To my family Jan-Olov, Sofia and Patrik
According to Need?
CONTENTS

ACKNOWLEDGEMENTS ................................................................. 5
ABSTRACT ...................................................................................... 7
SAMMANFATTNING ..................................................................... 9
ORIGINAL PAPERS ..................................................................... 13
INTRODUCTION ........................................................................... 15
BACKGROUND .............................................................................. 16
WELFARE STATE REGIMES ...................................................... 16
PUBLIC ELDERCARE IN SWEDEN ................................................. 17
  The development of public eldercare ....................................... 18
  Presently available services within public eldercare ............... 21
INFORMAL CARE ......................................................................... 22
PRIVATE SERVICES ....................................................................... 24
THE RELATIONSHIP BETWEEN FORMAL AND INFORMAL CARE ...... 25
  Substitution or complementarity – the international debate ... 25
  Substitution or complementarity in a Swedish perspective .... 27
RESEARCH QUESTIONS .............................................................. 30
FACTORS OF IMPORTANCE FOR RECEIPT OF FORMAL
AND INFORMAL CARE ................................................................. 31
SOCIO DEMOGRAPHIC FACTORS ............................................... 32
  Household composition ......................................................... 32
  Gender ................................................................................. 32
  Education ............................................................................. 33
SOCIAL NETWORK ....................................................................... 34
  Parental status ..................................................................... 34
  Contact with relatives and friends ........................................ 36
PSYCHIATRIC HEALTH ............................................................. 36
  Dementia ............................................................................. 36
  Depression .......................................................................... 37
FUNCTIONAL LIMITATIONS ....................................................... 38
STUDY SAMPLE AND METHODS .........................................................39

THE KUNGSHOLMEN STUDY ..........................................................39
Procedures for data collection ..................................................41
OUTCOME MEASURES ................................................................42
Home help services and institutionalization ..........................43
Informal care ............................................................................44
Private services .........................................................................44
PREDICTORS FOR FORMAL AND INFORMAL CARE ..................44

PRESENTATION AND RESULTS OF STUDIES ..........................47

I: DOES GENDER MATTER? DIFFERENCES IN PATTERNS OF INFORMAL SUPPORT AND FORMAL SERVICES IN A SWEDISH URBAN ELDERLY POPULATION ..........................................................47
II: THE EFFECTS OF MARITAL AND PARENTAL STATUS ON INFORMAL SUPPORT AND SERVICE UTILIZATION: A STUDY OF OLDER SWEDES LIVING ALONE ..........................................................49
III: DEMENTIA AND DEPRESSIVE SYMPTOMS AS PREDICTORS OF HOME HELP UTILIZATION AMONG THE OLDEST OLD: A POPULATION-BASED STUDY IN AN URBAN AREA OF SWEDEN ......................50
IV: PREDICTORS FOR RECEIVING PUBLIC HOME HELP AND ENTRY INTO INSTITUTIONS. RESULTS FROM A LONGITUDINAL STUDY OF A SWEDISH URBAN ELDERLY POPULATION ........................................51
SUMMARY OF RESULTS FROM STUDIES I - IV ......................53
Home help and institutionalization ...........................................53
Informal care, private services, and support from any source .57

GENERAL DISCUSSION .................................................................60

METHODOLOGICAL CONSIDERATIONS .................................60
Validity of the outcome measures ...........................................60
Generalizability of the findings .................................................63
DO PUBLIC ELDERCARE TARGET VULNERABLE GROUPS? .......67
LINKAGES BETWEEN FORMAL AND INFORMAL CARE ..........68
ACCORDING TO NEED? .............................................................72

REFERENCES .............................................................................73
ACKNOWLEDGEMENTS

When I began working at Åldrecentrum, Stockholm Gerontology Research Center in 1992, I thought I was a well-educated person with long experience from various fields of eldercare and social administration. I could not have been more mistaken. Entering this house was like entering a new world where people spoke about things I did not understand and used words I had never heard (even when they spoke Swedish). I really felt that I needed some further education to bring my old training as a social worker up to date. I turned to the Department of Social Work at Stockholm University, and began studying at the master’s level in 1994. This was the beginning of an educational journey that comes to a halt (but hopefully not a full stop) with this dissertation.

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Kristina Larsson

ABSTRACT

This dissertation studies factors that predict use of public eldercare, informal care, and purchase of private services in relation to an individual’s needs, social network characteristics, and sociodemographic factors. A further purpose is to examine whether use of public eldercare is correlated to receipt of informal care and purchase of private services in the Swedish welfare state.

The dissertation is based on the Kungsholmen Study, a population-based longitudinal study. Studies I–III used cross-sectional data from community-dwelling people aged 81-100 and examined (I) gender, (II) marital and parental status, and (III) dementia and depressive symptoms as predictors of use of home help. Study IV used longitudinal data and analyzed factors related to moving into institutional care and receipt of home help from 1994/96 to 2000.

The majority of support provided to elders living in the community comes from informal sources, even among people living alone. There was considerable overlap between home help and informal care. When all sources of care were considered, childless individuals had comparatively lower odds of receiving care. Factors predicting use of public eldercare and informal care differed depending on whether or not elders coresided. No gender differences in use of formal and informal care were found when controlling for household composition. Living alone, dementia, need of help with household chores, and walking limitations increased the likelihood of using public eldercare. Coresidence, informal care from outside the household, and use of private services decreased the likelihood. Depressive symptoms increased the likelihood of receiving home help and institutionalization when using longitudinal data, but not in the cross-sectional studies. Educational level was of importance and interacted with several factors; persons with higher levels of education were advantaged. Very few people moved into institutional care without previously having received home help services. Essentially the same factors that predicted receipt of home help services also predicted institutionalization.

Keywords: Home-based care, community-based services, predicting use of eldercare, home help services, informal care, institutionalization, dementia, depression.
According to Need?
SAMMANFATTNING

Avhandlingens syfte är att studera vilka faktorer som är av betydelse för personer som är över 80 år för att få hemhjälp respektive att flytta till särskilt boende. Syftet är vidare att studera sannolikheten att få hemhjälp om den äldre har hjälp från anhöriga eller köper privata tjänster.


Den största delen av all praktisk hjälp i hemmet kom från anhöriga, det gällde för både ensam- och samboende personer. Av de samboende fick 29 procent hjälp med praktiska insatser i hemmet från någon närstående utanför hushållet, och bland de ensamboende fick 49 procent hjälp av anhöriga. Studie I visar att majoriteten av alla som hade hemhjälp var kvinnor. Det fanns dock ingen skillnad mellan män och kvinnor i sannolikhet att få hemhjälp när man kontrollerade för att kvinnorna i större utsträckning än männen i samma ålder både var ensamboende och hade större vård- och omsorgsbehov. Den huvudsakliga skillnaden fanns inte mellan könen utan mellan ensamboende och samboende personer. Dubbelt så stor andel av de ensamboende hade hemhjälp (27 %) jämfört med de samboende (14 %).

Det stora flertalet av de allra äldsta som bor i egen bostad är ensamboende. De flesta var änkor eller änklingsmar i Kungsholmsstudien fanns också en grupp kvinnor som aldrig gift sig och inte hade barn. Detta gav möjlighet att studera betydelsen av att tidigare ha varit gift, respektive att ha barn, för sannolikheten för att få hemhjälp eller hjälp av anhöriga. Studie II visade att äldre personer utan barn hade större sannolikhet att få hemhjälp medan föräldrar hade större sannolikhet att få hjälp av anhöriga. Sammantaget hade dock personer med
barn betydligt större sannolikhet att få hjälp, antingen av anhöriga eller av äldreomsorgen. Förutom att hjälpa föräldrarna med praktiska göromål så kan man förmoda att barnen har kontakt med sina föräldrar och snabbare kan observera om funktionsnedsättning eller minnesproblem uppstår. Ensamboende personer i hög ålder, som saknar barn, är därför en grupp som löper risk att inte få sina vårdbehov tillgodosedda om inte äldreomsorgen aktivt söker upp dem.

Förekomsten av demens ökar med stigande ålder, men även depessiva symtom är vanliga i den äldre befolkningen. I studie III analyserades betydelsen av demens och depression för sannolikheten att få hemhjälp. Det framkom att ensamboende och samboende personer bör analyseras separat eftersom det delvis är olika faktorer som påverkar om man har hjälp. Bland ensamboende var demenssjukdom en avgörande faktor för att ha hemhjälp. Depressiva symtom däremot minskade sannolikheten att ha hemhjälp bland personer med kort utbildning, medan depressiva symtom inte hade någon betydelse för sannolikheten att få hemhjälp bland de högutbildade.


Sammanfattningsvis gav studie I – III följande resultat. Faktorerna ensamboende, demenssjukdom, gångsvårigheter, behov av hjälp med hushållsaktiviteter samt hög utbildningsnivå (bland ensamboende) ökade sannolikheten för att ha hemhjälp. Faktorerna samboende, hjälp från anhöriga utanför hushållet samt köp av privata tjänster minskade sannolikheten för att ha hemhjälp.
I studie IV följes den äldre hemmaboende befolkningen i Kungs-
holmen (81+) under en femårsperiod för att analysera vilka faktorer
som var av betydelse för att få hemhjälp (bland dem som inte tidigare
hade hemhjälp) eller flytta till institution (särskilt boende med
heldygnomsorg). Studien visade att i stort sett alla som flyttade till
institution hade hemhjälp dessförinnan. Endast 4 procent av de
ensamboende och 5 procent av de samboende flyttade till institution
utan att först ha haft äldreomsorg i hemmet. I stort sett samma fak-
torer som var av betydelse för att få hemhjälp, var också av betydelse
för att flytta till institution. Bland ensamboende var demens, depressiva
symtom och gångsvårigheter faktorer som ökade sannolikheten att få
hemhjälp. Till skillnad från studie I-III hade behov av hjälp med hus-
liga sysslor ingen betydelse för att få hemhjälp bland de ensamboende,
däremot för att flytta till institution. Bland samboende var demens en
viktig faktor för att flytta till institution. Hög utbildningsnivå bland de
samboende ökade sannolikheten att flytta till institution.

Resultaten från studierna bör ses mot bakgrund av de nedskärningar
som skett i kommunal äldreomsorg de senaste decennierna. Äldre-
omsorgens möjlighet att ge hjälp till vårdbehövande personer kan ses
som en indikator på hur den svenska välfärdsstaten fungerar. Trots att
lagstiftningen inte förändrers så har behovsbegreppet i praktiken
omdefinierats. I takt med att andelen äldre med kommunal äldre-
omsorg minskar ställs större krav på att personer med stora vårdbehov
fångas upp av äldreomsorgen. Detta gäller särskilt personer som inte
får hjälp av anhöriga.
According to Need?
This dissertation is based on the following studies referred to in the text by their respective roman numerals:


IV Larsson, K., Thorslund, M. & Kåreholt, I. Predictors for receiving public home help and entry into institutions. Results from a longitudinal study of a Swedish urban elderly population. Submitted.
According to Need?
INTRODUCTION

The Swedish eldercare system has undergone considerable changes during the last few decades. When I occasionally worked as a home helper at the end of the 1960s, home help was granted very generously to older people who only needed help with cleaning or shopping. I remember doing the house cleaning for an elderly woman whose adult son resided upstairs in the house, and was working on his dissertation. He used to come down and say hello when I was vacuuming the floors. None of us realized that this generous allotment of public eldercare might be a parenthesis in the history of the welfare state. Being the only child of a handicapped widowed mother I could follow the development of the public eldercare system during the 1980s and 1990s from a next-of-kin perspective and observe how economic constraints on the public sector gradually affected both the quantity and the quality of the care given.

In 1992 I started working at Stockholm Gerontology Research Center and became involved in a range of studies concerning the care of the elderly. Most of these studies dealt with how public eldercare practitioners targeted service and care to various vulnerable groups, such as elderly people receiving home nursing services, residing in nursing homes, or who had cognitive or mental health problems. After a series of interviews with elderly psychiatric home care patients I became particularly interested in how people with psychiatric symptoms managed at home. Most of them suffered from depression, lived alone, and in many cases they did not have children and had infrequent or no support from friends. Surprisingly, many of these elderly patients managed on their own, without support from the home help services, in spite of functional impairments common among the oldest old. This was the starting point of my research interest. I decided that I wanted to study to what extent the home help services targeted vulnerable groups of elderly people such as persons with physical impairments or mental health needs, people lacking informal caregivers, or those with a poor social network.

In light of the rationing of eldercare resources in Sweden during the past few decades, it is vital to study whether particular groups of elderly people are at risk for falling outside the realms of public care. The extent to which public eldercare provides services to dependent elderly
people can be seen as an indicator of how the Swedish welfare system supports the most needy.

The objective of this dissertation is to study factors that predict use of public eldercare, i.e., home help services or entry into institutional care. I am interested in addressing the overarching question of whether vulnerable groups of elderly people receive help according to their needs.

**BACKGROUND**

The rapid growth in the older populations of most nations, especially among the oldest old, has made it necessary to develop national and local policies that strategically serve the frail elderly at home. The extent to which individuals and their families can count on publicly financed or provided care or are expected to care for themselves, varies a great deal among different countries. Consequently, it is not possible to understand countries’ social policies without understanding how social care arrangements are rooted in their cultures and in their social and political histories (Sipilä, Anttonen, & Baldock, 2003). Esping-Andersen’s often-cited typology of different kinds of welfare state regimes (1990, 1999) provides a starting point for the discussion in this dissertation, as well as a theoretical framework for the empirical findings presented later in the dissertation.

**Welfare state regimes**

Welfare state structures differ at the macro-level depending on the way in which welfare production is allocated among the state, the market, and households. According to Esping-Andersen, the welfare-state variations we find are not linearly distributed, but clustered by regime-type. In one cluster we find the Scandinavian countries which belong to a “social democratic welfare state” in which all citizens are incorporated under one universal insurance system (Esping-Andersen, 1990, 1999). Rights of welfare are based on the individual’s needs and not restricted to certain groups without family resources, thereby removing the burden of providing services from the family.
A second type of cluster, the “conservative welfare state” is found for example in Germany, Austria and Italy. This regime shaped by the church is strongly committed to the preservation of family relationships and thus to the principle of subsidiarity, emphasizing that the state will only intervene when the family’s capacity to serve its members is exhausted.

The third type of cluster, the “liberal welfare state” is found for example in the United States, Canada, and Australia. Here the old age support system is guided by principles of eligibility, in which the state takes responsibility only when all else fails. The American approach to social welfare is characterized by an emphasis on family and market-based care over public responsibility (Achenbaum, 1983; Cook & Barrett, 1992) and a reluctance to support those who are deemed “undeserving” (Page & Shapiro, 1992).

Public eldercare in Sweden

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). This is in line with the social democratic welfare state regime in the Scandinavian countries, cited above. A closer look at Swedish eldercare, however, shows that home help and institutional care have changed considerably over the last few decades. The proportion of people receiving public eldercare and the scope of intervention, as well as the boundaries between home-based care and institutional care, have changed over time.

In my studies I used data from the middle and end of the 1990s. In order to place the situation in the 1990s in a larger context, I start with a short overview of the development of Swedish public eldercare in general. For those who are not familiar with Swedish home help services, I also provide a brief description of the kind of services that can be provided at the present time.
The development of public eldercare

Home help services to dependent elderly persons started in the beginning of the 1950s. Before that time, Swedish eldercare was almost entirely confined to institutional care. Following an intensive public debate on the future directions of old age care (Lo-Johansson, 1952) the municipalities gradually began to offer in-home support to elderly persons, in addition to care in old people’s homes, previously the poorhouses (Trydegård, 2000). Children’s legal obligation to care for their parents was also abolished in 1956 in social legislation, although it remained in family legislation until 1979 (Sundström & Johansson, 2004). Thus, the principles of remaining at home and receiving public help there became official goals of the Swedish eldercare at a relatively early date (Edebalk, 1990).

The home help services soon became very popular among older people and their use increased rapidly after the introduction of state subsidies to the municipalities in the mid-1960s. The rates of home help use reached a peak at the end of the 1970s, when nearly a quarter of the retired elderly population in Sweden received home help in the course of a year (Szebehely, 1998a).

The Social Services Act (Socialtjänstlagen, 1980:620) came into force in 1982. It confirmed the municipalities’ responsibility to provide social services and care to elderly people. The law obliged the municipalities to gather information about the conditions under which elderly people live and to actively inform them about the possibility of receiving support and help at home and other services (already stated in a revision of the Social Services Act in 1968).

During the 1980s the number of people who received home help or lived in institutions decreased, even though the number of elderly people in the population increased. Economic constraints on the public sector, in combination with an aging population, put pressure on eldercare affecting above all younger pensioners (Thorslund & Parker, 1994). At the same time criticism was directed at the existing organization of care for the elderly, particularly at the unclear demarcation lines of responsibility between providers of health care, the county councils; and providers of eldercare, the municipalities. The parliament therefore decided on a new eldercare policy in 1992, the
ÅDEL-reform. This policy gave the municipalities responsibility for nursing homes and for patients who still needed care after discharge from the hospital. To solve the problem with “bed-blockers,” the municipalities were obliged to pay for hospital care of patients whose in-patient care was considered completed (National Board of Health and Welfare, 1996b).

The ÅDEL-reform took place at the same time as budgetary reductions due to weakening economic growth, and resulted in a dramatic restructuring of the long-term care system (Johansson, 1997). In spite of the fact that the number of hospital beds was reduced and the average length of stay in acute hospital care decreased, the problem with “bed-blockers” almost disappeared (Styrborn & Thorslund, 1993). This development, however, increased the pressure on the municipal eldercare organization in terms of resources and competence.

The combined effects of budgetary reductions on health care and eldercare resulted in cutbacks that, above all, affected persons with lesser needs, younger elderly, and married people. The municipalities concentrated their resources on cases requiring more extensive care, while those predominantly in need of domestic services were omitted to an increasing extent (Thorslund, Bergmark, & Parker, 1997). Thus, a considerably reduced number of elderly people received home help services, but those who did received on average more hours (Palme et al., 2003). In the mid-1990s every third person with home help received help during weekends, and every fourth received help during evenings or at night (National Board of Health and Welfare, 1996a).

The oldest old, the age group I focus upon in my studies, were less affected by the rationing of eldercare resources than younger seniors. The reduction of home help took place in the first half of the decade. In 1990, 25 percent of the population 80 years of age or older received home help or home nursing, compared to 21 percent in 1995. No further reduction regarding coverage rates was seen; 21 percent of all people in the corresponding age group received home help or home nursing in 2000 (Ministry of Health and Social Affairs, 2003).

Even though the coverage remained unchanged in the second half of the 1990s, the number of hours received seems to have dropped. National surveys showed that less home help was provided for a given level of need (personal care and household activities) in 2000 than was provided in 1994 (Sundström, Johansson, & Hassing, 2002).
The proportion of people 80 years of age and older living in institutional care facilities did not change during the 1990s; 22 percent lived in special housing\(^1\) (särskilt boende) in 1990 and the same was true in 2000 (Ministry of Health and Social Affairs, 2003).

During the development of Swedish eldercare, the type of care provided changed considerably. In the 1950s and 1960s home help was given to persons with smaller care needs who mainly needed support with practical chores at home. Persons with more extensive care needs who lacked support from a spouse or from next-of-kin had to move to institutions, as care was not organized to provide in-home support to those needing help several times a day or on weekends. Although the principle of home-based care became a political ambition as early as the mid-1950s, the home help services were not organized to fulfill those ambitions for the most needy\(^2\). Using Peter Laslett’s scheme for dividing the life-course (Laslett, 1987) one can say that public home help services up to the beginning of the 1980s primarily helped facilitate living for persons in the “third age.” This was regardless of whether or not it was possible for them to receive care from informal sources. Persons in the “fourth age,” however, an age of final dependence and decrepitude, were referred to care in nursing homes or homes for the aged if they were not cared for by a coresider.\(^3\)

During the 1990s public resources were targeted at the most frail and dependent elderly, above all persons living alone, whereas persons with less extensive needs more often had to rely on family, friends, or commercial alternatives for domestic services (Szebehely, 2003). The economic incentive and the fact that municipalities were financially liable for “bed-blockers,” in combination with reductions of beds in

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\(^1\) Special housing includes service houses and institutional care with service around the clock such as nursing homes, old people’s homes, and group accommodations for people with dementia.

\(^2\) Even though this was the general trend, there are exceptions. In Stockholm, for example, home help also was given to people with extensive care needs, even at night, as there was a shortage of institutional care facilities in the 1950s and 1960s (Szebehely, 1995).

\(^3\) In this typology, the ”first age” refers to an era of dependence, socialization, immaturity, and education. The ”second age” refers to an era of independence, maturity, responsibility, and earning. The ”third age” stands for a time after retirement when people are economically independent, fairly healthy and can manage on their own.
geriatric care, brought about home help mainly for persons in the “fourth age.” Rapid developments in medical technology that resulted in new possibilities for treating elderly persons at home had also increased the demands upon the home help services (Thorslund, Bergmark, & Parker, 2001). As a consequence of the rising care load, the municipalities had given priority to people with the heaviest care needs (horizontal target efficiency) (Challis & Davies, 1986), and thereby transformed the home help services into a more medicalized form of care. More social needs, e.g., for social contact, were left to families and relatives, or neglected altogether (Andersson, 1996).

**Presently available services within public eldercare**

According to the Social Services Act, public eldercare in Sweden is a needs-tested benefit. The elderly person applies to the municipality for the help she or he considers necessary. A care manager⁴ is delegated by the social welfare committee to make an assessment of needs and decide if the person will receive help, and if so, what kind. The municipality can offer both home help services and institutional care and the care manager is responsible for needs assessments regarding all types of eldercare — in-home support as well as entry into special housing. (Home nursing is integrated with home help services in approximately half of the Swedish municipalities; in the other half it is organized within the primary health care organization.) If the elderly person requesting services is dissatisfied with the care manager’s decision, the case can be appealed in an administrative court, “Länsrätten”.

Depending on the individual’s needs, personal care (e.g., help getting up from bed, dressing, showering, going to the toilet) and help with domestic chores (e.g., shopping, cleaning, cooking/meals on wheels, washing clothes) can be given. Other forms of assistive technology, such as security warning devices, walking aids, and home adaptations are also available to facilitate life for individuals in their homes. Day care and respite care may also be offered to persons living at home, particularly to persons suffering from dementia or other chronic diseases.

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⁴ The care manager is usually a social worker but some municipalities employ nurses with further education in social work.
Users are charged a fee for home help services, and most municipalities apply a system whereby the charge varies according to both the users’ income and the scope of intervention. In the 1990s about 10 percent of home help recipients paid no fee at all, whereas persons with good incomes paid a fee that corresponded to the cost of buying the services out-of-pocket (Ministry of Health and Social Affairs, 1999). Approximately one out of six persons aged 75+ who reported that they needed help refrained from accepting home help because of the cost (National Board of Health and Welfare, 2001).

Institutional care was highly subsidized during the 1990s (user fees were estimated to cover about 3 percent of the total costs), even though the cost for individuals with good incomes or assets could be considerable (Ministry of Health and Social Affairs, 1999). A revision of the Social Services Act (2001:847) in 2002 put an upper limit on user fees for home help services and institutional care. After the reform came into force, 34 percent of eldercare recipients paid no fee (National Board of Health and Welfare, 2004).

Informal care

According to Esping-Andersen’s typology, countries belonging to the social democratic welfare regimes have emphasized the individual’s right to public care, whereas support from informal sources has received less attention from policymakers. It seemed that during the expansion years of the Swedish welfare state, informal care was considered merely a complement to public eldercare, and was more or less expected to fade away (Government Bill, 1987/88:176; Johansson & Sundström, 2002). Numerous studies, however, have shown that the bulk of support to community-dwelling elders comes from informal, mostly family, sources. It has been demonstrated that informal care plays a leading role in home-based care for the elderly in Sweden (Jeppsson Grassman, 2001; Jeppsson Grassman & Svedberg, 1999; Johansson & Sundström, 2002; Sundström, 1994; Szebehely, 1998b; Thoraeus Olsson, 1990; Thorslund et al., 1997) The amount of informal care has been estimated to be two to three times greater than the amount of formal care (Johansson, 1991; Johansson & Thorslund, 1992). Care by family members and friends is also the primary source of assistance for the majority of disabled elderly persons living in ordi-

When the Swedish economy faced financial constraints in recent years, informal care appeared on the political agenda. The municipalities’ responsibility for giving support to persons who provide informal care to elderly or functionally impaired people was emphasized in the revision of the Social Services Act (Government Bill, 1996/97:124). In connection with the National Action Program for Policies regarding the Elderly (Nationell handlingsplan för äldre-politiken), state grants for municipal projects supporting informal caregivers were temporarily granted (Government Bill, 1997/98:113) in order to improve the situation for family caregivers. Still, very few informal caregivers reported that they had benefited from any caregiver support. In Stockholm County about 8 percent of persons caring for a dependent coresider, and an equal proportion caring for a dependent person outside the household reported that they had received caregiver relief (Jegermalm, 2003; Jeppsson Grassman, 2001).

Several studies have shown that the decline in public eldercare provision during the 1980s and 1990s coincided with an increased family involvement in care of the elderly (Johansson & Sundström, 2002; Sundström et al., 2002; Szebehely, 1993, 2000). It seems that families were forced to fill the gap between the assistance needs of elderly people and the level of public care actually received. In particular, older couples were hit by restraints in provisions of public care. When the threshold for receiving eldercare rose, home help services were targeted away from coresiding persons, frequently leaving frail spouses (above all women) to care for their partners (Daatland, 1997; Szebehely, 1998b).

An increase in dependence on informal care could also be seen among elderly persons living alone. During the 1990s, the proportion of adult children (above all daughters) helping their parents almost doubled. This trend was most pronounced among older people whose offspring lived fairly nearby (Johansson, Sundström, & Hassing, 2003). Many municipalities began to include the availability of informal help outside the household in their needs assessments. One fourth of the municipalities inquires whether a relative living outside the household
could help out with household tasks (National Board of Health and Welfare, 2004). The municipalities thereby departed from the Swedish welfare tradition in which the individual and not the family is the focus of consideration (Millar & Warman, 1996; Szebehely, 1998a). The decision to consider family care resources in the assessment of eldercare needs was made in order to cope with budgetary restrictions, but can be seen as a step towards a conservative welfare system, as described above.

**Private services**

During the 1990s, the drop in the proportion of elderly people receiving home help services in Sweden also coincided with an increase in the use of market-based services that were paid for out-of-pocket. Not only did help allocation become stricter, but domestic services such as cleaning, laundry, or shopping also increasingly fell outside the scope of assistance provided by public eldercare. In combination with rising user fees in publicly financed eldercare, the market for privately paid services grew. In this respect, the Swedish eldercare system moved away from the ideas of the social democratic welfare state and toward the ideas of the liberal welfare state.

There seems to be a class-related pattern in how elderly people compensated for reductions in public eldercare. Persons with higher levels of education purchased private domestic services to a larger extent whereas individuals with lower levels of education more often received family support (Palme et al., 2003). (Commercial alternatives for personal care like bathing or dressing, paid out-of-pocket, or for institutional care without public funding are almost nonexistent in Sweden) (Szebehely, 1999a).
The relationship between formal and informal care

Given the different models of welfare states in Scandinavia and in other western countries, briefly described above, it is fairly evident that the discussion regarding the proper mix between public commitments and private responsibility also differs among countries with different kinds of welfare models. This is evident in the extensive debate on whether public care for the elderly is a substitute for or a complement to family care.

Substitution or complementarity – the international debate

A number of theories regarding linkages between formal and informal care of the elderly have been introduced during the last decades. Most of them originate from the United States, and mirror the discourse of what Esping-Andersen terms a liberal welfare state.

The substitution model suggests that as formal services are provided there will be a corresponding decrease in informal care (Greene, 1983). Although the theory just states that there is an inverse relationship between public eldercare and family care, it has been associated with the criticism that welfare state involvement undermines family care and weakens family solidarity (Lingsom, 1997). This hypothesis is based on the belief that in modern societies, older adults are abandoned by their families and unable to count on them for help or support. The substitution theory is put forward primarily by those who are concerned by the costs of community based services, especially by the increase in costs if formal services were more widely available (Denton, 1997). The model represents a line of thinking whereby family solidarity is seen as solely forced by necessity. Numerous studies have shown no support for the hypothesis that formal services erode levels of informal care (Denton, 1997; Penning, 2002). Nevertheless, the substitution theory continues to be a topic of debate.

The compensatory model also takes into account the individual’s preferences for help, which are seen as normatively defined and embedded within the cultural values of a society. This model is derived from
Cantor’s hierarchical model of social support in old age (Cantor, 1979, 1991), in which patterns of support follow an orderly hierarchical selection process determined by the individual’s preferences. Most elderly persons prefer to receive assistance from their spouse, according to Cantor. If a spouse is not available, their preference is for assistance first from a child, followed by other relatives, and then by friends and neighbors. Only if assistance is not available from the informal care network do elderly persons prefer care from the formal system.

The task specificity model argues that elders receive different but complementary kinds of care from formal and informal providers based on family characteristics and structures, such as emotional ties and physical proximity. In this model, the structure of the task is described as more important in determining the source of care than the elderly person’s preferences, or the availability of informal caregivers (Litwak, 1985). Family members are seen as best suited to providing everyday care, friends are important for providing emotional support, and formal services are more suited to performing technical and routine tasks.

The complementary model proposes that formal care has both compensatory and supplementary functions. The model indicates that the formal system supplements the informal care system when the needs of the older persons exceed the resources of the informal care system (Attias-Donfut & Wolff, 2000; Chappell & Blandford, 1991; Edelman & Hughes, 1990). Together the informal and the formal systems provide necessary care and form a partnership in caregiving, not in terms of task specificity, but in terms of sharing of overall task load. In contrast to the substitution model, the complementary model predicts an increase in the total amount of care provided to the dependent person (Lingsom, 1997).

These models of linkages between formal and informal care have been questioned. Ward-Griffin and Marshall (2003) have considered the theoretical underpinnings and empirical support for the models and revealed several problems. First, the models regarding the linkages between formal and informal care are guided by the interest of professional practitioners, rather than the seniors’ preferences, mainly as a way to limit costs of formal services such as eldercare. Second, the assumption that informal care is always preferred to formal care is
common in the conceptual models linking formal and informal care systems. Third, there is a tendency to implicitly assume a traditional perspective of roles within the family in which caregiving is seen as the woman’s duty, and thereby to disregard the gendered underpinnings of family care (Ward-Griffin & Marshall, 2003).

**Substitution or complementarity in a Swedish perspective**

In contrast to the discussion in liberal welfare states, where most of the theories regarding the interface between formal and informal care were developed, there has been no significant Swedish debate on the risk of public eldercare undermining informal care. Eldercare has traditionally been seen as one of the main areas of focus of public policy in Sweden (Korpi, 1995; Thorslund et al., 1997) and supported by public opinion (Andersson, 1993, 1996; Walker, 1999).

The objective of Swedish eldercare has undoubtedly been to substitute informal care for formal services in some respects. The introduction of home help in the 1950s made it easier for elderly persons to remain in their own homes and avoid institutionalization, or involuntarily having to move in with a family member. Public eldercare helped adult children (especially unmarried daughters) with care responsibilities move out of their parents’ homes and take on paid work. The introduction of respite care and day care was designed to reduce caregiver burden for husbands and wives caring for a disabled spouse. Although spouses have always been expected to care for each other, being married or having children in the vicinity did not prevent a considerable proportion of elderly persons from receiving home help during the expansion period in the 1970s and 1980s.

The assumption that informal care is always preferred to formal care does not seem to be in line with the opinion among elderly people themselves, at least not in Scandinavia. Swedish national surveys demonstrate that seniors are clearly in favor of receiving publicly provided care rather than receiving care from family members (Andersson, 1993). One third of elderly people who received family support with household chores or physical care would prefer publicly provided help, whereas only a few percent of those receiving home help would prefer help from informal sources (Andersson & Johansson, 1996).
According to Need?

Norwegian data show that a majority of elderly persons would turn to the public services when in need of long-term care, even when children are living close by. The preference for public care does not seem to be due to weak family ties, but rather the increased availability of public services allowing the elderly person a choice (Daatland, 1990).

A Danish study of frail elderly people, who rely on help from both their family and the public home care system, shows that elderly people do not want to be a burden on their family or to become dependent on others for meeting elementary needs, and thereby lose control of their own situation. Instead, the elderly people underline the importance of their autonomy and independence. The author argues that home help services have the effect of spreading the burden of gratitude that elderly people feel due to their increasing dependence on assistance from others (Lewinter, 1999).

You may, however, receive different answers depending on how you ask about preferences for care. A Swedish study on people 80 years old and older shows that the seniors express practical, emotional, and existential care requirements, and have different preferences for different care needs. The home help services can provide practical support, whereas informal caregivers seem to be more suited to provide emotional and existential support. These results are in line with the task specificity model, cited earlier (Thoraeus Olsson, 1990).

A comparative study in five countries (Norway, England, Germany, Spain, and Israel) addresses the extent to which people’s preferences for different sources of care for frail older people correspond with their type of welfare state regime. As expected, most Norwegians believe that public services should be the prime source of care whereas family care is more favored in conservative welfare states like Spain and Germany (Daatland & Herlofson, 2003). A preference for formal care increases with the age of the respondents in most countries. The seniors seem more reluctant to receive help from their family than their adult children are to provide it. (It should be noted, however, that the study measured attitudes regarding filial norms and not actual receipt or provision of care). These results are in line with previous studies showing that although elderly people want to have good contact with their children, they prefer "intimacy at a distance" (Rosenmayr & Köckeis, 1963).
According to Esping-Andersen, different family cultures are reflected in different welfare systems. The issue of eldercare in different welfare systems can also be viewed from another angle, with the focus on how welfare systems may influence families’ values. In countries with a high volume of community services, like the Scandinavian countries, where receipt of public eldercare is a viable option and not stigmatizing for the user, a higher proportion of the inhabitants prefer public services to family care compared to those in liberal or conservative welfare states (Daatland & Herlofson, 2003). This indicates that the availability of services influences the preferences regarding sources of support.

The different opinions regarding whether formal care substitutes for or complements informal care may thus be an issue of perception. Where one person sees a clear case of substitution, another may argue that services are supplements to family care (Daatland & Herlofson, 2001). Comparative studies among the European countries show, for example, that countries with the highest levels of public eldercare have the lowest level of family care (Andersson, 1993; Walker & Maltby, 1997). This may be seen as an example of substitution, in which formal services have crowded out family care. On the other hand, Lingsom (1997) showed that informal care increased in Norway at the same time as public home help services expanded during the 1960s and 1970s, indicating that home help services supplemented and supported family care, but did not replace it. She demonstrated that family care was remarkably stable both when the services expanded and when service levels declined. The total volume of non-resident care provided per capita was unchanged, but the average number of family helpers per recipient grew over time.

Lingsom did not find any evidence of reverse substitution in Norway when services were cut back to some extent in the 1990s. In Sweden, however, national surveys show that increased inputs from families matched the decline of public services and that a “reversed” substitution had been taking place both in the 1980s (Szebehely, 1993) and in the 1990s (Johansson et al., 2003).
RESEARCH QUESTIONS

A fundamental principle of the Scandinavian welfare system has been to provide widely available services, publicly subsidized, and not restricted to certain disadvantaged groups without family resources but used by everyone in need, irrespective of socioeconomic status (Sipilä, 1997). Economic constraints on the public sector in Sweden, in combination with an aging population, put pressure on public eldercare during the last decades. Resources have been rationed and targeted at very frail and dependent elderly people, above all, persons living alone. People with less extensive needs and people who coreside more often have to rely on informal caregivers, or privately paid services, or must cope on their own.

Ready available and adequate in-home support are crucial in enabling frail elderly people to stay in their own homes and avoid or postpone institutionalization. Informal care plays a leading role in home-based care for the elderly. It seems that informal caregivers have shouldered a heavier burden of care in recent years, although this does not seem to be in line with the preferences of either elderly people themselves or their families.

Even though the official ambition is to target public eldercare resources to the most needy, there is a risk that vulnerable groups of elderly people are being left without sufficient care in times of cutbacks. The extent to which public eldercare provides services to dependent people can be seen as an indicator of how the Swedish welfare system supports the most needy.

The purpose of this dissertation is to study factors that predict use of public eldercare, receipt of informal care, and purchase of privately paid services in an urban elderly population in relation to

- the individual’s needs such as functional limitations, dementia and depression;
- social network characteristics such as parental status and contacts with friends; and
- sociodemographic factors such as gender, age, household composition, and education.
A further purpose is to examine whether use of public eldercare is correlated to receipt of informal care and purchase of private services, in order to place the Swedish eldercare system in the context of the debate about the interface between formal and informal care cited above.

**FACTORS OF IMPORTANCE FOR RECEIPT OF FORMAL AND INFORMAL CARE**

The following literature review provides a brief overview of frequently used predictors of formal and informal care in gerontological studies, in Scandinavia and in other countries.

Different welfare states have various ways of allocating welfare production among state, market, and household, as mentioned above. This makes it difficult to compare results regarding formal and informal care from studies conducted in countries with different welfare state regimes. The concept of formal care may include publicly financed and provided care, publicly financed but privately provided care, as well as privately market-based care or service bought out-of-pocket. Contradictory results in the literature review regarding predictors of eldercare utilization may thus be due to dissimilar ways of defining the concept of formal care. They may also be due to actual differences in receipt of eldercare in different welfare states.

The same ambiguity can be found regarding the concept of informal care. Some studies include care from a coresider, whereas others restrict informal care to care given by someone outside the household. This influences the pattern of receipt of informal care for women compared to men, and may explain conflicting results in different studies.

In general, the studies cited in the literature review show results from multivariate analyses, in which differences in age and functional ability have been controlled for in the statistical analyses.
Sociodemographic factors

Household composition

Household composition is linked to use of formal in-home care. The highest rates of formal in-home care are found among elderly persons living alone both in Scandinavia (Daatland, 1997; Hansen, Milkær, Swane, Lindrum Iversen, & Rimdal, 2002; Johansson & Åhlfeldt, 1993; Thorslund, Norström, & Wernberg, 1991) and in other countries (Calsyn & Winter, 2000; Houde, 1998; Linden, Horgas, Gilberg, & Steinhagen-Thiessen, 1999).

Previous research has persistently shown that living alone correlates with risk of institutionalization for elderly persons in Scandinavia (Lingsom, 1997; Szebehely, 1999b) and in other nations (Egleston, Rudberg, & Brody, 1999; Freedman, 1996; Jette, Tennstedt, & Crawford, 1995; Miller & Weissert, 2000; Newman, Struyk, Wright, & Rice, 1990; Pearlman & Crown, 1992).

Household composition is also of importance for use of informal care and private services. A Swedish study showed that persons who lived alone were more likely to receive informal care from outside the household and to buy private market-based services than those who coresided. This was also true also when informal care or use of private services was combined with public eldercare (Szebehely, Fritzell, & Lundberg, 2001).

Gender

In Sweden, women are more often the recipients of formal care, and men more often the recipients of informal care. The main reason for this is differences in household composition. A majority of Swedish men, about 70 percent, live with a spouse when they die, whereas only one out of four women coreside at the end of their lives (Lundin & Sundström, 1994).

Among coresiding elders requiring care, men are more likely to be the recipients of informal care and women to be the recipients of formal types of assistance within the marital unit both in Scandinavia (Johansson & Åhlfeldt, 1993; Romøren, 2003; Szebehely, 1998b) and
in other countries (Arber & Ginn, 1992; Mutchler & Bullers, 1994; Peek, Zsembik, & Coward, 1997; Portrait, Lindeboom, & Deeg, 2000).

No gender differences regarding home help utilization could be seen in Sweden among men and women living alone (Szebehely, 1998b), and the same is reported from Denmark (Hansen et al., 2002).

Studies of gender differences regarding institutionalization have yielded somewhat mixed findings, possibly due to the fact that women often outlive their spouses and thereby lack support from a coresider in old age. In Scandinavia, the authors of Norwegian studies report no gender differences in institutionalization (Lingsom, 1997; Romøren, 2003). A Swedish study found that unmarried men had higher odds of living in special housing compared to unmarried women, whereas the opposite was found among married people (Szebehely, 1999b). Authors of studies conducted in various countries report a higher probability that women will enter institutional care (Portrait et al., 2000), others report a higher probability that men will enter institutional care (Gaugler, Kane, Kane, Clay, & Newcomer, 2003), and still others report no gender differences (Jette et al., 1995).

Education

Both Swedish studies (Parker, Thorslund, & Lundberg, 1994; Thorslund & Lundberg, 1994) and international studies (George, 1996; Manton, Stallard, & Corder, 1997; Pampel, 1998) have demonstrated socioeconomic inequalities in the health and functioning of elderly people. People with lower socioeconomic status have poorer health and functioning, even in the highest age groups.

Swedish surveys find no relation between educational level and use of public home help or institutional care (Palme et al., 2003). As mentioned above, people with higher levels of education more often buy private services whereas people with lower levels of education more often receive support from informal sources (Palme et al., 2003).

One might expect to find socioeconomic differences in the use of formal services and receipt of informal care in countries without universal access to services. Even in countries with universally insured populations, however, education seems to have an impact on service use. A Dutch study showed that higher education levels increased the probability of obtaining formal in-home care, at the expense of infor-
New York: Oxford University Press. doi: 10.1093/ageing/afy090

Patterson, F. R. (2002). Social care (Portrait et al., 2000). A Canadian study found that lower attained education was associated with higher risk of nursing home admission (Mustard, Finlayson, Derksen, & Berthelot, 1999).

Social network

Social network is commonly described as the web of social ties surrounding the individual. The concept refers to the structural characteristics of social ties, and typical measures are the size of the network, the frequency of contacts, the percent of network comprised of kin etc. (Berkman, Glass, Brissette, & Seeman, 2000). Social support is a closely related concept. Social support has been described as the types of resources that flow through social networks (Antonucci, 1985), although researchers have been inconsistent in both the definition and measurement of what they are studying (Antonucci & Jackson, 1987).

Parental status and frequency of contact with friends can be seen as different aspects of the social network because they indicate a structure of possibly available support, even though in some cases this support is untapped.

Parental status

Parental status may have an influence on use of eldercare in several ways. On the one hand, both in Sweden (Johansson et al., 2003; Szebehely, 1998a) and internationally (Barrett & Lynch, 1999; Linden et al., 1999), parents are less likely to receive in-home support from formal helpers than childless persons. On the other hand, numerous studies reveal that having relatives who may act as advocates in favor of their kin, particularly having adult children, enhances the use of formal services both in Scandinavia (Lingsom, 1997) and in the United States (Langa, Chernew, Kabato, & Katz, 2001). A study from Denmark, however, found no difference between elderly parents and childless individuals regarding the probability of receiving home help (Hansen et al., 2002).

Parental status may also influence the risk of institutionalization. Having an adult child caregiver reduces the likelihood of entering a nursing home in the United States (Pearlman & Crown, 1992), although this seems to be true only for parents with daughters and not
sons (Freedman, 1996). A Norwegian study showed that the duration of caregiving work was longer when daughters, rather than sons, were primary caregivers. However, no difference was found in the likelihood of being admitted to a nursing home between those whose primary caregiver was a daughter and those whose primary caregiver was a son (Romøren, 2003). A Swedish study from a middle-sized town (Sundsvall) showed that adult children played an important part when deciding on entry into institutional care. Almost all elderly parents who had moved reported that their children urged them to move into special housing (Thorslund, 2003).

The relationship between parental status and use of both formal and informal care is highly related to the proportion of intergenerational conjoint living. In the Scandinavian countries the percentage of elderly parents living with their children is low, about 4 percent in Sweden, whereas in Austria, Italy, and Spain, for example, more than 20 percent of elderly parents live with their offspring (Sundström, 1994).

Among elderly persons living alone, those who are parents appear to have a more supportive network than those who are not parents (Barrett & Lynch, 1999; Bengtson, Rosenthal, & Burton, 1990; Connidis & McMullin, 1999). Several studies in the United States find that elders without children have less overall support from relatives (Boaz & Hu, 1997; Choi, 1994; Gironda, Lubben, & Atchison, 1999; Johnson & Troll, 1992). The same pattern is found in the Netherlands (Broese van Groenou & Van Tilburg, 1996; Dykstra, 1993) and in Germany (Wagner, Schütze, & Lang, 1999). Research in Scandinavian countries has given mixed results. A nationwide survey of the Swedish 75+ population showed no difference in informal support between parents and childless individuals (Szebehely, 1998b). In Norway, a longitudinal population-based study of the oldest-old demonstrated that even though elders with no children received the same type of informal help as elders with children, the childless received help for shorter periods of time (Romøren, 2003).
Contact with relatives and friends

Friends are important sources of emotional as well as instrumental support in old age. When studying the effect of contact with friends, gender, marital status and parental status all have to be taken into consideration.

In general women have larger and more multifaceted social networks than men, and the nature of women’s social ties seems to be different from that of men. Whereas men turn to their wives for support, women turn not only to their husbands but also to their children, other family members, and friends (Antonucci, 1985; Antonucci & Akiyama, 1987).

Several studies show that never married and childless elderly persons, above all women, have developed an independent and extrafamilial life-style (Connidis & McMullin, 1992; Rice, 1989; Wenger, Scott, & Patterson, 2000). In contrast, single and previously married men without children may be at greater risk for not having diverse enough social networks to ensure that their emotional and/or instrumental needs are met regularly (Connidis & Davies, 1990).

Psychiatric health

Epidemiological studies of mental illness in old age prove that elderly people suffer from the same psychiatric disorders as people in younger age groups, with the exception of dementia (Hocking, Koenig, & Blazer, 1995). The review is restricted to a survey of the literature about dementia and depressive symptoms, because they are the most prevalent psychiatric health problems in old age.

Dementia

The prevalence of dementia increases with age, affecting about one percent of the population around 60 years of age, but more than 40 percent of individuals 95 years and older (Fratiglioni, De Ronchi, & Aguero-Torres, 1999).

It is well known that dementia is associated with increased levels of dependence in activities of daily living, and numerous studies have
shown that caregiving to family members with dementia is burdensome and distressing (Schulz, O'Brien, Bookwala, & Fleissner, 1995). A Swedish case study of demented community-dwelling persons showed that they received about eight times more informal care, measured in hours spent caring, than formal care (Wimo, von Strauss, Nordberg, Sassi, & Johansson, 2002).

The relationship between having impaired cognition and using in-home care seems to be mediated by the availability of a coresiding caregiver (Gill, Hinrichsen, & DiGiuseppe, 1998). The health or psychological distress of the primary caregiver influences the propensity for using home help in the United States (Levesque, Cossette, Potvin, & Benigeri, 2000; Toseland, McCallion, Gerber, & Banks, 2002), and Canada (Levesque et al., 2000). Studies in Germany (Gill et al., 1998), and the United States (Toseland et al., 2002; Vetter et al., 1998) have shown that behavioral symptoms in the care recipient also increase the probability of using formal care.

Cognitive impairment is a leading predictor of institutionalization in Scandinavia (Aguero-Torres, von Strauss, Viitanen, Winblad, & Fratiglioni, 2001; Romören, 2003) and Canada (St John, Montgomery, Kristjansson, & McDowell, 2002). The impairment is often combined with behavioral problems (Gaugler et al., 2003; Yaffe et al., 2002), thereby increasing the burden for family caregivers (Dunkin & Anderson-Hanley, 1998).

**Depression**

About 12-15 percent of persons in community samples are estimated to have depressive syndromes (Beekman, Copeland, & Prince, 1999). The prevalence of depressive symptoms among elderly persons is considerably higher as current methods of assessing depression leave many elders undiagnosed (Fiske, Kasl-Godley, & Gatz, 1998). A Swedish population-based study found that 28 percent of those 80 years and older had clinically significant depressive symptoms (Gatz, Johansson, Pedersen, Berg, & Reynolds, 1993).

Both diagnosed depression and elevated depressive symptoms are associated with varying degrees of cognitive dysfunction (Hooijer, Trede, & van Tilberg, 1995). In a representative sample of Swedish 85-
According to Need?

year-olds, 25 percent of demented and 20 percent of non-demented persons were diagnosed with a depressive syndrome (Skoog, 1993).

Depression is associated with significantly higher levels of dependency in the tasks of daily living (Ormel, Rijsdijk, Sullivan, van Sonderen, & Kempen, 2002). This is also the case with subthreshold levels of depression (Wilms, Kanowski, & Baltes, 2000). In spite of this fact, little attention has been paid to the impact of depression on use of formal services. A Dutch (Beekman, Deeg, Braam, Smit, & Van Tilburg, 1997) and a Canadian study (Hawranik, 2002) found no difference in use of formal home help between depressed and non-depressed individuals when controlling for functional limitations and cognitive impairment. A Danish study reported that depressive symptoms increased the odds of receiving home help services (Hansen et al., 2002).

Regarding institutionalization, Miller and Weissert (2000) identify nine studies that include depression in the analyses, and in four of them depression predicts institutionalization.

**Functional limitations**

Functional limitations are consistent predictors of formal care utilization. This is most commonly shown regarding dependence in ADLs (Activities of Daily Living) or IADLs (Instrumental Activities of Daily Living) in Scandinavian studies (Hansen et al., 2002; Szebehely, 1998b; Thorslund et al., 1991) and in other countries (Calsyn & Winter, 2000; Crowell et al., 1996; Liu, Manton, & Aragon, 2000; Miller & Weissert, 2000; Shapiro & Tate, 1997).

Other predictors of formal care use include difficulties in mobility outdoors (Sakari-Rantala, Heikkinen, & Ruoppila, 1995), and tiredness in daily activities (Avlund, Damsgaard, & Schroll, 2001).
STUDY SAMPLE AND METHODS

The Kungsholmen Study

This dissertation is based on a population-based longitudinal study undertaken in Stockholm, the Kungsholmen Study, the general aim of which was to study aging from medical, psychological, and sociological perspectives. The dissertation uses data from the second follow-up survey, carried out between 1994 and 1996 (Studies I – IV), and the third follow-up survey carried out between 1997 and 1998 (Study IV). Information from the municipality of Stockholm’s register on the use of home help and entry into institutional care between 1995 and January 1, 2000, also is included (Study IV).

The Kungsholmen Study consisted of all individuals 75 years and older who were registered in the parish of Kungsholmen, on October 1, 1987. All inhabitants were included, whether living at home or in an institution. Of the 2,368 eligible subjects, 1,810 persons participated in the baseline data collection, which was carried out between 1987 and 1989 (17 percent of the persons in the sample refused to participate, after excluding 181 persons who died between the selection of the study group and the start of the interviews). The persons who refused to participate or dropped out because they moved did not differ from the screened subjects in age and sex (Fratiglioni et al., 1991). In the first follow-up survey, carried out between 1991 and 1993, 1,105 persons participated (61 percent of those previously interviewed; 25 percent had died or moved and 14 percent refused to participate).

This dissertation is based on data from the second follow-up survey, carried out between 1994 and 1996. In that wave of data collection, 683 persons were interviewed (62 percent of subjects interviewed in the first follow-up; 34 percent had died or moved and 4 percent refused to participate).

Data from the third follow-up, carried out between 1997 and 1998, were included in Study IV to control for changes in household composition, functional ability, and other factors that had occurred between the second and the third follow-up. In the third follow-up 422 persons participated (62 percent of those interviewed in the second follow-up; 32 percent had died or moved and 6 percent refused to participate).
The study design is reported in detail elsewhere (Fratiglioni, Viitanen, Bäckman, Sandman, & Winblad, 1992; Fratiglioni et al., 1997).

The Kungsholmen area was selected for a population-based study because when the original study started, it had one of the oldest populations, not only in Sweden but also in the world. Sixteen percent of the population was 75 years or older, compared to 10 per cent in the municipality of Stockholm and 8 percent in Sweden. The Kungsholmen area did not differ much from the whole inner-city area of Stockholm when the study started regarding sex distribution and marital status, but the inner city differed compared to the rest of Sweden. As shown in Table 1, women were overrepresented in Stockholm’s inner city.

### Table 1. Population 75 years and above in 1987, by sex and geographic area (%)

<table>
<thead>
<tr>
<th>Sex</th>
<th>Kungsholmen n=2,368</th>
<th>Stockholm Inner City n=32,765</th>
<th>Stockholm Municipality n=65,443</th>
<th>Sweden n=652,956</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men</td>
<td>24</td>
<td>26</td>
<td>30</td>
<td>38</td>
</tr>
<tr>
<td>Women</td>
<td>76</td>
<td>74</td>
<td>70</td>
<td>62</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>


The Kungsholmen area, like the inner city of Stockholm, had a higher proportion of never married women compared to the whole country (Table 2).

### Table 2. Population 75 years and above in 1987, by sex and marital status (%)

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Kungsholmen n=2,368</th>
<th>Stockholm inner city n=32,765</th>
<th>Stockholm Municipality n=65,443</th>
<th>Sweden n=652,956</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Married</td>
<td>60</td>
<td>14</td>
<td>57</td>
<td>15</td>
</tr>
<tr>
<td>Divorced or widowed</td>
<td>32</td>
<td>59</td>
<td>33</td>
<td>62</td>
</tr>
<tr>
<td>Never married</td>
<td>8</td>
<td>26</td>
<td>10</td>
<td>23</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>

The Kungsholmen area also had an overrepresentation of individuals with education above the base level, compared to the rest of the country. Forty-nine percent of community-dwelling individuals in the second follow-up survey had more than seven years of education, compared to 24 percent of Swedes 65+ in the country as a whole (Statistics Sweden, 1993).

The four studies in this dissertation used data from the second follow-up survey conducted between 1994 and 1996. Even though there was attrition at each wave of data collection due to mortality and refusals to participate, the attrition did not influence the composition of the study group with regard to gender or marital status. Seventy-eight percent of the persons in the study group were women, whereas in Kungsholmen as a whole, 79 percent of persons were women. The proportion of married, widowed, and never married men and women were also nearly identical in the study group compared to the Kungsholmen population in 1995 (Stockholm Office of Research and Statistics, Area Data System).

**Procedures for data collection**

All inhabitants were sent a personal letter explaining the nature of the study and the importance of participation, but clearly stating that participation was voluntary and that they could, at any time, discontinue participating in the study without pressure or sanctions. The interviews took place on the premises of the Kungsholmen study or in the participant’s home (if necessary at the hospital or where they stayed at present). The data collection in the second and third follow-up surveys, used in this dissertation, was approved by the Ethics Committee of Karolinska Institutet; Dnrs 94:122, 97:413.

Each participant was interviewed by a nurse about marital and parental status, housing, education, frequency of contact with friends, functional ability, and need of support with household chores. They were asked whether they used public home help services or privately paid domestic services, and if so, with which type of household chores they received help. Also, they were asked whether they received support from informal sources, and if so, what kind of support they received. The information gathered during the interview was self-reported, and with regard to functional ability, was also based on the
nurse’s evaluation. In addition, each participant was assessed with an extensive medical examination by a physician, and cognitively assessed by a psychologist.

A family interview was performed with the next-of-kin or another close person. The interview included questions about the past and current health status of the participant, facilitating assessment of physical and mental health for persons who themselves could not fully contribute. The questions in the family interview about formal and informal care were almost identical to the questions in the participant interview. This made a cross-validation possible in the studies presented in this dissertation for those who had an informant (83 percent of those living in ordinary dwellings). If the answers regarding public home help services were unclear or contradictory, register data or home care records from the municipality of Stockholm were checked regarding whether the participant received home help services at the time the interview took place.

Register data also were used in Study IV to determine if and when the participant used public home help services or moved to institutional care.

**Outcome measures**

To measure formal and informal assistance the participants were asked “Do you get any practical assistance at home from a) a coresider, b) next-of-kin or a friend outside the household, c) privately paid service, d) a voluntary association, e) the home help services, f) someone else?”5 This global question was then followed by more detailed questions on formal and informal assistance. The participants were asked whether they received help with dressing/undressing, getting up from bed, shopping (groceries), cooking, and/or laundry, and if so, from whom (alternative a – f above).

The informants were asked similar questions in the family interview, which made it possible to compare their answers with those of the participants.

---

5 ”Får Ni någon praktisk hjälp i hemmet från a) anhörig inom hushållet (någon Ni bor tillsammans med), b) utom hushållet (annan anhörig/vän), c) privat avlönad hjälp, d) från frivilligorganisation, e) från hemtjänsten, f) annan?”
The participants’ answers to the global questions were compared with their answers to the more detailed questions cited above. The participants’ answers were treated in different ways depending on whether or not they were diagnosed with dementia. Nondemented participants who reported no assistance on the global question, but declared later in the interview that they received assistance with some specific chore were coded as receiving assistance.

The answers from individuals diagnosed with dementia were compared with the informants’ answers. If the participant’s answers were incomplete, information from the informant was used to fill in the gap. If they were contradictory, the protocols from both the participant and the informant were closely studied because the interviewer often added supplementary information to the protocol that could explain the difference. The participant’s answer was replaced by the informant’s answer when the informant reported that the participant received assistance and specified the type of support given, and the time between the two interviews was less than six months (1.5 percent of those living in ordinary dwellings).

**Home help services and institutionalization**

Studies I – III were based primarily on interview data, whether the participant received home help services or lived in an institutional care facility at the time the interview took place. In a few doubtful cases a check of home care register was made. Due to missing values regarding the number of hours of home help received, the information was dichotomized into has/has no public home help services.

In Study IV, information from the municipality of Stockholm’s computerized eldercare register was used because it provided continuous (monthly) information regarding home help and institutional care during the follow-up period (1995 – January 1, 2000).
Informal care

Informal care was an outcome variable in Studies I and II and was used as a predictor of home help utilization and institutionalization in Studies III and IV.

In Study I, care by the coresider and/or from outside the household was included, whereas Studies II – IV only included extraresidential care. The data were dichotomized into has/has no informal support.

Private services

Use of private services was an outcome variable in Studies I and II and a predictor of home help utilization or institutionalization in Studies III and IV.

No information was available about the type of service they purchased or how frequently it was used. The data were dichotomized into uses/uses no private services.

Predictors for formal and informal care

*Household composition.* In Study I, coresidence with a spouse (including consensual unions) and coresidence with others (children, grandchildren, siblings) were analyzed separately. As similar effects on receipt of formal and informal support were found for spouses and other coresiders, except for use of private services, in Studies II - IV the variable was dichotomized into coresides and lives alone.

*Education.* Level of education was assessed as elementary school or vocational training (between two and 7 years of education), or intermediate or higher education (8 years or more).

*Parental status.* The variable included biological children, adopted children and/or other children the participant had raised. No information was available about how far away the children lived, or if any child had died after the baseline interview.
Contact with friends. Visiting or receiving visits “daily,” “several times per week,” or “once a week” were coded as “often.” “Once a month” or “have no friends” were coded as “seldom/never.”

Dementia. Dementia diagnosis was made according to the DSM-III-R criteria (APA, 1987). The examining physician made a first preliminary diagnosis. Then a specialist independently reviewed all cases and made a second preliminary diagnosis. In case of agreement, this was the final diagnosis. In case of disagreement, a third opinion was sought before the final diagnosis was accepted. The procedure for diagnosing dementia is described in detail elsewhere (von Strauss, Viitanen, De Ronchi, Winblad, & Fratiglioni, 1999). Persons fulfilling the criteria for dementia were included in the demented group, and the variable was dichotomized into has/has no dementia diagnosis.

Depressive symptoms. Diagnostic criteria for depressive disorders according to DSM-IV (APA, 2000) were rated by the examining physician in accordance with the Comprehensive Psychopathological Rating Scale on a six-point scale (Åsberg, Montgomery, Perris, Schalling, & Sedvall, 1978). These criteria included depressed mood, diminished interest in activities, psychomotor disturbances, loss of energy, feelings of worthlessness, pessimistic thoughts, concentration difficulties, and suicidal thoughts. Data from the eight items were summed into a score from 0 (no depressive symptoms) to 26 (the highest number of reported symptoms). Lack of appetite and sleep problems, also included in the diagnostic criteria for depressive disorders, were left out to minimize chances that depressive symptoms reflected physical rather than mental health problems.

Chronic medical conditions. Information on chronic medical conditions was included in the analyses in Study III, as comorbidity with physical illness is common among persons with dementia and depression (Hocking et al., 1995). Data about diagnoses in four groups, including cardiovascular, metabolic, neurological, and lung diseases, was obtained from the clinical examination in the study and from the inpatient registry of the County Council of Stockholm. A score was derived ranging from 0 (no chronic conditions) to 4 (diagnosed with chronic conditions in each of the four groups).
Chronic medical conditions were not included in Study IV as this information was not statistically significantly related to receipt of home help or institutionalization, either in the full model or when controlling only for age and sex.

Walking limitations. The participant was asked if she or he could get around independently, indoors and outdoors, or needed any means of assistance such as a cane, crutch, walking frame, or wheelchair. Data from the questions were combined into a score ranging from 0 (no limitations), to 1 (can get around independently indoors but needs aids outdoors), and 2 (needs aids both indoors and outdoors).

Dependence in ADLs. The participants’ functional ability was assessed according to the Katz index of independence in ADLs (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963). The participants were asked about their ability to bathe, dress, go to the toilet, transfer, maintain continence, and eat. If they needed assistance in any activity, it was recorded as a disability in the corresponding item. The scores ranged from 0 (requires no personal assistance in any of the six activities) to 6 (requires assistance in all six activities).

Dependence in IADLs. The participants were asked if they could manage practical household activities such as cooking, shopping (groceries), laundry (washing clothes), and house cleaning on their own or if they needed help. Data from the four questions were combined into a score from 0 (no need of help with any activity) to 4 (need of help with all four activities).
PRESENTATION AND RESULTS OF STUDIES

This dissertation is based on four studies referred to in the text by their respective roman numerals. Studies I – III used cross-sectional data from the second follow-up survey of the Kungsholmen study, in which the participants were 81 years of age or older.

Study IV was based on an investigation with a longitudinal design, and data from both the second and the third follow-up surveys were used. In addition, continuous data on the use of home help services and entry into institutional care were used from 1995 to January 1, 2000.

I: Does gender matter? Differences in patterns of informal support and formal services in a Swedish urban elderly population.

Aims
The aims of the study were to compare (a) the proportion of men and women in residential care in the oldest age group in relation to having a coresiding caregiver, measured by marital status, and (b) the factors predicting use of public eldercare and/or informal support for community-dwelling men and women in the oldest age group, in relation to having a coresiding caregiver.

Results
Institutional care: Twenty-four percent of the population age 81+ (n=683) lived in different kinds of institutional care, the majority of them with service around the clock. There were no gender differences in the proportion of persons living in institutions. When relating housing to marital status, clear differences were found. Twice as many unmarried (i.e. widowed, divorced, or never married) persons (26 %) as married persons (14 %) lived in institutions. No gender differences were found in type of housing when controlling for marital status; 14 percent of both married men and married women lived in institutions,
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compared to 25 percent of unmarried men and 26 percent of unmarried women.

Community-dwelling persons: Eighteen percent of men and 26 percent of women (p=0.067) received public home help services. About twice as many persons who lived alone (27%) received home help, compared to those who coresided (14%). To get a more comprehensive picture of receipt of care, information about both informal support (from the coresider and/or from outside the household), and public home help services was combined. This mapping showed that two elderly persons out of three (69%) had support from either informal sources or the home help services, or both. In all, more men received support (78%) than did women (66%). However, no gender differences were found in receipt of formal or informal care when controlling for household composition.

Multivariate analyses were conducted to study gender differences in the utilization of formal and/or informal care, controlling for age and education, functional and cognitive limitations, and self-reported need of help with IADLs. Men had lower odds of receiving public home help services (odds ratio = 0.33), and higher odds of receiving help from informal sources (odds ratio=1.94) than women. Combining information about both informal support and public home help services showed that men had higher odds (odds ratio = 1.88) of receiving either home help or informal care, or both. Controlling for coresidence, however, removed the statistically significant gender difference in the use of public home help services, receipt of informal care, and receipt of support from any source.

Conclusions

The study showed that it was not gender, but rather the structural characteristic of coresidence with a caregiver that had a significant influence upon the ability to remain at home and avoid institutionalization in old age. Similarly, it was the structural characteristic of living with someone, rather than gender, that was of importance for access to in-home care when both formal and informal sources were taken into consideration.
II: The effects of marital and parental status on informal support and service utilization: A study of older Swedes living alone

Aims
The study investigated whether community-dwelling older people living alone benefit from having been previously married and having children in terms of informal care received, and whether those without such filial support were compensated by formal services.

Results
The sample consisted of community-dwelling persons (81+) who lived alone (n=390). Twenty-seven percent received home help, 49 percent received informal care, and 15 percent purchased private services. In total, 69 percent received care from one or more of the three sources.

In order to study the net effects of marital and parental status on different types of support, logistic regression equations were performed using type of care received as the dependent variable, controlling for age and education, functional and cognitive limitations, and self-reported need of help with IADLs.

Public home help services: The previously married persons with children were less than half as likely (odds ratio=0.46, p<0.10) to use home help services as the previously married persons without children, suggesting that parental status had a much more powerful effect than marital status on the use of public services. Persons with higher educational levels had more than double the odds of receiving public in-home support.

Informal care: Previously married persons with children were almost four times more likely to receive informal care (odds ratio=3.88) than previously married persons without children. No difference was found between childless persons who were previously married and childless persons who had never been married. Thus, having had children seemed to provide more benefit than having been previously married in terms of elevating the chances of receiving informal care.

Private domestic services: No differences in use of private services were found with regard to marital or parental history.
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**Formal and/or informal care:** Previously married persons with children were 3.5 times more likely to receive care from any source than were previously married individuals without children. No difference was found between previously married childless persons and never married childless persons. In addition, men who lived alone were less likely to receive care from any source than were women who lived alone.

**Conclusions**
Parents had considerably higher odds of receiving informal support whereas previously married individuals without children were no more likely to receive support than their never married counterparts. Public home help services did not fully compensate for the lower levels of informal care among childless individuals, showing that even in an advanced welfare state like Sweden, children are assets for receipt of care in old age.

**III: Dementia and depressive symptoms as predictors of home help utilization among the oldest old: A population-based study in an urban area of Sweden**

**Aims**
To investigate predictors of public home help utilization, particularly mental health problems such as dementia and depressive symptoms, also taking informal support and use of private services into consideration.

**Results**
The sample consisted of 502 community-dwelling persons age 81 and older. *Dementia* increased the odds of receiving home help among persons living alone. Among coresiding persons, it increased the odds of receiving home help, but only among those who also received informal support from outside the household. A possible explanation could be that informal caregivers, above all children who supported their parents, had acted successfully to obtain help. The result could also be due to poor health in both the participant and the spouse that
forced relatives to complement the home help services with in-home support.

Depressive symptoms were not related to receipt of home help in general. However, among persons with lower levels of education, living alone, depressive symptoms decreased the odds of receiving home help. One possible explanation is that depressive symptoms, such as lack of energy or decreased activity, in combination with lower levels of education, affected the individual’s ability to apply for help. The results also could be due to shortcomings in the care managers’ assessments.

Conclusions
Among community-dwelling elderly persons residing alone, public eldercare targeted individuals with extensive needs such as dementia and functional impairments. However, depressive symptoms either were not related to use of home help, or even reduced the odds of receiving help.

Among coresiding persons, dementia increased the odds of receiving home help only among those who received informal support from outside the household. Home help has been targeted away from co-residing people, leaving very frail spouses to care for their partners. Improvement of screening activities for assessing the public home help needs of community-dwelling elders might allow better targeting of limited social resources to the most needy.

IV: Predictors for receiving public home help and entry into institutions. Results from a longitudinal study of a Swedish urban elderly population

Aims
The aims of this study were to (a) identify factors that predict receipt of home help services, (b) identify factors that predict transition into institutional care, and (c) investigate whether factors that predict the use of public home help services also predict entry into institutions.
Results
Twice the proportion of people living alone as coresiding received home help. Only 4% of people living alone and 5% of those coresiding moved to institutions without previously receiving home help. Among people living alone, Cox regression models showed that dementia and increasing age predicted home help utilization and institutionalization. Female gender, depressive symptoms, and walking limitations predicted use of home help, but did not predict institutionalization. Dependence in IADLs predicted institutionalization but not receipt of home help.

Among nondemented coresiding people, depressive symptoms, dependence in ADLs, and extraresidential informal care increased the likelihood of home help utilization and institutionalization. Dementia combined with a higher educational level, increased the likelihood of institutionalization but not home help.

Conclusions
When controlling for household composition, approximately the same factors predicted the both outcomes. Home help was commonly the first alternative, thereby facilitating “aging-in-place.”

Use of incidence data can reveal new information about the temporal relationship between various predictors and actual receipt of care. It can also uncover changes in policies for granting eldercare that are difficult to detect using prevalence data. The fact that walking limitations predicted use of home help among persons living alone but IADL-limitations did not, indicates that the threshold for receiving home help had been raised. Depressive symptoms predicted use of home help as well as institutionalization ($p<0.10$), both among people living alone and those coresiding, pointing towards a change in needs assessment.
Summary of results from Studies I - IV

When comparing the results of the four studies, it is important to note that different research designs were used. Studies I – III used cross-sectional data and examined factors related to receipt of formal or informal care at the time when the interview took place (prevalence), irrespective of how long the individual had received help.

Study IV started with a sample of persons without home help (or not living in institutions when institutionalization was the event studied), and analyzed factors related to receipt of home help or moving into institutional care during the follow-up time (incidence).

This means that the studies comprised different groups of individuals. Those who received home help in Studies I – III were excluded from the analyses in Study IV, as the purpose of Study IV was to analyze factors related to the receipt of home help in the following five years. Therefore the studies also compared needs assessments from different points in time. The home help recipients in Studies I – III had been granted home help sometime before the interview, whereas Study IV comprised new needs assessments that were made between 1994/96 and 2000.

Home help and institutionalization

The above literature review was the point of departure for selecting relevant factors to be included in the analyses of the provision of eldercare to vulnerable groups of individuals. An overview of results regarding home help utilization and institutionalization is provided in Table 3.

Predictors that increased the likelihood (odds ratio or relative risk) of receiving home help services or the likelihood of entry into institutional care (p<0.05) are indicated with a plus sign, and those that decreased the likelihood are indicated with a minus sign. As the sample was not very large, results with a p-value between 0.05 and 0.10 are shown in parenthesis. Ns represents nonsignificant results (p>0.10), and 0 indicates variables that were not included in the analysis in that particular study.
According to Need?

Table 3. Summary of predictors of eldercare utilization

<table>
<thead>
<tr>
<th></th>
<th>Cross-sectional data</th>
<th>Longitudinal data</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Study I</td>
<td>Study II Lives alone</td>
<td>Study III Lives alone</td>
</tr>
<tr>
<td></td>
<td>Home help</td>
<td>Home help</td>
<td>Institutionalization</td>
</tr>
<tr>
<td>Sociodemographic factors</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Household composition (ref= lives alone)</td>
<td>– 0 0 0 0</td>
<td>0 0 0 0 0</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>ns ns ns ns</td>
<td>+ ns + ns</td>
<td></td>
</tr>
<tr>
<td>Gender (ref=male)</td>
<td>ns ns ns</td>
<td>+ ns ns ns</td>
<td></td>
</tr>
<tr>
<td>Education (ref=low)</td>
<td>ns + ns ns</td>
<td>ns ns ns +</td>
<td></td>
</tr>
<tr>
<td>Social network</td>
<td>Has children (ref=no)</td>
<td>0 (-) ns ns</td>
<td>ns (-) ns (-) ns</td>
</tr>
<tr>
<td></td>
<td>Contact with friends (ref=seldom)</td>
<td>0 (-) ns ns</td>
<td>ns (-) (-) ns</td>
</tr>
<tr>
<td>Health</td>
<td>Dementia (ref=no)</td>
<td>+ + + ns/+</td>
<td>+ ns + + + d</td>
</tr>
<tr>
<td></td>
<td>Depressive symptoms</td>
<td>0 0 ns/– ns</td>
<td>+ ns/+ c (+) ns/+ c</td>
</tr>
<tr>
<td></td>
<td>Chronic med. conditions</td>
<td>0 0 ns ns</td>
<td>0 0 0 0</td>
</tr>
<tr>
<td>Functional ability</td>
<td>Walking limitations (ref=0)</td>
<td>+ + + ns</td>
<td>+ ns ns (+)</td>
</tr>
<tr>
<td></td>
<td>Dependence in ADLs</td>
<td>ns ns ns ns</td>
<td>ns ns/+ c ns ns/+ c</td>
</tr>
<tr>
<td></td>
<td>Dependence in IADLs</td>
<td>+ + + (+)</td>
<td>ns ns + ns</td>
</tr>
<tr>
<td>Other sources of care</td>
<td>Extraresidential informal care (ref=no)</td>
<td>0 0 – (-) c</td>
<td>ns ns/+ c ns ns/+ c</td>
</tr>
<tr>
<td></td>
<td>Private domestic services (ref=no)</td>
<td>0 0 – ns</td>
<td>ns ns ns ns</td>
</tr>
</tbody>
</table>

Note: Relationship of variables to the use of eldercare; signs in parenthesis (p< 0.10); + = positive, – = negative, ns = no relation. 0 = not included. Among people: a: with extra-residential informal care, b. with lower levels of education, c. without dementia. d: Among people with no depressive symptoms, no ADL-limitations and who receives no extraresidential care.
Factors increasing the likelihood of receiving eldercare

Age: In Study IV, increasing age was a predictor of home help utilization and institutionalization among people living alone. This might be due to the longitudinal design of the study. In the cross-sectional studies (Studies I-III) the outcome (home help) was measured at the same time as the independent variables, and the effect of age became nonsignificant when functional and cognitive ability also were included in the analyses. In Study IV the outcome (home help or institutionalization) was registered at a later time than functional ability, in some cases several years later.

Gender: Female gender increased the likelihood of receiving home help in Study IV.

Education: Educational level was found to be of importance in eldercare utilization in three studies. In Study II, which was restricted to individuals living alone, people with higher levels of education had higher odds of receiving home help compared to those with lower levels of education.

Among participants in Study III, lower levels of education, in combination with depressive symptoms, reduced the likelihood of receiving home help.

In Study IV, coresiding people with higher levels of education had a higher likelihood of moving into institutional care compared to those with lower levels of education.

Dementia: Among people living alone, dementia was a consistent predictor of home help utilization. Dementia also predicted institutionalization both for persons who lived alone and those who coresided.

The results regarding home help utilization among coresiding people were more difficult to interpret, as we lacked information on the health and functional ability of the coresider. In Study III, dementia increased the probability of using home help only among coresiding seniors who received support from outside the household. In Study IV, depressive symptoms, limitations in ADLs, and informal care from outside the household had different effects depending on presence or absence of dementia.
LADLs: In Studies I-III, which used cross-sectional data, need of help with household chores predicted receipt of home help.

In Study IV, need of help with IADLs did not increase the probability of receiving home help during the follow-up period, but it increased the probability of entry into institutions among people who lived alone.

Walking limitations: Persons who needed aids to move indoors or outdoors (i.e. cane, crutch, walking frame, or wheelchair) had a higher likelihood of receiving home help in all studies, with the exception of coresiding people in Studies III and IV.

In Study IV, the presence of walking limitations did not predict institutionalization among people living alone. Among those who co-resided, it was statistically significant at the 10 percent level.

Factors decreasing the likelihood of receiving eldercare

Household composition: Study I showed that coresidence decreased the likelihood of receiving public eldercare. This was not only evident in the study sample, but also was clearly demonstrated in national figures on the proportion of people who received home help and lived in institutions.

Children and contact with friends: Having children or frequent contacts with friends tended to decrease the likelihood of receiving public eldercare in Studies II and IV; the results were significant at the 10 percent level.

Informal care: Informal care reduced the likelihood of receiving home help among people living alone. The same tendency was found among coresiding people without dementia, the result was significant on the 10 percent level (Study III).

Private services: Using privately paid domestic services decreased the likelihood of receiving home help, but only among persons who lived alone (Study III).
Mixed results

Depressive symptoms: Cross-sectional data showed that depressive symptoms decreased the odds of receiving home help among people with lower levels of education who lived alone (Study III).

Among people who lived alone and received no public eldercare at the beginning of the study period, depressive symptoms were positively related to receipt of home help during the follow-up period (Study IV). The same tendency was found regarding institutionalization, but was significant only at the 10 percent level.

Informal care from outside the household among coresiding people: Receipt of informal care from outside the household decreased the odds of receiving home help among people without dementia, as mentioned above. Among demented persons, on the other hand, extraresidential informal care increased the probability of receiving home help (Study III).

Analysis of new needs assessments from the second half of the 1990s showed that informal care increased the probability of receiving eldercare among those without dementia. Individuals with dementia, however, were more often censored in the analyses due to institutionalization or death (Study IV).

Informal care, private services, and support from any source

In Studies I and II, different sources of care were analyzed separately. The results regarding informal care, use of private services, and support from any source are provided in Table 4.

Voluntary associations were not included, as only 0.8 percent of the persons in the sample reported that they received practical assistance at home from a nonprofit organization.

Factors related to receipt of informal care

Household composition: Coresidence increased the probability of receiving informal care (when care from the coresident was included), regardless of whether he or she was a spouse or another relative.
According to Need?

Children, and contact with friends: A good social network (in the sense of having children and/or having frequent contact with friends) increased the probability of receiving informal care.

Education: Persons with higher levels of education, living alone, had lower odds of receiving support from informal sources, although this tendency was significant at the 10 percent level.

IADLs: Need of help with IADLs increased the odds of receiving informal care.

Factors related to use of private services

Household composition: Persons coresiding with children, grandchildren, or siblings were more likely to buy private services than those who lived alone. This was not the case among people who coresided with a spouse.

Education: Persons with higher levels of education had higher odds of buying private services than persons with lower levels of education.

ADLs and dementia: People with functional or cognitive limitations were less likely to use private services. Demented people living alone did not buy any private services.

IADLs: Need of help with IADLs increased the odds of purchasing private services.

Factors related to receipt of care from any source

Household composition: People who coresided people had higher odds of receiving support from any source than people who lived alone.

Gender: Among people who lived alone, women were more likely than men to receive support from any source.

Children, and contact with friends: Parents had higher odds of receiving support from any source. Frequent contacts with friends also increased the likelihood of receiving support from any source; significant at the 10 percent level.
LADLS, walking limitations, and dementia: Dependence in IADLs increased the probability of receiving support from any source.

Walking limitations and dementia increased the likelihood of receiving support from any source; significant at the 10 percent level.

Table 4. Summary of predictors of informal care, use of private services, and support from any source (including home help)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Study I</th>
<th>Study II Lives alone</th>
<th>Study I</th>
<th>Study II Lives alone</th>
<th>Study I</th>
<th>Study II Lives alone</th>
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Note: Relationship of variables to the use of informal care, private services or support from any source; signs shown in parenthesis (p< 0.10); + = positive, – = negative, ns = no relation, 0 = not included.

a. Includes care from coresiders in Study I.
b. Home help and/or informal (intra- and/or extraresidential) care in Study I.
c. Excluded from the analysis as no persons with dementia used private services
d. Among previously married persons (never married persons with children were omitted from the analyses).
e. No statistically significant relation among those coresiding with a spouse, but positively related to purchase of private services among those coresiding with someone else.
GENERAL DISCUSSION

The purpose of this dissertation is to study factors that predict use of formal and informal care in an urban elderly population in relation to individuals’ needs, social network characteristics, and sociodemographic factors. A second purpose is to examine linkages between formal and informal care.

Before turning to the results, I want to discuss some methodological considerations regarding the four studies on which the dissertation is based, such as the definition and validity of the outcome measures and the generalizability of the findings.

Methodological considerations

Validity of the outcome measures

Information on home help in Studies I – III was mainly based on information from the participants or, in some cases, from informants who provided information about the participants. A previous Swedish study found very high agreement between survey responses and register data regarding utilization versus no utilization of home help (Carsjö, Thorslund, & Wärneryd, 1994). The information from Studies I – III was restricted to whether or not people received home help at the time the interview took place. Number of hours received was not included in the analyses due to missing data. Thus, it was not possible to study factors that influenced the amount of help received, merely whether different factors had an influence on the likelihood (odds) of receiving home help.

Information on home help or entry into institutional care in Study IV was based entirely on register data. It is not known to what extent the official register was inaccurate; that is, to what extent it may have included persons who had declined home help or moved out of institutions, or may not have included information on all new care recipients. As the register data used in this study formed the basis for calculating user fees, the information on eldercare utilization is probably fairly valid. The municipality had an interest in collecting fees for
services they provided, and the seniors had an interest in paying only for services they used.

Information on informal care was based on answers to the question about whether the participant received any practical assistance at home from informal sources. Since no information was available on frequency of contacts or the number of hours of care given, people receiving informal care around the clock were included in the same category as people who received intermittent support from their relatives or friends. As with home help services, factors that predicted receipt of informal care were identified but it was not possible to estimate factors affecting the intensity of the care given.

It was more difficult to ascertain whether or not participants received informal care than it was to ascertain whether or not they received help from the home help services, even though the question about informal care was restricted to practical assistance at home. Most likely there were people who reported no support because they took regular visits (from a daughter, for example) for granted, even though she also helped out with practical tasks while she was there. The participants were asked both a global question on informal care, and more detailed questions about informal care later in the interview. Asking a general question first and more questions later gave respondents time to reflect upon whether or not they received informal care. The specific questions also helped the respondents think about types of assistance they may not have thought of immediately or may not have thought of as “informal care,” thereby allowing them to answer with greater accuracy. Thus, this method ascertained informal support that may have been missed if only a global question had been used. The questions did not take emotional aspects of carework into account, however, nor were time-consuming activities such as looking after a cognitively impaired parent included. Thus, the answers to the questions may not have provided information on all kinds of supportive contacts the elderly people may have had.

One advantage of the study design was the inclusion of relatives in the data collection process. Four out of five participants had a relative or other close person who acted as an informant in the study. This made it possible both to obtain information about care given to cogni-
tively impaired persons, who could not contribute with detailed information themselves, and to cross-validate participants’ responses.

It is possible that, in practice, there may be some overlap between informal care and use of private services. A Norwegian study showed that it was common for elderly recipients of family care to pay their helpers out-of-pocket; about one fifth did so (Lingsom, 1988). It is reasonable to believe, however, that the participants have answered according to how they generally perceive the service: informal if it is principally based on a bond of kinship or friendship, and privately paid if it is based on a businesslike relationship.

When discussing informal care, it is important to consider the extensive debate on the concept of care in general (James, 1992; Thomas, 1993; Ungerson, 1990). It has been suggested that the concept of care should be reserved to describe assistance provided to someone who is dependent on that assistance. The criterion of dependence thereby distinguishes caregiving from intergenerational, interspousal, or other intrafamilial aid (Walker & Pratt, 1995). This is in line with Kari Wærness’ typology, in which the power relationship between caregiver and care recipient, as well as the actual work involved in caring, is taken into consideration. According to Wærness, “caregiving work” is characterized by a relationship where the care recipient is incapable of self-care and hence in a position of dependency vis-à-vis the caregiver. “Personal service” on the other hand, is characterized by an unequal relationship between caregiver and care recipient, with services provided that the cared for could do himself or herself (Waerness, 1983).

In this dissertation I have used the concepts care, help, support, and assistance interchangeably. It is difficult to know whether elderly people who receive assistance are dependent on that support, given their advanced age, or if they would be able to manage a given task if they really had to.
Generalizability of the findings

The study population. This dissertation is based on data from Kungsholmen, a district in the inner city of Stockholm. Although the study population did not differ much from the whole inner-city population of Stockholm, the inner city differed compared with the rest of Sweden. The study population had an overrepresentation of women, particularly women who were wage earners all their lives, and never married. This reflects the fact that many women moved from rural to urban areas in the first decades of the twentieth century in search of employment and subsequently never married (Statistics Sweden, 1999).

The overrepresentation of never-married and childless women, who lacked the possibility of receiving support from adult children or in-laws, has most likely influenced the proportion of persons receiving informal care in the study population. Furthermore, there are also differences between different regions in Stockholm. A survey in Stockholm County found that informal care from outside the household was less frequent in urban areas than in rural areas (Jeppsson Grassman, 2001). On the other hand, a higher proportion of the participants in the study group reported that they received informal care from outside the household (29 percent of coresiding people, and 49 percent of those living alone) than persons in a national sample in the same age group (23 %) (Daatland, 1997). The high proportion of people reporting informal care in the Kungsholmen study may be due to the study design, which included gathering information from both the participant and an informant during the data collection process, and low attrition even among very old and frail individuals.

Stockholm has a higher proportion of people with relatively high levels of education. This was evident in the study population, in which twice the proportion of participants had education above the base level, compared with the population of Sweden as a whole. As there seems to be a class-related pattern that influences how elderly people compensate for reductions in public eldercare, the proportion of persons who purchased private services was presumably higher in the study group than in the population of Sweden as a whole. The supply of private firms offering domestic services is also most likely better developed in urban areas such as Stockholm than in rural areas. It is
not known whether the higher proportion of people with relatively higher levels of education has affected the findings beyond what could be controlled for in the regression analyses.

Public eldercare in Kungsholmen. Another question is whether the public eldercare in Kungsholmen, in the inner city of Stockholm, is representative of eldercare in other parts of Sweden. There seems to be only small differences between the proportion of people in the study group who received home help and the proportion of people who received home help in the Swedish population as a whole. A comparison using national survey figures at the turn of the year 1994/95 showed that 31 percent of community-dwelling Swedes who lived alone (80+) received home help, compared with 27 percent of persons in the study group (81+). Thirteen percent of coresiding Swedes received home help, compared with 14 percent in the study group (Daatland, 1997). The study population was also very similar to the nation as a whole with regard to special housing. Twenty-three percent of elderly Swedes (80+) lived in special housing, compared with 24 percent in the study group (National Board of Health and Welfare, 1996a).

One can call into question the validity of making generalizations about predictors of public eldercare utilization in all Swedish municipalities based on the predictors of public eldercare utilization in the district of Kungsholmen, when the proportion of the elderly population that receives home help or lives in residential care facilities is different in Kungsholmen than in the other districts or municipalities. 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 considerable local variations in the availability of care and services for elderly people (Trydegård & Thorslund, 2001). There are only a few population-based Swedish studies of the oldest old that have examined predictors of home help utilization, using multivariate analyses in order to sort out the separate contributions of different factors. Functional limitations and living alone are the most important predictors of home help utilization both in local (Herlitz, 1997; Thorslund et al., 1991) and national studies (Sundström & Hassing, 2000; Szebehely et al., 2001). Living alone and poor physical functioning are probably important predictors of home help utilization in all municipalities, irrespective of coverage rate, given the increasingly
stringent needs tests used to determine eligibility for receipt of home help. In addition, dementia or cognitive impairment is probably a predictor of home help in all municipalities, at least among people living alone, which would be in line with the results presented here.

Municipalities with a high proportion of institutional care may offer elderly people the option of moving to residential care in an earlier phase in the development of dementia, which might influence predictors of home help utilization. I can only speculate about whether different coverage rates influence other factors studied in this dissertation, because this is an empirical question. When a greater proportion of the elderly population receives home help services, people with depressive symptoms may have a higher chance of receiving help, even in cases where the care manager is unaware of their psychiatric health problems. A considerably higher proportion of the older population in Denmark than in Sweden is covered by home help services. A study of community-dwelling people in Denmark, 80 years of age and older, showed that depressed individuals had more than twice the likelihood of receiving home help as non-depressed individuals (Hansen et al., 2002). On the other hand, even in municipalities that offer home help to only a small proportion of the elderly population, well-functioning cooperation between primary health care providers and psychiatric care providers may do a good job of targeting individuals with depressive symptoms. One can argue, however, that in municipalities with relatively low coverage rates, needs assessments must be performed more precisely than in municipalities with higher coverage rates (and combined with preventive home visits to screen for unmet care needs), in order to claim that care needs are met as well as they are in the relatively high-coverage municipalities.

Data collection period. Data collection for Studies I – III took place mainly between 1995 and 1996, and for Study IV, between 1995 and 2000. For this reason, it is possible to question whether the data are representative of the current eldercare situation. There were only small reductions in the proportion of people 80 years and older receiving public eldercare in Sweden between 1995 and 2002.6

6 In the 80+ age group, a reduction of 0.3 percentage units in the proportion of people receiving home help took place between 2000 and 2002 (municipal home nursing without home help was not included in the statistics). A reduction of 1.3
According to Need?

Needs-assessment, however, became more restrictive between 1994 and 2000; fewer hours of home help were provided for a given level of need (Sundström et al., 2002).

It is difficult to know if the somewhat different results in Studies I – III compared with Study IV are due to the increasingly stringent needs assessments during the second half of the 1990s, or if they are a consequence of different study designs. In cross-sectional studies like in Studies I – III, the eldercare users were a mixed group of people who had been granted public eldercare at various points in time and who were still home help recipients (prevalence).

In Study IV, new needs assessments among people who entered the eldercare system were studied (incidence), irrespective of how long the people remained eldercare recipients after that. Studies using incidence data have the potential to reveal changes in policy for granting eldercare that are more difficult to detect using prevalence data. Among people living alone in Study IV, those who used walking aids had a higher likelihood of receiving home help but this was not the case among people who needed help with household chores. This indicates that the threshold for receiving home help had been raised as need of help with IADLs was a consistent predictor of home help utilization in Studies I – III. Depressive symptoms predicted use of home help and institutionalization in Study IV, both among people living alone and those coresiding. This also indicates a change in the needs assessment compared with the earlier studies.

Temporary state grants were directed to the municipalities in 1999 – 2001 to improve the situation for family caregivers. Therefore, changes regarding caregiver support may have occurred since the time the data were collected. However, in 2000 less than 10 percent of family caregivers in Stockholm County reported that they had received caregiver relief (Jeppsson Grassman, 2001), and probably even fewer family caregivers have received support since 2001.

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percentage units in the proportion of people living in special housing occurred during the same period (National Board of Health and Welfare, 2004).
Do public eldercare target vulnerable groups?

In broad outline, it seems that the home help services targeted persons with more extensive care needs such as functional and cognitive limitations. I did not find any large unmet needs in the study group when the data collection took place in the middle of the 1990s.

According to results presented here, there are, however, certain groups who may be in danger of unmet need for care.

**People without children, living alone.** Persons living alone are at greater risk for having insufficient support from informal sources in old age, and this is particularly true for those without children. Study II showed that parents were more than three times more likely than childless persons to receive support from at least one source.

Children often keep an eye on their mother or father and apart from acting as a primary caregiver, also intervene in other ways. The role of children as coordinators of formal caregivers has been shown in studies from many countries (Kröger, 2001). Childless persons may be at greater risk of having unmet needs for care when the threshold for receiving eldercare rises. If and when undertaking preventive home visits to screen for unmet care needs among the oldest old, particular attention should be paid to childless people who live alone.

**Depressed individuals.** Depressive symptoms are prevalent in old age, but little attention has been paid to the impact of depression on the use of formal services. Interview studies with care managers and home helpers in several Swedish municipalities confirm that elderly people with psychiatric care needs are at risk of not being recognized by the eldercare system (National Board of Health and Welfare, 2000).

Results regarding depressive symptoms differed among the studies that are discussed in this dissertation. Cross-sectional data (Study III) showed no relationship between depressive symptoms and use of home help among people with higher levels of education. Among people with lower levels of education, depressive symptoms decreased the probability of receiving home help. This could be an effect of the disorder; symptoms such as lack of energy or decreased activity may affect the individual’s ability to apply for help. This explanation, however, presumes that elderly people apply for home help them-
selves. A Swedish study (although with a small sample) showed that elderly people applied for home help themselves in approximately one third of the cases (Nordström & Dunér, 2003). Another explanation could be that next-of-kin failed to observe the elderly individuals’ symptoms. In both cases, people with higher levels of education may be better at verbalizing their symptoms than people with lower levels of education.

In Study IV, depressive symptoms increased the likelihood of receiving home help among people living alone and among coresiding people without dementia. It is not known whether the care managers were more observant of depressive symptoms in their needs assessments during the second half of the 1990s, or if there is another explanation for this result. People with psychiatric health problems are a vulnerable group and further research is needed regarding use of both eldercare and health care for this group.

_Elderly spouses caring for a demented partner._ It is well documented that marriage protects from institutionalization and this was also shown in these studies. Dementia was a consistent predictor of home help utilization among people residing alone. Among coresiding people, however, dementia only increased the likelihood of using home help among those who also received support from informal sources outside the household (Study III). The reason for this is not known. It is possible that poor health in both the participant and the spouse forced relatives to complement the public home help services. It could also be due to successful advocacy undertaken by the children who provide care. It seems that merely living with a spouse with dementia did not increase the probability of receiving home help. This confirms previous Swedish studies that show that even old and frail spouses frequently care for their partner without support from the public sector.

**Linkages between formal and informal care**

Previous studies have shown that the greater part of support to community-dwelling elders comes from informal sources, and this was also demonstrated in these studies. Twenty-nine percent of coresiding people received practical assistance at home from outside the household, and 49 percent of those living alone received such help (Study I).
As discussed in the background section, the resolution of the “substitution issue” lies in the eye of the beholder. Persons from different cultural or political contexts may well reach different conclusions regarding whether formal care substitutes or complements informal care - even from the same data. Nevertheless, there are interesting results to highlight when summarizing the results from the four studies presented here.

First, there was an inverse relationship between use of public home help services and receipt of informal care. Half the proportion of co-residing people received home help compared with those living alone (Study I), and the same was true among survivors five years later (Study IV). Having children and having frequent contacts with friends seemed to suppress use of home help among persons who lived alone (Study II). Informal care from outside the household decreased the odds of receiving home help among people who lived alone, and the same was found among (non-demented) co-residing people (Study III).

International debate on the relationship between formal and informal care has focused on whether families reduce their care obligations when they have the opportunity to do so, as proposed in the substitution model. However, data from the studies in this dissertation suggest that a reversed substitution had taken place. This is in line with results from national studies, cited earlier, which demonstrated that a decline in public eldercare provision during the past few decades coincided with an increasing level of family involvement in the care of the elderly. When home help was granted to people in the study population it seemed as though the care managers were including the availability of informal help from outside the household in their needs assessments, even among the oldest old (the participants were between 81 and 100 years old). It is possible, of course, that elderly people have themselves chosen to ask for help from family members. Having heard about stricter assessments and poor quality, they may have lower expectations about what formal care is available.

The Swedish public eldercare system thereby seems to be approaching that of a conservative welfare regime, in which the state only intervenes when the family’s resources are exhausted. This development, however, is not in line with the preferences of older people themselves. Swedish, Norwegian, and Danish elderly people
express similar desires not to be a burden on their family or dependent on them for meeting elementary needs, as discussed above (see page 27). In contrast to the situation in Sweden, in Denmark, receipt of informal care does not seem to reduce the probability of receiving home help among elderly people with children in the vicinity (Hansen et al., 2002).

Second, there was considerable overlap between public home help and support from informal sources. A majority of the home help recipients received practical assistance at home from informal sources (Study I), as did more than half of those who lived alone (Study II). This finding offers support for the complementary model, in which it is stated that the public eldercare system supplements the informal care system when the needs of the older person exceed the resources of the informal care system.

Third, the results from the studies in this dissertation demonstrate that public home help services did not counterbalance lack of informal care. Study I showed that even though persons who lived alone also received support from informal sources, the support they received did not add up to the combined support from public and informal sources received by those who lived with someone. This was clearly illustrated by the fact that twice the proportion of unmarried as married persons had moved into some type of institutional care.

Study II showed that among persons living alone, parents had considerably higher odds of receiving informal support compared with those without children. Even though childless persons had higher odds of receiving public home help, they still appeared to be underserved compared with persons who had children when all sources of care were considered.

Fourth, previous studies have indicated that having relatives may enhance the use of formal care, because relatives can act as advocates in favor of their kin (see page 34).

Among persons living alone, there was no indication that having children increased the probability of receiving home help; rather the results indicated that informal care substituted for public eldercare, as described above.
Among coresiding people, however, results suggest that relatives may be of importance; they may be instrumental in procuring public eldercare. In Study III, coresiding individuals diagnosed with dementia who also received informal support from outside the household were more likely to receive home help than coresiding individuals diagnosed with dementia who did not receive extraresidential care. When the “new cases” in Study IV were analyzed (i.e., people granted eldercare for the first time), it was found that coresiding people with informal support from outside the household were more likely to receive home help and to move into institutions than coresiding people who did not have informal support from outside the household. This was shown only for people without dementia whereas demented individuals were more often censored in the analyses due to institutionalization or death.

Fifth, the class-related pattern reported earlier (Palme et al., 2003) regarding how elderly people compensated for reductions in public eldercare, was also seen in this study population. Whereas twice the proportion of home help recipients with higher levels of education received no informal support in this study population, they were twice as likely to buy private services out-of-pocket (Studies I and II). This indicates that the Swedish eldercare system have moved toward the ideals of the liberal welfare state in so far as reductions in public eldercare were compensated by market-based services.

Educational level also seemed to be of importance for use of public eldercare. Among persons living alone, those with higher educational levels were more than two times more likely to receive public home help after controlling for functional and cognitive limitations (Study II). People with lower levels of education in combination with depressive symptoms were less likely to receive home help (Study III). Among coresiding people, a higher educational level increased the likelihood of moving into institutional care in the second half of the 1990s (Study IV).

A fundamental principle of the Scandinavian welfare system has been to provide widely available services, used by everyone in need, irrespective of socioeconomic status (Sipilä, 1997). Despite this fact, educational level appears to influence the likelihood that people will receive public eldercare. At the present time, we do not know why this
is the case. It is possible that people with higher levels of education were more accustomed to contacts with the authorities than those with lower levels of education. Persons with higher education (or their children) may also have had a greater awareness of their rights or better access to information. An interview study of older Swedes receiving public eldercare found that persons with lower levels of education felt more powerless or less able to influence the social worker’s decisions, whereas persons with higher levels of education reported no such problems (Möller, 1996).

**According to need?**

My research interest started as a result of my studies regarding care and services to vulnerable groups of elderly people. Caring for an elderly mother gave me further understanding of informal care from a next-of-kin perspective. This led to my interest in studying the way public eldercare targets various groups of elderly people.

The concept of need plays an important part in social and health care policy. It is a key concept in the Social Services Act that came into force more than twenty years ago, although it remains mainly undefined (Thorslund & Larsson, 2002). Along with reductions in the proportion of the elderly population receiving public eldercare, the notion of what constitutes need has been redefined. The legislation and official ambitions, however, remain unchanged. It is doubtful whether the old woman who lived with an adult son, mentioned in the introduction, would receive home help today. If she did receive home help, you would expect to find that her son had acted as an advocate on her behalf, or in some other way succeeded in persuading the care manager to grant home help. Today you have to be very old and frail and live alone, or coreside with an even frailer spouse, to receive public home help services.

The question of whether elderly people receive care according to need is vast and complex. Additionally, there are questions concerning quality, preference and satisfaction. This dissertation deals with factors that predict use of formal and informal care in relation to individuals’ needs, social network, and sociodemographic characteristics. The studies contribute to the complex picture of needs and services provided in the field of eldercare.
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