Capturing Health in the Elderly Population

Complex Health problems, Mortality, and the Allocation of Home-Help Services

Bettina Meinow

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Stockholm
University

To my parents

Abstract

This thesis investigates health trends among very old people and the allocation of public home-help services. A further aim is to examine methodological issues in mortality analysis. Three data sources are used: (1) The Tierp study of community-dwelling persons (n=421, ages 75+), (2) the SWEOLD nationally representative samples (n=537 in 1992 and n=561 in 2002, ages 77+), and 3) SNAC-K comprised of home-help recipients in a district of Stockholm (n=1108, ages 65+).

Study I suggests that the length of the follow-up period may explain some of the differences found in predictor strength when comparing mortality studies. Predictors that can change rapidly (e.g., health) were found to be strongest for the short term, with a lower average mortality risk for longer follow-ups. Stable variables (e.g., gender) were less affected by length of follow-up.

Studies II and III present a measure of complex health problems based on serious problems in at least two of three health domains. These were diseases/symptoms, mobility, and cognition/communication. Prevalence of complex health problems increased significantly between 1992 and 2002. Older age, female gender, and lower education increased the odds of having complex problems. Complex problems strongly predicted 4-year mortality. Controlled for age, gender, health, and education, mortality decreased by 20% between 1992 and 2002. Men with complex problems accounted for this decrease. Thus, in 2002 the gender difference in mortality risk was almost eliminated among the most vulnerable adults.

Study IV revealed that physical and cognitive limitations, higher age, and living alone were significantly related to home-help allocation, with physical and cognitive limitations dominating. Psychiatric symptoms did not affect the assessment.

The increased prevalence of complex health problems and increased survival among people with complex needs have important implications concerning the need for collaboration among service providers.

Key words: oldest old, health trends, complex health problems, frailty morbidity, mortality, mortality trends, follow-up time, home-help services, predictors, Sweden

Sammanfattning

Avhandlingens syfte är att studera utvecklingen av komplexa hälsoproblem och funktionsnedsättning i den äldre befolkningen. Denna utveckling – liksom sambandet mellan ohälsa och död – är central för planering av sjukvård och äldreomsorg. Syftet är vidare att studera faktorer som är av betydelse för antalet hemhjälpstimmar som beviljas till hjälptagare i den kommunala äldreomsorgen.

Avhandlingen bygger på tre olika datakällor:

1) *Tierp-studien* omfattar 421 slumpmässigt utvalda personer, 75 år och äldre boende i det ordinära bostadsbeståndet i Tierps kommun. Dessa intervjuades och bedömdes 1986 av distriktssköterskor med avseende på hälsa, funktionsförmåga och levnadsförhållanden.

2) *SWEOLD* är en riksrepresentativ studie av levnadsförhållanden bland personer 77 år och äldre. Intervjuer genomfördes 1992 (n=537) och 2002 (n=561) av professionella intervjuare.

3) *SNAC-K* omfattar samtliga personer i en stadsdelsförvaltning i Stockholm (Kungsholmen) som vid 2002 års baseline var beviljade hemtjänst (n=1108). Data omfattar biståndshandläggarnas bedömningar av hälsa, funktionsförmåga, bostads- och sociala förhållanden, samt beviljad hemtjänst.

Tierp studien och SWEOLD har kompletterats med uppgifter om dödsdatum från dödsorsaksregistret.

Studier som analyserar dödsrisker är i allmänhet baserade på en baselineintervju och uppföljning av dödligheten under olika långa tidsperioder. Resultaten skiljer sig ofta mellan studier. Studie I, som baseras på Tierpstudien, analyserade hur sambandet mellan dödlighet och olika hälsoindikatorer och olika sociala faktorer förändrades under en 15-års period. Resultaten visade att faktorer som kan förändras snabbt efter intervjun (t.ex. vissa hälsoindikatorer) hade ett betydligt starkare samband med dödlighet de första 1–2 åren efter intervjun än under de följande åren. Sambandet mellan konstanta faktorer (t.ex. kön) eller mindre snabbt föränderliga faktorer och dödlighet påverkades däremot endast i liten grad av uppföljningstidens längd. Resultaten pekar på att skillnader i uppföljningstidens längd i olika studier kan vara en förklaring bakom de skilda resultaten i litteraturen när det gäller prediktorer för dödlighet.

I Studie II analyserades hur förekomsten av komplexa hälsoproblem – att ha svåra problem inom flera olika hälsoområden – förändrats mellan 1992 och 2002 i två representativa urval av Sveriges befolkning 77 år och äldre.

De hälsoområden som analyserats – sjukdomar och symptom, nedsatt mobilitet samt kognitions- eller kommunikationsproblem – är centrala för individens livskvalitet och förmåga att klara sig själv och speglar behov av olika typer av vård och omsorg. En person bedömdes ha komplexa hälsoproblem när han eller hon hade svåra problem i minst två av dessa tre hälsodimensionerna. Resultaten visade en ökning mellan 1992 och 2002 av såväl andelen personer med svåra problem i en hälsodimension (från 25 % till 31 %) som med komplexa hälsoproblem (från 19 % till 26 %). Ökningen kvarstod efter kontroll för skillnader i urvalens sammansättning vad gäller kön, ålder och utbildning. Högre ålder, kvinnligt kön och lägre utbildning ökade oberoende av varandra sannolikheten att ha svåra problem i ytterligare hälsodimensioner.

Studie III analyserade dödlighet över en 4-års period efter datainsamlingarna 1992 och 2002. Totalt minskade dödsrisken med 20 procent mellan 1992 och 2002, kontrollerat för ålder, kön, hälsa och utbildningsnivå. Komplexa hälsoproblem var starkt relaterade till dödlighet både i 1992 års och i 2002 års undersökning. Framför allt hade dödligheten minskat bland män med komplexa hälsoproblem. Detta har lett till att dödligheten bland de skröpligaste männen har sjunkit till kvinnornas nivå. En tolkning av resultaten från Studie II och III kan vara att den ökade förekomsten av komplexa hälsoproblem bland de allra äldsta i Sverige beror på en ökad överlevnad bland skröpliga äldre.

Ökad överlevnad även bland äldre personer med komplexa hälsoproblem kan ses som ett gott betyg för sjukvården och den svenska välfärdsstaten. En ökad andel mycket gamla personer med sammansatta vårdbehov innebär samtidigt en utmaning för äldreomsorgen och sjukvården – både vad gäller resurser och kunskap. Dessutom ställs ökade krav på samverkan mellan olika vård- och omsorgsgivare.

I den fjärde delstudien, som baseras på SNAC-K data, analyserades olika bestämningsfaktorer för mängden hemhjälp som beviljas i den kommunala äldreomsorgen. Framför allt var det nedsatt förmåga att klara vardagliga aktiviteter (IADL/ADL) och kognitiv nedsättning som påverkade insatsernas omfattning. Mängden hemhjälp ökade med 39 procent för varje ytterligare IADL-nedsättning och med 29 procent för varje ytterligare ADL nedsättning. Personer med lättare kognitiv nedsättning hade 25 procent mer hemhjälp och de med måttlig/svår nedsättning hade 56 procent mer hemhjälp än personer utan kognitiva problem, kontrollerad för fysisk funktionsnedsättning. Förekomsten av psykiska och existentiella problem verkade inte påverka besluten.

Sammanboende hemtjänsttagare fick 28 procent mindre insatser än ensamboende, givet funktionsnedsättningar. Mängden hemhjälp ökade till viss del med högre ålder, vilket kan bero på att åldersvariabeln täcker ytterligare dimensioner av skröplighet som inte fångas av de andra behovsindikatorerna. Kön hade ingen betydelse för hjälpinsatsernas omfattning när hänsyn

togs till behovsindikatorer samt att kvinnor oftare är ensamboende när de är i behov av vård och omsorg. Bostadsförhållanden, regelbunden hjälp av närstående utanför hushållet och egen inkomst var inte relaterade till mängden beviljad hemhjälp. Studie IV pekar på att den kommunala biståndsbedömningen framför allt fokuserar på behovsindikatorer som är relaterade till fysisk och kognitiv funktionsnedsättning. Psykiska och existentiella problem verkar däremot inte påverka antalet beviljade hemtjänsttimmar.

List of original publications

The thesis is based on the following studies referred to in the text by their respective Roman numerals.

I   Meinow, B., Kåreholt, I., Parker, M.G. & Thorslund, M. (2004). The effect of the duration of follow-up in mortality analysis: the temporal pattern of different predictors. *Journal of Gerontology: Social Sciences 59B*(3), *181–189*

II   Meinow, B., Parker, M.G., Kåreholt, I. & Thorslund, M. (2006). Complex health problems in the oldest old in Sweden 1992–2002. *European Journal of Ageing*, *3*(2), 98–106.

III   Meinow, B., Parker, M.G., Thorslund, M. (2008). Complex health problems and mortality in the oldest old in Sweden: Decreased risk for men between 1992 and 2002. SUBMITTED

IV   Meinow, B., Kåreholt, I. & Lagergren M. (2005). According to need? Predicting the amount of municipal home help allocated to elderly recipients in an urban area of Sweden. *Health and Social Care in the Community, 13*(4), 366–377.

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Abbreviations

Databases

CSHA	Canadian Study of Health and Aging
CHS	Cardiovascular Health Study
H–70	The Gerontological and Geriatric Population Studies in Gothenburg
LNU	Swedish Level of Living Survey
SWEOLD	Swedish Panel Study of the Oldest Old
SNAC	Swedish National Study of Ageing and Care
SNAC–K	Swedish National Study of Ageing and Care – Kungsholmen
ULF	The Swedish National Survey of Living Conditions

Health indicators

ADL	Activities of daily living: e.g., bathing/showering, dressing, toileting, moving around or eating
IADL	Instrumental activities of daily living: e.g., house cleaning, grocery shopping, use of public transport, food preparation or doing laundry
SRH	Global self-rated health
MMSE	Minimental state examination
AMI	Acute myocardial infarction

Public authorities

NBHW	National Board of Health and Welfare (Socialstyrelsen)

Statistical terms

OR	Odds Ratio
HR	Hazard Ratio

Contents

1 Introduction

1.1 Mortality trends and population aging

During the twentieth century many societies witnessed enormous progress in regard to aging, reflecting advances in living conditions as well as in medical technology. During the first half of the century life expectancy increased mainly due to reduced infant mortality and mortality at younger ages. In the second half of the century there has been a transition from a pattern of high mortality from infectious diseases to one of lower overall mortality with cardiovascular diseases being the major cause of death. Since World War II, life expectancy has increased largely as a consequence of falling mortality in ages over 65 (National Board of Health and Welfare, 2005; Oeppen & Vaupel, 2002). Specific to many industrialized countries is the progressive aging of the elderly population itself (Statistics Sweden, 2003). Since the 1950s the number of people aged 80 years and older has more than quadrupled.

However, the chances of leading a long life are not evenly distributed throughout the population. In Sweden, as in most countries, women have a higher life expectancy than men. Women born in Sweden today can expect to live almost 83 years, men almost 79 years. At age 65 , women can expect to live almost 21 years longer and men 18 years longer (Statistics Sweden, 2007b).

Life expectancy is in general higher in southern Sweden and lower in the northern part of the country. The difference between the highest and the lowest life expectancies among the 80 largest municipalities is 4.7 years for men and 3.4 years for women (Statistics Sweden, 2007a).

Inequalities in life expectancy have also been shown with respect to socioeconomic status in a number of European countries, including Sweden (Mackenbach et al., 1997; Statistics Sweden, 2004). The relationship has been found to persist into old age (Huisman et al., 2004; Huisman et al., 2005; Kåreholt, 2000; Lundberg & Kåreholt, 1996).

Countries with a high proportion of elderly people and high life expectancy may be seen as precursors of population aging. In 2006 Sweden had one of the world's oldest populations with 5.5 percent of the population (482,000) 80 years or older (Statistics Sweden, 2007b). About 17 percent (more than 1.5 million people) of the population were 65 years and older.

1.2 Emergence of a third and fourth age

In regard to functional capacity and independence on the population level researchers often distinguish between different stages in the life cycle. The *first age* refers to an era of dependence, socialization, immaturity and education in childhood and teenage years. The *second age* stands for a time of independence, maturity, responsibility, and earning.

When the Swedish retirement system was begun in 1913, life expectancy was around 10 years below the retirement age of 67 years. Most people either died before retirement or were worn out and faced poor health and functional impairment after retiring. Since then, average life expectancy has increased while actual retirement age in many developed countries has fallen even lower than the official one, often 65 years. The average exit age from the labor force in 2004 was, for example, 62.8 years in Sweden, 58.8 in France and 61.3 in Germany (Eurostat, 2007).

From the perspective of health states and needs of care, on the population level, two stages, referred to as the *third age* and *fourth age,* have emerged (Laslett, 1987, 1996). The third age refers to a period after retirement when the individual's chances of leading an active life are not seriously curtailed by ill health or disability, and at the same time the person is in a secure financial position (Laslett, 1987, 1996). According to the British sociologist Peter Laslett, an important precondition for the emergence of a third age was the increase of the average life expectancy several years beyond retirement age, the development of a pension system that permitted people supporting oneself after retirement, and a well-developed healthcare system. This historically new phenomenon occurred around the 1950s in Great Britain and other developed countries but is still absent in many less-developed nations.

The *fourth age* is characterized by poor health and impaired functional abilities in the final stage of life, when individuals are no longer able to manage on their own. While the third age is a time of personal fulfillment, also referred to as the gerontological good news, the fourth age, characterized by dependency, decrepitude, and death, has been called the gerontological bad news (Baltes & Smith, 2003). In planning healthcare and eldercare there is a substantial difference between people who for age reasons have left their occupations but who can live independently, i.e., they experience the third age, and people who are dependent on the help of others for their daily living and are in the fourth age.

Obviously, the division into a third and fourth age is a gross simplification. It is related to but not dependent upon chronological age. People enter the fourth age at different chronological ages, some die suddenly without going through a fourth age, and some never experience a third age when fatal diseases or functional limitations start in younger ages. However, a common way to roughly capture these concepts on the population level is to divide the older population into age classes that describe them as *young old*

(often 65–79) and *oldest old* (80 and above). In this study, from the perspective of planning for healthcare and eldercare, focus is on health trends of the oldest old.

1.3 More years of health or ill health?

Substantially increased survival among the older population during the twentieth century is undoubtedly an indication of the success of social policies and has become a symbol for economic prosperity and improvements in living conditions. Of course, the significant decrease of mortality in the older population does not qualify as an indicator of health among the living (Fritzell & Lundberg, 2007).

For the individuals and their families there are health problems that cause much pain and suffering and reduce the ability to lead an independent life. From a social policy perspective, increasing proportions and numbers of elderly people in the population have raised the question of how this affects needs for healthcare and long-term care. Projections made by the European Union's Economic Policy Committee (European Commission, 2006) demonstrated that future spending on healthcare and long-term care is very sensitive to assumptions of health status. As the prevalence of ill health increases sharply with age (Akner, 2004b; Larsson & Thorslund, 2006; Statistics Sweden, 2006), this applies particularly for people aged 80 years and over, the fastest growing sector of the population in most European countries. Thus, studies on health trends among the oldest old are of particular interest when estimating future resource needs for healthcare and long-term care.

The issue whether the years 'added' to life are characterized by good health and independence, or by health problems and care needs has been a controversial question for several decades. In other words: Is it the third or the fourth age that has expanded? Figure 1 illustrates several hypotheses that have evolved to describe the dynamics of health changes in the oldest sectors of the population and the interplay of mortality and morbidity patterns with demographic change (Myers, Lamb, & Agree, 2003).
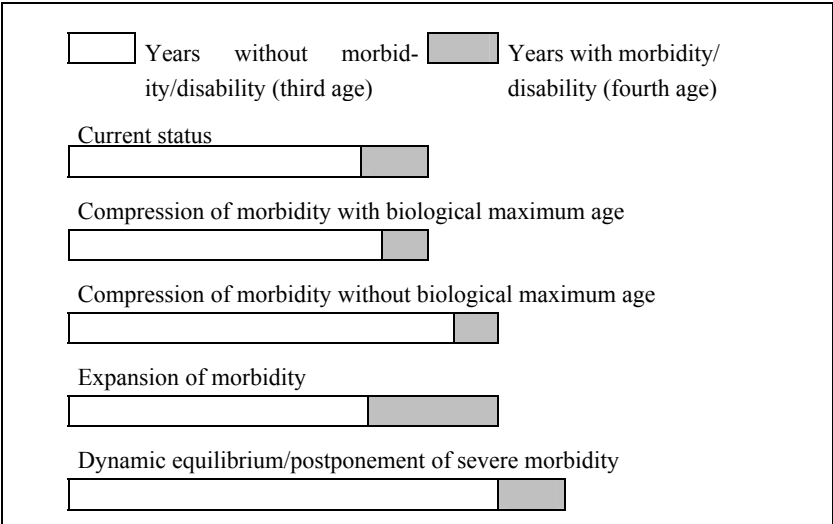
Figure 1. Hypotheses about the relation of mortality and morbidity/disability

Compression of morbidity
The compression of morbidity hypothesis maintains that improved living conditions, healthier ways of life, and progress in medical treatment cause the onset of chronic diseases and disability to be postponed to increasingly higher ages (Fries, 1980, 1983, 1986). In the original version it was assumed that humankind has a genetically determined albeit individually variable, biological maximum age. Morbidity then would be "compressed" into the last years of life before the fixed time of death.

Since mean life expectancy is increasing even in low-mortality countries (Oeppen & Vaupel, 2002; White, 2002), in a refined version of the compression of morbidity hypothesis it is assumed that if declines in morbidity are greater than increases in life expectancy, the overall period of morbidity in the population will decrease (Fries, 2003).

Accordingly, as the numbers of old people in the population increase, the need for care resources may not increase proportionately (Batljan & Lagergren, 2004). Nonetheless, even the most optimistic prognoses foresee an absolute increase in resource needs because of an increase in the proportion of the oldest old in most low-mortality countries.

Expansion of morbidity
The expansion of morbidity hypothesis is a directly opposed hypothesis (Gruenberg, 1977; Olshansky et al., 1991). It argues that medical advancements result in a higher proportion of people surviving with their health problems to an advanced age. In its pure form, the hypothesis assumes that disease-free/disability-free life expectancy remains unchanged despite in-

creased life expectancy. What increases, instead, is the number of years of ill health. This reflects the medical paradox implying that more saved lives eventually presents the healthcare services with more health problems.

Dynamic equilibrium – Postponement of severe morbidity
A third alternative scenario is the dynamic equilibrium (Manton, 1982; Manton, Stallard, & Corder, 1995), also referred to as postponement of severe morbidity. The dynamic equilibrium maintains that longer survival is associated with an increase in total morbidity. However, medical interventions and improved lifestyles will slow the progression of chronic disease. As a result time spent with severe morbidity and disability remains approximately constant when life expectancy increases (Manton, 1982).

Towards a general theory on population aging
Robine and Michel (2004) reconcile the hypotheses of compression, expansion, and postponement of morbidity and present a wider conceptual framework regarding the relation of mortality and morbidity among the older populations.

They recognized that health expectancies (e.g., disease-free life expectancy or disability-free life expectancy) are not evolving in parallel with life expectancy. The diverging national patterns in morbidity trends during the past decades were supposed to depend on specific geographic, cultural, socioeconomic, and medical contexts. Different countries are found to be at different positions of demographic and epidemiological development. This involves a transition from a pattern of high mortality and fertility, with infectious diseases as the main cause of death, to a pattern of low mortality and fertility with predominantly degenerative or aging-related causes of death. Robine and Michel (2004) identified four factors that influence health trends in the elderly population:

a) After an initial decrease in infant mortality, the improvement of living conditions and healthcare services that occurred in low-mortality countries after World War II eventually contributed to a reduction of the mortality of older people. Subsequent expansion of morbidity is explained by the initial increase in the survival rates of sick persons in the population.

b) Gradually, better control of the progression of chronic diseases leads to a subtle equilibrium between the fall of mortality and the increases in disability.

c) As new cohorts experiencing better living conditions such as higher educational levels and better health practices (Allaire et al., 1999; Costa, 2002) enter into old age, compression of morbidity is observed.

d) Decrease in mortality and improved living conditions and medical services eventually result in the emergence of very old populations with multiple chronic conditions.

Because change in these factors is variable, health trends in elderly populations will vary, both between countries and over time within countries.

1.4 Implications for care needs

Researchers have been able to provide evidence supporting each of the above-named hypotheses. Beyond differences in morbidity patterns between countries at different positions in demographic and epidemiological development (Robine & Michel, 2004), it has been pointed out that the choice of health indicator and differences in methodology probably explain a substantial part of the diversity in health trends (Gudex & Lafortune, 2000; Thorslund & Parker, 2005).

Most research in medicine, epidemiology, sociology, and social services has focused on specific conditions, studied one at a time. Since more and more people survive to advanced ages, in recent years it has been noticed that health problems often are interrelated and exist simultaneously in late life (Canadian Study of Health and Aging Working Group, 2001; Marengoni, 2008; Myers et al., 2003). Because of higher rates of comorbid conditions among elderly people and the interaction of diseases with the aging process, indicators that reflect the cumulative effects of morbidity are more revealing when it comes to describing health in the elderly population (Manton, 1990a).

Most people who live to an advanced age can expect a slow decline in health with progressive disability, dependency on others in daily life and a need for healthcare and social services before dying (Baltes & Smith, 2003; Covinsky et al., 2003; Ernsth Bravell, 2007; Lunney et al., 2003). Lunney et al. (2002) classified care trajectories prior to death among U.S. Medicare beneficiaries between 1993 and 1998 and concluded that sudden deaths were uncommon. Nearly half of the descendents showed a pattern of sustained, multiple functional declines accompanied by extensive medical care before death.

A Norwegian study analyzing trajectories concerning physical function, cognition, and care utilization also found that few people after age 80 died suddenly with few or no disabilities (Romoren & Blekeseaune, 2003). The probability of dying without having spent any time in institutional care was extremely small. Women lost their ability to carry out activities of daily life (ADL), such as dressing themselves or moving around in their homes, on average 3.2 years before they died; for men it was 1.8 years before death.

A study from Great Britain confirmed a clear gender pattern in which women had a longer period at the end of life accompanied by disease and

functional impairments than men had (Brayne et al., 2001). Thus, most people who live to an advanced age, especially women, can expect a period of multiple health problems, dependency on others in daily life, and need for medical and long-term care.

Elderly people with multiple functional declines accompanied by the need for extensive medical care most likely need a mix of services from multiple providers. Trends in the prevalence of and survival with such complex care needs have broad ramifications for resources as well as the organization of the healthcare and eldercare system. Therefore, it is important to follow health indicators over time that cover several dimensions of health and thereby reflect different services needs. This is an important complement to single variables, which may follow different trends over time.

1.5 Goals and resource allocation in eldercare

Care of elderly people is a main focus of public policy in Sweden, and universalism and extensive coverage are official goals (Government Bill, 1997/98:113). Scandinavian healthcare and social services have been characterized by their comprehensive nature, professional workers, and availability to and use by everyone in need irrespective of socioeconomic position (Sipilä, 1997). Despite unchanged official ambitions and legislation since the 1980s, resources in the Swedish eldercare system have not kept up with the demographic development (Szebehely, 1999). Resources have been concentrated to those elderly people with the most extensive care needs, and thresholds to institutions and for the receipt of home-help services have risen. As a result, more very frail persons live at home and need medical and rehabilitative services. At the same time, there have been signs that health in the elderly population has been deteriorating (Parker, Ahacic, & Thorslund, 2005).

As there are no statutory guidelines concerning which elderly persons and which kinds of needs should be prioritized when facing limited public resources, it is essential to identify the factors which influence the allocation of resources in public eldercare today. This is crucial both for the estimation of service needs in the near future and in order to evaluate to what extent resources are allocated in agreement with official policy, which is according to need.

1.6 Aims

As more and more people survive to very old age, health trends among the oldest sectors of the population are of particular interest in planning for the resource needs of healthcare and long-term care. Likewise, in the context of cutbacks in public eldercare, it is important to evaluate factors that guide the allocation of available resources. There were two general aims of this study: One purpose was to investigate mortality and health trends among the oldest old as well as factors related to the receipt of home-help services in Sweden during the 1990s and beginning of the 2000s. As studies have revealed diverging results in mortality and health trends, a second aim was to investigate how different methodological decisions may affect results.

More specifically, the objectives were as follows:

1. To present a model of the mechanisms affecting the predictive strength of different variables over time in mortality analyses. Does the length of follow-up matter (Study I)?
2. To introduce a measure of complex health problems covering several health-related domains that are essential for the individual in maintaining independent living and relevant for the planning and provision of adequate care and social services (Study II).
3. To describe changes in prevalence rates of complex health problems between 1992 and 2002 (Study II).
4. To investigate change between 1992 and 2002 in the relation of complex health problems and mortality risk among the oldest old. Are there different trends in the association of complex health problems and mortality for different subgroups of the older population (Study III)?
5. To investigate factors influencing the allocation of home help services (Study IV).

2 Background

2.1 Health trends in the elderly population

Mortality rates are relatively easy to measure and follow over long periods of time in most countries with census data. Morbidity, on the other hand, is a vague concept that covers several dimensions which can be measured in various ways (Parker & Thorslund, 2007). Using primarily single health indicators, researchers have been able to provide evidence supporting each of the hypotheses described in 1.3.

Beyond differences across indicators, age groups, and time periods, the picture of health trends is also complicated by different patterns for different subgroups of the elderly population. Older women generally report more ill health and disabilities than men of the same age, but results are ambiguous and tend to vary across health indicators and age groups (Freedman, Martin, & Schoeni, 2002; Lahelma et al., 1999; Schön & Parker, 2008; von Strauss et al., 2003).

Individuals with lower socioeconomic status are also more likely to experience ill health and disability in later life (Fors, Lennartsson, & Lundberg, 2007; Huisman, Kunst, & Mackenbach, 2003; Mackenbach et al., 1997). One Swedish study among people aged 65 to 84 years reported an increased health gap between people having different educational levels in two periods, 1975/79 and 1995/99 (Batljan, 2007). Another study of people aged 55 years and older found no change in social class inequalities in health between 1992 and 2002 (Fors et al., 2007).

2.1.1 Positive trends between the 1970s and early 1990s

Empirical studies up to the beginning of the 1990s revealed a predominantly positive development in health status among elderly people in Sweden, as well as in other low-mortality countries. Primarily based on trends among the young old they gave support to the compression (Cutler, 2001; Robine, Mormiche, & Sermet, 1998) or postponement (Lagergren & Batljan, 2000; Manton, Corder, & Stallard, 1997) of morbidity hypotheses.

One of the first longitudinal studies that included a representative sample of elderly people was the Gerontological and Geriatric Population Study in Gothenburg (H-70) (Steen & Djurfeldt, 1993; Svanborg, 1977). It showed improvements in several health indicators, such as self-assessed health, physical function, and symptoms among three subsequent cohorts of 70-year- old people between 1971 and 1981 (Steen, 2002; Wilhelmson, Allebeck, & Steen, 2002).

The nationwide Swedish Level of Living Survey (ULF) also revealed improvements in several health components during the 1980s and early 1990s among people aged 65 to 84 years (e.g., in physical function, disability, self-reported health, mobility, and vision) (Persson et al., 2001).

Many studies have equated morbidity with disability or physical function, measures that are closely related to the need for social services and long-term care. Studies typically use some form of primary activities of daily living (ADLs; e.g., ability to dress, use the toilet, bathe, eat) and secondary instrumental ADLs (IADLs, e.g., ability to clean the house, prepare food, shop for groceries) or physical function (e.g., walking, climbing, running). The general trend during the 1980s and into the early 1990s points towards improvements in disability and physical function in Sweden (Ahacic, Parker, & Thorslund, 2000, 2003; Rosén & Haglund, 2005) and, for example the U.S. (Crimmins, 2004; Freedman et al., 2002; Manton & Gu, 2001), Finland (Malmberg et al., 2002), and Austria (Doblhammer & Kytir, 2001).

Studies included different age groups and often had an age ceiling or high nonresponse among the very old. This leads probably to an underestimation of the prevalence of health problems in the total older population and hampers reliable conclusions about health trends among the oldest old.

2.1.2 Conflicting trends since the 1990s

Studies of health trends since the 1990s, more often including the oldest old, have revealed divergent and even conflicting results. In spite of differences in methodology, trends can be traced along a number of health dimensions.

Specific diseases and symptoms
With respect to specific diseases and symptoms, recent trend studies generally point towards a worsening. Studies showed increased prevalence of symptoms and diseases since the late 1980s, e.g., in the U.S. (Crimmins, 2004; Crimmins & Saito, 2000; Freedman & Martin, 2000), France (Robine et al., 1998), Australia (Wen, 2004), the U.K (Jagger et al., 2007) and Sweden (Parker et al., 2005; Parker, Schön, & Thorslund, 2006; Rosén & Haglund, 2005). According to the Swedish ULF survey (ages 65–84), the prevalence of diabetes, heart disease, and hypertension increased by more than 20 percent among men but only 5–11 percent among women between 1988–1994 and 1995–2002 (Rosén & Haglund, 2005). With regard to the

oldest old (ages 77+), the Swedish Panel Study of the Oldest Old (SWEOLD) reported that both men and women accounted for an increase in fatigue, pain, and hearing between 1992 and 2002. Leg ulcers, hypertension and depression only increased among women, whereas myocardial infarction only increased among men (Schön & Parker, 2008).

Disability
Studies using disability measures, most often ADLs, tended towards improvement or little change during the 1990s (Aijanseppa et al., 2005; Bronnum-Hansen, 2005; Cutler, 2001; Freedman et al., 2004; Freedman et al., 2002; Jacobzone, 2000; Jagger et al., 2007; Manton, Stallard, & Corder, 1998; Martin et al., 2007; Parker et al., 2005; Schoeni, Freedman, & Wallace, 2001). It has been suggested that improvement in IADLs accounted for most of the improvement in disability measures (Spillman, 2004). A review of eight Organization for Economic Co-operation and Development countries (OECD) found gender differences in trends in some countries, with men showing improved ADL while women showed either less improvement or increases in disability (Jacobzone, 2000).

Functional limitations
In regard to physical functional limitations studies revealed mixed trends, e.g., a decline in prevalence of lower body limitations but no change for upper body limitations (Freedman & Martin, 2000). Mobility has been found to remain unchanged in the U.S. between 1984 and 1999 (Spillman, 2004), to slightly improve in Finland during the 1990s among persons up to the age of 84 (Pitkala et al., 2001; Sulander, Rahkonen, & Uutela, 2003) and in Sweden among people aged 65 to 84 (Persson et al., 2001). A study among Swedes aged 77 years and older found a worsening in self-reported mobility and a peak-flow test between 1992 and 2002 only among women. Both women and men accounted for worsening in tests of cognition and physical capacity (Schön & Parker, 2008).

Global self-rated health
Studies investigating global self-ratings of health also reveal an ambiguous picture. There are improvements in Austria for respondents aged 60 to 84 between 1978 and 1998 (Doblhammer & Kytir, 2001) and in the U.S. for people aged 70 years and older between 1982 and 2003 (Martin et al., 2007) and those above the age of 75 between 1993 and 2001 (Zack et al., 2004). However, no improvement occurred among the oldest old above the age of 80 (Martin et al., 2007) or 85 years (Doblhammer & Kytir, 2001).

Despite women's higher levels of morbidity, the gender difference in self-reported global health appears to be modest (Arber & Cooper, 1999; Martin et al., 2007). A recent Swedish study based on SWEOLD found that despite the fact that women showed a worsening in more areas of health than men

between 1992 and 2002, their assessment of self-rated health remained stable. Men, on the other hand, assessed their self-rated health worse in 2002, thereby further narrowing the gender gap (Schön & Parker, 2008).

Compression of disability and expansion of other health problems
Apparently, different health dimensions are moving in different directions simultaneously. Beyond methodological differences the general tendency seems to be that older sectors of the population report more diseases and health problems while these have become less closely linked to disability during the 1990s (Crimmins, 2004; Jagger et al., 2007; Parker et al., 2005; Rosén & Haglund, 2005; Spillman, 2004; Waidmann & Liu, 2000). Thus, an expansion of other health problems may evolve in parallel with a compression of disability (Cutler, 2003; Parker & Thorslund, 2007).

There seems not to be any absolute correlation between the increased prevalence of long-term illness and how older people themselves experience their health problems. A Danish study of people above the age of 65 showed that disability-free life expectancy and expected lifetime in self-rated good health increased between 1987 and 2000 while life expectancy without longstanding illness decreased during the same period (Bronnum-Hansen, 2005). A Swedish longitudinal study of persons aged 86–94 (NONA Study) found a decline in objective health indicators whereas the subjective perceived health remained stable during the four-year follow-up (Ernsth Bravell, 2007).

2.2 Methodological challenges of health trend studies

Beyond diverging health trends across indicators several additional methodological differences complicate comparisons between studies. Prevalence rates may differ between studies due to the methods used when measuring health (e.g., types of data, representativeness of samples, time periods, statistical methods) and differences in health-related conditions between countries. Studies re-examining datasets using different methods found that relatively small changes can influence results (Freedman et al., 2004; Freedman et al., 2002; Gudex & Lafortune, 2000; Wolf, Hunt, & Knickman, 2005). *Changes* in morbidity rates over time may arise due to actual change or change in reporting.

2.2.1 Methodological factors affecting morbidity rates

Types of data: Self-reports, medical records, performance tests
There is no consensus about how to best measure health and function in population surveys. Different types of data encompass different characteristics that have to be deliberated in regard to the specific aim of the study.

Self-reports of disability, functional limitations, and symptoms always encompass subjectivity in terms of individual interpretations and expectations and may reflect a myriad of underlying causes. Global self-rated health, for example, may measure different dimensions across individuals (Idler, Hudson, & Leventhal, 1999). However, its reliable relationship to mortality and its easy administration make it a commonly used health indicator (Idler & Benyamini, 1997; Lundberg & Manderbacka, 1996).

Disability is constructed through a combination of personal and contextual factors (Schneidert et al., 2003), including both characteristics of the physical environment (housing standards, assistive technology, accessibility of buildings and public transportation, microwave ovens) as well as the social context (social policy, gender roles). Thus, an individual may be classified as disabled in one context but not in another.

Self-reports of diagnoses require that the respondent be diagnosed, that he/she (or a proxy) remember the diagnosis, and that it be reported during the interview. A study of elderly disabled women found good agreement between self-reported and medical records (Simpson et al., 2004).

Performance tests and information from *medical records* may be less susceptible to individual interpretations, expectations, and environmental factors. Yet, the main disadvantage of performance tests is that they can only be used in direct interviews, thus excluding the most impaired individuals in a population (Rockwood, Jones et al., 2007). Health trends based on performance tests probably underestimate health problems in older populations.

Even medical records may deviate from "true" health status in an older population. Documented diagnoses need the respondent to be aware of a health problem, to seek medical care, and to be diagnosed. People may be motivated to different degrees to seek professional help. Little is known about people who seldom seek medical care and are therefore less likely to be diagnosed. Moreover, the point in time of incidence may be vague as health problems may develop gradually and have existed some time before diagnosis.

In general, there is a trade-off between the ambition to collect as valid information about health status as possible and the inability of the most vulnerable subgroup of the elderly population to perform tests or respond to questionnaires. In these cases researchers have the choice between nonresponse and the inclusion of proxy information. The reliability of proxy data has been found to differ with respect to the setting and measures used (Todorov & Kirchner, 2000). Best agreement between self-reports and proxy information has been found for general settings (Medical Research Council Cognitive Function and Ageing Study, 2000) and overall instrumental function (Magaziner et al., 1997).

Representativeness of samples

Conflicting results may also arise when selected groups are excluded from studies, either by sample design or selective nonresponse. This leads to underestimations of health problems in the total older population. Studies often exclude persons who are too sick to participate in an interview or those who are institutionalized and/or cognitively impaired (Brayne et al., 2001; Fried et al., 2001). Even if the institutionalized population is small, its inclusion is important as thresholds for access to institutions may change over time in response to changes in policy and resource allocation, thereby affecting prevalence rates of health problems among those living in the community. An age ceiling is also likely to lead to underestimations of health problems in the entire older population. There may also be different trends in health variables for the young and the old old (Martin et al., 2007).

Patterns of nonresponse probably differ between studies as a result of fieldwork practices. In general, non response is likely to be higher among individuals with more health problems and thereby, on average, with higher age. Patterns may also change with cohort or period changes in willingness to participate in surveys. During the past decades, there has been an increase in nonresponse rates in some studies with repeated survey waves (Thorslund et al., 2004). The effect of this is controversial. One study based on the Swedish ULF survey claimed that the effect of nonresponse on health was negligible (Johansson et al., 2006). Another study traced the health of non-responders using mortality and sickness registers and concluded that nonresponse leads to an underestimation of problems in the elderly population (Lagergren, 2004).

Study periods

Comparisons between studies are also complicated by the fact that they most often do not explore exactly the same time periods. General trends may be blurred as few studies with morbidity measures stretch over more than a decade, particularly for the older sectors of the population (Lafortune, Balestat, & Disability Study Expert Group Members, 2007). In addition, when only comparing two time points, variations in patterns within parts of the entire time period may be hidden.

For example, at first glance, the findings of two Swedish studies analyzing morbidity rates seemed to conflict. A study of Swedes aged 77 and older found significant worsening in a number of health indicators between 1992 and 2002 (Parker et al., 2005). Comparing 1980 to 2005, findings based on the ULF survey, on the other hand, showed improvement for most function variables. However, most of this improvement occurred during the 1980s and early 1990s. Any improvement after the mid-1990s was negligible, and some indicators, in particular ADL, showed signs of worsening (Parker et al., 2008).

Statistical methods

Statistical methods used to analyze health indicators in population surveys may also account for differences in results. For example, health trends in older populations are of interest both in absolute terms as well as relative to distributions in gender and age. From an epidemiological perspective, it is of interest to what extent changes in morbidity rates are due to actual health change rather than compositional changes within the elderly population. Studies taking this perspective control for changes in, e.g., gender, age and educational composition. From an administrative perspective, nationally representative estimations of raw prevalence rates provide key information for delivering and planning appropriate healthcare and social services.

Studies analyzing health problems as risk factors for negative outcomes (e.g., mortality) also find different predictor strength depending on how time since the baseline interview is handled. Results may differ depending on whether it is only considered *if* an individual dies during follow-up (e.g., in logistic regressions) or if it is also considered *when* deaths occur during follow-up (hazard regressions). The length of follow-up time may also affect the strength of predictors for negative outcomes (Ljungquist, Berg, & Steen, 1996).

2.2.2 Factors affecting change in morbidity rates over time

Health trend studies capture change in both actual health and other factors related to health, such as environmental modifications, changes in social roles, social policy, and reporting.

Actual changes in the prevalence rates of health problems may be a result of changes in morbidity incidence and/or changes in survival despite morbidity (Jagger et al., 2007). Increased prevalence rates of a number of symptoms and diseases have been attributed to the fact that older people survive longer with disease, and that the reduction in incidence is not sufficient to counter the effect of increased survival (Crimmins, 2004; Rosén & Haglund, 2005). For example, in Sweden the incidence of myocardial infarction declined by about 20 percent between 1987 and 2001, but mortality sank even more. The risk of suffering a stroke has been relatively unchanged since the 1990s while mortality slightly decreased. Better treatment methods have meant that those who now contract these diseases are surviving to a larger extent than formerly (Rosén, 2006). Improved visual ability is another example of change in morbidity rates due to improved treatment (Larsson & Thorslund, 2006). In Sweden, the number of performed cataract operations increased from 30,000 to 82,000 between 1982 and 2002 (Swedish association of local authorities and regions, 2005).

With respect to cognition there is a lack of evidence concerning changes in incidence of dementia over time. Some increases in prevalence rates may

be ascribed to increased survival among persons with dementia, especially in less developed countries (Wimo et al., 2003; von Strauss et al., 1999) or to learning effects (Rodgers, Ofstedal, & Herzog, 2003).

Decrease in disability may reflect environmental improvements that allow for greater independence despite impairment (Spillman, 2004). Better accessibility to public transport, housing adaptations, microwave ovens, and pre-prepared meals make it easier to maintain independence in IADLs.

Morbidity rates may also change due to changes in reporting despite unchanged underlying prevalence. Increased reporting can be a result of greater awareness of a problem (Myers et al., 2003), better diagnoses, or that it has become more socially acceptable to report some symptoms or diseases, (e.g., mental health problems or incontinence). The increase of depression among Swedes aged 77 years and older during the 1990s may, for example, be partly due to underreporting in the earlier data collection (Parker et al., 2005). Changing expectations concerning health among elderly populations may also contribute to changing prevalence rates in morbidity. On the one hand, self-rated health, for example, has been reported to improve with age (Jylhä et al., 2001). On the other hand, more recent cohorts of elderly people may expect to be healthy up to a higher age than former cohorts and therefore more likely to report more health problems.

2.2.3 Country specific factors affecting morbidity rates

Prevalence rates of health problems not only depend on indicators and methods used but are also affected by country-specific conditions. Robine and Michel (2004) suggested that health trends may depend on the demographic/epidemiological phase currently being experienced by the studied population. They compared time series of both life expectancy and disability-free life expectancy for different countries and found that the *initial* levels of mortality and morbidity, pinpointing a countries position in the transition stage, may be of importance in determining if a decrease of mortality is followed by a decrease or increase in morbidity. Expansion of disability was found to go with the highest life expectancy and compression of morbidity with the lowest.

Smoking rates, alcohol consumption, nutrition, physical activity and access to medical care are other country-specific factors affecting patterns of old-age mortality (Janssen, Mackenbach, & Kunst, 2004). The same factors influence old-age morbidity. A comparison of ten European countries suggested that the dynamics of physical functioning may differ across cultures. Comparing 1988–91 and 1999–2001, mobility disability among men and self-care disability among women were found to decrease more in southern countries than in northern countries (Aijanseppa et al., 2005).

2.3 Multidimensional health problems

In the epidemiologic tradition, most studies of health problems among older adults have focused on specific conditions, studied one at a time. In late life, however, health problems often exist simultaneously and are interrelated (Fillenbaum et al., 2000). Cognitive problems, for example, are associated with physical health problems and disability (Canadian Study of Health and Aging Working Group, 2001; Fratiglioni & von Strauss, 2006). Comorbidity has also been found to heighten the risk of disability (Fuchs et al., 1998; Laukkanen et al., 1997; Marengoni et al., 2004) and mortality, over and above the risk of individual diseases (Fillenbaum et al., 2000; Fried et al., 1999; Verbrugge, Lepkowski, & Imanaka, 1989).

People experiencing multidimensional health problems involve challenges from a clinical as well as social policy perspective. At a clinical level, it is more demanding to treat a patient who has multiple, interacting health problems than one who has a single health problem. On a population basis, people with multidimensional health problems represent a challenge to coordination and collaboration between different providers of medical care and social services (Boyd et al., 2007; Ferrucci et al., 2004; Fried, 2003).

Although attention to complex health profiles has been increasing during the last decade, there is no consensus about how to capture this complexity and empirically identify the weakest and most vulnerable subset of the older population. Studies have often implicitly used the concepts of frailty, disability and comorbidity/multimorbidity interchangeably. Although there is a broad overlap, these comprise distinct concepts (Fried et al., 2004). Comorbidity/multimorbidity entails the simultaneous presence of two or more diseases (Fillenbaum et al., 2000). Disability generally refers to difficulties or dependency in carrying out tasks, often measured by self-reported impairments in IADLs and ADLs.

People having serious problems in several health domains (e.g., diseases, physical and cognitive function, disability) most probably have complex care needs involving different providers of medical and social services. Neither measures of multimorbidity nor measures of disability provide sufficient information about the mix of services needed. People experiencing multimorbidity may live relatively unaffected with effective medication. Disabled people may only need help with practical tasks or face more complex health problems, including medical conditions and cognitive problems. During the last decade increasing attention has been put on the concept of frailty to identify vulnerable older adults (Fried et al., 2001; Hogan, MacKnight, & Bergman, 2003). In the following section different perspectives on frailty are identified and examples of different types of frailty measures are discussed.

2.3.1 The concept of frailty

Although frailty is a commonly used term in research, as well as in clinical, administrative contexts, and everyday speech, there is no standard definition (Bergman et al., 2007). Partly, the ambiguity of the term frailty may stem from the fact that research definitions of frailty do not fully equate to what people working in healthcare, eldercare, and administrative contexts may have in mind when they envision a frail elder (Whitson, Purser, & Cohen, 2007). However, even within the research context frailty has been called "a syndrome in desperate need of description and analysis" (Gillick, 2001). Although now general agreement has established that frailty refers to a multifactorial state brought about by accumulated conditions and age-related processes, conceptualizations vary with researchers' perspectives and aims.

Researchers interested in the biological aging process primarily investigate the etiology of frailty as a physiologic vulnerability to stressors, with reduced ability to maintain or regain homeostasis after a destabilizing event (Walston et al., 2006). This may be compared to the straw that broke the camel's back, meaning low reserve capacity and the body's decreased ability to manage complex physiologic stress (Lipsitz, 2002).

The clinical approach to frailty as a medical syndrome intends primarily to identify persons at risk for negative outcomes (death, disability, institutionalization) and who might benefit from interventions (Fried et al., 2001; Hogan et al., 2003). Researchers aim to determine a state of physical vulnerability *before* devastating functional loss, comprising persons *at risk* for functional decline. This has important implications for the development of preventive measures and new treatment modalities in order to improve health and well-being for the most vulnerable older adults (Whitson, Purser et al., 2007). In recent years, there have been repeated attempts to harmonize conceptualizations of frailty from the clinical perspective (Ferrucci et al., 2004; Walston et al., 2006). Variations in definitions concern predominantly the question how to operationalize the theoretical concept, i.e. how to measure frailty with a few items.

As compared to the biological and clinical definition of frailty involving a state of purely physiologic vulnerability, a broader and more traditional notion of frailty takes into account functional limitations and external factors such as environment and social support (Fisher, 2005; Fried et al., 2004; Rockwood, 2005a, 2005b). This broader approach can be useful from a social policy perspective focusing on those elderly people who *are already* severely functionally limited or disabled. From this perspective, the objectives are not primarily to find effective preventive measures and interventions. Instead, focus is on the challenge for the medical care and eldercare system to provide care for individuals experiencing physical vulnerability in combination with severe functional losses and/or poor psychosocial support. Representative population-based prevalence rates of frailty in this broader

sense are relevant both with regard to resource allocation to medical and social services as well as to organization of services.

2.3.2 Empirical frailty measures

As described above, the concept of frailty is used in a spectrum that reaches from pure physiologic vulnerability with relatively preserved function to a broader notion of multidimensional vulnerability that includes more severe functional compromise and also reflects the cumulative effect of disease-related, psychosocial, and environmental challenges (Whitson, Purser et al., 2007). The ambiguity of frailty definitions complicates a review of the growing body of literature. On the one hand, there are studies that aim to investigate frailty but actually limit their operationalization to measures of disability (e.g., ADL). On the other hand, some studies do not even mention the word frailty but deal with multidimensional health problems that would fit in a broader definition of frailty as described above.

Both kinds of studies are included in the following presentation of frailty measures, summarized in Table 1. Frailty is used here as a general term including physiologic vulnerability with or without functional compromise and psychosocial and environmental issues. Table 1 is not a comprehensive review; instead, it intends to demonstrate the variations in estimated prevalence rates, probably due to different measures used and different groups of elderly people included in or excluded from the samples.

Most empirical investigations explicitly dealing with frailty have adopted the clinical perspective. Accordingly, measures are commonly validated by their ability to predict negative outcomes, e.g., death, disability and institutionalization (Fried et al., 2004; Mitnitski et al., 2005; Puts, 2005; Rockwood et al., 2004; Rockwood et al., 2006).

Rules-based frailty measures

Operational definitions of frailty are typically rules-based, i.e. a person is defined as frail if a certain number of given criteria are present (Rockwood et al., 2005). One of the most widely used instruments to identify clinically frail older adults builds upon clinical consensus among 62 geriatricians at six academic medical centers in the U.S. and England. The phenotype comprises five dimensions of physical health: weakness, poor endurance, weight loss, low physical activity, and slow gait speed. Individuals with three or more of these components were considered frail, participants with one or two components were considered prefrail, and those with no components were considered robust. Based on data from the Cardiovascular Health Study (CHS), a sample of community-dwelling adults aged 65 and older who lived in four communities in the United States, 7 percent were considered frail. The proportion increased steadily with age, up to 30 percent among those aged 80 years and older (Fried et al., 2001).

A Dutch study, comprising a random sample of directly interviewed community-dwelling individuals aged 55–85 expanded on this definition to include the psychological markers of cognition and symptoms of depression (Puts, Lips, & Deeg, 2005). They also introduced a dynamic definition of frailty based on a relevant decline in frailty markers between two time points. In the static sense 14 percent of the women and 18 percent of the men were frail in 1995/96; i.e., they scored above the cutoff on three or more frailty markers. The prevalence of dynamic frailty, defined as relevant decline in frailty markers between 1992/93 and 1995/96 was similar in men and women (17 % vs. 18 %). Combined static and dynamic frailty occurred among 7 percent of the men and 10 percent of the women.

Several frailty measures are based on the Canadian Study of Health and Aging (CSHA) (McDowell, Aylesworth et al., 2001; McDowell, Hill, & Lindsay, 2001; McDowell, Stewart et al., 2001). One study defined frailty as dependency in one or more ADLs and categorized 8 percent of the males and 15 percent of the females as frail. Considering three, more comprehensive, alternative definitions combining problems with ADL, IADL, and cognition and counterbalancing positive characteristics such as having someone to assist in time of need, high level of education, and excellent self-rated health, between 25 and 30 percent of the males and 33 to 40 percent of the females were classified as frail (Canadian Study of Health and Aging Working Group, 2001).

Another operationalization of clinical frailty based on CSHA data defined a four-graded scale including problems with ADL, IADL, mobility, incontinence, and cognition. In that option, 5 percent of the sample was rated as severely frail and 16 percent as mild/moderate frail (Gutman et al., 2001).

A seven-graded scale expands on this definition and systematically takes the "slowing up" impact of disease symptoms into account. According to this definition, 8 percent of the sample was classified as severely frail and 16 percent as moderately frail (Rockwood et al., 2005).

Several researchers published a consensus report advocating that criteria to define physical frailty should be based on impairments in physiological domains that include mobility, balance, muscle strength, motor processing, cognition, nutrition (often operationalized as weight change), endurance (including feelings of fatigue and exhaustion), and physical activity (Ferrucci et al., 2004).

Frailty as deficit accumulation

As opposed to rules-based definitions, summing up the number of health problems rather than specifying *which* deficits should be considered has been proposed as another way to define frailty (Rockwood et al., 2005). Like rules-based operationalizations used in a clinical perspective, the concept of frailty as deficit accumulation intends to stratify risks for negative outcomes. Health problems comprise a wide range of deficits that can be identified by

means of abnormal test results, disabilities (e.g., ADLs), physical function (e.g., irregular gait pattern, mobility problems, poor standing posture), symptoms (headache, abdominal problems, mood problems, restlessness, sleep changes) and diseases (e.g., cardiac problems, congestive heart failure, history of diabetes). Relative frailty is calculated as a percentage difference from the average score for people of that age. This frailty measure is not meant to be dichotomized into frail or robust (Rockwood et al., 2005).

Studies including a wide range of deficits demonstrated that the sum of deficits was a robust indicator of survival regardless of which deficits were considered (Rockwood, Andrew, & Mitnitski, 2007; Rockwood et al., 2004; Rockwood et al., 2006). This was found for population-based and clinical/institutional surveys in several developed countries, including the H–70 study in Gothenburg (Mitnitski et al., 2005).

Other measures of multidimensional health problems

Some studies do not mention the word frailty but examine concurrent problems in different health domains and their combined effect on adverse outcomes (e.g., disability or death). For example, a British study including community-dwelling and institutionalized persons above the age of 64 examined functional, cognitive, and physical health problems. The proportion of persons with at least two of the three problems was 3 percent for men and 5 percent for women in the youngest age group of 65–69 years. Among those 90 years and older, 45 percent of the men and 68 percent of the women reported problems in at least two of the three dimensions (Brayne et al., 2001).

Another study found that participants with coexisting visual and cognitive impairment were at greater risk for several measures of disability (Whitson, Cousins et al., 2007).

Although there are several studies estimating the proportion of frail people in the population, according to various definitions, little attention has been paid to changes in prevalence rates over time. A few studies, however, reported prevalence rates of concurrent health problems over time. One study investigated the prevalence of at least three longstanding diseases between 1980 and 2002 among members of the Swedish population aged 65 to 84 years (Rosén & Haglund, 2005). Predicted proportions for 70-year-olds increased from 19 to 23 percent for men and from 25 to 30 percent for women. A British study that compared two cohorts of persons aged 65 to 69 in 1991/92 and 1996/96 found a similar trend; the prevalence of persons who reported at least three chronic diseases/conditions increased significantly from 10 percent to 14 percent (Jagger et al., 2007). The Swedish National Survey of Living Conditions (ULF), conducted by Statistics Sweden, included a four-graded health index that combined general self-rated health, mobility restrictions, and restrictions in functional capacity due to chronic disease (Boström & Persson, 2001; NBHW, 1997). According to this com-

posite measure, the proportion of people aged 65–84 with severe ill health declined from 22 percent in 1975/79 to 17 percent in 1995/99 (Batljan, 2007). The same tendency applied regarding moderately severe ill health while the proportion of slight ill health increased (Lagergren & Batljan, 2000). The Statistics Sweden health index has been used to calculate how many years a person may expect to live at different health levels in the age interval 65–84 years, provided that he or she has reached 65. The longer period of life after 65 years for the period 1996/99 compared to 1975/80 consisted for both sexes chiefly of years with slight ill health. The years with severe ill health decreased for both sexes, most for men (Boström & Persson, 2001). Another study, also based on ULF, estimated the proportion of people aged 65 years and older who reported one or more of the following severe health problems: Impaired mobility requiring aids or assistance from another person to move about, severe pain, impaired vision, severe trouble from nervousness and anxiety. In 2002/03 among people aged 65–79 approximately one in ten and among those aged 80 years and older about one in four had two or more severe problems. There was no change in the proportion of people with these health problems between 1988/89 and 2002/03 (Larsson & Thorslund, 2006).

It is obvious that prevalence rates of multidimensional health problems differ between studies with regard to the measures used, age groups included, and the time point and country studied. Sample characteristics, such as the exclusion of selected groups of the older population as well as response rates, are other important potential sources of diverging prevalence rates. However, beyond differences in measures and samples, a clear gender and age pattern appeared in all studies. In general, women are frail/have multidimensional health problems more often and during a longer period before death than men. Prevalence rates clearly increase with age for all measures.

Table 1: Examples of studies estimating the prevalence of frail elderly people (in order as they are referred to in the text)

Reference	Study characteristics	Operationalization	Prevalence rates		
Fried, et al., 2001	**Study:** Cardiovascular Health Study (CHS) **Setting:** 4 communities in the U.S. **Year:** 1989/1990 **Participants:** n = 5317; community-dwelling (exclusion of persons with a history of stroke, MMSE<18, and those taking antidepressants). **Data collection:** direct interviews, performance test, medical records **Ages:** 65–101 **Validation:** prediction of falls, worsening mobility or ADL disability, hospitalization, mortality.	**Presence of at least three of the following five components:** Exhaustion Weight loss Low activity (kcals) Slow walks (s) Grip strength (kg)	**Men, %** **Women, %** **65–69** 1.6 3.0 **70–74** 2.9 6.7 **75–79** 5.5 11.5 **80–84** 14.2 16.3 **85–89** 15.5 31.3 **90+** 36.8 12.5 **Total** 4.9 7.3		
Puts et al., 2005	**Study:** Longitudinal Aging Study Amsterdam (LASA) **Setting:** 11 municipalities **Year:** 1992/93 – 1995/96 **Participants:** n = 2257; community-dwelling **Data collection:** direct interviews, medical interview **Ages:** 55–85 **Response rate:** 72.6% **Validation:** prediction of mortality, institutionalization	**Static frailty** (low scores on three or more frailty markers in 1995/96): BMI, peak expiratory flow, cognition, vision, hearing, incontinence, sense of mastery, depressive symptoms, physical activity **Dynamic frailty:** Change in frailty markers between waves	**Static frailty:** **Dynamic frailty:** **Static + dynamic frailty:**	**Men, %** 13.6 17.6 6.9	**Women, %** 17.8 18.3 10.0

Chin et al., 1999	**Study:** Zutphen Elderly Study **Setting:** town of Zutphen, Netherlands **Year:** 1990–1993 **Participants:** n = 450 community-dwelling men **Data collection:** direct interviews **Ages:** 69–89 **Response rate:** 77.2% **Validation:** prediction of mortality + functional decline	**3 Measures of frailty:** **1) inactivity + low energy intake** **2) inactivity + weight loss** **3) inactivity + low BMI**	1) 7% 2) 6% 3) 6%		
Canadian Study of Health and Aging Working Group, 2001	**Study:** Canadian Study of Health and Aging (CSHA–1) **Setting:** five geographical regions in Canada **Year:** 1991/92 **Participants:** n = 8949; community-dwelling **Data collection:** in-home interviews + clinical examination **Ages:** 65+ **Validation:** prediction of institutionalization, mortality	**4 Measures of frailty** Partially or total dependent in **1) one or more ADL–items** **2) one or more ADL or IADL items** **3) dependence in ADL or cognitive problems** **4) balance definition:** deficits include limitations in ADLs and IADLs and cognition. The deficit score is reduced if there is available support, high education or good SRH.	**Men, %** 1) 8.0 2) 24.7 3) 29.9 4) 26.0	**Women, %** 14.8 39.2 33.3 37.9	
Gutman, et al., 2001	**Study:** Canadian Study of Health and Aging (CSHA–1) **Setting:** five geographical regions in Canada **Year:** 1991/92 **Participants:** n=8914; community-	**Frailty Scale of Rockwood et al. (1994)** 1) **healthy**: no functional or cognitive impairment 2) isolated **urinary incontinence** 3) **mild/moderate frailty**: 1 of the	**Men, %** 0) 75.3 1) 7.8 2) 12.5 3) 4.4	**Women, %** 61.1 14.2 18.3 5.9	**Total, %** 67.1 11.6 15.9 5.3

				65–75 %	75–84 %	85+ %
	dwelling **Data collection:** Direct interviews **Ages:** 65–101 **Validation:** prediction of mortality, institutionalization	following: assistance with mobility or 1 or more ADLs, has cognitive impairment without dementia, has bowel or urinary incontinence. **4) severe frailty:** two or more of: totally dependent in transfers, one or more ADLs, incontinent of bowel and bladder, diagnosed with dementia	1) 2) 3) 4)	80.5 10.6 7.5 1.4	62.6 12.9 18.4 6.1	39.6 11.1 34.5 14.7
Rockwood, et al. 2005, 2007	**Study:** second clinical examination of the Canadian Study on Health and Aging (CSHA–2) **Setting**: five geographical regions in Canada **Year:** 1996 **Participants:** n = 2305, community dwelling + institution **Data collection:** clinical examination **Ages:** 70+ **Validation:** prediction of mortality + institutionalization	**Comparison of the CHS frailty phenotype, the CSHA clinical frailty scale and the deficit accumulation (FI)** **CHS frailty components:** exhaustion, weight loss, low activity, slow walk, grip strength. **1) robust:** no components **2) pre–frail:** 1–2 components **3) frail:** at least 3 components	1) 47.7 2) 35.7 3) 16.5		

		CSHA clinical frailty scale	Total, %
		1.) very fit (most fit for their age group)	1) 9.4
		2.) well, (without disease but less fit than people in category 1)	2) 11.3
		3.) well (with treated comorbidities, diseases symptoms are well controlled compared to category 4)	3) 20.7
		4.) apparently vulnerable (commonly complaints of being "slowed up" or having disease symptoms)	4) 15.2 5) 13.2 6) 21.6 7) 8.4
		5.) mildly frail (limited dependence on IADL)	
		6.) moderately frail (needs help with ADL+IADL)	
		7.) severely frail (completely dependent in ADL+IADL or terminally ill)	
		Deficit accumulation FI: frailty index comprising 70 deficits, e.g., disabilities, physical and cognitive limitations, symptoms, and diseases. Relative frailty for an individual is calculated as a percentage difference from the average for people of that age.	Moderate correlation ($R = 0.65$) of the CHS phenotype and the FI. High correlation ($R = 0.80$) of the CSHA frailty scale and the FI

Brayne et al., 2001	**Study:** MRC CFAS **Setting:** England and Wales Three urban and two rural sites **Year:** 2001 **Participants:** n= 13009 community–dwelling + institution, **Ages:** 65+ **Data collection:** direct interviews **Response rate:** 80% **Validation:** descriptive, provision of profile of disorders and disabilities in the older population	**Measure of concurrent** **health problems** Low scores in at least two of the following three: MMSE, ADL, self–reported illness + interviewer reported sight and hearing problems	**Age-group** 65–69 70–74 75–79 80–84 85–89 90+	**Men, %** 3.1 5.1 10.0 14.1 26.1 44.6	**Women, %** 5.1 6.0 12.3 27.5 42.4 67.9

2.3.3 Frailty – A tool for clinicians and for social planning

Most empirical studies employ a clinical perspective on frailty. In order to evaluate and follow up specific clinical samples, these studies often include detailed eligibility criteria. For example, one study using the CHS frailty criteria presented above, described the progression of frailty and the association of frailty with mortality among older men. To be eligible for participation at baseline, men must be able to provide consent, be able to walk without assistance from another person or aid, be aged 65 and older, and not have had bilateral hip replacements (Cawthon et al., 2007).

Many studies investigating frailty restrict their data collection to direct community-based interviews, often in combination with performance tests and/or medical assessments, and exclude cognitively impaired individuals (Brayne et al., 2001). Some studies have been restricted to men or women (Cawthon et al., 2007), or they used an age ceiling (Puts et al., 2005). Such drop-out "by definition" probably entails an underestimation of frailty, however defined, in the entire older population.

Beyond various eligibility criteria employed in studies, representativeness is also challenged by nonresponse at baseline or, in the case of longitudinal studies, at subsequent follow-ups. Individuals may also be lost due to partial nonresponse on specific items. When reported, response rates often range between 70 and 80 percent (Chin et al., 1999; Puts et al., 2005). One study found that those who were lost to follow up were more likely to be male, unmarried, older, to have more chronic diseases, more depressive symptoms, and to be cognitively impaired (Puts et al., 2005). Thus, higher nonresponse probably also leads to an underestimation of frailty.

In clinical contexts, health indicators need to be very precise when deciding on treatment and drug prescription. Consequently, clinical studies often contain detailed information on specific health problems, usually including medical examinations. In population surveys, for practical reasons, clinical precision cannot be accomplished. On the other hand, if representative health trends at the population level are the goal, then crude indicators that are not necessarily clinically relevant may be sufficient.

Approaching frailty from a social policy view, prevalence rates aim to reflect the extent of complex care needs involving different sources of medical and social services in the entire older population. Rather than identifying people at risk for negative outcomes who can be targeted for interventions, the focus is on those elderly people who are *already* overtly functionally compromised and experience multidimensional health problems. Frailty in this broader sense most often coincides with the fourth age. In order to avoid the loss of the most impaired individuals (i.e., cognitively impaired or very weak individuals) measures have to be feasible with proxy interviews.

2.4 Trends in public eldercare in Sweden

Studying mortality and health indicators in the older population provides insight into how the increasing number of older people is related to health on the level of the population and thereby to potential needs in terms of healthcare and eldercare. In the following sections, recent trends in resource allocation are elucidated as well as implied changes among care receivers and the type of care provided.

2.4.1 Public eldercare and the welfare state

Whereas patterns of functional decline at the end of life may be similar in most developed countries the scope and way of organizing formal eldercare varies considerably between nations. Esping-Andersen's classic work identified three welfare-state regimes involving different arrangements concerning the division of responsibility for care provision between state, market and family (Esping-Andersen, 1990). The Scandinavian welfare states are grouped into the social-democratic welfare regime which is characterized by universal welfare programs encompassing the entire population under one universal insurance system. This is in contrast to liberal welfare states, where means-tested assistance and modest social-insurance plans dominate (e.g., in the U.S., Canada, and Australia). The conservative welfare state regime is based on the principle of subsidiarity, meaning that the state will only intervene when the family's resources are exhausted (e.g., Austria, Germany, Italy).

When considering the international literature, findings on factors related to the utilization of formal eldercare are mixed or conflicting. This could be a result of variation across samples or the specific services under investigation (Mitchell & Krout, 1998). Furthermore, utilization patterns also depend on the country-specific context, encompassing public finances and the way social care arrangements are rooted in their cultures and in their social and political histories (Sipilä, Anttonen, & Baldock, 2003). A negative association of access to informal care and use of formal services can, for example, be expected to be stronger in societies where the welfare system and social norms expect the family to account for the main responsibility of the care for elderly people.

Bearing in mind the importance of the country-specific context that shapes the association between individual and (social and physical) environmental characteristics with formal service use, the following review of recent developments in formal eldercare is restricted to the case of Sweden.

2.4.2 The Swedish context – Official policy

Care of elderly people has for decades been a main focus of public policy in Sweden. In compliance with official ambitions, elderly people should have the possibility to age in security, with maintained independence and access to good medical treatment and care (Government Bill, 1997/98:113).

Scandinavian health and eldercare has been characterized by its comprehensive nature, provision by professional workers, and availability to and use by everyone in need, irrespective of socio-economic position (Sipilä, 1997). According to the Social Service Act (1982), all who need help to support themselves in their day-to-day existence have the right to claim assistance *"if their needs cannot be met in any other way"*. As old age care in Sweden officially is a public responsibility, children have no legal responsibilities to provide care or financial security for their aged parents (Sundström & Johansson, 2004). Only about 2–3 percent of adult children share their homes with their elderly parents (NBHW, 2007a).

The 290 municipalities are responsible for providing long-term care and services for older persons. As the municipalities, within the limits prescribed by existing legislation, have a high degree of autonomy, there is considerable variation in the nature and extent of services available (Trydegård & Thorslund, 2001). One study, however, ascribed these local variations to variation in needs profiles between municipalities (Davey et al., 2006; NBHW, 2005a).

Public eldercare is largely financed by local taxes. User fees that vary according to a person's income cover about 5–6 percent of the costs of institutional care and home-help services (NBHW, 2007a). In 2002, an upper limit was put on user fees. As a consequence, one third of old age care recipients pay no fee at all (NBHW, 2005b).

Municipalities offer both home-help services and special housing (särskilt boende). Special housing comprises institutional care facilities with service around the clock (nursing homes, old people's homes, and group accommodations for people with dementia) and sheltered accommodation (service-hus). Sheltered accommodations do not include automatic around-the-clock service. Instead, specified care and services are allocated according to the same principles as home-help services in ordinary dwellings. Home help includes help with household tasks (e.g., shopping, cleaning, cooking/meals on wheels, washing clothes) and personal care (e.g. help getting up from bed, dressing, showering, and going to the toilet). Home nursing is integrated with home-help services in about half of the Swedish municipalities and organized in primary healthcare in the other half. Home help or home nursing may be offered several times a day, as well as at night and on weekends. Transportation service and assistive technology (e.g., security warning devices, walking aids, and home adaptations) are also available to enable people remaining in their homes. Day care and respite care may also be offered.

Public eldercare is needs-tested but not means-tested. Older adults have to apply to the municipality for the help they consider necessary. A care manager, delegated by the municipal social welfare committee makes an assessment as to whether a person will receive assistance and if so, how much and what kind. There is no standard assessment for how much help a person should receive, given the degree of dependency. Considerable variations in the decisions have been found between municipalities as among individual care managers (Lagergren & Johansson, 1998; Trydegård & Thorslund, 2003).

2.4.3 The Swedish context – In practice

Between the 1960s and late 1970s, public eldercare and in particular home-help services, expanded at a faster rate than the number of people over the age of 80. In this age group the proportion receiving home-help services or living in institutional care facilities more than doubled from 30 percent in 1960 to 67 percent in 1978. Among people 65–79 years old there was an increase from 5 to 16 percent (Lagergren, 2005). Needs assessments focused on individual needs regardless of access to informal care, i.e., the existence or state of health of a spouse or access to relatives living nearby (Szebehely, 1998a).

However, economic constraints on the public sector, in particular during the 1990s, in combination with an aging population put pressure on the public eldercare system. During the past few decades, it has undergone significant changes, both with respect to organization and the scope and type of services delivered (Szebehely & Trydegård, 2007). While the number of people aged 80 years and over, which is where the majority of care recipients are to be found, increased by 86 percent since 1980, public resources have not kept up with the demographic change (Larsson, 2004; Thorslund, 2005). The percentage of people aged 80 years and older receiving public eldercare decreased from 62 percent in 1980 to 37 percent in 2006 (NBHW, 2007c; Szebehely & Trydegård, 2007).

Legislation and official ambitions, on the other hand, have remained unchanged. As the Social Service Act is a framework law, the content of "need" is not specified. In any case, the combined effect of budgetary reductions on medical and eldercare during the 1990s has entailed higher thresholds of what is considered a "need" (Szebehely, 1999). In an international perspective, Sweden still has a well-developed system of publicly provided and financed long-term care that corresponds to about 3 percent of GDP (in 2005), compared to around 1 percent in many OECD countries, e.g., Great Britain, Germany, and Australia (OECD, 2005).

Since the Ädel reform was enacted in 1992 (NBHW, 1996), municipalities have the comprehensive responsibility for institutional care facilities and are financially liable for patients whose in-patient care is considered com-

pleted but who still need care after discharge from hospital. The number of hospital beds was close to being cut in half between 1992 and 2005, and treatment periods were drastically reduced (NBHW, 2007a). The decrease was partly due to a restructuring of care provision, including the introduction of new treatment practices, but also to budget constraints (Larsson, 2007).

This development increased the pressure on the municipal eldercare organization in terms of both resources and competence. Fewer hospital beds meant that more people who had previously been treated in internal medical or geriatric wards moved into special housing. As a consequence, the threshold to institutions has risen and more persons with extensive care needs live in their own homes and need medical, rehabilitative and household services (Larsson & Thorslund, 2005). Shorter hospital-care periods also meant that older people living in ordinary dwellings were discharged with significant needs for medical care and rehabilitation (Gurner & Thorslund, 2003).

Resources were targeted at individuals with the most extensive care needs, above all those with functional and cognitive limitations, and people living alone and having no relatives nearby (SOU, 2004). People with less extensive needs, younger elders, married people, and those with relatives nearby fell increasingly outside the public realm (Larsson, 2004; Palme et al., 2003; Szebehely, 2003; Thorslund, Bergmark, & Parker, 2001). As a consequence, care loads increased both among people living in institutional care facilities and those living in ordinary dwellings (Palme et al., 2003; Szebehely, 2005b).

In the public eldercare system, the *aging-in-place* strategy has been crucial to the allocation of resources for the past decades (Szebehely, 1998a). In the 2000s, the number of beds in institutional care has dropped by almost one fifth. Today, the majority of elderly people living in institutions comprise those with cognitive impairment (NBHW, 2007b).

With respect to home-help services, coverage rates declined in particular during the first half of the 1990s, but recipients were on average allotted more hours (Palme et al., 2003). During the second half of the 1990s the coverage rate remained relatively stable. Instead, less home help was provided for a given level of need in 2000 than was provided in 1994 (Sundström, Johansson, & Hassing, 2002). Among persons aged 80 years and older, the percentage receiving home help first dropped from 23 percent in 1993 to 18 percent in 2000 and then slightly increased to 21 percent in 2006 (NBHW, 2007c). This was partly as a consequence of the decrease in institutional places.

2.4.4 Is public eldercare provided according to need?

In spite of the increasing number of very old people in the population the percentage living in institutional care facilities or receiving home help has decreased during the past few decades. Two important questions following this development are, whether cutbacks correspond to better health and functional ability among the older population and if available resources actually hit those individuals with the most extensive needs (horizontal target efficiency) (Davis & Challis, 1986).

In general, changes in access (coverage rates) and intensity (volume) of public eldercare during the past decades cannot be explained as rational responses to varying needs (Thorslund, 2004). The expansion of both home-help services and institutional care during the 1960s and 1970s hardly related to a corresponding increase in care needs in the elderly population. Instead, it was part of a general growth of the Swedish welfare system (Lagergren & Batljan, 2000; Szebehely, 2000). Cutbacks in the eldercare system, in particular during the 1990s, were enforced by a weakening financial base for any further growth of the public system rather than a decrease in care needs in the older population (Thorslund, 2005). Taking a number of needs-related factors into account, several studies concluded that the reduced supply of eldercare is not compensated by corresponding advancements in health and functional ability (Lagergren & Batljan, 2000; Larsson, 2006; Parker et al., 2005). Rather, a stricter interpretation of need coincided with signs of deteriorating health, in particular among the oldest old (Parker et al., 2006; Parker & Thorslund, 2007; Rosén & Haglund, 2005).

Turning to the question of target efficiency, in broad outline, it seems that the public eldercare system targets persons with more extensive care needs. Besides functional limitations (mostly measured as dependence in ADLs and IADLs) (Larsson, 2004; Szebehely, 1998b), and cognitive impairment (Larsson, Thorslund, & Forsell, 2004), living alone is found to be the most important predictor of receiving home-help services, as well as institutional care (Larsson, 2004). Needs of a more social nature seem to affect the allocation of public eldercare to a lesser extent or are neglected altogether (Larsson et al., 2004; Palme et al., 2003). Even if resources are targeted to the most impaired individuals, this does not guarantee that the provided services are sufficient to meet care needs. Certain groups of elderly people have been found to be in danger of unmet need for care: depressed individuals, childless people living alone (Larsson & Thorslund, 2002), and elderly spouses caring for a cognitively impaired partner (Larsson, 2004).

2.4.5 Informal care – A gendered and class-related issue

In spite of an official emphasis on public responsibility, in Sweden as in other countries, the family, primarily the spouse or adult children, remains the dominant provider for care to elderly people (Jeppsson Grassman, 2001; Sundström et al., 2002; Szebehely, 2005a). Several studies indicate that the decline in public eldercare provision since the 1980s coincided with an increased family involvement in care of elderly people (Johansson & Sundström, 2002; Larsson, 2006; Sundström et al., 2002; Szebehely, 2000; Szebehely & Trydegård, 2007). When the threshold for receiving eldercare rose, many municipalities began to include the availability of informal help in their needs assessments (NBHW, 2004c). In particular, spousal carers are often left without any formal support (Jegermalm, 2004).

During the expansion years of the Swedish welfare state, informal care was considered merely a complement to public eldercare (Government Bill, 1987/88:176). Facing financial constraints, in a revision of the Social Services Act (Government Bill, 1996/97:124), municipal responsibility for giving support to informal carers was emphasized. Although state grants for municipal projects supporting informal caregivers were temporarily granted (Government Bill, 1997/98:113), support for family caregivers is still a very small part of the formal eldercare system (Jegermalm, 2005), and few informal carers reported that they had benefited from any caregiver support (Forsell, 2004; Jegermalm, 2003, 2005; Jeppsson Grassman, 2001). In general, there is an uncertainty about data and methods for continuous evaluation of caregiver support (Mossberg Sand, 2005).

There is a clear gender pattern both with regard to receipt and provision of informal care. Women live longer than men on average, tend to marry men who are older than themselves, and have lower remarriage rates. Accordingly, the probability of living alone when facing dependency in old age is higher for women. This makes women more dependent upon a well-functioning home-help system and more vulnerable to cutbacks in services. Most men, on the other hand, cohabit until the end of their lives (Larsson, 2007).

Shifting to the caregiver perspective, it is more common among women, in particular middle-aged daughters, to help someone outside their own household (Jeppsson Grassman, 2003). Among informal helpers, women have been found to dominate among those who give personal care while men more often perform practical tasks (Jegermalm, 2006). Among spouses, there are indications that old women more often are the only caregiver for their husband. Vice versa men have been found to be more likely to be supported by the home-help service or by adult daughters in their caregiver role (Szebehely, 2004).

The international debate on different models of welfare states has circled around the question of whether public care for elderly people is a substitute

or a complement to informal care. Research from Sweden as well as other Scandinavian countries revealed no negative relationship between informal and public care provision (Dahlberg, 2004, 2006). Rather, different care resources complement each other (NBHW, 2005a). In Sweden signs of a reversed substitution have been identified: As formal provisions have been cut, families have had to fill the emerging gaps in care for older people (Larsson, 2004; Mossberg Sand, 2005). This informalization trend has particularly affected the situation of women, as it have been mostly wives and daughters who have filled the gap left by cuts in the coverage levels of formal services (Szebehely, 2003). This trend also follows a class-related pattern. While less-educated elderly people more often receive assistance from family members elderly people with higher levels of education more often turn to privately purchased help (marketization) (Szebehely, 2003). This pattern has strengthened since the late 1980s (Szebehely & Trydegård, 2007).

3 Material and Methods

3.1 Data

Three different surveys were used. In Study I data from the Tierp study were analyzed. Studies II and III used data from the Swedish Panel Study of the Oldest Old (SWEOLD). Study IV was based on the Care and Services Section of the Swedish National Study of Aging and Care-Kungsholmen (SNAC-K). While SWEOLD is a nationally representative study of the Swedish population aged 77 years and older, the two other surveys are local studies. The Tierp study was conducted in a rural community in central Sweden and is restricted to community-based persons aged 75 years and older. The SNAC-K study is located in an inner city district of Stockholm (Kungsholmen) and comprises all home-help recipients aged 65 years and older. Table 2 gives an overview over basic sample characteristics of the three surveys.

3.1.1 Tierp study

The Tierp study was based on an interview survey of community-based persons aged 75 years and older conducted in 1986 in a rural municipality in central Sweden (n = 421). Every eighth person aged 75–84 years (n = 161) was randomly selected from the population register, and all persons aged 85 and older (n = 260) were selected for interview. To adjust for this sampling procedure in the analyses, younger respondents were given a weight eight times that of the older age group. Nonresponse not weighted was 3.9 percent.

Structured interviews were conducted by district nurses who met with all respondents in their homes. For persons with poor cognition or very poor health, proxy interviews were conducted with relatives or municipal home-help personnel. In all there were 1.7 percent proxy interviews and 8.8 percent proxy-assisted interviews. Questions included ADLs and IADLs, mental health, physical health, symptoms, drug use, housing and social contacts.

The prevalent policy in Sweden during the 1980s has been to allow elderly people to remain in their homes as long as possible with support from municipal home help and home nursing. Therefore, the community-based

elderly population covered a wide spectrum of levels of functional ability and morbidity. The socioeconomic distribution was rather homogenous in this study population. Former farmers, blue-collar workers, and low-level white-collar-workers were the dominating groups.

3.1.2 Swedish Panel Study of Living Conditions of the Oldest Old (SWEOLD)

SWEOLD is based on the Swedish Level-of-Living Survey (LNU), a panel interview survey of the Swedish population aged 18–75 years that was begun in 1968 (Erikson & Åberg, 1987). This is a sociological survey that evaluates living conditions in a national representative sample. In subsequent survey waves, people older than 75 years are dropped from the panel.

The major goal of SWEOLD is to maintain a general level of living survey targeted towards the oldest old. Questions include identical areas of living conditions as the LNU surveys, (e.g. economy, housing, social relations, activities and political resources). Questions on job careers, however, are reduced and instead, a number of key variables in the context of gerontological research are added (e.g., health indicators and the use of medical and social services).

In 1992, all persons older than 75 years who had been interviewed in at least one LNU survey were traced. The survivors comprised the SWEOLD 1992 study (n = 563). Nonresponse was 4.6 percent. In 2002, the same procedure was repeated. Nonresponse in SWEOLD 2002 (n = 634) was 11.5 percent. SWEOLD 1992 and 2002 can be seen as national representative samples of survivors of the birth cohorts 1892–1925 and comprise approximately 1 per thousand of the Swedish general population aged 77 and older (Lundberg & Thorslund, 1996).

In both surveys professional interviewers carried out structured interviews with subjects. Telephone interviews were conducted in some cases, mainly due to unwillingness to receive an interviewer in the home. In cases where the respondent could not be interviewed, due to cognitive impairment or severe illness, a close relative or caregiver was interviewed. Distribution of interview mode (direct, proxy, telephone) changed only marginally between the two studies. The percentage of persons living in institutions, age, and gender distributions reflect the national average for the two years.

3.1.3 Swedish National Study on Aging and Care (SNAC)

The Swedish National Study on Aging and Care (SNAC) is an ongoing study that consists of a population part and a care and services part. The goal of this approach is to create a database that allows the investigation of the development of care needs in the elderly population together with the actual

meeting of these needs by the public system and/or other forms of care and services.

SNAC is conducted in four areas of Sweden: (1) five municipalities in the region of Skåne in the southern part of Sweden, (2) Karlskrona municipality in Blekinge county council in the south-east part of the country, (3) an inner city district of Stockholm (Kungsholmen), and (4) the municipality of Nordanstig in Gävleborg county council, a rural area in northern Sweden. (For a detailed description of SNAC in the four areas, see Lagergren et al., 2004).

In the population part, a representative panel of elderly people in different age cohorts is followed over time to record different aspects of the aging process. For a detailed description see Lagergren et al. (2004).

The main purpose of the care and services part of the SNAC study is to monitor individual provision of public medical care and social services in relation to different need indicators. These include functional ability, specific health problems, and living conditions of the recipients.

The target sample in the care and services part consists of all persons 65 years and older living in the included areas and receiving long-term (two months or longer) public care and services from the municipality and/or the county council. This includes home-help services, home healthcare or home rehabilitation, or any kind of special accommodation. Persons who only have meals-on-wheels, alarm service, or transportation services are excluded.

The kind and amount of services allotted, as well as the care managers' evaluation of health indicators and living conditions, is continuously collected in connection to assistance decisions. A new registration is made in the case of substantial changes in the provision of services. In the case of no changes in provided services, disability status is registered at least once a year. Thus, data in the care and services part of SNAC do not reflect the care recipients' statements about their health status and living conditions but are based on the care managers' assessment, registered in connection with assistance decisions.

Study IV was based on the 2002 baseline study of the care and services part in the district of Kungsholmen (hereinafter SNAC-K). The study sample consisted of all home help recipients 65 years and older living in ordinary dwellings or sheltered accommodation (i.e. a rented flat in a communal building with access to shared facilities such as a restaurant) in the district of Kungsholmen (n = 1237). This corresponded to 14.8 percent of the total population 65 years or older. The drop-out rate was 10.4 percent, resulting in 1,108 registered recipients of public home-help. As all drop-outs occurred when care managers failed to fill in questionnaires, they were not associated with any specific characteristics of home-help recipients.

Table 2. Sample characteristics in SWEOLD, SNAC-K, and the Tierp study

Characteristic	SWEOLD				SNAC-K		Tierp study	
Year of data collection	1992		2002		2002		1986	
	%	n	%	n	%	n	%	n
Response pattern								
Response	95.4	537	88.5	561	76.2	943	96.1	421
Nonresponse	4.6 [a]	26	11.5[b]	73	10.4	129	3.9	17
Excluded due to partial non-response	0.01	3	0.01	7	13.3[c]	165	0-1.2 [d]	0-5
Type of data collection								
Professional interviewer:								
home visit interview	81.1	439	79.9	448				
direct telephone	6.3	34	7.3	41				
proxy dir./tel.	11.9	64	12.8	72				
District nurse:								
home visit interview							98.3	421
home visit proxy-interview							1.7	7
Registration by care manager					100	943		
Living situation								
In institutions	12.8	69	14.6	82				
In community	87.2	468	85.4	479	100	943	100	421
Age group								
65–74					9.3	88		
75–84					32.8	309	38.2	161
77–84	68.6	370	62.1	348				
85+	31.1	167	38.0	213	57.9	546	61.8	260
Gender								
Male	39.5	212	40.6	228	21.3	201	45.6	192
Female	60.5	325	59.4	333	78.7	742	54.4	229

a) Since the inclusion criteria for SWEOLD 1992 was earlier participation in at least one of the LNU survey waves, non-responders in LNU were not included in the SWEOLD 1992 sample, probably contributing to a lower nonresponse in SWEOLD 1992. If surviving LNU non-responders in the actual age group had been included in the SWEOLD 1992 sample and if all of them would have been non-responders in SWEOLD 1992, too, the nonresponse rate would have been 11.1 %.

b) In SWEOLD 2002 surviving non-responders from previous LNU survey waves were included in the sample, resulting in a nonresponse rate of 15.6%. However, in order to obtain comparable datasets for SWEOLD 1992 and 2002, LNU non-responders were excluded in Studies II and III.

c) Excluded subjects did not differ substantially from included subjects in regards to the average number of hours allocated (8.7 vs. 9.1), the average age (84.9 vs. 85.4 years), the proportion of females (72 % vs. 79 %), and the proportion of persons living alone (85 % vs. 89 %).

d) Not weighted. Due to oversampling of the age group 85+, in analyses in Study I, respondents aged 75–84 were given a weight that was eight times that of the older age group. Partial nonresponse varies between 0 and 5 cases (0–1.1%) due to different nonresponse patterns for different variables.

3.2 Indicators used in the analyses

Different types of indicators were included in the four studies depending on the specific aim/outcome:

Study I analyzed the role of follow-up time for the strength of different predictors of mortality. Both health indicators directly associated with mortality and indicators that affected mortality through different physiological and psychosocial pathways were included (For a review, see Miller & Weissert, 2000). These covered self-reported health variables, drug use, social variables and sociodemographic indicators as well as nurses' evaluation of the respondents' health status.

Studies II and III focused on change in prevalence rates of complex health problems and possible change in the relation of complex health problems and mortality. Measures that are less vulnerable to environmental change (e.g., housing standard, assistive technology) and changes in expectations and social norms were included. For example, mobility was studied instead of the widely used ADL.

Study IV investigated predictors of the amount of home help allocated among recipients. Relevant needs for home help arise from the inability to perform activities necessary to managing an independent life at home independently of the underlying reason for inability. In this case, rather crude measures of function and disability may be more appropriate than specific diagnoses or symptoms. Predictor variables in Study IV included direct health and function-related indicators that, according to the Social Service Act, should guide allocation of home help services. Characteristics of the social environmental and the physical environment, and sociodemographic characteristics that could influence assistance decisions were also included.

In the following sections, outcome measures and independent variables are presented broadly. For details of the item construction, see Studies I–IV in the appendix.

3.2.1 Outcome measures

3.2.1.1 Mortality

Mortality was an outcome variable in Studies I and III. Swedish personal identification numbers and population registers facilitated the collection of date of death. This was obtained from the Swedish National Cause of Deaths Register which maintains records of death certificates.

In Study I, based on the Tierp study, mortality was followed from the day of the interview in 1986 until the end of January 2001 when 94 percent of the sample was deceased. Average follow-up time was about 15 years. Time under risk was measured in days from the time of the interview until date of death or censoring at the end of the follow-up period

In Study III, based on SWEOLD 1992 and 2002, mortality was followed from the day of the interview until 20 July 1996 for the 1992 study and 12 April 2007 for the 2002 study. This resulted in an average follow-up time of 1625 days (about 4 years and 5 months). During the follow-up time, 39 percent of the participants in the 1992 study and 40 percent of the 2002 study died.

3.2.1.2 Complex health problems

Complexity in health problems was an outcome variable in Study II and was used as a predictor of mortality in Study III. Using population-based SWEOLD, a measure of complex health problems was developed, showing one possible strategy of capturing the most vulnerable subgroup of the oldest old. Three different health dimensions were included: mobility, diseases/symptoms, and cognition/communication. People with serious problems in two or three of these domains were considered to have complex health problems. Complexity is often implicit in frailty and multi-morbidity, and the definition used in Studies II and III cut across concepts of multimorbidity, disability, and frailty. Health domains were chosen on the basis of three inclusion criteria:

1. Measures were selected to reflect serious problems in different health domains important to the individual in maintaining independence and well-being.
2. Measures are relevant to the planning of medical care and long-term care. Individuals with serious problems in several of the included health domains are most likely to need a mix of care and services from multiple providers.
3. In order to make nationally representative estimates comparable over time, only identical items that were available for the 1992 and 2002 surveys and for all respondents, including proxy-interviewed and persons living in institutional care facilities were used. This excluded tests of function (with exception of a cognition test, see below) and subjective evaluations of living situations.

Having serious problems in the physical, functional and cognitive domains was defined as follows:
Diseases/symptoms: A summed index was constructed based on a list of common diseases and symptoms. Individuals specified whether, during the last 12 month, they had had no, mild, or severe problems with respect to general fatigue/sleeplessness, dizziness, leg ulcers, diabetes, stomach pain, myocardial infarction/other heart problems, stroke, breathlessness, chest pain, hypertension, joint pain, back pain, shoulder pain, and low BMI. A cutoff point indicating severe problems in the diseases/symptoms domain

was determined, comprising the highest quintile for the 1992 survey. Persons belonging to that category had, e.g., at least three severe diseases/symptoms or two severe and three mild. The same cutoff point was used for the 2002 sample.

Mobility: Respondents were asked if they could walk 100 meters fairly briskly without difficulties, walk up stairs, rise from a chair without difficulty, and stand without support. Persons having at least three limitations were considered to have serious mobility problems.

Cognition/communication: A measure combining cognition and communication problems was constructed. SWEOLD includes 18 of the 30 items from the Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975). A cut-off best distinguishing demented from nondemented individuals for this shortened version of the MMSE was determined using data from a larger Swedish study HARMONY (Gatz et al., 2005) which examined identically scored MMSE items against clinical dementia diagnosis. The vast majority of proxy interviewed persons were too sick or weak to participate. Respondents who scored below the cut-off in the test or did not do the test or were not able to be interviewed directly were classified as having serious cognitive/communication problems. Thus, this measure is not an indicator of pure cognition but rather roughly captured respondents having at least mild dementia or being unable to communicate with the interviewer involving an important dimension of dependence in daily life.

3.2.1.3 Home-help services

The amount of home help allocated to recipients was an outcome variable in Study IV. Information on recipients of home-help services was obtained from the registry of the Stockholm municipality, which maintains data on users of public eldercare. As these also are the basis for user fees, information from the register can be regarded as valid. Weekly hours of allotted municipal home-help services were registered by the care managers in connection with assistance decisions.

3.2.2 Independent variables

3.2.2.1 Health indicators

Diseases/symptoms
SWEOLD and the Tierp study include self-reported information on diseases and symptoms. For the summed diseases/symptoms index based on SWEOLD (Studies II and III) see 3.2.1.2 on *complex health problems.*

Based on the Tierp study (Study I), a summed somatic symptom index was constructed using a list of the following self-reported somatic symptoms related to mortality: chest pain, back pain, stomach pain, constipation, joint pain, rheumatism, bronchial problems, breathlessness, swollen legs, loss of appetite, insomnia, frequent tiredness, urination difficulties, and skin problems. No information on symptom severity was available. Numbers of symptoms that had similar correlation to mortality were collapsed.

The SNAC-K questionnaire (Study IV) comprised information on a number of *medical conditions and special needs*. These included incontinence, visual impairment, hearing impairment, pain, dizziness, leg ulcers, pain treatment, injections, feeding via tube, intravenous nourishment, blood transfusion, dialysis, and changing dressings. However, none of these conditions or special care needs were bivariately related to the amount of home help allocated and therefore were excluded from further analysis.

Mobility

SWEOLD and the Tierp study included self-reported measures of mobility consisting of four items. In the Tierp study (Study I), the mobility index referred to the ability to rise from an armless kitchen chair, get in and out of bed, walk indoors, and walk outdoors. Respondents were classified into three groups, including individuals with no, some, and many difficulties. For the mobility measure in SWEOLD (Studies II and III), see 3.2.1.2.

SNAC-K (Study IV) included the care managers' assessment of mobility problems. However, when controlling for ADLs and IADLs, mobility problems were no longer associated with the amount of home help allocated and thus excluded from analyses.

Activities of daily living (ADLs)

Limitations in ADLs and IADLs have been shown to be related to mortality (Miller & Weissert, 2000) as well as to the use of home-help services (Larsson, 2004). The Katz index of independence in ADLs (Katz et al., 1963) is easily administered by care managers and widely used in studies on service utilization among older people. The Tierp study (Study I) contained both self-reported and nurses' evaluations of ADL disability. Self-reported ADL disability included limitations in bathing/showering, washing oneself, getting in and out of bed, dressing and undressing oneself, going to the toilet, and eating. On the basis of their observations during the interview the nurses made a global assessment of ADL status, distinguishing between independent and dependent individuals. In SNAC-K (Study IV), disability in ADLs covered limitations in bathing/showering, dressing, going to the toilet, moving around and, eating.

Instrumental activities of daily living (IADLs)
Since the ADL scale originally was developed for hospital patients, it does not give sufficient information about functional ability for persons living in ordinary dwellings. In the Tierp study (Study I), the self-reported ability of IADLs was based on the ability to do the house cleaning, to make the bed, and to prepare food. These three activities had previously been shown to be representative for all IADL activities (Norström & Thorslund, 1991). In addition, nurses classified the respondents roughly into dependent or independent in IADLs. Dependency in IADLs is also a widely used indicator of the need for assistance with household tasks. IADL limitations included in SNAC-K (Study IV) were house cleaning, grocery shopping, use of public transportation, food preparation, and doing the laundry.

Global self-rated health
Global self-rated health reflects the total picture of health, including dimensions of health that are most meaningful for each individual (Idler et al., 1999). Although questions of self-rated health may measure different dimensions across individuals, this simple health indicator has proved to be reliable and predicting mortality (Idler & Benyamini, 1997; Lundberg & Manderbacka, 1996). In the Tierp study, global self-rated health distinguished between individuals considering themselves to be "very or fairly healthy" and those feeling "somewhat or very sick" (Study I).

Cognitive impairment
Cognitive impairment has been shown to be related to the use of formal care (Larsson, 2004) as well as mortality (Bosworth, Schaie, & Willis, 1999). All three surveys included measures of the participants' mental status. In the Tierp study, mental status was also assessed by the nurses' observations and classified as "healthy" and "somewhat or very sick" (Study I). As described in 3.2.1.2, in Studies II and III, based on SWEOLD, a measure combining cognition and communication skills was used. In SNAC-K (Study IV), cognitive impairment was assessed by a shortened version of the Berger scale (Berger, 1980). This is a simple and widely used instrument that allows care personnel to roughly assess through observation whether a person is cognitively impaired to a degree that affects the individual's ability to manage life at home. Participants are classified in three categories: having no memory problems (Berger 0), having some memory problems/being sometimes disorientated and confused (Berger 1), having obvious memory problems and being often disorientated and confused (Berger 2–4) or being completely forgetful, and suffering from constant, severe disorientation and confusion (Berger 5–6).

Psychiatric symptoms

Psychiatric symptoms, in particular depression, have been shown to be associated with higher levels of dependency in the tasks of daily living (Ormel et al., 2002). The care manager may also allow extra time for individuals needing psychological support, irrespective of their physical capacity. SNAC-K (Study IV) included a psychiatric symptom index that was based on the sum of three symptoms: Occurrences of behaviour considered unmanageable/difficult to cope with in everyday care, anxiety and depressive feelings.

Drug use

Drug use is used as a health indicator in Study I (Tierp). Drugs taken by the respondents were classified into eleven groups: heart medicine, diuretics, blood pressure medication, diabetes, pain, sulfa drugs and penicillin, sleeping medicine and psychopharmaceuticals, decongestants, vitamins, eye drops, and others.

3.2.2.2 Social variables

Access to informal care

Previous studies indicated that many municipalities began to include the availability of informal help in their needs assessments when the threshold for receiving eldercare rose (Johansson, Sundström, & Hassing, 2003; NBHW, 2004c; Szebehely, 1998b). In order to analyze whether the amount of home help received was affected by the care managers' knowledge about access to informal care, it was recorded if care recipients got help from family or friends with IADLs or ADLs at least once a week (Study IV).

Living situation

Coresidence distinguished between those living alone and those living with others, in nearly all cases a spouse, among persons residing in ordinary dwellings or sheltered accommodation, in Studies I and IV.

Social contacts

There is a large array of research showing the importance of social relationships for health and well-being as well as mortality (Berkman & Glass, 2000). The Tierp study (Study I) included a measure of social contacts distinguishing between individuals who either participated in organizations or had someone to talk to personal matters (other than a spouse) and those who did not.

3.2.2.3 Physical environment

SNAC-K (Study IV) includes a number of characteristics of the physical environment that could facilitate or hamper independence of elderly people living in the community and thereby affect their need for home-help services.

Housing adaptations

The number of housing adaptations for functional disability was the sum of the following items: removal of thresholds, making wheelchair-accessible bathrooms, installing shower cabins to replace bathtubs, adding an automatic oven switch-off, mounting a permanent alarm.

Residence accessibility

Residence accessibility from the outside considered whether the residence was inaccessible for people with disabilities, whether there was an elevator and at most one flight of stairs, whether there was an elevator and at most a few steps, or whether the residence was wheelchair accessible.

Type of housing

The type of housing distinguished between individuals living in ordinary dwellings and those residing in sheltered accommodation. Home help services in sheltered accommodation are allocated on the same principles as apply to people living in ordinary dwellings. However, services are concentrated and it is easier to meet extensive care needs and visit the care recipient many times a day.

3.2.2.4 Sociodemographic indicators

As mentioned previously, several sociodemographic indicators are related to patterns of mortality, health problems, and the use of formal versus informal care. *Age* and *gender* were recorded for the subjects in all four studies. Personal taxed *income* was the only available indicator of socioeconomic status in SNAC-K (Study IV). Personal identification numbers could be linked to municipal files providing data on personal income. In Study II and Study III, *years* and *level of education* were used as indicators of socioeconomic status.

4 Overview of the studies

4.1 Study I. The effect of the duration of follow-up in mortality analysis: The temporal pattern of different predictors

Studies analyzing factors associated with mortality have revealed considerable differences in the predictive strength of similar indicators. Beyond differences in populations, measurements and statistical methods used, differences in predictor strength may arise from different follow-up times.

Aim

The aim of the study was to analyze the strength of commonly used predictors for mortality at different intervals after baseline and to present possible explanations of how time since baseline affects predictor strength.

Methods

The study originated in an interview survey that was conducted in 1986 in a Swedish community (Tierp) and included community-based elderly persons (n = 421) aged 75 years and older. Fifteen-year mortality was analyzed with proportional hazard regressions with piecewise constant baseline intensity. The dependent variable was death risk per day.

Predictor domains were chosen that have been shown to predict mortality in other studies: sociodemographic variables, self-reported and nurses' evaluations of health indicators, drug use, life satisfaction, and social contacts.

When analyzing mortality risks at successive one-year intervals it became evident that differences between time periods were most obvious when comparing the first year (or, for some variables the first two years) with later years of the follow-up. In order to highlight variations in mortality risk differences between categories of the independent variables (e.g., persons with 0, 1–2, 3–6 and 7–10 somatic symptoms) as clearly as possible, the follow-up period was divided into two discrete periods: The first year (or the first two years) after the baseline interview and years 2 (or 3) to 15 after the interview.

Results

The somatic symptom index, number of different types of drugs, self-rated health, and living situation were strongly correlated to mortality during the first year of follow-up and had a smaller correlation after that. Life satisfaction, mobility, and self-reported and nurse's evaluations of ADL and IADL had a stronger correlation to mortality the first two years and less afterwards.

For example, individuals reporting 7–10 symptoms at baseline had a 27 times higher mortality risk than those without any symptoms during the first year but only a three times higher risk during years 2 to 15 after baseline (*Figure 2*). Relative mortality risks for the second time period were similar to the average risk for the whole follow-up. Gender, social contacts, and nurse's evaluation of mental status were about equally correlated to mortality throughout the follow-up period.
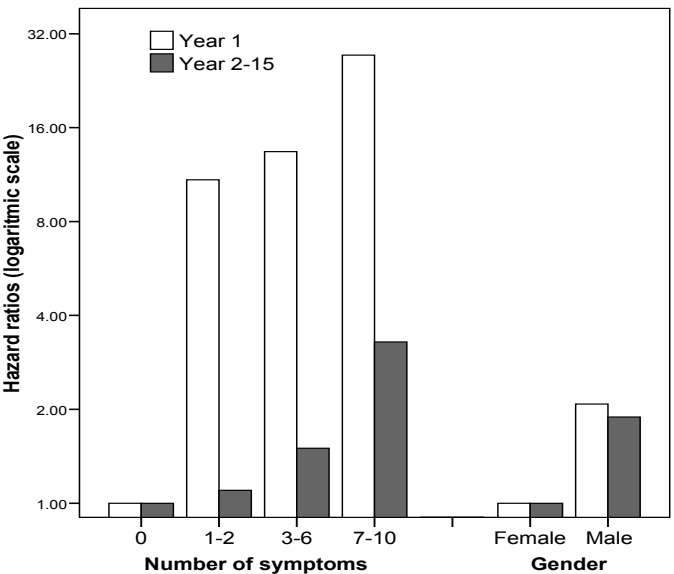
Figure 2. Relative mortality risks (hazard ratios). Since hazard ratios show relative risks, a logarithmic scale is used.

Conclusions

When mortality is related to baseline information, relative risks show the *average* correlation over the entire follow-up time. Results suggest instability of predictors over time. Especially in the oldest parts of the population, predictors that can change rapidly (e.g., health) are strongest for the short term, revealing a lower average mortality risk for longer follow-ups. Rather stable variables (e.g., gender) are less affected by the length of follow-up.

4.2 Study II. Complex health problems in the oldest old in Sweden 1992–2002

Studies of population health trends have predominantly investigated specific conditions, studied one at a time. However, health problems are often inter-related and exist simultaneously in late life. Individuals with health problems in several domains present a special challenge to care services. Studies of complex health problems have mostly been cross-sectional at one point in time. Few studies are based on representative samples, including persons living in institutional-care facilities, and cognitively impaired and proxy-interviewed persons.

Aim

The aims of the study were to
- a) identify prevalence rates of serious problems in three health domains (diseases/symptoms, mobility, cognition/communication) in two representative samples of the Swedish population aged 77 years and older.
- b) study changes between 1992–2002 in the prevalence of individuals having serious problems in no, one and two/three domains (= complex health problems).

Methods

The study was based on the SWEOLD surveys conducted in 1992 (n = 537) and 2002 (n = 561) and comprised a representative sample of the Swedish population aged 77 and older. Variables used in the analyses included measures of symptoms/diseases, mobility, and cognition/communication, the number of domains with serious health problems, the survey year, and the covariates age, gender, and years of education.

Prevalence rates for 1992 and 2002 were derived regarding
- a) problems in the single items included in the three health domains.
- b) individuals classified as having serious problems in each of the three included health domains, and
- c) individuals having serious problems in 0, 1, or 2-3 domains.

Binary logistic regressions were performed in order to calculate odds ratios for the difference in prevalence rates between 1992 and 2002, with and without controlling for differences in the age and gender distribution. Ordered logistic regression was used to analyze the impact of the survey year on the odds of having serious problems in additional domains as well as the impact of possible confounders (age, gender, education). Ordered logistic regressions allows the use of a dependent variable with several categories when there is no assumption about linearity, i.e., the intervals between categories (serious problems in 0, 1, or 2-3 domains) are not necessarily equal.

Results

In all three health domains serious problems increased significantly between 1992 and 2002. The increase was highest for multiple diseases/symptoms (from 21 % to 32 %). Of the 12 items in this domain, 9 items increased, both symptoms, (e.g., pain, fatigue/sleeplessness) and diseases (e.g., severe myocardial infarction/other heart problems). The increase of multiple diseases/symptoms remained significant after controlling for different age and gender distributions in the two surveys. No specific symptom/disease explained the increase of serious problems.

When considering the *number of domains* with serious problems (*Figure 3*) results showed a significant increase in the prevalence of having serious problems in one domain (from 25 % to 31 %), as well as having complex health problems (from 19 % to 26 %). These trends persisted when controlling for different age and gender distributions.
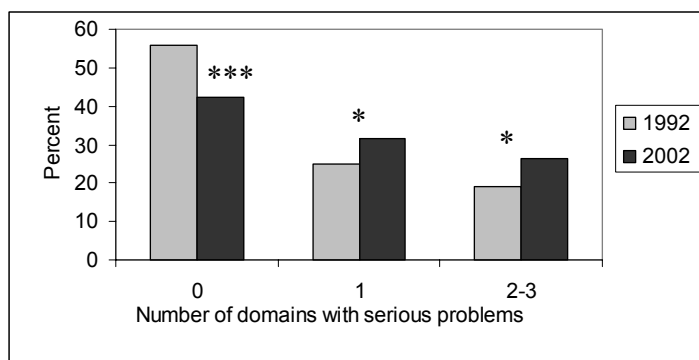

Figure 3. Prevalence of individuals with serious problems in 0, 1, or 2–3 health domains in 1992 and 2002. Significance testing is based on binary logistic regression with control for age and gender (*** $p<0.001$;* $p<0.05$).

Compared to 1992, the odds of having serious problems in additional domains in 2002 was 71 percent higher, controlling for age, gender, and years of education, all of which are factors known to be related to health. Controlling for age, education, and survey year, women had 64 percent higher odds of having additional severe problems compared to men. For every year of age, the odds of having additional serious problems increased by 13 percent. By contrast, for every additional year of education the odds decreased by 11 percent.

Conclusions

Results suggest a worsening of health during the 10-year period and an increase of complex health problems, with and without control for changes in age and gender distributions. Concerning the debate of whether subsequent cohorts of elderly people tend to have better health, this study suggests that

severe and complex health problems among the oldest old increased in Sweden between 1992 and 2002.

4.3 Study III. Complex health problems and mortality among the oldest old in Sweden – Decreased risk among men between 1992 and 2002

A general decline in mortality in older ages has been reported for most low-mortality countries during the past decades. However, it remains unknown whether this is a universal trend in the older population or if there are specific subgroups that have experienced a more favourable development than others. Little is known, especially, about trends in mortality risks among the most vulnerable subset of the oldest old, experiencing serious problems in several health domains (= complex health problems).

Aim
The aims of the study were to
  a)   investigate change between 1992 and 2002 in the relation of complex health problems and mortality in a representative Swedish sample of people aged 77 and older.
  b)   examine if there were different trends in the relation of complex health problems and mortality for different subgroups in terms of gender, education and age.

Methods
The study was based on two cross-sectional population-based surveys (SWEOLD) from 1992 (n = 537) and 2002 (n = 561), including representative samples of the Swedish population aged 77 and older. Dates of death were obtained from the national death registry. The impact of complex health problems on four-year mortality was analyzed using Cox proportional hazard regressions. Other covariates were age, gender, having basic education, and the survey year.

Results
Complex health problems were strong predictors of four-year mortality in both 1992 and 2002. When both survey years were collapsed, those with serious problems in one domain had a 2.2 times higher mortality risk compared to individuals with no serious problems in any domain, and those with complex health problems had a 4.1 times higher risk. Men had a 62 percent higher risk compared to women. Mortality risk increased with age, approximately 10 percent for every year. Education was not significantly related to

mortality when taking health problems into account. Mortality decreased by 20 percent between 1992 and 2002, independent of all other variables.

A closer look at subgroups indicated that gender differences in the association of complex health problems and mortality changed over the 10-year period. The mortality risk among people with serious problems in no or one domain did not change significantly during the 10-year period. By contrast, among individuals with complex health problems, men's mortality risk decreased considerably, whereas women's risk did not change significantly. Thus, in 2002, gender differences in mortality risk were almost eliminated among the most vulnerable older adults. The decrease of the mortality risk among men with complex health problems accounted for most the general decrease in mortality in 2002 compared to 1992.

Conclusion
One possible explanation for the substantial decrease in mortality risk among men with complex health problems during the 10-year period may be the decrease in cardiovascular mortality that has occurred in recent years, in Sweden and other countries. Since cardiovascular disease is more common among men than among women, the potential gains from healthcare interventions and progress in treatment may be larger for men (Rosén & Haglund, 2005). Other possible contributing factors could be convergence in risk-factor behavior among men and women (OECD, 2007) or gender inequities in access to healthcare (NBHW, 2004b; Shaw et al., 2004; Swedish association of local authorities and regions, 2007b).

4.4 Study IV. According to need? Predicting the amount of municipal home help allocated to elderly recipients in an urban area of Sweden

Although different welfare states have different approaches guiding welfare policies for their elderly citizens, they share the increasing gap between care needs and available care resources. Given the cutbacks which have been carried out in the Swedish welfare state it is of interest to evaluate present factors that influence the allocation of home help services.

Aim
The study identified the predictive value of need factors versus sociodemographic, environmental (social and physical), and structural factors associated with the amount of home help allocated to recipients in an urban community in Sweden.

Methods
Data originated in the population-based care and services section of the 2002 Swedish National Study of Aging and Care – Kungsholmen (SNAC-K). All home help-recipients (aged ≥ 65) living in an inner-city district of Stockholm (Kungsholmen) (n = 943) were analyzed with ordinary least square regressions to identify predictors of the number of hours of home help. Available predictor variables concerned physical and cognitive functioning (ADL and IADL limitations, cognitive impairment), psychiatric symptoms, sociodemographic characteristics (age, gender, personal income), characteristics of the physical and social and environment (housing accessibility, housing adaptations, sheltered accommodation, regular access to informal care, cohabitation), and the specific care manager who made the assessment.

Results
Physical and cognitive need indicators were the strongest predictors of more hours of home help. For every additional IADL limitation, the amount of home help increased by nearly 40 percent. Psychiatric symptoms, on the other hand, were not related to hours of home help. The addition of sociodemographic, environmental, and structural factors contributed only marginally to the explained variance. Controlled for all other variables, hours of home help increased by 2.5 percent for every five years of age. Coresiding persons had 28 percent less home help compared to those living alone. Personal income, informal care, and housing conditions were not significant predictors.

About half of the variation of hours of home help between recipients was explained by the variables available. Variations regarding the allocation decisions of different care managers accounted for 5 percent (ns) of the unexplained variance when considering age, and physical and cognitive impairment.

Conclusions
Physical and cognitive need criteria were the dominating predictors of the amount of home help allocated among recipients. Psychiatric symptoms, on the other hand did not seem to affect needs assessments. The slightly positive effect of age on the amount of home help could indicate some kind of weakness not captured by the other indicators of functional ability or an age bias in needs assessment. Whether or not fewer hours of home help for coresiding persons can be seen as unfair would require information about the health status of the coresiding person.

5 Discussion

The study of health and mortality and their correlates in elderly populations are central issues in gerontological research as they provide insight into how increasing numbers of elderly people affect resource needs in healthcare and long-term care. There were two general aims in this study: One purpose was to investigate mortality and health trends among the oldest old and factors related to the receipt of home help services in Sweden during the 1990s and beginning of the 2000s. A second aim was to investigate how methodological decisions may affect results when studying mortality and morbidity in older populations. In the following, main findings and aspects of generalizability are discussed relative to the aims of each specific study.

5.1 Methodological factors affecting morbidity and mortality

5.1.1 Generalizability of the findings

5.1.1.1 Do samples represent the population?

SWEOLD. The SWEOLD surveys comprised approximately 1 per thousand of the Swedish population aged 77 years and older. Institutionalized persons and proxy interviews were included. Age and gender distributions reflected national figures for the survey waves in 1992 and 2002 (Thorslund et al., 2004). Therefore, health and mortality patterns can be expected to be representative for the general Swedish population aged 77 and above.

Tierp. Representativeness concerns both the question of whether the population of Tierp represents the rest of Sweden, and whether the study sample represents the total elderly population of Tierp. In this rural community the proportion of the population aged 65 years and older was somewhat higher than in the country as a whole. This reflects the urbanization of people in working ages and should not affect patterns of mortality in the older population. The rather homogenous socioeconomic position in Tierp, with former blue-collar workers and lower white-collar workers being the dominating

groups, may be associated with a higher prevalence of health problems compared to the national average for people aged 75 and older. The restriction of the baseline data to community-dwelling persons, on the other hand, probably entailed a somewhat healthier and younger sample compared to the total population 75 years and older in Tierp. Even though these deviations may affect the prevalence of health problems, there is no reason to believe that they affect the general pattern of change in predictor strength at different time intervals after the baseline survey.

Kungsholmen. SNAC-K comprised all home-help recipients aged 65 and older in an inner-city district (Kungsholmen) of Stockholm. One question is whether the older population of Kungsholmen is representative of the rest of Sweden with respect to factors related to need for eldercare. Another question is whether the public eldercare system in Kungsholmen is representative of eldercare in other parts of Sweden.

While the percentage of the population aged 65 years and older was similar, the proportion of people above the age of 80 was somewhat higher in Kungsholmen than in the rest of Sweden. Women, particularly women who never married and were wage earners all their lives, and highly educated people were also overrepresented (Larsson, 2004). The net effect of these sociodemographic characteristics on need factors for home-help services is not clear. On the one hand, women and older people are more likely to have functional limitations and to live alone. On the other hand, higher education is associated with lower levels of functional limitations.

The coverage rate for home-help services in 2002 was higher in Kungsholmen compared to the average for the country. Swedish municipalities have considerable freedom in determining the type and mix of eldercare services as well as the level of services provided, and there are substantial local variations in the availability of care and services for elderly people (Trydegård & Thorslund, 2001). One study, linking individual data on need indicators with coverage rates of home-help services, however, found that municipal differences in coverage rates largely vanished when taking into account local variations in need indicators (Davey et al., 2006). The extent to which assistance decisions reflect differences in guidelines and resources between municipalities has to be further explored.

Even if similar factors could be assumed to account for the relative distribution of resources among recipients, the strength of predictors may vary across communities. In addition, even when predictors have similar strength, the absolute number of hours of home help received may differ between municipalities.

5.1.1.2   Is nonresponse a problem?

Nonresponse is a particular problem in studies of old people as it is likely to be systematically related to indicators of poor health. Accordingly, the sys-

tematic loss of individuals with poor health leads to an underestimation of health problems in elderly populations.

Tierp. In the Tierp study, 3.9 percent of the sample refused to participate. This low nonresponse rate is not likely to have a significant effect on the prevalence rates of the analyzed variables. Nor is it likely to affect the temporal pattern of relative mortality risks at different intervals after the interview in 1986.

SWEOLD. In both surveys, nonresponse was relatively low, although it increased from 4.6 percent in 1992 to 11.5 percent in 2002. Conclusions about change in the prevalence of complex health problems over the 10-year period may primarily be affected by the *change* in nonresponse rates. Assuming nonrespondents had more health problems than respondents, the increase in nonresponse is more likely to lead to an underestimation of the increase in complex health problems among the oldest old. Response patterns may also depend on the mode of interview (Walsh & Khatutsky, 2007). The distribution of direct, proxy, and telephone interviews changed only marginally between the two survey waves.

SNAC-K. While nonresponse in population-based interviews may be systematically related to characteristics of the individuals included in the samples, nonresponse (10.4 %) in register data used in SNAC-K rather occurred when care managers failed to fill in the questionnaires. Dropouts were not associated with any specific characteristics of home-help recipients and thus were unlikely to affect predictors of the amount of home help allocated to recipients.

5.1.2 Duration of follow-up and mortality predictors

Studies analyzing factors associated with mortality have revealed considerable differences in the predictive strength of similar indicators. Study I adds to the literature by showing that the length of follow-up time may explain some of the differences found in predictors and predictor strength when comparing different mortality studies. This exemplifies the effect of methodological decisions on results (Manton, 1990b).

All the health variables studied, living conditions, and life satisfaction were much stronger predictors of mortality during the first 1 or 2 years of the 15-year follow-up than during later years. Gender, social contacts, and mental status were about equally correlated to mortality throughout the period. In general, there are several conceivable explanations for change in the predictive strength of a variable over time.

Duration effects: Actual changes in the strength of a predictor. A predictor itself may become more or less correlated to mortality over time (Blossfeld & Rohwer, 1997). For example, the association of smoking or diabetes with mortality probably increases over time. Acute health conditions such as a heart attack, on the other hand, may become less related to mortality the longer they date back. No information about specific diseases was included in Study I. Instead, a summed index of the *number* of symptoms combined a variety of different symptoms.

Age effect: Different predictor strengths at different ages. The effect of a predictor variable may also change with age (e.g., the effect of a femur fracture may be more serious at older age). In Study I, a possible age effect on the changes in predictor strength was controlled for by adding an interaction term between age and each of the predictor variables. This did not change results.

Period and cohort effects: Secular changes in medical care and lifestyle. Developments in medical care and changing lifestyles may result in period and cohort effects. Since only one study population was followed over time in Study I, there is no cohort effect. Period effects, such as progress in the treatment of specific diseases, are not likely to play the major role for the observed decrease in strength of predictors over time. This is due to the combination of a variety of different symptoms in the summed index.

Selective mortality. Selective mortality is an important consideration when researching very old people, as selection may influence the relative mortality risk over time (Hertzog, 1996; Markides, 1989). Early deaths among the least robust individuals may leave a healthier subsample for which predictors are less predictive. Gender differences in mortality, for example, appear to decline at high ages (Markides, 1989). However, in Study I relative mortality risk differences between men and women remained nearly unchanged throughout the study period, thus indicating that selective mortality seems not to play a major role in the observed decrease of the predictive strength of some variables.

Instability of predictors: Unmeasured change. Another possible explanation for decreasing mortality risk differences between categories of variables over time is instability of predictors during the follow-up period. As individuals change status (e.g., health) after the interview, the baseline information gets less and less accurate as time passes. Thus, in Study I, health variables that are particularly unstable will have the strongest correlation on a short follow-up period. The effect shown for the first period is most probably closer to the "true" effect of the independent variables. The basically constant effects of gender, social contacts, and the nurse's global assessment of mental status

may be due to the fact that these variables either do not change at all (e.g., gender), or they change more slowly than health indicators.

Previous studies have basically centered on the refinement of measures and statistical methods. Few other studies have examined temporal changes in mortality predictors. One study compared the strength of mortality predictors 5 years, 10 years, 15 years, and 20 years after baseline. Using logistic regression, not taking the timing of deaths during follow-up into account, different patterns were found for different variables, ages, and gender (Ljungquist et al., 1996). However, this approach does not reveal the change of predictor strength *during* the follow-up period (i.e. between baseline and year 5, between years 5 and 10, and so forth). Our results support speculations of Ferraro and Kelly Moore (2001) that long follow-up periods tend to result in weaker effects of baseline self-rated health. Results concerning mental status and social contacts are in line with analyses of data from the Berlin Aging Study that suggested that the effects of psychological risk factors did not change over time. Based on follow-up periods that ranged from 3 to 6 years the correlation between well-being and mortality did not change over time (Maier & Smith, 1999), which conflicts with our findings of change in the predictive strength of life satisfaction. However, the two constructs, were quite different. In addition, a possible change in the predictive strength of well-being may not be discernable when comparing follow-up periods ranging from 3 to 6 years.

No precise recommendations can be made for the follow-up time of studies investigating predictors of mortality. Study I suggests that especially in very old populations, unstable health variables reveal considerably stronger correlations for the short term, probably closer to "true" predictor strength. A lower average mortality risk is revealed for longer follow-ups. When comparing studies on predictors of mortality it is important to consider different factors that may be associated with change in the predictive strength of a variable over time.

5.2 Increased prevalence of and survival with complex health problems

Studies of health trends in older populations have predominantly focused on specific conditions, studied one at a time. As health problems often exist simultaneously and are interrelated (Fillenbaum et al., 2000), attention to complex health profiles has been increasing during the last decade. As discussed in 2.3, the accumulation of health problems itself presents a challenge to individuals and their families, the care personnel involved, and for social policy concerned with medical care and social services (Boyd et al., 2007; Ferrucci et al., 2004; Fried, 2003). Studies capturing multidimensional health

problems in different ways have mostly investigated prevalence rates at one point in time.

Studies II and III add to the literature by revealing change in prevalence rates and survival with serious problems in several health domains between 1992 and 2002. A measure of complex health problems was used that included serious problems in three health domains. Complexity was defined as having serious problems in at least two of three health domains including diseases/symptoms, mobility, and cognition/communication. In order to facilitate nationally representative estimates that would be useful for developing social policy, only items available for all respondents were used, and that included people who were interviewed by proxy and those living in institutional-care facilities.

According to Study II, the proportion of persons with serious problems increased significantly in each of the three health domains. The greatest increase occurred in multiple diseases/symptoms, for which the increase was independent of slightly different age and gender distributions between the two survey years. Most other Swedish and international studies agree on an expansion of the prevalence of symptoms and diseases among the oldest old during the 1990s (Crimmins, 2004; Parker & Thorslund, 2007; Rosén & Haglund, 2005). The trends in functional limitations seen in the international literature are less consistent and seem to vary across age groups, gender, and measurements used (Parker & Thorslund, 2007). With regard to trends in cognition, there is a lack of evidence concerning changes in the incidence of dementia. However, some increases in prevalence rates have been ascribed to increased survival among individuals with dementia (Wimo et al., 2003; von Strauss et al., 1999). In Study II, the increase in the prevalence of persons with poor cognition/communication skills lost significance when controlling for differences in age and gender distributions between survey waves. This may reflect the older mean age of the 2002 sample and increased survival among individuals with severe dementia or other health problems associated with proxy interviews.

With respect to the number of health domains with serious problems, the largest change was the decrease of individuals who had no serious problems in any of the three domains. Correspondingly, the proportion of persons with serious problems in one domain and those with complex health problems increased significantly. The results remained stable when adjusting for the different age and gender distributions in the two survey waves. There is only limited evidence concerning trends that capture multidimensional health problems. Studies restricted to chronic conditions/diseases reported an increase in the prevalence of people reporting at least three chronic conditions/diseases in Sweden between 1980 and 2002 in the age group 65–84 (Rosén & Haglund, 2005) and in the U.K between 1991/92 and 1995/96 in the age group 65–69 (Jagger et al., 2007). Health trends based the ULF survey using the Statistics Sweden's health index (combining measures of gen-

eral self-rated health, mobility, and chronic illness), on the other hand, revealed a decline in the prevalence of severe ill health among people aged 65–84 between 1975/79 and 1995/99. Another study based on ULF that also included persons aged 85 and older found no change in the prevalence of one or more severe health problems (including impaired mobility, severe pain, impaired vision, severe trouble from nervousness and anxiety) between 1988/89 and 2002/03. There are several possible explanations for different health trends seen in SWEOLD and ULF. Beyond differences in measures and time periods, trends based on the Statistics Sweden's health index did not include the oldest old. There are indications that the prevalence of ill health in the highest surveyed age group in the ULF studies is underrated (Lagergren, 2004, 2005).

When analyzing self-reported health items, there is always uncertainty about the extent to which changes over time must be attributed to changes in reporting (e.g., greater awareness, social acceptance, more frequent diagnosing of health problems) and environmental modifications. In Study II items were chosen for inclusion in the measure of complex health problems on the basis of minimal susceptibility to environmental change and changes in expectations; e.g., mobility was analyzed instead of the widely used ADL.

Based on the finding of increased prevalence rates of complex health problems between 1992 and 2002 Study III investigated possible changes in the relation of complex health problems and mortality. Results showed that complex health problems were a strong predictor of 4-year mortality, both in 1992 and 2002. However, the mortality risk generally decreased by 20 percent during the 10-year period. No single health item explained the decrease in mortality risk.

A closer look at subgroups of the oldest old indicated that men with complex health problems accounted for most of the decrease. Since women's mortality risk remained almost unchanged during the 10-year period, the gender difference in mortality risk was almost eliminated among individuals with complex health problems in 2002.

Several OECD countries have reported a narrowing of the overall gender gap in mortality since the mid-1980s (OECD, 2007). In Sweden between 1992 and 2002, the survey years of Study III, the average life expectancy at 65 years increased by 0.7 years for women and 1.4 years for men (Statistics Sweden, 2007b). Changes in mortality risk differences among specific categories of men and women (e.g., those with complex health problems) could partly account for the narrowing of the overall gender gap in mortality reported in official statistics.

The mortality risk decreased only among men with complex health problems but remained rather unchanged for healthier individuals. This suggests that progress in medical care may explain some of the decrease in mortality risk among the most vulnerable men (Rosén & Haglund, 2005). Accordingly, some of the increase in the prevalence of complex health problems

between 1992 and 2002 may be explained by "sick survivors". It remains to be seen how far the trend of an increase in complex health problems is attributable to increased survival with diseases/symptoms, earlier diagnosis, or to cohort differences in the underlying disease-disability processes.

One explanation for the decrease in mortality risk only among the most vulnerable *men* could be that progress in medical interventions primarily concerned health problems that are more common among men, such as cardiovascular disease. Thus, potential gains from healthcare interventions and progress in treatment achieved in the 1990s may have been larger for men than for women (Persson et al., 2006; Rosén & Haglund, 2005).

Another possible contributing factor to the observed convergence in mortality risk of men and women with complex health problems could be a convergence of risk-factor behaviors (e.g., smoking) (OECD, 2007). The increased prevalence of smoking in subsequent cohorts of women has thus far only led to a moderate increase of smoking prevalence among very old women. The inclusion of information about actual or previous smoking habits in Study III did not affect results.

Consistent with previous research on factors affecting health there were independent significant effects of gender, age, and education on the odds of having complex health problems (Crimmins & Saito, 2001; Jagger et al., 2007; Leveille, Resnick, & Balfour, 2000; Marengoni, 2008; Melzer et al., 2000; Parker, Thorslund, & Lundberg, 1994).

Age did not affect the association of complex health problems and mortality; that is, having complex health problems was about equally related to mortality throughout all ages above 77 years. Younger age groups may show different patterns. For example, a study of men aged 65 and above found that the association between frailty and mortality was stronger in younger men than in men above the age of 80 (Cawthon et al., 2007). However, this was a clinical study based on a community-dwelling sample with additional eligibility criteria and results may therefore differ from population-based results.

Socioeconomic inequalities in mortality have been found to persist even among older people (Bassuk, Berkman, & Amick, 2002; Huisman et al., 2004). Study II confirmed the well-known socioeconomic gradient in health outcomes (Huisman et al., 2003). Fewer years of education were associated with higher odds of having complex health problems. However, when taking health problems into account, educational level was not significantly related to mortality (Study III). Thus, our results, like those of an American study (Clark et al., 2007), suggest that less educated people are at greater risk of having complex health problems. However, once people have complex health problems there was no evidence of educational differences in mortality risk.

5.3 Emergence of a very frail and old population?

As described in 1.3, several hypotheses concerning the relation of mortality and morbidity patterns in the older population have figured in the literature (Fries, 1980, 2003; Manton, 1982; Manton & Vaupel, 1995; Olshansky et al., 1991; Robine & Michel, 2004). Since increased prevalence and survival with complex health problems reflects an increase in serious morbidity, Studies II and III support neither the compression of morbidity nor the dynamic equilibrium hypothesis.

Longer survival in spite of complex health problems suggests that the frail fourth age may have been prolonged, at least among men. This development probably reflects the medical paradox: As more severely ill old people stay alive, the prevalence of morbidity in the older population will increase. During the 1990s, progress in the treatment of cardiovascular disease contributed substantially to prolonged live expectancy (Boersma et al., 2003; Topol, 2004). In particular, survival among even very old people with stroke and cardiac infarct has improved (Rosén & Haglund, 2005). Many of those who survive medical events today will, however, live with chronic conditions and be likely to contract other diseases and functional impairments (Persson et al., 2006; Rosén & Haglund, 2005; Waidmann & Liu, 2000).

Health trends may vary with respect to health components, age groups, study periods, and countries. Although Studies II and III found an expansion of complex health problems between 1992 and 2002 among the oldest old in Sweden, trends may differ for other health indicators, younger age groups, other time periods, and countries. In addition, correlations between different health components also change (Parker & Thorslund, 2007). For example, several researchers found that diseases became less closely linked to disability during the 1990s (Crimmins, 2004; Jagger et al., 2007; Parker et al., 2005; Rosén & Haglund, 2005; Spillman, 2004). Increased survival among the oldest old with complex health problems may reflect the emergence of a very frail old population. As proposed by Robine and Michel (2004) this will probably be discernable first in countries with a high life expectancy.

5.4 Determinants of the amount of home help

Exploring trends in mortality and morbidity in the older population provides insight as to how the increasing number of older people is related to the development of potential needs for healthcare and social services. As there is no standard instrument for assessing elderly people's care needs it is important to identify the factors that influence the allocation of public eldercare in order to have an informed debate about which kinds of care needs should be prioritized when facing limited public resources. In Sweden, care managers

(biståndsbedömare) delegated by the municipal social welfare committee, act as gatekeepers and decide whether a person will receive assistance, and if so, how much and what kind.

The vast majority of previous research regarding the assessment procedure focused on predictors of entry into the municipal home-help system. Study IV adds to the literature by focusing on factors related to the amount of services among recipients. The study elucidated the role of need indicators versus sociodemographic, environmental, and structural factors in determining resource allocation among those elderly people who both applied for and were approved to receive home-help services in an urban community.

Findings suggest that similar factors previously reported to be associated with the overall use of home-help services (Larsson, 2004; Larsson & Thorslund, 2002; Sundstöm & Hassing, 2000) also predicted the amount of help allocated to recipients. Consistent with studies on the overall receipt of home help (Larsson, 2004; Larsson, Thorslund, & Kåreholt, 2006), need indicators, as measured by physical functional and cognitive impairment, were the strongest predictors of the amount of home help received.

Psychiatric symptoms, on the other hand, were not related to the amount of help received when taking physical and cognitive functioning into account. This is consistent with a previous cross-sectional study identifying predictors of the overall receipt of municipal home help in the mid-1990s in the same geographical area as Study IV. The authors found no effect of depressive symptoms among highly educated people who lived alone and among cohabiting people of any education. Among people with lower levels of education who lived alone, however, the presence of depressive symptoms decreased the likelihood of receiving home help, indicating that this could be a vulnerable group with unmet needs (Larsson et al., 2004). A later study in the same area that analyzed subsequent entry into the home help system between 1994/96 and 2000 found a slight significant increase of the likelihood of receiving home help for each additional depressive symptom (Larsson et al., 2006). Differing results regarding the impact of depressive symptoms on the overall receipt of home-help services may depend on the different study designs.

The slightly positive effect of age on the amount of home help could indicate some kind of weakness not captured by the other indicators of functional ability or an age bias in needs assessment.

While gender was not related to the amount of help allocated, coresiding people received significantly fewer hours when need indicators were taken into account. Results confirm earlier analyses of predictors of the overall receipt of home help, showing that the structural characteristic of living alone, rather than gender was of importance for the likelihood of receiving home help (Larsson & Thorslund, 2002; Thorslund, Norstrom, & Wernberg, 1991). Since about 90 percent of the home-help recipients in Study IV lived

alone, this applies to the present sample as well. Whether or not the fewer hours of home help for co-residing persons can be seen as unfair would require information about the functional ability of the spouse or other coresiders.

Personal income and access to informal care were not significant predictors of the amount of home help allocated to recipients. This may be an effect of the maximum fee of 1570 SEK per month in 2002 in the municipality of Stockholm, irrespective of the number of hours provided. However, no information on assets or total household income was available to give a more complete picture of recipients' resources. Among elderly people outside the public realm an increasing duality in sources of care has been traced: market solutions for the better off and more family care for the less well off. This may be a combined effect of raised thresholds for receiving home help, higher fees and changes in the nature of the help available (Palme et al., 2003).

Characteristics of the physical environment were not related to the amount of help received in Study IV. As elderly people with disabilities in Sweden may receive needs-tested state-paid housing adaptations, this was probably due to more prevalent housing adaptations among people with most disabilities. Also, individuals residing in sheltered accommodation (servicehus) did not receive significantly more hours of help.

Previous research reported considerable variations in assistance decisions between municipalities as well as between care managers (Lagergren & Johansson, 1998; Trydegård & Thorslund, 2003). In Study IV, individual variations in allocation decisions between care managers did not significantly account for the variation in the amount of home help allocated when physical and cognitive impairment and age were taken into consideration.

Need indicators as measured by physical and cognitive impairment explained nearly half of the variation in the amount allocated among recipients. The addition of sociodemographic, environmental, and structural factors contributed only marginally to the explained variance. Unexplained variation in the amount of home-help services allocated could be related to unmeasured characteristics of the care recipients and their living conditions (e.g., health of spouse) or due to inconsistencies in the decisions made by individual care managers. It is important to consider that the dependent variable was the care managers' decision about the suitable number of hours of help. Thus, Study IV provides no information about how much, and above all, what kind of help recipients actually received.

Findings from Study IV suggest that resource allocation in the Swedish home-help system in the early 2000s, besides cognitive impairment, predominantly focused on physical care needs that arise from dependence in IADLs and ADLs. Psychiatric symptoms, such as anxiety and depressive feelings, relate to an individual's need for psychological security and sense of coherence. The narrow prioritization of care needs related to physical and

cognitive impairments within public eldercare has been questioned (Westlund & Sjöberg, 2006).

5.5 Implications and future perspectives

Increased survival even among very old people with complex health problems can be considered a sign of success for the welfare state. If this trend persists, however, there are broad ramifications concerning resource needs for various healthcare and social services, the collaboration between service providers and the discussion regarding the scope of public responsibility for care and services.

5.5.1 Care resources

Publicly provided care includes services ranging from highly specialized medical care to rehabilitative and long-term care, including institutional care and social services. The increased prevalence of serious problems in one health domain and of complex health problems, as revealed in Study II probably implies additional resource needs that concern both manpower resources and special competence.

In regard to medical care, the importance of access to geriatric expertise has been emphasized (Akner, 2004a). With respect to the home-help system, resources have increasingly been focused on people with the most extensive care needs. Recipients today comprise a very vulnerable group who often need help with personal as well as rehabilitative and medical care (Larsson, Silverstein, & Thorslund, 2005; Thorslund et al., 2001). SWEOLD data also indicate an increased care load among home-help recipients. Among recipients, the proportion of persons with complex health problems increased from 27 percent to 42 percent between 1992 and 2002 (according to unpublished analysis for Study II). Better medical treatment and assistive technology will probably not be able to fully counterbalance the increased need for medical services and long-term care. The targeting of individuals with the heaviest care needs has meant that the demands on the staff providing in-home care have increased from housewife skills to medical skills (Larsson et al., 2005).

The increased complexity of care needs among home-help recipients also means that needs assessments have become more complex and have to take into account a variety of factors. At the same time, assessing need is often intertwined with an assessment of available resources (Lindelöf & Rönnbäck, 2004; Westlund, 2001). In the absence of official guidelines, budgetary restrictions have in many cases led to great demands on the care managers to give priority to certain individuals and needs (Thorslund, 2005).

5.5.2 Collaboration between service providers

In Sweden, county councils are responsible for most medical care, and municipalities are responsible for long-term care and social services. People with extensive needs for health and social services represent a special challenge to care systems that are divided into several disciplines and administered by several authorities. Moreover, among the most vulnerable older adults the ability to navigate the healthcare system without help may be limited (Brayne et al., 2001; Fried et al., 2004).

In Sweden, as in other countries, the medical care system has succeeded in meeting the episodic needs of healthy people who experience acute illness and injuries. A mismatch has been identified between the acute and specialized care orientation of the medical care system and the complex chronic care needs often associated with long periods of frailty and high use of a variety of services (Akner, 2004b; Boyd et al., 2007; Gurner & Thorslund, 2001, 2003; Lunney et al., 2002). Researchers in several countries have recognized an increased need for coordination and collaboration between different providers of medical care and social services (Boyd et al., 2007; Ferrucci et al., 2004; Fried, 2003; Gurner & Thorslund, 2003). Discharge from the hospital has been identified as one critical point when patients may between the cracks caused by lack of information and cooperation with primary healthcare and the eldercare system (Gurner & Thorslund, 2003).

5.5.3 The scope of public responsibility

A stricter interpretation of need in the municipal eldercare system coincided with signs of deteriorating health in the elderly population in terms of single health dimensions (Parker et al., 2006; Parker & Thorslund, 2007; Rosén & Haglund, 2005) as well as complex health problems (Study II and III). Restricting access and focusing resources on the most frail elderly people raises the question about the future scope of public responsibility.

Several Swedish studies have demonstrated that family involvement in the care of elderly people increased in parallel with cutbacks in formal care provisions (Johansson & Sundström, 2002; Johansson et al., 2003; Larsson, 2004, 2006; Mossberg Sand, 2005; NBHW, 2004a; Sundström et al., 2002; Szebehely & Trydegård, 2007). Change in the sources of help have been found to follow a class-related pattern: Less-educated elderly people are more likely to receive assistance from family members outside the household whereas more educated people tend to replace public eldercare with services paid out of pocket (Szebehely, 2003). This pattern appears to have strengthened since the late 1980s (Szebehely & Trydegård, 2007).

Beyond providing help with practical tasks, adult children in particular act as advocates to help elderly people obtain formal services (Langa et al., 2001; Lingsom, 1997). Especially for the most vulnerable elderly people

informal carers assist in navigating the heathcare system and act as coordinators between different care providers (Gurner & Thorslund, 2003).

Increased pressure on the public eldercare system has also affected official policy. A revision of the Social Services Act (Government Bill, 1996/97:124) emphasized municipal responsibility to support persons who provide informal care to elderly persons. Although governmental funding of support services for informal caregivers has increased considerably since the late 1990s (Swedish association of local authorities and regions, 2007a) support for family caregivers is still a very small part of the formal eldercare system (Jegermalm, 2005). Swedish researchers have also begun to examine the role of voluntary organizations in eldercare (Jeppsson Grassman, 2005).

Financially constrained public resources meeting the extensive care needs of a growing proportion of elderly people are an increasingly common scenario in most industrialized countries. However, this is a particular challenge for the Scandinavian welfare state model, being committed to an official policy of universalism, extensive coverage rates (Government Bill, 1997/98:113) and no legal responsibilities of adult children for their aged parents (Sundström & Johansson, 2004). It has been argued that a significant shift away from universalism and equality promotion towards unpaid care and more private market-based care services has lead to more segmented welfare. This may imply a departure from the Scandinavian model (Szebehely, 2005b).

5.5.4 Future health trends and care needs

Health trends among the oldest old, the fastest growing sector of the population, have received much attention because of the rising costs of healthcare, long-term care and social services. Most health trend studies have investigated single health and function variables. Diverging results in these studies may be explained by the use of different health indicators, the composition of the study population in terms of age, gender, education, and the inclusion or exclusion of institutionalized individuals and proxy interviews. Up to now there is limited evidence concerning trends that capture multidimensional health problems. Studies II and III suggested a measure of complex health problems that captures serious problems in different health domains and reflects the need for care from different providers.

Several important questions arise from the results suggesting an increase in complex health problems among the oldest old between 1992 and 2002. One obvious question is if the trend of an increase in complex health problems also applies to other low-mortality countries.

As there is no consensus regarding the definition of multidimensional health problems, would the findings persist when combining other health domains, e.g., including a psychosocial dimension? Research on the general population has shown that different kinds of welfare problems are likely to

cluster, e.g., economic hardship, labor market marginalization, psychosocial strain and health problems have been found to be interconnected (Halleröd & Larsson, 2008). Expanding on a broader notion of vulnerability beyond health, what would the development have been when studying a broader range of welfare problems, e.g., economic hardship and social isolation? Would the proportion among the oldest old experiencing serious problems in several welfare dimensions simultaneously also have increased?

Beyond investigating if observed increases in complex health problems among the oldest old hold for other countries and other indicators, we must follow the trend to see if it persists. The availability of only two time points in Study II limits the generalizability of the findings. One study investigating ADL limitation among elderly people between 1980 and 2005, for example, found a positive development over the entire study period. Most of the improvement, however, occurred during the 1980s and the beginning of the 1990s followed by an upswing in limitations after that (Parker et al., 2008).

Both mortality and morbidity vary across different categories of the population. In Study II, consistent with previous research, female gender, higher age, and fewer years of education increased the odds of having complex health problems. Accordingly, projections about the future size and composition of the older population, and thereby also the prevalence of health problems, differ along with the characteristics included in calculations. Swedish and Dutch projections maintain, for example, that the expected increases in severe ill health as a result of the aging population may, to some extent, be counteracted by the increasing proportion of individuals with higher levels of education in subsequent cohorts. These tended, on average historically, to be healthier than people with lower levels of education (Batljan, 2007; Joung et al., 2000). Study III revealed that gender differences in the relationship between complex health problems and mortality have decreased. Will this trend persist? Or will women experience an increase in complex health problems that is similar to men? Whether educational and gender differences in morbidity change over time and how these are related to mortality is a question demanding for future study.

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