78+years) living in a rural area in Sweden. *Arch Gerontol Geriatr* 2014;58:370-375.
- IV. **Sjölund BM**, Wimo A, Engström M, von Strauss E. Incidence of ADL disability in older persons, physical activities as a protective factor and the need for informal and formal care – results from the SNAC-N project. Manuscript

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LIST OF ABBREVIATIONS

ADL	Activities of Daily Living
CI	Confidence Interval
CIRS	Cumulative Illness Rating Scale
HR	Hazard Ratio
IADL	Instrumental Activities of Daily Living
IR	Incidence Rate
KP	Kungsholmen Project
MMSE	Mini-Mental State Examination
MNA	Mini Nutritional Assessment
NP	Nordanstig Project
OR	Odds Ratio
PAR	Population Attributable Risk
PEF	Peak Expiratory Flow
RUD	Resource Utilization in Dementia
SNAC-N	Swedish National study on Aging and Care in Nordanstig

PREFACE

My interest in examining the physical functioning in older adults arose during my professional career as a nurse in elderly care. I have mainly been working within long-term and short-term care, night patrol, residential care, home care, and finally as the medical responsible nurse (Medicinskt Ansvarig Sjuksköterska - MAS) in a municipality. The older adults I was meeting often suffered from several illnesses, e.g. stroke, and had lost some of their ability to function physically and thus become ADL-disabled and in need of help from a relative or home care services. Many times I experienced their frustration when needing assistance with activities they previously were able to do by themselves and that the body now betrayed them. It was wonderful to see the joy of those who, with the help of rehabilitation, regained their ability to manage things by themselves that they had needed assistance with.

Unfortunately, I sense that the time and maybe also the interest to help older adults to maintain their physical functioning or to regain their ability have decreased in today's elderly care. I therefore with the present studies wanted to examine the occurrence of physical functional ability in older adults over time, its causes, and factors associated with ADL-disability. Furthermore, I am interested in what staff working in elderly care, as well as in primary care, can do to facilitate.

Another reason for my interest is that I myself is getting older and beginning to be aware of functional limitations, and reflecting about what I can do to reduce the risk for becoming disabled in ADL when I get older.

This thesis uses data from three population-based studies including older adults from two areas in Sweden, the municipality of Nordanstig (rural area) and the inner city of Stockholm (urban area). The topic is physical functioning in old age, defined as the capacity needed to be independent in basic activities for daily living (ADL). The individual studies focus on the prevalence of ADL disability in old age, whether and how the prevalence of ADL disability changes over time, and the association between ADL and different diseases, muscle strength, lifestyle factors and mortality.

1 INTRODUCTION

1.1 AGING OF THE POPULATIONS

The proportion of adults 60 years and older will increase worldwide from 10.0% in 2000 to 21.8% in 2050, and then to 32.2% in 2100 due to an increase in life expectancy and low birth rate (1, 2). Also in Sweden the proportion of older people will increase drastically in the years to come. According to Statistics Sweden, the Swedish population in 2003 was 8.98 million and is estimated to increase by 18% to 10.6 million by the year 2050. In 2003, approximately 1.54 million people were 65 years and older, and in 2050 the population of 65+ years will increase by 59% to 2.45 million. At the same time, the population of people between 20-64 years will only increase by 0.49 million (9.3%), from 5.28 million in 2003 to 5.77 million people in 2050 (3). Of those born in 2013 in Sweden, an estimated 67% of girls and almost 60% of boys will still be alive at the age of 90. This can be compared with those born 90 years ago, that is in the early 1920s. Of them 25% of women and 10% of men reached the age of 90 (3). The increasing numbers and proportion of older people in the population reflect improved health and economic status. Although the success of a society may be quantified in terms of increasing life expectancy, the care and the needs of impaired older adults are not well understood and measured. Future demands on the health and care system will depend on whether we add healthy years or years with morbidity and disability to our lives (4-6). One definition of aging is that it is a general progressive and irreversible process that affects everyone. This is something we cannot do anything about, but external factors can accelerate the process. What takes place in the body and affects physical functioning during the normal aging process are, e.g., that the heart and lung capacity decreases, bones deteriorate due to reduced formation and the loss of muscle mass (7-10). The loss of skeletal muscle mass and strength (sarcopenia) – defined as age-related, involuntary loss of skeletal muscle mass and strength – is one important cause of functional decline and loss of independence in older adults. The causes of sarcopenia in older adults can vary and include, e.g., inactivity and chronic illness (10-12).

1.2 PHYSICAL FUNCTIONING IN OLD AGE

Disability in physical functioning is an age-related condition leading to poor quality of life, increased health-related care costs, and increased mortality (13-16). In this thesis, physical functioning is defined as the capacity needed to be independent in basic activities for daily living (ADL) and is measured using the instrument Katz index of ADL (17). It is a hierarchical scale that consists of six activities and measures level of dependence in basic activities of daily living: bathing, dressing, going to the toilet, transferring, continence and feeding. Physical functioning is affected regardless of whether the person has an impairment or not. The definition of disability is in that case “not a personal characteristic, but is instead a gap between personal capability and environmental demand”(18).

1.2.1 Occurrence of ADL disability

The prevalence of ADL disability in older adults has varied across studies, and comparison between studies is difficult due to the use of different ADL measurements and age groups. In 2003, a study from Lebanon reported that the prevalence of ADL disability in a population 60 years and older (mean age 68.4) was as high as 25.7% (19). In more recent studies from 2008 the prevalence of ADL disability is lower; in a population 65 years and older in China the figure was 14.9% ADL disabled (20), while the prevalence of ADL disability (65+) in the US was 18.4% (21) and in Malaysia 10.6% (60+) (22). One difference between these studies was that the population in Malaysia was younger (mean age 69.0) compared to the populations in China (mean age 75.1) and the US (mean age 74.5) (20-22).

Studies examining gender differences in ADL disability have found that women are more disabled than men (19, 21-25). In the study from Lebanon, women were more disabled than men: women 31.3% vs. men 18.7% (19). A study on a population 65 years and older from Spain in 2006 found that the prevalence of ADL disability was higher in women than in men, 15.8% vs. 10.6% (23). The gender differences can partially be explained by higher mortality among men than women (26), but also by a higher incidence of ADL disability in women than in men with longer duration and lower rates of recovery than in men (27, 28). That the incidence of ADL disability is higher in women than in men has been found in several studies, even if the literature in this area is sparse. In a study from the Netherlands between 1990 and 1999, among persons 55 years and older, who were disability free at baseline, 26.7% were ADL disabled at the follow-up six years later, and the incidence of ADL disability was higher in women (33.2%) than in men (19.7%) (29). The incidence rate for ADL disability was also higher in women than in men in a study from Brazil examining persons 60 years and older. The persons were disability free at baseline and at follow-up six years later the incidence rate for women was 42.4/1000 person-years and for men 17.5/1000 person-years (30). Contrary to those studies, a review study found that there were no differences in incidence of disability by gender, after controlling for socioeconomic factors, health conditions and social relations (31), even in a study from Sweden no gender differences in ADL were found (32).

Previous studies have reported different results on time trends and ADL disability. A study from the US examining older adults, 79 years and older, between 1977 and 1999 and another study from Europe examining older adults, 70 years and older, between 1988-2001 reported a decline in prevalence of ADL disability (25, 33). Stability across time was found in studies from the US and Sweden examining older people at various time intervals between 1982 and 2009 (21, 32, 34, 35). Increased ADL disability was found in a study from Spain examining older adults, 65 years and older, between 2000 and 2007 (23). Mixed results have also been found in some studies. Increased ADL disability in men and decline in women were found in a study from China (20), while stability across time in men and increased ADL disability in women were found in a study from the US (36).

One reason for the different results could be the variety of instruments used for measuring ADL. The differences in the instruments can consist of how many activities are included and how the questions are posed, for example, if you ask the person whether they have difficulty dressing or whether they need help with dressing. Another explanation can be that many studies exclude institutionalized persons or persons with dementia, and that can also affect the results. There are few population-based studies that include persons living in residential care or/and with dementia; see Table 1.

1.2.2 Physical performance tests

There has been an increasing interest in using physical performance tests, which can help in identify older adults at risk of becoming disabled (37, 38). Such tests could also be easy for health professionals to implement and require no special equipment. The most common performance tests are grip strength, gait speed, and chair stand (39-41).

Grip strength is a measure of upper extremity muscle strength and is measured using a handgrip dynamometer. Grip strength has been reported to be associated with both mortality (42, 43) and disability and can be useful as a predictor (44, 45). A study from the Netherlands found that lower grip strength at baseline in a population of older adults, 85 years and older, was a predictor of accelerated decline in ADL disability and cognition at annual follow-ups (45). Another study from Hawaii, measuring grip strength in healthy men 45-68 years of age at baseline, found that persons with lower grip strength at baseline had higher risk of disability after 25 years (44). However, a review study of the measurements of grip strength found that it is difficult to compare studies using grip strength due to the variation in methods used to measure grip strength and called for development of a standardized method (39).

Gait speed, using time walk, is an objective measure of lower extremity function in both clinical and research settings (41, 46), and a decline in gait speed has been shown to be associated with disability and loss of independence (38, 40) as well as with mortality (15). A Japanese study, examining 10,351 persons 65 years and older, found that gait speed <1 m/s was strongly correlated with needing help from another person, and among those with a gait speed slower than 0.8 m/s, 90% were dependent on personal care (38). A population-based study from Italy found that fast gait speed was associated with cognitive decline in a 3-year follow-up. Measuring fast gait speed in older adults may be helpful in identifying persons at risk for cognitive decline (47).

Chair stand is a test of lower extremity function and has been found to reflect older adults' lower extremity muscle force, balance, and physical functioning in healthy older community-dwelling individuals (48, 49), but also in persons with different diseases, for example chronic obstructive pulmonary disease (50). A study from Canada examining 622 older persons, 50-85 years, without mobility disability at baseline found that inability to complete the chair stand test in < 13.7 seconds was a predictor of disability at a 3-year follow-up (37).

Table 1. Time trend studies on ADL disability in older persons: age structure of study population, disability measures and main results.

Author, year, country	Participants (age) and data collection (year and sample).	ADL-Disability		
		Measures	Gender*	Time trend **
Aijanseppa et al 2005 (25) 10 European countries	70+ N=3496 1988-2001 Persons living in psychogeriatric nursing homes were excluded.	ADL 6 items (dress and undress, use toilet, wash yourself, in/out of bed and eating)	w>m	men ↓ women ↓
Feng et al 2013 (20) China	65 + N T1=2763, N T2=3222, N T3=1680, N T4=2195 1998-2008 Persons living in institutions were excluded.	Difficulty with ADL activities, 8 items (eating, dressing, moving on and off bed, transferring indoor, washing face and brushing teeth, toileting, bathing and moving upstairs and downstairs)	Not examined	men ↑ women ↓
FullerThomson 2009 (36) US	65+ 2000-2005 N=512 768-601 875 (2000-2004) and 1 924 527 (2005)	Difficulty with ADL, 3 items (dressing, bathing and getting around inside)	Not examined	men → women ↑
Hung et al 2011 (21) US	65+ N T1= 10390 N T2=10621 N T3=10557 1998-2008	Difficulty in bathing, dressing, eating, toileting or transferring (5 items)	w>m	Both →
Lin et al 2012 (35) US	70 + N=218955 1982-2009 Persons living in institutions were excluded.	Needing help of other person with ADL, 4 items (eating, bathing, dressing or getting around the home)	Not examined	Both →
Murabito et al 2008 (33) US	79 + N T1=280, N T2=257, N T3=293 1977-1999 Persons with dementia were excluded	Modified Katz ADL with 5 items (bathing, dressing, eating, getting from bed to chair, and walking across a small room)	w>m.	men ↓ women ↓

Palacios Cena et al 2012 (23) Spain	65 + N T1=21 058, N T2=21 650, N T3=29 478 2000-2007 Persons living in institutions were excluded.	Difficulty with ADL, 5 items (eating, dressing, walking, getting in and out of bed, bathing/showering) followed by a question on whether they can do it by themselves or need help from someone	w>m	men ↑ women↑
Schön et al 2011 (32) Sweden	77+ N T1=537, N T2=561 1992-2002	Modified Katz ADL with 5 items (bathing, dressing, eating, getting from bed to chair, and transferring)	w=m	Both →
Seeman et al 2010 (34) US	60 + N T1=4688 N T2=4239 1988-2004	Difficulty in 4 item, (walking from room to room on the same level, getting in and out of bed, eating and dressing)	Not examined	60-69 years ↑ 70+ years →

**ADL disability increases over time (↑); no change in ADL disability over time (→).

*Women are more disabled in ADL than men (w > m); no gender difference in ADL disability (w = m).

1.2.3 ADL disability and associated factors

Many studies have found that cognitive impairment and dementia have a strong link with impaired physical functioning and ADL disability (24, 51, 52). Other illnesses associated with ADL disability are cardiovascular diseases (53, 54) and depression (55). However, the direction of the association between ADL disability and depression is unclear, that is, whether disability causes depression or vice versa (56, 57). A study from the US examining older adults, 65+ years, who were disability free at baseline found that people with depression at baseline had a higher risk of disability at a 6-year follow-up (58), one possible explanation being that persons with depression were less physically active. Multimorbidity has also been found to have a strong association with ADL disability (59, 60). There are also studies reporting gender differences in the factors that cause ADL disability. One study found that, besides decreased mobility and balance, it was diseases leading to cognitive impairment that caused ADL disability in men and reduction in muscle strength and osteoarthritis that caused ADL disability in women (30). Another study also found that osteoarthritis, fractures, osteoporosis, and depression causes ADL disability in women (55). Comparing gender differences in ADL disability, a study conducted in Lebanon found that women were more physically inactive and also suffered more than men from, e.g., vascular diseases, arthritis, depression, osteoporosis, chronic back pain and neurological disorders (19).

Few studies have examined differences in ADL disability and health based on living area (rural vs. urban), and most such studies are from Asia (61-66). The studies from Asia have all reported that older adults in rural areas are more ADL disabled and have poorer health conditions than do older adults in urban areas (61, 64, 66). A study from Canada examining differences in rural areas found an association between rurality and health in adults 18 years and older, adults in “more” rural area displaying poorer health (63). Another study comparing rural and urban areas in Canada and Australia found that adults, 18 years and older, in the rural areas of both countries had poorer health (65). A study from Finland examining differences between rural and urban areas in health and health behavior in adults 52 years and older, found poorer health in the rural areas. Adults in the rural areas also had an unfavorable health and lifestyle profile, e.g., less physical activity, more unhealthy diet, smoking and obesity (62).

Factors that have been shown to have a positive effect on physical functioning and ADL in older adults are physical activities and exercise (31, 67-69), which can therefore reduce the risk for becoming ADL disabled (70-72). An intervention study in older adults (70-89 years) found that the physical activity group had improved their physical functioning after 12 months (71). A study in adults 65 years and older found that persons with lower levels of physical activity were at high risk of being ADL disabled at a 3-year follow-up (70). An association between less disability and greater total physical activity was also found in older adults in a study from the US (72). Physical activity has also been found to have a positive effect on cognitive function in older people (73), and it may also postpone dementia (74, 75). The association between physical activity and cognition is interesting, as cognitive impairment is also one of the risk factors for ADL disability (51, 52). According to a study from the US,

recommended activities for older adults are moderate-intensity aerobic activity, muscle-strengthening activity and balance exercises (76).

1.2.4 Formal and informal care

Care of older persons who have ADL disability involves a complex interaction between formal and informal care resources. Formal care is the care provided by the municipality, and informal care is provided by relatives, neighbors and/or friends. The major providers of home-based care for older adults in Sweden are informal caregivers (77). A recent study in Sweden found that publicly funded home care has declined in the past decades and that informal care has increased among older people, especially among older people with lower education levels (78). Most of the studies examining amount of care include a selected population, e.g., older adults with dementia, and are often focused on costs (14, 77, 79-81). A multi-center study of care cost in a population of persons with Alzheimer's disease from different countries, found that informal care constituted of 82-86% of the total cost of care and that ADL ability was the strongest predictor of cost of care (80). Another study examining time use and costs of care for older adults with or without dementia in residential care in Sweden found that costs increased by more than 85% for people who were dependent on help with 5–6 ADL activities compared to persons with no functional dependency, and by 30% for persons with dementia compared to those without dementia (82). Informal care was more extensive than formal care in a population-based study among older adults with and without dementia, and informal care was a substitute for rather than a compliment to formal care (83). Although many studies on formal and informal care are focused on older adults with cognitive impairment or dementia, another Swedish study showed that the level of ADL functioning was a better predictor of costs than was cognition (14). Being an informal caregiver is associated with greater burden, isolation and lower perceived health compared to persons of the same age who are not providing informal care, and therefore is it important for, e.g., nurses in elderly care to support also informal caregivers to improve their situation. Such support can include education, time for respite care and recreational activities (84-86).

1.3 RATIONALE FOR THE STUDIES

ADL disability is an age-related condition that leads to poor quality of life, increased health-related care costs, and increased mortality (13-16). The proportion of older adults (60+ years) is increasing worldwide (1, 2), especially in the developing countries. What is characteristics for the developed countries is the aging of an already aged population (80+years). It is therefore uttermost important both for society and the individual that research generate knowledge about the process leading to ADL disability and how to identify persons at risk. The most effective design for following the aging process is found in population-based studies that include all older persons, both those living at home and those living in residential care. However, many population-based studies exclude older persons living in residential care or older persons with dementia. Previous studies on temporal trends in ADL disability report different results, and there are few population-based studies examining the incidence

rate of ADL disability. More studies examining the association between ADL disability and other factors, e.g. lifestyle factors, performance test scores and physical activity, are needed. Studies on physical activity mainly concern physical activity in old age and not how physical activity earlier in life might affect physical functioning in old age. Being ADL disabled is associated with a need for help from another person, often from a relative or from home care. This is a complex interaction and more research is needed in this area, as formal and informal care in relation to levels of ADL disability have not been particularly well explored.

2 AIMS

2.1 GENERAL AIM

The general aims were: 1) to examine temporal changes (prevalence, incidence, time trends) in physical functioning in older men and women; 2) to identify the underlying development of new disability and functional decline; and 3) to explore geographical variation in physical functioning between urban and rural elderly habitats. We also wanted to describe the amount of informal and formal care in relation to levels of ADL disability. The ultimate aim was to identify factors suitable for prevention.

2.2 SPECIFIC AIMS

The specific aims of the four different studies (Paper I-IV) included in the thesis:

Study I. To describe morbidity and functional status in two elderly populations (aged 75+ years); and to examine how living in different community types (urban vs. rural) may be related to chronic diseases and disability.

Study II. To explore the association between ADL disability, muscle strength, disease severity and mortality in an elderly rural population, with a focus on upper and lower muscle strength.

Study III. To study time trends in the prevalence of ADL disability, defined as a need for assistance in one or more ADL activities, and survival among men and women 78 years and older by comparing two defined cohorts.

Study IV. To examine the incidence of impaired physical functioning defined as ADL disability in relation to gender; and to explore whether being physically active earlier in life are significant predictors of being disability free at follow-up. Due to the relationship between ADL disability and resource use and costs, we also wanted to describe the amount of informal and formal care in relation to levels of ADL disability.

3 METHODS

To give an overview of the studies included in the thesis, the design, sample, data collection, instruments and the analysis methods are presented in Table 2. Data from three population-based studies conducted in Sweden – the Kungsholmen Project (KP), the Nordanstig Project (NP) and the SNAC-Nordanstig (SNAC-N) study – were used. Study I describe the differences in morbidity and ADL disability in two elderly populations according to living area and examine the association between different diseases and ADL disability (KP and NP). Study II examine the associations between ADL disability, upper and lower muscle strength, different diseases and mortality in a population of persons 60 years and older (SNAC-N). Study III is a time trend study and examines the changes in prevalence of ADL disability and survival in two populations of persons 78 years and older (NP and SNAC-N) between 1995-1998 and 2001-2002. However, the prevalence of ADL disability is affected by both survival rate and incidence rate, and therefore Study IV examine the incidence rate of ADL disability over six years and also whether physical activity can be a protective factor for becoming non-disabled in a population of persons 78 years and older at baseline (SNAC-N). Study IV also examines the need for formal and informal care in relation to ADL disability.

Table 2. Overview of studies I-IV used in the thesis.

Study	Design	Sample	Data collection	Instrument	Data analysis
I	Cross-sectional	75+years older adults from the KP (n=1222) and from the NP (n=919) Population-based	Interviews and clinical examinations using standardized protocols	KATZ index of ADL	Descriptive and comparative statistics Logistic regression Population Attributable Risk (PAR)
II	Cross-sectional	60 +years older adults from the baseline collection in SNAC-N 2001-2003 (n=766) Population-based	Interviews, performance tests and clinical examinations using standardized protocols	KATZ ADL Grip strength Chair stand Gait speed PEF MNA CIRS	Descriptive and comparative statistics Cox survival curves Logistic regression
III	Time trend	78+ years older adults from the NP-population (n=303) and from the SNAC-N population (n=406) Population-based	Interviews and clinical examinations using standardized protocols	KATZ ADL MMSE	Descriptive and comparative statistics Logistic regression Cox Hazard ratio Kaplan Meier Survival Curves
IV	Longitudinal	78+ years older adults from SNAC-N (n=325) who were independent in ADL at baseline (2001-2003). Follow-up after three and six years. Population-based	Interviews and clinical examinations using standardized protocols.	KATZ ADL MMSE RUD Physical activity	Descriptive and comparative statistics Incidence rate Logistic regression

3.1 DESCRIPTION OF THE POPULATIONS

3.1.1 Urban area

The Kungsholmen Project (KP), representing the urban area in this study, was a longitudinal population-based study on aging and dementia ongoing in the central part of Stockholm, the capital of Sweden, during the period 1987 to 2000 (87, 88). The name of the project is derived from the area in the city where the study population was originally located, Kungsholmen. The city of Stockholm had at the time 674,000 inhabitants, and of them 15,000 lived in the area of Kungsholmen. Study I use data from the KP.

3.1.2 Rural area

The rural area, the Municipality of Nordanstig, is represented in this thesis by two study populations: the Nordanstig Project (NP) and the SNAC-N study. In 1995, a rural area (Nordanstig) 330 km north of Stockholm was included, and this part of the project was named the Nordanstig project. The Municipality of Nordanstig in the northern part of Hälsingland County had at that time approximately 11,000 inhabitants. This coastal district has no city or central areas, instead there are several small villages, and it covers an area of 1 380 square kilometers. The largest village is Bergsjö with approximately 3,100 inhabitants (89). Study I and III use baseline data from the Nordanstig project.

SNAC-N is part of a larger national study promoted in 1999 by the Swedish Ministry of Health and Social Affairs in order to monitor and evaluate the elderly care system in Sweden: the Swedish National study on Aging and Care. The other three areas involved in the SNAC study, except Nordanstig, are five municipalities in the region of Skåne, Karlskrona Municipality in Blekinge County Council, and the district of Kungsholmen in the City of Stockholm. The general aim of SNAC is to increase our understanding of the aging process, to identify possible preventative strategies to improve health and care in older adults, and to monitor the use of care and services in relation to needs. SNAC-N represents a rural area in northern Sweden (90) (SNAC, see homepage, <http://snacsweden.wordpress.com/>). Study II and III use baseline data, from SNAC-N 2001-2003 and Study IV uses baseline data and data from the 1st and 2nd follow-up; see Figure 1.

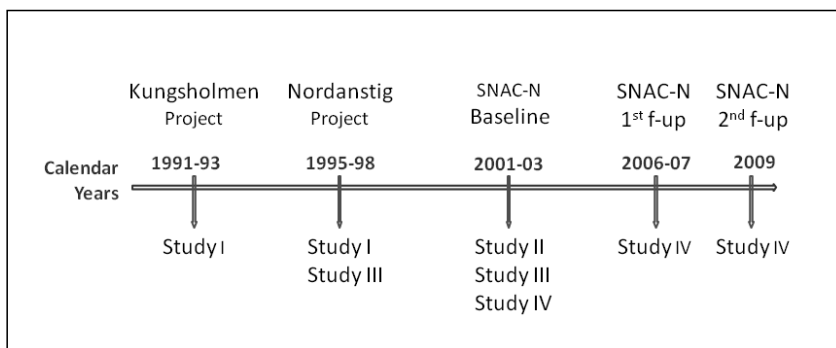


Figure 1. Overview of the populations and the studies in the thesis.

3.1.3 Recruitments of participants

In all the included population-based studies (KP, NP, SNAC-N), the same recruitment procedure was used for all participants. All inhabitants in Sweden are registered and identified according to residency, and lists of all inhabitants in the studied areas were obtained from the local authorities. In the KP and the NP, all inhabitants aged 75 years and older were invited to participate in the project through a personal letter describing the outline and purpose of the study. A nurse contacted the potential participants by telephone to check their availability. At their first appointment, written informed consent was obtained. The recruitment procedure for participants in the SNAC-N study was the same as the earlier studies of the KP and NP. In SNAC-N, participants were 60 years and older and from eleven age cohorts. The age cohorts were chosen at different intervals, 6-year intervals in the younger cohorts (60-78 years old), and 3-year intervals in the older cohorts (78+ years old). The age groups were chosen to match the follow-up intervals, six years for the younger and three years for the older, due to their more rapid changes and higher attrition rate.

3.2 DATA COLLECTION

In the KP, the NP and the SNAC-N study, all participants, whether living at home, sheltered accommodations or in residential care, were examined using standardized protocols, including a social interview, a neuropsychological battery, and a medical examination with laboratory tests, lasting approximately 3 hours. Trained nurses interviewed the participants on educational background, living conditions, functional status and social factors. All persons were clinically examined by a physician. The assistant nurse took blood samples, weight and length and in the SNAC-N study also PEF, vision and conducted various performance test such as grip strength, chair stand, gait speed. In the SNAC-N study, participants were re-examined after three or/and six years using the same protocols, excluding basic questions about education, etc. In addition, a proxy interview with a next-of-kin or other close person was carried out. If the participants' answers were incomplete or if they were diagnosed with dementia,

information was taken from the informant interview. The interview concerned the past and current health status of the older participant, as well as selective risk factors for the most common chronic degenerative diseases.

3.3 STUDY VARIABLES

3.3.1 Sociodemographic variables (Study I-IV)

Sociodemographic data were on age, gender, marital status, education and living situation. Education was assessed as the highest educational level achieved. Living situation in Study I included living at home or in a residential care, alone or together with someone. In Kungsholmen, the participants lived at home (apartment or house), in sheltered accommodation (service building) or in a residential care (nursing home). The difference between a sheltered accommodation and nursing home in Kungsholmen was that only the nursing homes were staffed around the clock. In Nordanstig, the participants lived at home or in a residential care, staffed around the clock. The participants living in sheltered accommodation in Kungsholmen were more similar to the participants living at home in terms of physical functioning and cognition, and therefore the two groups are combined in the analysis.

3.3.2 Physical functioning (Study I-IV)

Functioning was measured using the Katz index of ADL, a hierarchical scale formed by dependency in six basic activities: dependency in bathing, dressing, going to the toilet, transferring, continence, and feeding (17). Level of dependency was expressed in grades, 0 being the most independent (requiring no personal assistance in any of the six activities) and 6 being the most dependent grade (requiring assistance in all of the six activities.) The reliability and construct validity of this scale, when administrated by nurses, have been reported to be good (91). Both in the KP, the NP and the SNAC-N study, nurses collected the data by questioning and observing the participants or by asking an informant.

In Study I and II, the level of dependency in ADL was divided into three levels: zero (0) was defined as independent in all activities and needing no assistance, partially dependent was defined as needing assistance in one or two activities (1-2) and dependent was defined as needing assistance in three or more activities (3-6). In Study III, disability in ADL was defined as needing assistance in one or more activities. Study IV used a modified version of Katz ADL, where only five basic ADL activities were included: bathing, dressing, going to the toilet, transferring and feeding. Incontinence was not included because other studies have often avoided the item as it does not necessarily reflect physical function and may also be difficult to measure (30, 92). Disability was defined as needing assistance in one or more activities.

3.3.3 Physical performance tests (Study II)

Grip strength was measured in Newtons using an electronic instrument Grippit®. Participants were instructed to squeeze the handle of the dynamometer as hard as they

could. Three scores for grip strength were measured: maximum value, mean value, and the score after 10s. The Grippit instrument has a good reliability (93). Grip strength was measured for both hands, and as there was no information on whether the participant was right or left handed, this study used the best result for either side.

Gait speed was assessed using a timed walk. Participants who normally walked at fast or normal speed were asked to walk 6 meters, whereas those who normally walked slowly or very slowly were asked to walk 2.4 meters. Each participant walked twice, once at normal speed and once as fast as they could. The time of the faster of the two walks was used for scoring (94).

Chair stand test measured the time it took to stand up five times from an armless chair. Participants were asked to fold their arms across their chest and stand up from a sitting position; if they successfully rose from the chair, they were asked to stand up and sit down five times as quickly as possible. Timing with a stopwatch started on the command “go” and stopped at the end of the completed fifth stand, when the participants were seated again (40, 50, 94). This performance test has been shown to have good validity (95) and reliability (96).

Peak Expiratory Flow (PEF) was used for testing lung function and measures, in liters per minute, the maximal flow achieved during the maximally forced expiration initiated at full inspiration (97).

3.3.4 Physical activity (Study IV)

Physical activities earlier in life and/or during the past 12 months were measured at baseline. In the question, physical activity was defined as having engaged in regular light exercise, e.g., walking, golf, short-distance cycling, and the five response alternatives were: every day, several times/week, 2-3 times/month, less or never.

3.3.5 Morbidity, mental health and malnutrition (Study I-IV)

In Study I, only chronic diseases were included, and morbidity was defined as having one or more chronic diseases. Included diseases were cardiovascular diseases (arrhythmia, heart failure, angina pectoris, and cardiac failure), stroke, malignancy, Parkinson’s disease, diabetes mellitus, and fractures (occurring within the 5-year period prior to participation). Diagnoses were made according to the *International Classification of Diseases, Ninth Revision* and performed by the physician during the examination or taken from medical records (98). In Study II morbidity/physical health was assessed diagnosed according to the Cumulative Illness Rating Scale (CIRS). The CIRS measures the severity of 15 different chronic diseases by taking into account their chronic medical illness burden (cardiac, hypertension, vascular, respiratory, eye/ear/nose/throat, upper gastrointestinal, gastrointestinal, hepatic, renal, other genitourinary, musculoskeletal, neurological, endocrine/metabolic, dementia and psychiatric/behavioral diseases). The physician rated each disease from one to five, where one represented no impairment, two and three indicated that the disease was moderate and associated with some impairment that needed treatment, and four and

five meant that the disease was either life-threatening, needed immediate care or was untreatable (99, 100).

Diagnosis of *major depression* (Study I) was performed by the physician according to the Diagnostic and Statistical Manual of Mental Disorders (DSM), Fourth Edition (101), using data from the Comprehensive, Psychopathological Rating Scale (102). In Study II, the physician asked the participants whether they felt depressed, and responses were defined as yes or no. The examining physician decided whether the response was relevant.

For the clinical diagnosis of *dementia* (Study I), DSM, Third Edition, Revised, (DSM-III-R) diagnosis criteria were used, including a combination of findings from the medical examination, cognitive testing, patient history as well as information from the proxy, and followed a 3-step diagnostic procedure (103, 104): (1) the examining physician made a preliminary diagnosis; (2) all cases were then independently reviewed by a specialist who made a second diagnosis; (3) in case of disagreement, a third opinion was requested from a senior physician before the final diagnosis was accepted.

In Study I - IV, *mental functioning* was measured using the Mini-Mental-State Examination (MMSE) (105), which was administered by nurses. MMSE is a brief psychometric 30-point questionnaire test, introduced by Folstein et al. in 1975, that is used to screen for cognitive impairment and also often used in medicine to screen for dementia. At a test duration of about 10 minutes, it samples functions including arithmetic, memory and orientation. The test scores range from 0 to 30, with the highest score indicating intact cognitive functioning. The Swedish version of this test (106) was used, with a score <24 indicating cognitive impairment. If the person could not answer due to physical disability, or if the person refused to answer a question, a score of zero was given.

The *Mini Nutritional Assessment* (MNA) is a valid nutritional screening tool that can identify older persons (65+) who are malnourished or at risk of malnutrition. The original MNA contains 18 questions. In this study, the MNA short form (MNA-SF) (Study II) consisting of only six questions was used; it has good sensitivity compared to the full MNA (107).

The physician or nurse also assessed *hearing and vision impairment* during the examination. Hearing impairment was defined as being able to hear the interviewer's voice only if she spoke with a loud voice or if the person was dependent on a hearing aid. Vision impairment was defined as being blind or almost blind, and in Study II vision impairment was defined as being blind or unable to read a text of 13 inches or less, as tested by the Jaeger eye chart.

3.3.6 Formal and informal care (Study IV)

The amount of formal and informal care was calculated using the Resource Utilization in Dementia (RUD) instrument. This instrument calculates the amount of care in IADL, ADL and surveillance (108). In Study IV, the amount of formal and informal care includes help with IADL and ADL measured at baseline and follow-ups as well as in participants living at home. Formal care is the care provided by the municipality, and informal care is that provided by relatives, neighbors and friends. The RUD instrument has been shown to be a valid and reliable substitute for observations of ADL and IADL (108, 109). Data were gathered by interviewing the participants or a proxy if the participant could not give reliable information. Owing to the type of care, the time frame for questions about IADL was the past month, while for basic ADLs it was the past week. In Study IV, data on IADL and ADL for both formal and informal care are presented as hours per month.

3.4 STATISTICAL ANALYSIS

Study I. Possible associations between urban and rural area, sensory functioning, disability and morbidity were explored using age- and gender-specific prevalence figures for sociodemographic characteristics (education, living situation), ADL disability, and morbidity. To compare age and gender differences in the study variables, chi-square tests were used. Logistic regression analyses were performed to detect factors that could explain area differences in disability and morbidity; the results were presented as odds ratios (ORs) and 95% confidence intervals (CIs). Additional regressions split according to living area and gender were also performed. Finally, the population attributable risk (PAR) and 95% CIs were calculated separately for the urban and the rural areas. In the present study, PAR expresses the proportion of ADL disability in the study population that is attributable to exposure and thus could be eliminated if the exposure (disease or condition) were eliminated. Analyses were performed using SPSS version 17.0 (SPSS, Inc., Chicago, IL).

Study II. Sociodemographic characteristics of the study population were distributed by age cohort using the following measures: gender, marital status, living situation and education. To compare age and gender differences in, e.g., sensory functioning (hearing, vision), disability (e.g., ADL, performance tests) and morbidity, chi-square tests were used for categorical variables and analysis of variance for continuous variables. Plotted Cox survival curves adjusted for age, gender, cognition and education were used to verify the impact of disability on mortality for functionally independent and dependent subjects. Functionally dependency was measured using Katz ADL, ability to perform the chair stand test, walking performance and grip strength. Survival time was calculated as the time (years) between baseline and the 6-year follow-up or death in case the participant died before follow-up. To estimate the association between ADL disability in one or more basic ADL activities and upper and lower muscle strength, as measured by grip strength, chair stand, gait speed and lung functioning, logistic regression models were used. First the association was evaluated separately and then included in the final model, the models were controlled for the effect of age,

gender, cognition and education. The results are presented as odds ratios (ORs), and 95% confidence intervals (CIs) were calculated based on the binomial distribution.

Study III. To compare and identify differences in age, gender, education and cognition between participants in the two surveys, chi-square tests were used. The prevalence of ADL disability was presented for the crude population, both total and divided by gender, for both study cohorts as well as an age- and gender-specific figure for prevalence of ADL disability for both study cohorts. Binary logistic regression was used to calculate odds ratio (ORs) and 95% confidence intervals (CIs) for disability in SNAC-N versus NP participants. Results are presented from the univariate model and the model that was adjusted for age, gender, education and cognition using the MMSE scale, 0-30 points. To examine the impact of ADL disability on mortality in the populations, using the NP cohort as a reference, analysis with Cox Hazard ratios for mortality, adjusted for age, gender, education and cognition, was used. For the study populations, Kaplan Meier survival curves by ADL disability status were created. Survival time was calculated as the time (year) between baseline and 8-year follow-up or death in case the participant died before follow-up. The IBM SPSS Statistics version 19.0 for Windows (IBM SPSS Inc., Chicago, IL) was used for modeling analyses and statistical tests.

Study IV. At both the 3-year and 6-year follow-up, age- and gender-specific incidence figures were calculated using as the numerator all cases identified with ADL disability (needing assistance in one or more or two or more ADL activities), and as the denominator the examined population. Age- and gender- specific incidence rates were calculated as the number of new cases divided by the person-years at risk. The population was stratified into two age groups: 78-81 and 84 years and older. The Poisson distributions were used to calculate the 95% confidence intervals. For non-disabled subjects, person-years were calculated as the time between baseline examination and the follow-up examinations. For the ADL-disabled subjects, half this time was assumed, due to the uncertainty of disability onset. Once the subject had become ADL disabled, he/she was no longer considered at risk. Divided by gender and the two age groups, the incidence rate was calculated in two separate analyses, needing assistance in one or more (ADL1+) or two or more (ADL2+) ADL activities. A Poisson distribution was used to calculate 95% confidence intervals. To estimate the association between physical activity and ADL disability, logistic regressions were used and adjusted for gender and cognition. The results are presented as adjusted odds ratios (aORs) and 95% CIs. Mean values for the number of hours per month of informal and formal care that the persons received were calculated using univariate analyses of variance (One-Way ANOVA). The IBM SPSS Statistics version 20.0 for Windows (IBM SPSS Inc., Chicago, IL) was used for modeling analyses and statistical tests.

4 ETHICAL CONSIDERATIONS

Population-based studies include all habitants in, for example, a municipality and may also include cognitively impaired persons. When the research involves older adults who are frail or have a cognitive impairment, it is important to carefully consider ethical issues, at the same time as it is important that these individuals be represented in the study population. The subjects included in the present studies had been asked to participate due to their age and residence. They were not volunteers or a selected group of hospitalized persons. Thus, they were contacted without having requested any participation or having expressed any previous will, wish or need. They may have felt that their privacy was violated and/or that they were contacted against their will (110). Furthermore, as the present studies are follow-up studies the participants may be affected by the research activities for many years.

In this thesis, Study I-IV involves both participants who are healthy and participants with cognitive impairment. All potential participants in these studies were invited through a personal letter. The letter contained a brief description of the study, stated that participation was voluntary and that participants could withdraw from the study at any time. Shortly after receiving the letter, the potential participants were contacted via telephone by a nurse and asked if they would like to participate. To receive informed consent from participants with cognitive impairment, a proxy or a legal representative was asked for consent. The proxy or legal representative who is asked to decide often does so on the basis of the participant's best interests, considering what the participant him-/herself would have decided (111, 112). During the examination, it was important to pay attention to whether the interviewee expressed anguish or discomfort, and if this happened the interview was interrupted.

All studies have been approved by the Ethics Committee of the Karolinska Institutet and later by the Regional Ethical Review Board in Stockholm: KI 90:251; KI 94:122; KI 01-114; REPN 04-929/3; CEPN 2007/279-31.

5 RESULTS

The general aims were: 1) to examine temporal changes (prevalence, incidence, time trends) in physical functioning in older men and women; 2) to identify the underlying development of new disability and functional decline; and 3) to explore geographical variation in physical functioning between urban and rural elderly habitats. We also wanted to describe the amount of informal and formal care in relation to levels of ADL disability. The ultimate aim was to identify factors suitable for prevention. Below the main results will be presented separately for each study included in the thesis.

5.1 CHARACTERISTICS OF THE POPULATIONS

This thesis is based on three population studies, the KP, the NP and the SNAC-N study. In the KP, of the study population of 1,524 persons in the urban area, 1222 (80%) participated. Causes for attrition were: death (6.2%), moved from the area or not reachable (2.3%) and refusal to participate (11.3%). In the NP, 919 (79%) persons of the 1168 in the rural population participated in the study. Causes for attrition were: death (12.6%), moved from the area or not reachable (2.4%) and refusal to participate (6.3%). There were no significant age or gender differences between persons who participated and those who did not. In the SNAC-N study, 766 (75.4%) persons of the 1016 in the study population participated. Causes for attrition were: death (1.6%) and refusal to participate (23.0%). More women than men refused to participate, 25.5% vs. 19.9% ($p < 0.05$). Sociodemographic data for the populations in each study are presented in Table 3.

5.2 STUDY I

We aimed to describe morbidity and physical functioning in two elderly populations (75+) and to examine how living in different community types (urban vs. rural) may be related to chronic diseases and ADL disability.

When comparing rural and urban participants 75 years and older, the rural population was more disabled in ADLs than the urban population, even after controlling for age, gender, and education ($OR = 1.8$, 95% $CI = 1.4-2.5$). We found no gender differences in ADL disability in the rural area, whereas women, 85 years and older, in the urban area were more disabled in ADL than urban men in the same age group ($p < 0.05$). Older men (85+) living in the urban area had significantly less ADL disability than men and women of the same age in both areas.

Analysis using population attributable risk (PAR) for sensory function, chronic diseases and cognitive impairment was carried out to examine the association with ADL disability as well as to estimate the proportion of ADL disability that could be eliminated if the exposure were eliminated. Using this analysis, we found that cognitive impairment ($MMSE < 24$) was the factor with the strongest association with ADL disability in both rural (72.8%) and urban (61.1%) areas. The most common disease in both living areas was cardiovascular disease, but it was only in the rural area it seemed to have an influence on ADL disability ($PAR = 0$ vs 15.3%). Diseases and sensory

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

	Study I		Study II	Study III		Study IV	
	Rural (NP)	Urban (KP)	SNAC-N	NP	SNAC-N	SNAC-N Aim 1 and 2	SNAC-N Aim 3
Number of participants	919	1222	766	303	406	307	316
Age years							
Mean (SD)	82.3 (4.6)	83.6 (5.2)	75.1 (10.5)	83.1 (4.6)	83.8 (4.9)	83.1 (4.5)	83.0 (4.3)
Range	75-98	75-100	60-101	78-98	78-101	78-100	78-96
Female gender%	58.9	76.4	54.2	59.1	59.9	57.0	57.0
Education* n (%)							
Elementary (2-7 yrs)	843 (92.7)	595 (48.9)	519 (70.9)	281 (93.7)	322 (84.6)	258 (84.0)	260 (83.6)
High (8-14 yrs)	62 (6.9)	538 (44.2)	182 (24.9)	18 (6.0)	52 (13.6)	43 (14.0)	45 (14.5)
University (15-23 yrs)	4 (0.4)	84 (6.9)	31 (4.2)	1 (0.3)	7 (1.8)	6 (2.0)	6 (1.9)
Living situation n (%)							
At home	743 (80.8)	1097 (89.8)	681 (88.9)	246 (81.2)	325 (80.0)	293 (95.4)	316
In residential care	176 (19.2)	125 (10.2)	85 (11.1)	57 (18.8)	81 (20.0)	14 (4.6)	---
Disability [§] I+ n (%)	204 (22.2)	201 (16.7)	97 (13.0)	62 (20.5)	92 (22.8)	0	24 (7.6)
MMSE Mean (SD)	23.1 (7.4)	23.7 (7.4)	27.1 (5.7)	22.8 (7.7)	25.0 (7.1)	27.7 (3.1)	27.7 (3.1)

*Missing data on education for 10 persons in NP and 5 in KP in study I, 34 persons in study II, 3 persons in NP and 25 persons in SNAC-N in study III and 5 persons (aim 3) in study IV. [§]Missing data on ADL disability for 2 persons in NP and 15 persons in KP in study I, 19 persons in study II, 1 person in NP and 3 persons in SNAC-N in study III and 2 persons (aim 3) in study IV.

functions with significant differences in PAR between urban and rural area were found for ADL disability due to stroke (5.6 %vs 32.2%), diabetes mellitus (1.2% vs 6.1%), fractures (1.4 % vs 10.7%) and hearing impairment (8.7% vs 22.0%). In both living areas, the PAR for ADL disability was higher for having two or more diseases than for having one disease, but the difference was greater in the rural area. The participants in the rural area had also a higher prevalence of multimorbidity (≥ 2 diseases) than the participants in the urban area, 64.9% vs. 50.9%. Perhaps this could be one explanation for the higher prevalence of disability in the rural area. Including only the diseases that had most influence on disability, the proportions in respective living area are shown in Figure 2.

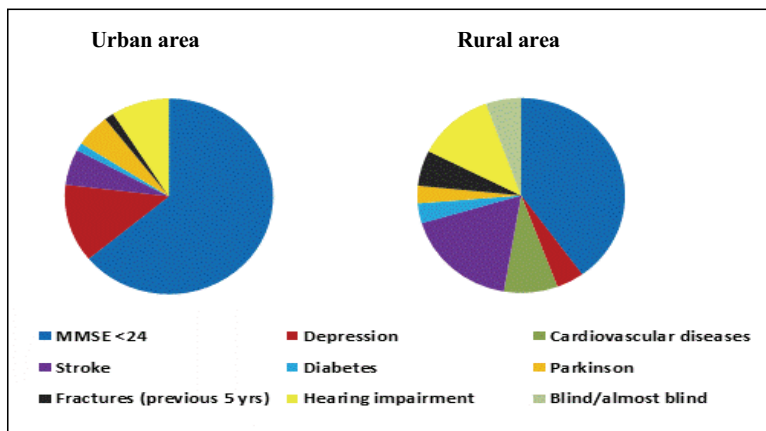


Figure 2. Population Attributable Risk (PAR %) for diseases associated with risk of disability divided by living area.

5.3 STUDY II

The aim of this study was to explore the association between ADL disability, muscle strength, disease severity and mortality in older adults in a rural population, with a focus on upper and lower muscle strength.

Muscle strength, measured by hand grip strength, gait speed and chair stand test, and being ADL disabled in one or more ADL activities decreased with age, with a tendency (non-significant) for women 80 years and older to be more disabled in ADL than men of the same age. The proportion of individuals who felt depressed was higher in participants who required help with one or more ADL activities than in those who were independent in ADL, 28.0% vs. 6.3% ($p < 0.001$).

According to the Cumulative Illness Rating Scale (CIRS), musculoskeletal and cardiac diseases were the most common diseases and also had the greatest impact on ADL disability (CIRS 3-5). Other diseases that had a negative effect on physical functioning were genitourinary diseases among the oldest men, eye/ear/nose/throat diseases at the age of 72, and for the oldest old (90+), dementia had the greatest impact on physical

functioning (CIRS 4-5). Although not significant, there was a tendency for women to be more dependent in two or more ADL activities when compared to coeval men.

Survival time was calculated as the time between baseline and 6-year follow-up or death if the participant died before follow-up. Participants who were dependent in one or more ADL activities had a significantly shorter survival time than did independent participants (requiring no assistance). Participants who were unable to perform the walking test and the chair stand test had a significantly shorter survival time, except for women for whom there was no difference in survival between the groups in chair stand test. Survival curves on grip strength comparing quartiles in strength showed that men with lower grip strength had shorter survival times. There was no difference in survival when comparing grip strength in women

A statistically significant association was found between needing assistance in one or more ADL activities and having reduced lower muscle strength as indicated by not being able to perform gait speed tests (OR 17.3; 95% CI 4.1-72.2) and not being able to perform chair stand tests (OR 6.6; 95% CI 2.6-16.8). No association was found between needing assistance in basic ADL and malnutrition, nor upper muscle strength as measured by grip strength or lung capacity. When the same analyses were performed split by gender, the association with needing assistance in ADL remained for lower muscle strength, although it was much stronger for women (OR 52.3; 95% CI 5.9-165.1 and OR 10.9; 95% CI 2.8-42.8) than for men (OR 22.6; 95% CI 2.0-254.0 and OR 4.7; 95% CI 1.2-18.7) for gait speed and chair stand, respectively

5.4 STUDY III

The aim was to study trends in ADL disability, defined as a need for assistance in one or more ADL activities, among men and women 78 years and older between 1995-1998 and 2001-2003.

There were no significant differences in the age- and gender-specific prevalence rates of ADL disability for NP and SNAC-N except for the differences in ADL disability between men and women 84 years and older in SNAC-N: 23.3% and 36.7%, respectively ($p < 0.05$). Adjusted for age, gender, cognition and education, the prevalence of ADL disability was stable from 1995-1998 to 2001-2002 for men, while women became more disabled in ADL during the time period, OR 2.36 (1.12-4.94), see Figure 3. Participants with ADL disability were significantly more cognitively impaired (MMSE < 24) than were non-disabled participants. Eighty-seven percent of participants with ADL disability in NP were cognitively impaired as compared to 21.7% of the non-disabled participants ($p < 0.001$). In the SNAC-N cohort, corresponding figures for SNAC-N were 70.9% vs. 9.7% ($p < 0.001$). There was no significant difference in survival time between the populations in either ADL-disabled persons or non-disabled persons. There was a tendency for increased survival for non-disabled persons in SNAC-N compared with NP, although it was not significant; this was particularly true for women. In general, women survived longer than men did regardless of whether they were ADL disabled or not.

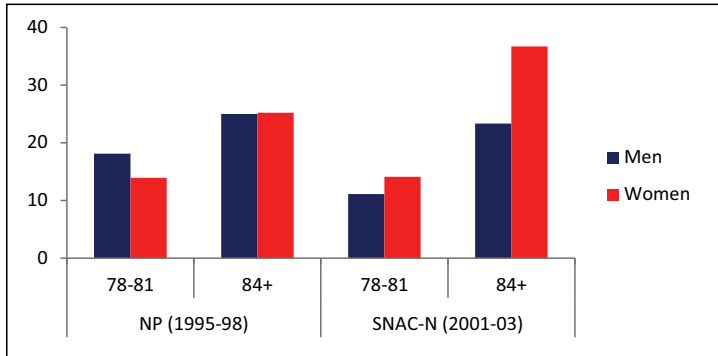


Figure 3. Prevalence of ADL-disability in the NP cohort (1995-1998) and the SNAC-N cohort (2001-2003). Divided by age and gender.

5.5 STUDY IV

The aim was to examine the incidence of impaired physical functioning defined as ADL disability in relation to gender; and to explore whether being physically active earlier in life and/or during the past 12 months are significant predictors of being disability free at follow-ups. Due to the relationship between ADL disability and resource use and costs, a third aim was to describe the amounts of informal and formal care in relation to levels of ADL disability.

There was a tendency for more men than women in the age group 78-81 to become ADL disabled at the follow-ups, and in the age group 84 years and older, women become more ADL disabled than men; the difference between men (23.8%) and women (57.6%) was significant ($p < 0.05$). Both at 1st and 2nd follow-up and need for assistance with one or more activities (ADL 1+), or two or more (ADL 2+), women in the age group 84 years and older had become more ADL disabled than women in the age group 78-81 ($p < 0.05$). There were no significant differences in ADL disability between men in the two age groups. Examining the incidence rate (IR) for ADL disability, in participants 78 years and older, between baseline and follow-ups found that the incidence rate for ADL disability was higher for women (59.3/1000 person-years) than for men (42.4/1000 person-years). Between baseline and follow-ups the IR for men was similar in the age groups 78-81 and 84 years and older, 42.3 vs. 42.5/1000 person-years. The IR for women in ADL disability increased significantly from the age group 78-81 to the age group 84 years and older, 20.8 vs. 118.3/1000 person-years for ADL1+ and for ADL 2+ (8.5 vs. 81.5/1000 person-years), see Figure 4.

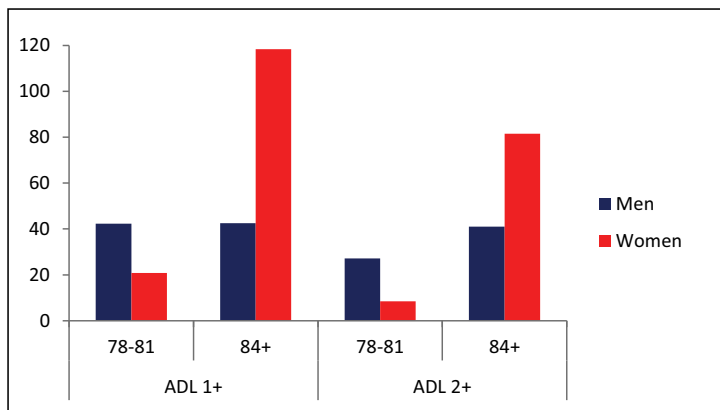


Figure 4. Incidence rates for needing assistance in one or more activities (ADL 1+) and needing assistance in two or more activities (ADL 2+). Distribution by age and gender.

In the age group 78-81 years, having been physically active in the form of regular light exercise (walking, golf, short-distance cycling) earlier in life and/or during the past 12 months before baseline examination were significant preventive factors for ADL disability, aOR 6.2 vs. 2.9, respectively. No association was found between physical activity and ADL disability in persons 84 years and older. The majority of the participants in the age group 78-81 were physically active every day or several times a week earlier in life (74%) and during the past 12 months (56%); there were no differences between genders. In the age group 84 years and older, 77% had been physically active every day or several times a week earlier in life and 47% during the past 12 months. In this age group, there was a tendency for women to have been more physically active earlier in life than men (86% vs. 66%) and for men to have been more physically active the past 12 months than women (54% vs. 42%); see Table 4.

Table 4. Physical activity during the past 12 months before baseline and earlier in life. Distributed by age and gender.

Age (years)	Frequency	The past 12 months		Earlier in life	
		Men	Women	Men	Women
78-81	- Every day or several times/week	(n=50) 27	(n=76) 43	(n=40) 30	(n=60) 44
	- 2-3 times/month	7	11	8	12
	- Less or never	16	22	2	4
84+	- Every day or several times /week	(n=37) 20	(n=47) 20	(n=36) 24	(n=44) 38
	- 2-3 times/month	2	7	4	3
	- Less or never	15	20	8	3

The amount of informal and formal care in relation to levels of ADL disability was examined in the study population of both ADL-disabled and non-disabled persons. The mean number of hours per month in the study population for informal care was 15.7 and for formal care 4.6. The amount of both informal and formal care increased with the number of ADL activities the persons required help with, and the differences in amount of care between the ADL groups were significant ($p < 0.05$). Informal care mainly consists of assistance with IADL and formal care of assistance with both IADL and ADL.

6 DISCUSSION

6.1 SUMMARY OF THE MAIN FINDINGS

The main results presented in this thesis can be summarized as follows:

- 1) The prevalence of ADL disability was higher in women than in men, especially in the oldest old (84 years and older). While the prevalence of ADL disability was stable for men over time it increased in women, and primarily in women aged 84 years and older, due to a higher incidence rate and longer survival than men.
- 2) Diseases and other health conditions that were found to have a negative influence on ADL were cognitive impairment, cardiovascular diseases, multimorbidity (having two or more diseases), musculoskeletal diseases, and depression.
- 3) The rural elderly population was more disabled and had more diseases compared to the urban elderly. There were also significant differences of how specific chronic conditions influenced the risk of disability between the rural and urban areas.
- 4) Both upper and lower muscle strength decreased with increasing age, but only reduced lower muscle strength was found to have an association with ADL disability and risk of mortality. Furthermore, being physically active both earlier in life and in old age was associated with being less ADL disabled in old age.
- 5) The amount of both informal and formal care increased significantly with the number of ADL activities the persons required help with.

6.2 OCCURRENCE OF ADL DISABILITY

This thesis shows that ADL disability increases significantly with age from the age of 87 years, and that women are more disabled than men in ADL, especially in old age, 84 years and older (Study I-IV). The reported prevalences of ADL disability in older adults, 60 years and older, are different in different studies, ranging from 10.6% in Malaysia to 25.7 % in a population in Lebanon (19, 22). The differences in prevalence of ADL disability may be due to use of different instruments to measure ADL disability as well as to different study populations, as some studies exclude, e.g., persons with dementia or living in residential care (20, 23, 25, 33, 35), which may result in underestimation of the prevalence of ADL disability. No gender differences in ADL disability were found in the rural area (Study I), but older men in the urban area were significantly less disabled in ADL compared with both same-age rural men and women in the urban and rural area. Women 80 years and older had a tendency, non-significant, to be more disabled in ADL than men in the same age group (Study II), and women 84 years and older were significantly more disabled in ADL than coeval men (Study III). Previous studies also support results showing that women in very old age are more disabled than coeval men (19, 24, 113). The gender differences may partly be due to higher mortality in men and higher incidence of ADL disability in women (Study IV).

Higher mortality among men than women (26) and higher incidence of ADL disability in women than in men have also been found in other studies explained by that women suffers from diseases with longer duration and lower rates of recovery than in men (27, 28).

Three studies (I, II and III) presented in this thesis support the notion that ADL ability over time decreases in women and is stable in men, and that the prevalence of ADL disability seems to increase in women is also supported by the results of Study III and IV. Examining the time trend in ADL disability (Study III) showed no significant difference in the crude prevalence of ADL disability between the two cohorts. Because there was a significant difference in cognition between the two cohorts, we expected decreased ADL disability in the SNAC-N, given that cognitive impairment is a strong risk factor for being ADL disabled (51, 52, 114). After adjusting for age, gender, cognition and education, the odds of being disabled in ADL were significantly higher in the SNAC-N cohort as compared to the NP cohort, with an OR for all of 1.82 (CI 1.08-3.10) and for women 2.36 (1.12-4.94). A study from the US also found that the prevalence of ADL disability in adults, 65 years and older, was stable between 2000 and 2005 in men and had at the same time increased in women (36), while other studies have reported other scenarios (20, 23, 32, 35). Another study from Sweden, examining gender differences in ADL between 1992 and 2002 in adults 77 years and older, found that the prevalence for ADL not had increased over time and that there were no significant gender differences ADL disability (32). Why studies find different results is difficult to explain, perhaps due to different populations e.g. different living area, but it also shows that we need more studies that follow how ADL disability change over time. And even if the prevalence's of ADL disability are different, it is more important to identify persons at risk for being disabled, as studies have shown that being dependent in ADL and needing help from another person may lead to poor quality of life for both persons with ADL disability and their spouses (84, 115-117).

Two factors that affect the prevalence of ADL disability are incidence rate and survival. In Study IV, there was a tendency for more men than women in the age group 78-81 to become ADL disabled during follow-ups, and in the age group 84 years and older, women become more ADL disabled than men; the difference between men (23.8%) and women (57.6%) was significant ($p < 0.05$). There was also a significant difference between women in the two age groups, in needing assistance with one or more activities (ADL 1+) or two or more activities (ADL 2+); in the age group 84 years and older, women had become more ADL disabled than women in the age group 78-81 ($p < 0.05$). No significant difference was found in ADL disability between men in the two age groups. A study from the Netherlands also found that the prevalence of becoming disabled was higher in women than in men at 6-year follow-up in a non-disabled population of adults 55 years and older at baseline (29). Study IV also examined the incidence rate (IR) for ADL disability, in participants 78 years and older, between baseline and follow-ups in the SNAC-N study and found that the incidence rate for ADL disability was higher for women than for men (59.3 and 42.4/1000 person-years respectively). The incidence rate for disability increases with age, especially for women. The participants were divided into two age groups, 78-81

and 84 years and older. Comparing the age groups, the IR was higher for women than for men in the age group 84 years and older, and for women the IR for ADL disability increases significantly from the age group 78-81 years to the age group 84 years and older both for ADL1+ (20.8 vs. 118.3/1000 person-years) and for ADL 2+ (8.5 vs. 81.5/1000 person-years). There was no difference in the IR between men in the age group 78-81 years and the age group 84 years and older, 42.3 vs. 42.5/1000 person-years. This result of increasing IR for ADL disability in women 84 years and older may be one explanation for the higher prevalence of ADL disability in very old women. Few studies have looked at incidence of ADL disability, but a study from Brazil examining adults 60 years and older also found that women had a higher incidence rate than men in ADL disability, 42.4/1000 vs. 17.5/1000 person-years (30).

Differences in survival may also be an explanation for the differences in prevalence of ADL disability. If we will live longer with ADL disability, the prevalence of ADL disability will increase (92). The mortality rate may also be different between men and women. In a study from the Netherlands showing higher prevalence for women than men in ADL disability, the mortality rate for men was higher than that for women (29). Examining survival time for participants with and without ADL disability in Study III, using Kaplan-Meier survival curves, showed that ADL-disabled participants had a shorter survival time than the non-disabled participants ($p < 0.05$). There were no significant difference in survival time between participants with and without ADL disability in the cohorts, but there was, especially among women, a tendency for increased survival for non-disabled persons in SNAC-N compared with those in NP. In general, women survived longer than men did regardless of whether they were ADL disabled or not. In study III, mortality was also analyzed for likelihood of death using HR adjusted for age, gender, education and cognition. Examining the likelihood of death in Study III revealed a tendency for decreased likelihood of death in SNAC-N compared with NP, especially for women with no disability in SNAC-N compared with NP, but there were no significant differences. The reason why there were no significant differences in survival in the present study but perhaps a tendency toward longer survival may be the short time between the cohorts. A study from the US reported decreased survival in persons with ADL disability and longer survival in women than in men (92).

6.3 GEOGRAPHICAL VARIATION

Comparing ADL disability in rural and urban areas, revealed that older adults in the rural area were more disabled in ADLs than were older adults in the urban area (Study I). We also found that women 85 years and older in the urban area were more disabled in ADL than men in the same age group ($p < 0.05$). Older men, 85 years and older, in the urban area were significantly less ADL disabled than same-age men in the rural area and women in both areas. Cardiovascular disease was the most common disease in both the rural and urban area, but it was only in the rural area that it was associated with ADL disability. The reason for this may be that older adults in the rural area had more severe heart problems and more severe heart disease (e.g., ischemic heart attack was

more common in the rural area). Other differences due to living area were found in PAR for ADL disability, both the prevalence of the diseases and the PAR for ADL disability were higher in the rural area for stroke, diabetes mellitus, fractures, and hearing impairment. Moreover, we found a greater difference in PAR for ADL disability between those who had two or more diseases and those with one disease in the rural area than in the urban area. The higher prevalence in the rural area of diseases associated with ADL disability is probably one of the reasons why the population in the rural area is more ADL disabled than that in the urban area. This demonstrates again the importance of prevention in primary and elderly care to reduce the incidence of these diseases, as they are often caused by unhealthy lifestyle factors. Poorer health in rural areas has also been found in other studies comparing urban and rural areas (62, 63, 65).

A study from Finland examining adults 52 years and older found also that participants in a rural area were more disabled than participants in an urban area. Their explanation for the difference was more unhealthy lifestyles in the urban area with higher prevalence of obesity, fat intake and smoking, but the result could also be explained by the fact that the rural population had a lower educational background and were less physically active (62). In this thesis as well, the participants in the rural area had a lower educational level. Perhaps the differences between living areas also can be explained by other factors. A study from Canada found that older adults in the rural area compared with the urban area made fewer visits to the healthcare facilities (118). Perhaps the accessibility of healthcare providers underlies the difference in health between urban and rural areas. The differences in ADL disability and health as a function of area of residence also raise questions concerning how the healthcare and the social services (home-care and residential care) are distributed, taking into account that older people in one area may have poorer health and more disabilities than in another area, or is it only the age distribution that matters?

6.4 ASSOCIATED FACTORS

Diseases and other health conditions that this thesis identified as having a negative influence on ADL were cognitive impairment (Study I, II, III), cardiovascular diseases (Study I), multimorbidity (2+ diseases) (Study I, II), and musculoskeletal diseases (Study II). Previous studies have also reported a strong association between ADL disability and chronic conditions, e.g., dementia, stroke, psychological disorders, obesity and low BMI (53, 54, 59, 119). Dementia had the greatest impact on physical functioning in Study II, with CIRS 4-5 in older adults 90 years and older. In Study III, participants with ADL disability were significantly more cognitively impaired than non-disabled participants in both cohorts. Cognitive impairment or dementia as a risk factor for ADL disability is well known and has been reported in other studies (51, 52). Cardiovascular disease was only associated with ADL disability in the rural area in Study I. Also in Study II, cardiac diseases together with musculoskeletal diseases were the most common diseases in both genders. These diseases also had the greatest impact on physical disability (CIRS 3-5). A study from France examining the impact of chronic conditions on ADL, in a population of adults 18 years and older, reported that

neurological, musculoskeletal and cardiovascular diseases had the highest impact on ADL disability on the whole population and also on adults 65 years and older.(53). As those diseases are the most common diseases and also had the highest impact on ADL disability both in this thesis and in other studies (53, 54), so is it very important with health promotion early, e.g. during the health checks that are offered to those turning 40 years old. It is also important with specific interventions (secondary prevention) for persons who have these diseases. Why cardiovascular diseases only was associated with ADL disability in the rural area and not in the urban area (Study I) maybe can be explained by that more severe heart diseases e.g. ischemic attack was more common in the rural area.

Multimorbidity was also associated with ADL disability (Study I and II). The PAR for ADL disability was higher for having two or more diseases compared with having one disease, especially in the rural area. Having an increased number of diseases graded CIRS score 4-5, also increased the risk of being dependent in two or more ADL activities. The difference in being dependent in two or more ADL activities in persons with three or more diseases with CIRS 3-5 vs CIRS 1-2 was 18.5% vs. 3.5%. Except for having one special disease with high impact on ADL disability so is multimorbidity also strongly associated with ADL disability and that have also been found in other studies (59, 60).

Other diseases/conditions that have been found to be risk factors for ADL disability, e.g., low BMI, obesity (119), were not associated with ADL disability in this thesis. There is no simple explanation for why this association not was found in the present studies. Perhaps it is due to the size of the study population or simply that there is no association between BMI and ADL disability in this population.

To decrease the prevalence of ADL disability in older adults, is it important that prevention of diseases associated with ADL disability begin early in life, preferably already in midlife, and that health care, doctors and nurses, works with health promotion before individuals suffer from e.g. diabetes, cardiovascular diseases etc. A study of older adults, 60 years and older, found that adults with fewer behavioral risk factors at middle age had less ADL disability in old age (120). Motivational interviewing conducted by a physician or nurse can motivate patients with risk factors such as overweight, smoking, stress and physical inactivity to change and start living a healthier lifestyle, thus reducing the risk for cardiovascular diseases, diabetes and hypertension (121).

In this thesis (Study II), feeling depressed increased with increasing age, and there was a tendency for a higher prevalence of depression in women than in men. There was also a higher proportion of feelings of depression among participants who were ADL disabled than among those who were non-disabled, 28.0% vs. 6.3 %.

Depression has also in other studies been found to be associated with ADL disability (56-58), even if it is unclear whether depression causes ADL disability or whether being ADL disabled causes depression. Perhaps causation goes in both directions, and

when depression is common in older adults (122), is it therefore important to prevent both depression and ADL disability in old adults.

In the present thesis, performance on a gait speed test had the strongest association with ADL disability, and this has also been reported in other studies (38, 40). Inability to perform the walking test was also associated with an increased risk of death. Perhaps performance tests measuring, e.g., gait speed can be useful in clinical settings for identifying persons at risk for becoming ADL disabled. Compared with men, women showed a tendency for poorer performance in gait speed and chair stand tests. Even if participants managed to complete the performance tests, the time they needed increased with age. The fact that participants needed more time to perform the tests the older they were also needs to be considered in elderly care. It is important to give older persons the time they need to dress or move instead of helping them to do things faster.

Inability to perform the chair stand test was also associated with ADL disability, but it only increased the risk of death for men. There was no association between grip strength and ADL disability, while weaker grip strength increased the risk of death for men. In previous studies these performance tests have also been associated with ADL disability and mortality (37, 42-45). No association was found between ADL disability and malnutrition (MNA) or lung capacity (PEF). This thesis examined the association between ADL disability and different performance tests, but perhaps the results would have been different if it had followed the subjects to see who developed ADL disability over time. Loss of muscle mass in old age causes ADL disability in older adults. For this reason, performance tests measuring upper and lower muscle strength can be useful in identifying persons who are losing muscle strength. Moreover, maintaining muscle strength decreases the risk for falls in older adults (69).

Being physically active earlier in life and/or during the past 12 months prior to baseline examination were, in the age group 78-81 years, associated with being non-ADL disabled at the follow-ups, with aOR 2.9 (1.3-6.2) for the last 12 month and aOR 6.2 (1.3-29.3) for earlier in life (Study IV). Other studies have also found that being physically active in old age reduces the risk for becoming ADL disabled (68, 70-72). Few studies have examined the association between physical activity earlier in life (midlife) and being ADL disabled in old age. Physical activity in midlife may also reduce the risk for dementia (68), which is also a risk factor for being ADL disabled (51, 52). Being physically active also improves balance and muscle strength (123) and may also be a protective factor for other health problems, e.g., hypertension (124). The elderly care today is mainly focused on helping older adults with ADL and IADL, even though modern care should take a rehabilitative approach and also work with health promotion. In Sweden today, the municipalities are also responsible for rehabilitation, health care and health promotion in the elderly care. It would seem to be a good idea for elderly care, to a greater extent than it does today, to encourage and support older adults by giving them opportunities to engage in physical activities.

6.5 FORMAL AND INFORMAL CARE

Being ADL disabled is associated with low quality of life (115, 116), but being an informal caregiver is also associated with a great burden, and such caregivers need support from the elderly care system to find coping strategies for managing their situation (84). Study IV found that the amount of care, formal and informal, increased with the number of ADL activities the persons needed help with, and the differences between the ADL groups were significant ($p < 0.05$). The mean number of hours per month for the study population of both ADL-disabled and non-disabled older adults living at home was 15.7 for informal care and 4.6 for formal care. Informal care mainly consisted of help with IADL activities. Other studies have also found that ADL ability is strongly associated with the amount of informal and formal care (80, 82). A Swedish study reported that informal care was a substitute for rather than a compliment to formal care (83). Study IV of this thesis also supports this result, as well as showing that having a wife or husband at home who can help with the care seems to be important for being able to live at home longer. Of those 34 older adults with ADL disability in 0-5 activities who had moved to residential care between baseline and the follow-ups, 30 persons were living alone at home before they moved. The other four persons were living together with their wife and were dependent on receiving help with 4 or 5 ADL activities. As informal caregivers seems to be important for living at home in old age is it also important to give the informal caregivers support so they can provide the care. Providing help often lead to frustration, resignation, and negative health effects (chronic stress, depression) for the informal caregiver (84, 86). A review study of the effect of caregiver support reported that respite care can reduce depression and stress and that group support and technology-based interventions can reduce the caregiver burden, depression and also improve the caregivers coping ability (85). Due to the decline in publicly funded home care in Sweden in the past decades and the increased informal care (78) there is a need to follow the time trend of formal and informal care so that the appropriate efforts can be taken when required.

6.6 METHODOLOGICAL CONSIDERATIONS

The strength of the studies included in this thesis are that population-based cohorts were used including older persons at home or in residential care, and the results are therefore representative and can be generalized to the entire population in the area. Among the oldest old, the number of participants was small, resulting in insufficient statistical power, but trends could still be presented and the results are based on the whole population. The data were mainly collected through observations and interviews, thus reducing the risk of bias. The data were collected using standardized protocols and the same questions were used in both living area (Stockholm and Nordanstig), and that the studies used validated instruments, e.g., MMSE, Katz index of ADL, RUD. The data collection team members in Nordanstig were almost identical in the NP, the SNAC-N study and the 1st and 2nd follow-ups, thus minimizing reliability problems.

Study I. The results of this study, comparing different living areas (urban vs rural), may be difficult to generalize to other parts of the world, but it shows that different living area can affect disability and morbidity. There were five years between data collection in the urban and rural area, and we cannot ignore the fact that this difference in time could have influenced the results.

Study II. The strength of this study was the use of comprehensive and validated diagnostic procedures for measuring disability and morbidity. Another strength was that the study used standardized protocols and performance tests. To estimate associations between mortality and disability, we also integrated survival with the prevalence data. The response rate in the study was high, and although more women than men refused to participate, we do not believe this has affected the results.

Study III. There was only a small difference in the drop-out rate between the cohorts, but there was a difference in the reasons for dropping out. There was more drop-out caused by death (13%) in NP and fewer refused to participate (6%) than in SNAC-N, because the study population in the NP cohort was selected once. In SNAC-N, the study population was selected continuously; drop-out caused by death was 3% and 25% refused to participate. In the NP population, 3% could not be traced. Those with missing data on education and MMSE did not differ from those who participated in the study regarding age and gender and consisted also both of persons who were disabled and non-disabled in ADL, and thus we do not believe this has affected the results of the study. The limitations of the study may be the relatively small size of the cohorts and the short time between the two studies.

Study IV. The limitation of this study may be the size of the study population. The reason why there were so few people receiving assistance in two or more ADL activities was probably because the majority of people with disability in two or more ADL activities had moved to residential care. The strengths of the study was its longitudinal individual population-based design, which is preferable to cross-sectional designs.

7 CONCLUSIONS

1. Women are more ADL disabled than men, especially in old age, 84 years and older. ADL ability over time seems to decrease in women and to be stable in men. Maybe due to longer survival and higher incidence rate for ADL disability in women.
2. Older men and women in rural area are more ADL disabled than in urban area. Older adults in rural area also have more diseases that have a negative influence on ADL ability. The reason for this may be that men and women in the rural area have an unhealthy lifestyle e.g. fat intake, physical inactivity etc. but also perhaps fewer visits to the healthcare.
3. Cardiovascular and musculoskeletal diseases, cognitive impairment and depression are diseases with high impact on ADL and are also factors that are suitable for prevention.
4. Performance tests as e.g. gait speed can be used to identify persons at risk for death.
5. Being physically active during the lifetime is associated with less ADL disability in old age.
6. The amount of both informal and formal care increased significantly with the number of ADL activities the persons required help with, and it is therefore important both with prevention to postpone the onset of ADL disability and also provide support to the informal caregivers.

8 IMPLICATIONS FOR PRACTICE

This thesis shows an increase in ADL disability due to living longer, but also shows how diseases affect ADL ability. The diseases with the highest impact on ADL were cognitive impairment, cardiovascular and musculoskeletal diseases and depression. The diseases that negatively affect ADL e.g. cardiovascular diseases, hypertension are often due to unhealthy lifestyle, e.g., physical inactivity, obesity, smoking, etc. Being ADL disabled is associated with low quality of life and increased health-related care costs. These results in this thesis indicate the importance of health promotion and prevention of the factors causing ADL disability – prevention that should preferably begin in midlife, to postpone the onset of ADL disability so we can live longer without ADL disability. Being physically active was associated with less ADL disability in old age and it is important that health care professionals encourage persons in midlife to be physically active but also to help older adults which are becoming disabled in ADL with support in order to maintain or improve their ADL ability.

Older adults with ADL disability are dependent on help from another person. The help often comes from a family member (informal care) and as this study shows it is larger than the formal care. Other studies have shown that informal caregivers often have poor quality of life and it is therefore important to provide these caregivers the support they need to have the strength to continue. It is also important to monitor the development of the informal and formal care in order to provide the right interventions early in e.g. time for respite care and recreational activities, education, technical solutions etc.

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122. Nazemi L, Skoog I, Karlsson I et al. Depression, prevalence and some risk factors in elderly nursing homes in Tehran, Iran. *Iran J Public Health* 2013;42:559-569.
123. Gschwind YJ, Kressig RW, Lacroix A et al. A best practice fall prevention exercise program to improve balance, strength / power, and psychosocial health in older adults: Study protocol for a randomized controlled trial. *BMC Geriatr* 2013;13:105.
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11 APPENDIX

List of dissertations from the Aging Research Center and the Stockholm Gerontology Research Center, 1991-2013

1991

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

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)

Lipinski 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 epidemiological study.

Björk Hassing Linda. Episodic memory functioning in nonagenarians. Effects of demographic factors, vitamin status, depression and dementia. (In collaboration with the Department of Psychology, University of Gothenburg, Sweden)
Hillerås Pernilla. Well-being among the very old. A survey on a sample aged 90 years and above. (Licentiate thesis)

1999

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

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

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

2000

Hillerås Pernilla. Well-being among the very old. A survey on a sample aged 90 years and above. (In collaboration with H.M.Quenn 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. The rational use of drugs in a population of very old persons.

2003

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

Yonker EJ. Hormones and Cognition: Testosterone and Visuospatial Ability, Estrogen and Episodic Memory. Stockholm University.

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?

Larsson Kristina. According to Need? Predicting Use of Formal and Informal Care in a Swedish Urban Elderly Population. (Stockholm University)

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

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

2005

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

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.

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

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

2006

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

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

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

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

2007

Batljan Ilija. Demographics and future needs for public long term care and services among the elderly in Sweden. The need for planning.

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

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

Nordberg Gunilla. Formal and informal care in an urban and a rural elderly population. Who? When? What?

Rehnman Jenny. The role of gender in face recognition.

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

2008

Agahi Neda. Leisure in late life. Patterns of participation and relationship with health.

Gavazzeni Joachim. Age differences in arousal, perception of affective pictures, and emotional memory enhancement.

Haider Syed Imran. Socioeconomic differences in drug use among older people. Trends, polypharmacy, quality and new drugs.

Marengoni Alessandra. Prevalence and impact of chronic diseases and multimorbidity in the aging population. A clinical and epidemiological approach.

Meinow Bettina. Capturing health in the elderly population. Complex health problems, mortality, and the allocation of home-help services.

Rovio Suvi. The effect of physical activity and other lifestyle factors on dementia, Alzheimer's disease and structural brain changes.

Xu Weili. Diabetes mellitus and the risk of dementia: a population-based study.

2009

Atti Anna-Rita. The effect of somatic disorders on brain aging and dementia. Findings from population-based studies.

Livner Åsa. Prospective and retrospective memory in normal and pathological aging.

Paillard-Borg Stéphanie. Leisure activities at old age and their influence on dementia development.

Masud Rana AKM. The impact of health promotion on health in old age: results from community-based studies in rural Bangladesh.

Thilers Petra. The association between steroid hormones and cognitive performance in adulthood.

2010

Fors Stephan. Blood on the tracks: life-course perspectives on health inequalities in later life.

Keller Lina. Genetics in Dementia – Impact of sequence variations for families and populations.

2011

Caracciolo Barbara. Cognitive Impairment in the Non-demented Elderly. Occurrence, Risk Factors, Progression.

Rieckmann, Anna. Human aging, dopamine, and cognition. Molecular and functional imaging of executive functions and implicit learning.

Schön Per. Gender Matters. Differences and Change in Disability and Health Among our Oldest Women and Men.

2012

Haasum Ylva. Drug use in institutionalized and home-dwelling elderly persons.

Lovén Johanna. Mechanisms of women's own-gender bias and sex differences in memory for faces.

Mangliasche Francesca. Exploring the role of vitamin E in Alzheimer's disease.

2013

Hooshmand, Babak. The impact of homocysteine and B vitamins on Alzheimer's disease, cognitive performance and structural brain changes.

Rizzuto, Debora. Living longer than expected: protective and risk factors related to human longevity.