CHANGES IN PLACE OF DEATH IN SWEDEN, 2004-2011

A study of urban elderly receiving public eldercare services

Amanda Spethman

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University of Tampere

School of Health Sciences

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ABSTRACT

Background: Most people prefer to die at their place of residence, yet appropriate end-of-life care is not always available there. This lack of access to care is of particular concern in the context of Swedish eldercare, where the supply of publically financed services at all levels have been cut significantly in recent years.

Aims: The aim of this study is to investigate whether the distribution of places of death has changed in recent years, and discuss how this might have been affected by changes in the public eldercare system during the same period.

Data: The data come from a longitudinal study of recipients of public eldercare in one district of Stockholm. The sample includes all deaths in the study from March 2004 through February 2012, for which the date of death and place of death were recorded.

Methods and Results: Descriptive analysis showed significant changes in the distribution of places of death from 2004 through 2011: hospital deaths decreased from 20% to 12%, nursing home deaths decreased from 70% to 57%, and home deaths increased from 10% to 32%. Logistic regression analysis showed that, after adjusting for age, sex, and place of residence, year of death was negatively associated with hospital death. Stratified analysis based on place of residence revealed that the bulk of this effect of time emerged from the subgroup of individuals residing in private homes prior to death. Those living in other types of residence showed no significant changes in place of death over time.

Conclusions: Dying in private homes is a growing trend among elderly persons, which warrants careful planning and regulating to ensure that these individuals receive timely, good quality end-of-life care, and that this care is equally accessible to all. In addition, the finding that those who live in nursing homes almost always die there highlights the need for guaranteed availability of palliative care services in these settings.

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ACKNOWLEDGEMENTS

ABBREVIATIONS

QoL = Quality of Life

QoC = Quality of Care

Eol = End-of-Life

COPD = Chronic obstructive pulmonary disease

LTC = Long-term care

POD = Place of Death

POR = Place of Residence

SNAC-K = Swedish National study on Aging Care – Kungsholmen

PADL = Personal activities of daily living

IADL = Instrumental activities of daily living

OR = Odds ratio

CHAPTER 1: INTRODUCTION

1.1.   Background: Why is Place of Death an outcome of interest?

The term 'place of death' is the most common phrase used to denote the type of location where an individual dies, though sometimes it may also be referred to as the 'location at time of death.' It is usually noted in the individual's death certificate, along with other basic data such as the individual's name, social number, sex, date of birth, date of death, cause(s) of death, etc. In many countries, including Sweden, the place of death has traditionally been categorized into two options: hospital or not hospital. This dichotomization reflects the fact that historically most deaths occurred either in a hospital or a place or residence. This no longer reflects reality, so further division of the categories is becoming more common; for example, a three-category division is now popular: (hospital / care institution / private home). Some countries, such as the UK, divide the categories even further: (hospital / care institution / hospice / private home / other).

Place of death is an important outcome when trying to assess the quality of care (QoC) and quality of life (QoL) of individuals at the end-of-life (EoL). This is because individual autonomy and physical comfort (or at least absence of pain) are important aspects of QoC and QoL, and different types of locations generally correspond to different types and levels of care and comfort that can be provided. This is true not only in the sense of medical care, but also informal, psychological, emotional, or spiritual care. Most importantly, the dying process cuts to the heart of the human condition, so individuals and families feel vulnerable and different locations can imply different levels of safety. When surveyed, most individuals across different societies state that their preferred place of death is 'at home,' however, when the only other option is 'in a hospital', this choice may only reflect a preference for 'not in hospital' (Higginson, 2000). Of course some individuals do prefer the perceived safety of the hospital setting, perhaps combined with the desire to ease the burden on family members (Aaltonen, 2010). It should also be noted that these preferences about the place of death can change over the course of time, progress of a terminal disease, or life events. For example, family changes

may decrease access to informal care, thereby weakening the preference for home death (Jakobsson, 2006). Also, some causes of death arise too suddenly to allow appropriate care to be organized in the preferred place of death. For this reason, it is sometimes helpful to categorize causes of death as sudden / non-sudden or palliative care eligible / not palliative care eligible.

Given that people have different preferences about place of death, and that these preferences can change, data about 'place of death' and even 'preferred place of death' must be interpreted with caution. The ideal would be to know whether the individual's actual place of death coincided with the individual's preference just before they died, and the reason for any incongruence. This kind of data is not commonly gathered, so the actual place of death is often used as a proxy, with the assumption that most people prefer to die at their place of residence.

The advance of western medicine in the 20th century, with its possibilities for postponing and even averting death, affected end-of-life behaviors (and thus place of death patterns) through two mechanisms: 1) the hospital became a potential source for prolonging life in the case that individuals and their families are not emotionally ready to allow the individual to die, and 2) the hospital became a source for pain and symptom management at the end of life. Hence, hospitals became the primary place of death. One consequence of this was that death became "medicalized," despite the fact that the ultimate goal of medical practitioners was to avoid death. This 'anti-death' medical culture imposes obstacles to the humane treatment of dying people and their families, so in the 1950s Dr. Cicely Saunders started a movement in England to improve the care of dying people (Loscalzo, 2008). In the 1960s Elisabeth Kübler-Ross pioneered a similar movement in the United States. Notable results of these movements were the establishment of a new medical subspecialty called 'palliative medicine' and the addition of more service options for the provision of appropriate end-of-life care. These service options opened up the possibility for end-of-life care to be provided in hospices (more common in the UK) and private homes (more common in the USA). As their popularity grew, these locations were added to the place of death categorization.

While this advance of palliative care is seen as a success, major challenges remain in that the movement has historically been limited to deaths caused by cancers. This is because knowledge and medicines for the treatment of cancer pain have historically been the most advanced, combined with the fact that cancers develop slowly enough to allow the initialization

of palliative care. However, by the turn of the 21st century, pain management possibilities for other major causes of death like COPD, dementia, and heart failure have become possible, so the major limiting factor now is healthcare systems and their ability to quickly identify and implement pain management for all dying individuals, regardless of the cause of death (Murray, 2008). This means that until equal access to palliative care (in all possible places of death) is offered to all individuals with a life-limiting disease, we should be cautious in inferring too much meaning about QoC or QoL from data about the place of death, unless the cause of death was cancer.

1.2. Place of Death in the context of Swedish elderly persons

Sweden employs the 'Nordic Welfare model,' characterized by high taxes which finance relatively generous public services. In Sweden, many of these public services have been 'privatized,' meaning that they may be provided by private companies, but are still financed primarily by public funds. These public funds are not centralized at the national level – instead, different levels of government are responsible for organizing and financing different types of services. Regarding the healthcare, social care, and institutional care of elderly citizens (65 years of age and older), the 290 municipal governments are responsible for providing home services, home care and special housing (more details in the next paragraph), whereas the 21 county governments are responsible for hospitals and all varieties of healthcare services (Szebehely, 2012). Within this framework, home health care services straddle the boundary between county and municipality responsibilities: "County councils are responsible for providing home health services, but can transfer this responsibility to the municipalities if agreed. More than half of the municipalities in Sweden have taken over the responsibility for home health care in ordinary housing" (OECD, 2013). Indeed, these statistics coincide with an ongoing national reform aiming to transfer all home health care (up to nurse level) from counties to municipalities by 2014.

In order to enroll in eldercare services or special housing, an individual must pass a needs-test administered by a municipal care needs-assessor. The types of municipal eldercare service offerings are listed below:

a) Home help and home nursing care

b) Institutional care, broadly named 'special accommodation':

- Special housing units called 'service housing' designated for elderly where they can easily arrange for services (analogous to 'sheltered housing' or 'assisted living')

- Nursing homes for those with functional impairment from any cause, as well as nursing homes specifically for those with cognitive disability (i.e., dementia)

Since we are interested in the QoC and QoL of elderly at the end of life, it is important to note that end-of-life palliative care is a combination of healthcare and social care which may be delivered (by public or private providers) at any location in Sweden – home, nursing home, or hospital. Hospices which accept older people are extremely rare in Sweden, and the popular perception about palliative care is that it is a privilege rather than a right, and is intended for 'younger people dying from cancer' ('younger' in this case meaning less than 65 years old). However this attitude is likely to change as the size of the elderly population grows (due to the phenomenon of population aging), and palliative medicine continues to improve.

Looking to the past and future, it is clear that the strategy for providing good quality necessary services to the elderly population in Sweden will have to change. The first publically-financed eldercare services beyond institutional care were established in the 1950s, at which point the elderly population was relatively small and the economy was healthy, so it was possible to provide generous benefits (Bengtson, 2009). As time has progressed, though, population aging has lead to a growing elderly population (both in absolute and relative terms), living for more years beyond 65 than previous cohorts did. Thus the demand for eldercare services is growing along two dimensions (number of individuals and time of utilization), and this growth stands to accelerate as the baby boom generation approaches the mean age of entry into the public eldercare system. If the average age of public care entry of 84 years were to remain the

same (Lagergren, 2010), the baby boom generation would reach this age around 2030. It should be noted that the baby boom generation (born 1946-1952) already started to reach the age of eligibility for eldercare benefits in 2011 (two years ago). "According to OECD projections, spending on LTC services is set to double by 2050, in line with demographic ageing. About 10% of the Swedish population will be aged 80 years and over in 2050, up from 5.5% in 2011" (OECD, 2013).

Concerns around the quality, financing and efficiency of eldercare were already gaining political attention in the early 1990s, as can be seen in the 'Ädel reform' of 1992. This set of reforms aimed to improve the quality and efficiency of eldercare in Sweden, by encouraging the philosophy of 'Aging in Place' and by "giving municipalities the main responsibility for elderly care, and financial [dis]incentives [in order] to reduce [the length of] hospitalizations of old people" (OECD, 2013). The latter point has remained controversial, as any kind of financial incentive raises fears that elderly citizens might not receive the hospital care they need; however, the policy is set up in such a way that doctors (who make the decisions about hospital utilization) are not subject to any financial motivation. The disincentive only affects the municipal care system, which becomes involved after the doctor has decided the patient no longer needs hospital services, yet still needs some kind of care beyond what is currently provided at their place of residence. In such a case, the municipality needs to arrange for appropriate care of the patient upon discharge – in the past this process took too long, resulting in unnecessary hospital bed utilization, known as 'bed-blocking.'

In describing the effects of this aspect of the Ädel reforms, an expert from the National Board of Health and Welfare states that it was successful in reducing 'bed-blockers' by around 15%, but it also indirectly instigated a spiral of reductions in the number of hospital beds supplied (in order for county councils to save money), including a 75% reduction in geriatric beds. According to data from 2010, Sweden has the lowest hospital bed rate in the EU of 2.7 per 1,000 population, declining from 4.7 in 2000. In comparison, the EU average in 2010 was 5.3 per 1,000 population (OECD, 2012).

With this historical context in mind, we are interested to see if the restricted supply of hospital beds may have affected the end-of-life care of elderly people: for example, fewer beds

leading to fewer deaths in hospital, and therefore more deaths at places of residence (home and nursing home).

In the next chapter I will look to published academic literature to see what is already known about place of death patterns in Sweden, factors affecting these patterns, and whether any changes have been observed over time. If a lack of studies exists, I will also look for relevant studies in countries with health and social care systems similar to Sweden's (e.g., Norway, Finland, Denmark, Netherlands, Belgium, UK).

CHAPTER 2: LITERATURE REVIEW

I used a semi-systematic literature review strategy to find relevant prior studies about place of death (POD) patterns in Sweden and other Nordic countries, searching PubMed for all the relevant key word combinations and then conducting a backwards search through the reference lists of the resulting articles. Some examples of the keywords I used in combination with each country name were 'place of death,' 'location of death,' 'location at time of death,' 'end of life,' and 'last year of life.' I conducted an additional search after our group discovered limitations in our study data and it was decided that I should focus on changes over time, rather than the more common analytical question of finding predictors of POD. These two search phases are reflected in the division of this chapter in two sections, as described below.

2.1. Studies reporting POD distributions in Sweden

Table 1: Summary of Swedish POD studies

Table 2: Summary of relevant POD studies in other countries

2.2. POD studies which address changes over time

Table 3: Summary of studies about POD changes over time, any location

Prior studies about place of death in the population context are limited in number, but growing. Most often they have been conducted by the Palliative Care Research community in Europe, the USA, or Australia. Among the Nordic countries, POD studies have only been published thus far in Denmark and Sweden. This chapter contains an overview first of the POD distribution studies undertaken in the Swedish context, then in a number of other countries with comparable healthcare systems, and finally a handful of studies that look at POD changes over time in different countries.

2.1.   POD studies from Sweden, in order of publication year

Through a systematic search of published academic literature, I found twelve studies that report statistics about the place of death distribution in different populations in Sweden. In this section I describe the first eleven of these studies, their major findings, and limitations. At the end of this section, Table 1 contains a summary of the findings from these eleven studies. Then for the sake of reference and exploring international comparisons, Table 2 contains similar published findings from several other northern European countries and the USA Medicare system (which is comparable in the sense that it is publically funded). These non-Swedish studies will not be described in detail, as that is beyond the scope of this thesis.

2.1.1. Axelsson 1996: POD correlated to Sociodemographic factors

The first published study about POD in Sweden was in 1996, conducted by B. Axelsson at Ostersund Hospital. The aim of this retrospective study is clear through its title, "POD correlated to Sociodemographic factors." The sample consisted of 203 cancer deaths from 1990 in one rural county of Sweden. The results indicated that home deaths comprised 12%, nursing home deaths 24%, and hospital deaths 64%. The factors that seemed to result in nursing home death, as opposed to hospital death, were: age older than 80, living more than 40 km from a hospital, and "living in an area where the local health care centre had a nursing home attached." This study differs from my research in two main ways: the study population consists of only cancer deaths, whereas our data does not differentiate by cause of death; and Axelsson's aim was to find predictors of POD, whereas my aim is to isolate the effects of one particular predictor. The time span of one year is also quite different from our time span of 8 years (Axelsson, 1996).

2.1.2: Sahlberg-Blom, 1998: The last month of life: continuity, care site, and place of death

The next published study about place of death in Sweden was from Eva Sahlberg-Blom at Uppsala University in 1998, entitled "The last month of life: continuity, care site, and place of death." The sample was made up of 56 deaths from the most prevalent cancers at a hospital that had recently opened a hospice ward, in the years immediately following the Ädel reforms: 1992 through 1995. Among the many results was the place of death distribution: 18% at home, 36% in the hospital's new hospice ward, 7% in a nursing home, and 39% in the hospital's cancer ward. However the sampling method used means that these percentages are not representative of what they would be in an actual population of cancer patients. The major finding of the study was that the type of cancer affects the location of end-of-life care and death, which is interesting considering that many POD studies group all cancer deaths together, assuming that the same effect applies to all of them. Like Axelsson's study, this study differs from mine foremost in the disease-specific sampling strategy, as well as the prospective design. This reflects the differing aims of their study, which include the measuring of other quality of care aspects like continuity of care and culture of care (Sahlberg-Blom, 1998).

2.1.3. Carlsson 2003: A comparison of patients dying at home and patients dying at a hospice: sociodemographic factors and caregivers' experiences

The next Swedish POD study, from M.E. Carlsson in 2003, also focuses on hospice deaths, looking for patterns in sociodemographic independent variables and quality of care dependent variables: "A comparison of patients dying at home and patients dying at a hospice: sociodemographic factors and caregivers' experiences." The sample selection was retrospective, the data gathering method was a questionnaire mailed to the family caregivers of the decedents followed by analysis of the decedents' medical records. The comparison was made between three samples grouped according to the decedent's use of an advanced palliative home care team and place of death (home or hospice). The main results were that the highest caregiver satisfaction and patient quality of life ratings occurred in the home death group, and that the place of death "varied according to gender and cohabitation status. Men died to a greater degree

at home compared with women." It is unclear whether this is after controlling for age or not. The conclusions draw attention to a need for better understanding of the differences between male and female family caregivers (Carlsson, 2003). Relative to my research, this study has a very different sample population, though the method of analyzing sociodemographic independent variables is probably similar. Our data also contains a variable for "Sex of main caregiver," so we may also try to do some exploratory analysis if the number of missing values does not preclude it.

2.1.4. Ahlner-Elmqvist 2004: Place of death: hospital-based advanced home care versus conventional care

The next study is the last of the small-sample comparative studies that I found among the published Swedish POD studies. "Place of death: hospital-based advanced home care versus conventional care" was published in 2004 by Marianne Ahlner-Elmqvist at Malmö University Hospital, also affiliated with NTNU, Trondheim. The aim of the study was to see which kinds of patients choose hospital-based advanced home care over conventional care, and whether use of these services increases the probability of dying at home. The study design was a prospective follow-up of a sample of 297 adult cancer patients with a prognosis of 2~12 months. The individual patients chose which arm of the study to be in: advanced home care or conventional care, and the subsequent analysis was a comparison between these two groups of their eventual places of death and patient characteristics (both sociodemographic and medical). Allowing subjects to choose their study arm creates much room for unobserved confounding, so we should interpret the results with caution.

Among the total sample, 24.6% died at home, 29.3% died at a hospice, and 46.1% died at a hospital. The authors conclude that "Preference for and referral to a hospital-based AHC were not related to socio-demographic or medical characteristics. However, death at home was associated with living together with someone. [AHC] targeting seriously ill cancer patients with a wish to remain at home enable a substantial number of patients to die in the place they desire" (Ahlner-Elmqvist, 2004). I would argue that the last statement could be an over-reach of the

results, because the patients that died at home may have died at home regardless of using AHC. In addition, some patients do actually prefer to die in the hospital rather than at home. A better study design for measuring the effect of AHC may have been to ask the patients their reasons for choosing AHC over conventional care, then include these reasons as independent confounding variables in the analysis, or use them in conducting a matched analysis. Also, if the authors wish to report on the success of meeting patients' desires for place of death, this desire needs to be measured and compared with their actual places of death.

2.1.5. Jakobsson 2006: End-of-life in a Swedish population: demographics, social conditions and characteristics of places of death

Eva Jakobsson's 2006 study marks the beginning of the published Swedish POD studies which take a broader population approach and provide more standard statistics about place of death distributions. "End-of-life in a Swedish population: demographics, social conditions and characteristics of places of death" focuses on a randomly selected sample of all 229 non-sudden adult deaths in the county of Västra Götaland in 2001. The data collection method is a "retrospective review of death certificates, medical records, and nursing records." The foremost finding of this is study was the existence of a large population of individuals living alone at the end-of-life, as well as many living separated from their partners. Another important finding was that "places of death other than hospitals and residential care facilities are uncommon, if not rare." The POD proportions reported were: 9.2% home, 1.7% hospice, 41.9% residential care facility, 46.7% hospital, 0.4% other. Another important finding placed POD in the context of continuity of care: "51% died where they last lived" (Jakobsson, 2006).

This study has an ideal design for a POD population study: a random sample of all non-sudden deaths, with data taken directly from care records and death certificates, so additional relevant details about the health, family and living circumstances of the decedents are possible to be included. While Jakobsson's study is like the SNAC-K study in many ways, and I plan to compare the results from my research, major differences appear in the sample inclusion criteria, the one-year time span, and the exploratory aim that results in a purely descriptive statistical

analysis. Whereas my research leans more toward an explanatory analysis, focusing on one specific independent variable, year of death.

2.1.6. Andersson 2007: Health care consumption and place of death among old people with public home care or in special accommodation in their last year of life

The next study uses data from one of our sister studies in southern Sweden, the Swedish National study on Aging and Care (SNAC), Skåne location. The title of the article, by Magdalena Andersson of Lund University, 2007, indicates the ambitious nature of the study: "Health care consumption and place of death among old people with public home care or in special accommodation in their last year of life." The sample inclusion criteria are approximately the same as for our study, except the age limit was older at 75 years and older, and the only study years available at that point were 2001 through 2004. This overlaps with our data for one year, so a direct comparison might be made there. The data about health care consumption came from linking the municipal care data (already included in the SNAC studies) with the outpatient and hospital data from national registers. The consumption variables included number and length of hospital stays (in days) and number of visits to outpatient care.

The results regarding the place of death distribution among the 1198 decedents in the study were given only in terms of hospital deaths: 24.9% of the total sample, 38.6% of those living at home, and 17.3% of those living in special accommodation. The explanatory analysis is similar in structure to POD studies in other countries, consisting of three regression models: one for the total sample, and two stratified analyses to separate home dwellers from nursing home dwellers. I would like to follow this structure of analysis for my research as well. The results of these three regression analyses suggest that the number of outpatient visits, living in special accommodation, and low PADL are strong predictors of hospital death, even when controlling for other variables. Among home dwellers, low IADL was an important predictor of hospital death, whereas for special accommodation dwellers it was the number of outpatient visits and low PADL (Andersson, 2007). All of these predictors are related to health status, which I

suspect would be correlated with disease diagnosis, a variable that is available in their dataset, but not used in the regression analyses.

2.1.7. Bravell 2010: End-of-life care in the oldest old

The next article, "End-of-life care in the oldest old" is from a longitudinal study very similar to the SNAC-K population study (our partner study), but located in Jönköping. The longitudinal study is called NONA and focuses on the health of the oldest old in one Swedish municipality. NONA followed a randomly selected sample of 300 elderly individuals from 1999 through 2003. These 300 individuals were all older than 86 years at the start of study, and the subsample used for this article's analysis consisted of the 109 individuals who died over the four-year study period. The aim of this article by Marie Ernsth Bravell is "to describe the last year of life of a sample of the oldest old, focusing on end-of-life care and its trajectories, status of health, social networks, and ADL." The inclusion of self-reported and perceived health variables, as well as interviews with family members post-mortem increase the accuracy of the end-of-life data and give a more holistic picture of place of death within the context of the dying process and social support. Particularly helpful is a diagram on page 340 that shows the three basic pathways (called "care trajectories") from the initial place of residence to the eventual place of death, and the descriptive statistics of participants that followed each pathway.

The study results regarding place of death distribution were as follows: 4.9% 'in the community,' 74.5% in an institution, and 20.6% in a hospital. Another notable finding was that among those who died in the hospital, the mean length of the final hospital stay was longer for the home-dwellers than for the institution-dwellers, ranging from 0.5 days to 3 weeks (Bravell, 2010). It would be interesting to see if this difference remains after controlling for the cause of death. If so, this finding would seem to indicate that institution-dwellers are able to postpone the final transition to hospital longer than home-dwellers.

2.1.8. Introduction of the Swedish Register for Palliative Care (SRPC)

The next three studies return to a disease-specific approach, and make use of the recently established Swedish Register for Palliative Care (SRPC). One of the advantages of using SRPC data is that POD congruence is an explicit variable in the data: "Did the patient die in his/her preferred place?" This is a better measure of quality of care than the usual generalization that home death is preferable to hospital death for most individuals. The major shortcoming of SRPC at this point is that it was so recently established (2005) that it does not yet have the universal coverage that is usually associated with 'nation-wide registers' (Lundström, 2012). This means selection bias is highly likely until all institutions that provide end-of-life data are actively participating. Most of the authors who have used SRPC data thus far neglect to mention this in their publications, including the three articles described below.

2.1.9. Lundquist 2011: Information of imminent death or not: Does it make a difference?

The aim of the first study is to see how the act of informing a patient about his/her imminent death affects end-of-life outcomes, including achieving the preferred place of death. The main author is Gunilla Lundquist of Umeå University, and the title is "Information of imminent death or not: Does it make a difference?" The sample base was "all cancer deaths between 2006 and 2008 for which the patient did not lose his or her decision-making capacities until hours or days before death (N=13,818)." The authors state that this sample comprised 20% of total cancer deaths in Sweden during that period. To compensate for the bias created by the small number of uninformed patients, a matched analysis was performed, which resulted in a subset of 2,382 cases from the original sample, with an equal distribution of informed and uninformed patients. These matches were also evenly distributed for age, sex, place of death, and time of loss of decision-making capacity.

The main findings were that informed patients generally had better personal outcomes (achieving preferred place of death, family was also informed and was offered bereavement support), and these patients significantly more often had appropriate drugs prescribed. However no difference was found in symptom prevalence. Among the matched sample (both groups

combined) the POD distribution was 24.0% private home, 38.5% palliative in-care unit, 25.1% residential care facility, and 12.3% conventional hospital ward. Among the entire unmatched sample of cancer deaths from 2006 through 2008, the POD distribution was somewhat different, with an apparent trade-off between palliative in-care units and residential care facilities: 26.6% private home, 47.5% palliative in-care unit, 11.9% residential care facility, 14.0% conventional hospital ward (Lundquist, 2011). Due to the aforementioned likelihood of selection bias, I would hesitate in using these figures to draw conclusions or make comparisons with other cancer populations.

2.1.10. Brännström 2012: Unequal care for dying patients in Sweden: a comparative registry study of deaths from heart disease and cancer

The second of the three SRPC-based POD studies broadens the focus from only cancer deaths to a comparison with heart disease deaths, for a total sample of 31,060 deaths from 2006 through 2008. Margareta Brännström's aim and findings from this study are evident in the title: "Unequal care for dying patients in Sweden: a comparative registry study of deaths from heart disease and cancer." The context for this concern about inequality and the use of cancer deaths as a comparator is that palliative care in Sweden has historically been targeted at younger cancer patients, presumably because cancer deaths were traditionally thought to be the most predictable and manageable. Heart disease, on the other, has been shown to be particularly difficult to predict, with an average of only five days from the turning point of entering into the dying phase until death (Jakobsson, 2006). An interesting follow-up study for this article would be to add age into the analysis as one of the independent variables of interest or as an interaction with the cause of death. As it stands though, the main finding of this study is compelling: in the last week of life, the cancer group fared better in all measures of quality of care used in the study, even after controlling for age, sex, and place of death.

In terms of the place of death, the article only reports two categories: "Specialized palliative care" (at home or in hospice) and "Other" (home care, nursing home, or hospital). It should be noted that these definitions do not seem to acknowledge the existence of specialized palliative care in nursing homes or hospitals. Regardless of these technicalities, the results show

clearly that among the registered deaths for these two broad causes, 70% of the cancer patients died in the specialized palliative care settings, whereas 89% of the heart disease patients died in the "other" less ideal settings (Brännström, 2012). This categorization makes it difficult to compare these findings to any other published statistics, in addition to the issue of selection bias previously discussed. The selection bias can clearly be seen after adding the POD numbers to find the aggregate POD distribution, which shows only 41.1% died in "normal" settings, but 58.8% died in specialized palliative care settings: clearly there is an over-representation of cancer patients in this dual-disease sample.

2.1.11. Martinsson 2012: Registration in a quality register: a method to improve end-of-life care – a cross-sectional study

The final of the three studies based on SPRC data that reports POD statistics is by Lisa Martinsson at Umeå University in 2012. The study analyzes data from 503 healthcare units that provided end-of-life care to a total of 30,238 patients in the 3-year study period from May 2007 through April 2010. The primary aim is to see if outcomes associated with quality of care improved over the 3 years. The study concludes that there was improvement in the following quality of care factors: lower prevalence of symptoms, higher proportion of appropriate medication prescriptions, higher proportion of patients achieving their preferred place of death, and higher proportion of next of kin offered support after the patient's death. While these results are compelling, the authors overreach when concluding that participation in the data register is correlated with these improvements. First, because participation in the register is a constant over the study period, and second because there is no comparison group of non-participating care providers. While it is certainly plausible that those care providers that participate in the quality register are more concerned about improving their quality of care than those who do not (and thus they will be more likely to achieve improvements), nothing conclusive can be said without also comparing changes over time in the quality of care of the providers that did not participate. It should also be noted that this element of non-participation could be a source of selection bias in the study results.

In terms of the actual place of death, the SRPC data divides the outcome into six categories, with the following distribution aggregated over the 3-year study period: inpatient palliative ward 34.6%, nursing home 22.5%, specialized palliative home care 14.3%, hospital (non-palliative ward) 20.1%, short-term care home 7.4%, and "basal" home care 1.1%. Combining these groups into the usual POD categories yields a distribution of hospital 20.1%, nursing home 29.9%, private home 15.4%, and hospice 34.6% (Martinsson, 2012).

2.1.12. Wallerstedt, 2012: Identification and documentation of persons being in palliative phase regardless of age, diagnosis and places of care, and their use of a sitting service at the end of life

The twelfth of thirteen published studies that report Swedish POD statistics is from Birgitta Wallerstedt, a PhD student at Örebro University, called "Identification and documentation of persons being in palliative phase regardless of age, diagnosis and places of care, and their use of a sitting service at the end of life." This title combines many issues into one sentence. First, the issue of identification of a person being in the palliative phase is a central issue, because this is the turning point mentioned earlier in the context of Brännström's and Jakobsson's work (Jakobsson, 2006). It is the point at which the dying process has begun, so the patient should start to receive exclusive palliative care if that is what is desired, and the patient's family should be informed of the impending events. The primary aim of this study was "to describe individuals who were identified and documented as being in a palliative phase in a Swedish municipality, with respect to demographics, use of a sitting service, continuity of care in the last month of life and the place of death." The sitting service offered was 24-hour care from an enrolled nurse educated in palliative care.

The sample consisted of 174 decedents, from any diagnosis, documented as being in palliative phase, drawn from one rural Swedish municipality in 2007. The main findings were that the individuals in the sample comprised 51% of all 2007 deaths in that municipality, the mean age was 83, and that the sitting service "significantly increased the possibility of dying at home, but did not affect how often of the place of care changed during the last month of life." With regard to the place of death distribution, 63% died in a nursing home, 18% in a palliative care unit, 12% at home, and 6% in a hospital. Of those without relatives, almost all (11 out of

14) died in a nursing home. When stratifying according to use of the sitting service or not, those who used the service more often died at home and less often in a hospital, the majority of non-cancer diagnoses died in nursing homes either way, and the same proportion achieved their preferred place of death in both groups (Wallerstedt, 2012).

At first glance, these results would seem to indicate that the sitting service did not improve the achievement of preferred place of death, but this is probably just due to selection bias. It is likely that those who chose the sitting service more often preferred to die at home and the sitting service enabled that, whereas those who did not choose the sitting service probably preferred to die in a nursing home or hospital, which could probably be achieved just as well without the sitting service. The relevant statistics about preferred place of death were not reported in the article.   Other limitations of this study are the small sample size, which precludes any kind of analysis to isolate the effects of different factors, but this might be overcome by including more years in the sample. Also, the geographic focus means the results may only be generalizable to other small rural communities in Sweden.

2.1.13. Summary of results from POD studies in Sweden and other various countries

Table 1: Summary of results of Swedish POD studies						
SAMPLE POPULATION	POD = HOSPITAL	POD = NURSING HOME	POD = PRIV. HOME	POD = HOSPICE	TIME SPAN	CITATION
Sweden: one rural county (cancer, n=203)*	64	24	25	--	1990	Axelsson 1996
Sweden: one hospital (cancer, n=56)*	39	7	18	36	1992-1995	Sahlberg-Blom 1998
Sweden: Mälmo (cancer, n=297)*	46.1	--	24.6	29.3	1995-1999	Ahlner-Elqvist 2004
Sweden: Västra Götaland (non-sudden, random sample, n=229)*	46.7	41.9	9.2	1.7	2001	Jakobsson 2006
Sweden: Skåne (age 75+, using municipal care, n=1198)*	24.9	--	--	--	2001-2004	Andersson 2007
Sweden: Jönköping (age 86+, random sample, n=300)*	20.6	74.5	4.9	--	1999-2003	Ernsth Bravell 2010
Sweden: national (cancer, palliative care register, n=14637)*	14.0	11.9	26.6	47.5	2006-2008	Lundquist 2011
Sweden: national (cancer and heart disease, palliative care, n=31,060)*		41.1		58.8	2006-2008	Brännström 2012
Sweden: one rural municipality (palliative phase, n=174)*	6	63	12	18	2007	Wallerstedt 2012
Sweden: nation-wide (all causes, but register has not attained full coverage yet, n=30,283)*	20.1	29.9	15.4	34.6	2007-2010	Martinsson 2012
Sweden: nation-wide (all deaths age 65+, n≈1.5 million)	40		60		2005	Åhsberg 2012

*Sample base is not all-cause deaths nation-wide

SAMPLE POPULATION	POD = HOSPITAL	POD = NURSING HOME	POD = PRIV. HOME	POD = HOSPICE	TIME SPAN	CITATION
Table 2: Summary of results of relevant POD studies in other countries						
Deaths from all causes						
Switzerland: national (one insurance company, n=58,732)	38.4	35.1	26.6	--	2007-2011	Reich, 2013
Netherlands: Amsterdam (random sample of elderly, n=270)*	32	32	35	--	1995-1999	Klinkenberg, 2005
USA: national (random 20% Medicare decedents, n=270,202)	32.6	27.2	30.7	--	2000	Teno, 2013
USA: national (random 20% Medicare decedents, n=291,819)	26.9	25.3	34.9	--	2005	Teno, 2013
USA: national (random 20% Medicare decedents, n=286,282)	24.6	27.6	33.5	--	2010	Teno, 2013
England: national (age 45-64)	50	3	32	11	2010	Gomes, 2011
England: national (age 65-74)	54	7	28	9	2010	Gomes, 2011
England: national (age 75+)	54	25	17	3	2010	Gomes, 2011
Finland: national (age 70+, all deaths in 1998, random sample from 1999-2001, n=75,578)	74.5	10	16.3	--	1998-2001	Aaltonen, 2010
Belgium: national (age 1+, all deaths)	55.1	18.3	23.0	--	1998	Houttekier, 2011
Belgium: national (age 1+, all deaths)	51.7	22.6	22.5	--	2007	Houttekier, 2011
Deaths from cancer						
Denmark: Funen County (cancer, n=4386)*	55	16	28	--	1996-1998	Aabom, 2005
Denmark: Aarhus County, (cancer, use palliative home care, n=153)*	34.6	15.0	49.7	--	Mar-Nov 2006	Neergaard, 2010
Deaths from dementia						
England (dementia, n=17,044)	36.0	59.7	3.7	0.3	2003	Houttekier, 2010
Scotland (dementia, n=2,324)	33.9	67.5	5.0	0.4	2003	Houttekier, 2010
Wales (dementia, n=1,220)	46.3	50.2	3.2	0.1	2003	Houttekier, 2010
Netherlands (dementia, n=6,984)	2.8	92.3	3.8	0.5	2003	Houttekier, 2010
Belgium (dementia, n=2,709)	22.7	65.9	11.4	0.0	2003	Houttekier, 2010
Deaths from palliative subset of diseases						
Belgium: Brussels (palliative, n=3,672)*	63.0	21.6	15.1	--	2003	Houttekier, 2009

*Sample base is not all-cause deaths nation-wide

2.2. Studies about changes over time in place of death distributions

A number of studies have been published which explore changes over time in where people die, using data from different countries around the world. Most of these studies approach the question with a primarily descriptive analysis, reporting the usual POD statistics at different points in time. Only one such study has been published in Sweden until now, by Åhsberg in 2012, which I will describe next. In terms of studies that try to isolate the effect of year of death on POD, I only found two: Teno from the United States, 2013 and Houttekier from Belgium, 2011. Unfortunately, Teno's categorization of the year of death variable into groups and his fundamentally different set of independent variables make it impossible to compare his regression methods and results with ours (Teno, 2013). Therefore, I have only included Teno's basic descriptive findings for reference in Table 2 and Table 3. Houttekier's study will be described in more depth, as it is our plan to use a similar analytical method. The results from these three studies that look at changes over time in place of death are summarized in Table 3, at the end of this chapter.

2.2.1. Åhsberg 2012: Changes in place of death among elderly in Sweden – a register study

In this study, Elizabeth Åhsberg uses data from two Swedish population registers to investigate the effects of the 1992 Ädel-reform, which had as one of its aims to decrease unnecessary hospital utilization in elderly. The two outcomes of interest in this study are place of death, defined as in-hospital or out-of-hospital, and deaths associated with a hospital discharge less than two weeks before death. The reason for the second outcome is that it is defined in the policy as an undesirable outcome, to be avoided. The sources for the data were the National in-Patient Register (NPR) and the Cause of Death Register (CDR).

The finding of this study was that in the years immediately before and after the time of the policy reforms, "the number of elderly dying in a hospital decreased suddenly." This result was only reported in terms of absolute numbers, rather than proportions, but considering that the total number of elderly deaths (the denominator of the ratio) did not change significantly during these years, the absolute numbers are still compelling: a decrease in hospital deaths from around

55,000 per year before the reforms to around 30,000 per year after the reforms. The change in out-of-hospital deaths mirrored the change in in-hospital deaths: an increase from around 20,000 before the reforms to around 50,000 after. This statistic was also reported in terms of proportion of total deaths: out-of-hospital deaths increased from 29% to 60%. Åhsberg looked deeper to see if this trend was the same across all levels of age and sex, and found that the change was more dramatic for those who died at age 80 and older, and a bit stronger for men than for women, though this could just be a reflection of the age effect (or vice versa). No attempt was made to isolate the effects of age or gender or passage of time.

In terms of the second outcome, 'deaths shortly after discharge from hospital,' the study found an increase from around 3,000 deaths per year before the reforms to more than 7,000 per year after. The corresponding change in percentages was from approximately 2% to 8%. The report does not state whether this change was statistically significant, but considering the large sample size, we can presume that it was and this is just a reporting oversight. While these percentages are small in absolute terms, the proportional change represents a 3-fold (300%) increase, and thousands of individuals affected (Åhsberg, 2012).

These outcomes (hospital death and near-death hospital discharge) are not direct indicators of quality of care, however they are generally considered to be non-ideal, so the results of this study should be carefully considered. It is also possible that the changes in these outcomes could have been caused by changes in factors other than the Ädel-reform, but this seems unlikely considering the change in outcomes happened in the same year as the policy reforms, and the outcomes are directly connected to the policy change.

2.2.2. Houttekier 2011: Study of recent and future trends in place of death in Belgium using death certificate data: a shift from hospitals to care homes

The final study under consideration in this literature review is from Dirk Houttekier of the End-of-Life Care research group in Belgium, entitled "Study of recent and future trends in place of death in Belgium using death certificate data: a shift from hospitals to care homes." The title of the article is a straightforward statement of the aims, data source, and findings of the study. The primary variable of interest is the year of death, and in the descriptive analysis Houttekier gives a detailed presentation of the changes in all variables of interest year-by-year from 1998 through 2007. The greatest strength of this study is the inclusion of additional variables that might be expected to affect healthcare utilization, particularly at the end of life: cause of death (not only in subcategories, but also in terms of possibility to use palliative care), educational attainment, living arrangement, urbanization, and local availability of different kinds of healthcare beds. Other strengths are the large sample size (n = 661,773), national base population, and the division of place of death into four categories.

The descriptive results about place of death distribution from year to year showed that home deaths remained approximately constant around 23%, hospital deaths decreased from about 55% to 51.7%, care home deaths increased from 18.3% to 22.6%, and deaths in 'other' places remained steady around 3%. The decrease in hospital deaths (3.6 percentage points) was similar to the increase in care home deaths (4.3 percentage points), so we may consider that a direct shift could have occurred. Houttekier explains that this may be explained by a change in the healthcare organization: "During the study period many residential beds in the care homes were replaced by skilled nursing home beds." This means that the possibility of receiving advanced healthcare in nursing homes increased, consequently decreasing the necessity for transfers to hospitals at the end-of-life.

The study also employed a set of regression analyses to isolate the effect of the different independent variables on the place of death outcome, with particular interest in the year of death variable. A stratified approach was taken, splitting the sample according to the place of residence (private home or care home), and defining the outcome in terms of death at residence

(Y=1) versus death in hospital (Y=0). From the home death model, there were no significant changes over time, but it is interesting to note that the factors increasing the odds of dying at residence (or 'not in-hospital') were cancer cause of death, older age (85+), not living alone, lower urbanization level, and fewer hospital beds available. These results make intuitive sense, when considering that cancer deaths are more easily treated in the home setting (though it would have been more meaningful to use the palliative subset definition for this variable), cohabitation enables elderly or sick individuals to live at home longer, and lower urbanization and fewer hospital beds inhibit hospital admissions. From the care-home death model, the year of death did have a significant and increasing effect on the place of death from 2002 onward, with odds ratios varying from 1.11 to 1.21 in favor of care-home death. The other factors increasing the odds of dying at a care-home (or "not in-hospital") were non-cancer cause of death, older age, female sex, and lower education (Houttekier, 2011). These results are not surprising when considering that care home dwellers are more often older ages and female, and lower educational attainment is often thought to be associated with lower utilization of healthcare services.

Table 3 shows a summary of the statistics reported in the last three studies which explore changes over time in POD. Increases in the proportion of deaths are indicated by (+), decreases by (-), and no change by (≈). A more in-depth comparison is discussed in Section 6.3, incorporating the new results from our study.

2.2.3. Summary of results of studies reporting POD changes over time

Table 3: Summary of results of studies reporting POD changes over time						
SAMPLE POPULATION	Change in POD = HOSPITAL	Change in POD = NURSING HOME	Change in POD = PRIV. HOME	Change in POD = HOSPICE	TIME SPAN	CITATION
Sweden: nation-wide (all deaths age 65+, n≈1.5 million)	(-)		(+)		1987-2005	Åhsberg, 2012
Belgium: nation-wide (all death age 1+, n=661,773)	(-)	(+)	≈	--	1998-2007	Houttekier, 2011
USA: nation-wide (random 20% Medicare decedents, n>270,000)	(-)	≈	(+)	--	2000-2005	Teno, 2013
USA: nation-wide (random 20% Medicare decedents, n≈290,000)	≈	≈	≈	--	2005-2010	Teno, 2013

CHAPTER 3. AIMS AND RESEARCH QUESTIONS

Broad Aims:

1. To investigate the distribution of place of death and its changes over time among public eldercare recipients in one district of Stockholm, and to compare these results with other studies in Sweden.

2. To discuss the effects of previous policies and make some additional policy recommendations based on our results.

3. To provide a basis for further research questions regarding the quality of eldercare, or the quality of health- and social- care at the end of life.

Specific Research Questions:

1. What is the distribution of place of death among the participants of our study population for each calendar year, 2004-2012? Has the distribution changed significantly over these years?

2. After adjusting for the most important individual factors, is there an association between year of death and place of death in the same years, 2004-2012?
   a. Does the association between year of death and place of death differ for individuals who live in private homes versus in nursing homes?

CHAPTER 4: MATERIALS AND METHODS

Contents of this chapter:

    1.   General study design

    2.   Study subjects

    3.   Measures

    4.   Procedure for data gathering

    5.   Delimitations and Limitations

    6.   Data analysis methods and procedure

4.1. General Study Design

The strategy for answering the research questions within this thesis does not constitute a study design per say, as the data used is "secondary data" that has already been gathered and stored within the context of a larger study. The relevant details of the larger study are imparted below.

The overarching study is of a longitudinal design, starting from March 2001, and is called the Swedish National study on Aging and Care (SNAC). It has two parts: the Population Study, which focuses on health outcomes and aging processes using a representative sample of the local population, and the Care System Study, which includes all individuals in the municipality who have been approved by a needs-assessor to receive public eldercare services. Contrary to the name of the study, the target population is not all elderly persons in Sweden, but rather those individuals living in four specific areas, which are thought to collectively represent all levels of urbanization in Sweden. Each of the four locations has its own independent office for the management of the two sister studies (Population and Care System) in that location. Among the four locations effort is made to use similar data collection methods in order to allow the merging or comparison of data between sites.

The data for exploring the research questions in this thesis comes from the Kungsholmen location of SNAC – Kungsholmen being a district in Stockholm that was of great interest at one point in time because it had the highest proportion of elderly persons of any district in Sweden (however this is no longer the case). As of 2011, the total population of Kungsholmen was around 63,000. Hereafter this location of the SNAC studies will be referred to as SNAC-K. As in all SNAC locations, SNAC-K consists of two sister studies, and the data for this thesis comes from the Care System study. The broad aim of the study is "to monitor the individual provision of services in relation to different measures of needs" (Lagergren, 2004). The data collection generally focuses on individual needs, as represented by measures of physical and cognitive function and social support. The prior data analyses until now have focused on how these needs correlate with utilization of social services, mainly for the purpose of social policy and resource planning. Additional data about medical care utilization or other individual characteristics can also be included through linking with outside data registers.

4.2. Study Subjects

The participants included in the SNAC-K Care System study are Kungsholmen residents age 65 and older who have had at least one encounter with the public eldercare system in Sweden. More specifically, these individuals have been granted permission by a needs-assessor to live in a residential institution ("service housing" or "nursing home"), or they have been deemed eligible for home-help services. It should be noted that these participants may not always be actually receiving the services identified in the data, due to time lag in organizing the services or waiting lists, but this incongruence has been shown to be negligible (Lagergren, 2004). The total number of participants included in the eight years from March 2002 until February 2010 was 5,527 (Lagergren, 2010). The estimated response rate is 95% (Lagergren, 2010). Further details about the study design and data collection methods can be found in a previous publication listed in the bibliography, Lagergren 2004.

4.3. Measures

The measurements of Place of Death and Year of Death are done by way of a questionnaire filled out by a care staff member trained in its administration. A former printed version of this questionnaire, also known as the 'protocol,' can be found in Appendix 1. The general description of the data collected, from the SNAC-K website, is included in Appendix 2. The measures related to death are completed within the context of a section of the protocol dedicated more broadly to any event where a participant would leave the study. Death is one of the options for exiting the study, and the person filling out the questionnaire should also enter the date of death and choose from three options for the place of death: at home, in a nursing home, or in a hospital.

A wide variety of other measures are also collected, the ones being of most interest for our study being as follows: age, gender, place of residence, marital status, cohabitation status, sex of main care giver, physical functional disability, and cognitive disability.

4.4. Procedures for Data Collection

Participants are enrolled in the study by the municipal authority needs-assessor at the point when they are first approved to receive eldercare services from the municipal authority. Data collection for the Care System study occurs within two separate processes: individual baseline interviews conducted by the needs assessor upon enrolling in the study, followed by updates by a trained municipal care staff member (nurse) when the individual's need for services changes significantly. Both data submission processes occur using computerized forms submitted online to the SNAC-K office. When the level of need for care remains constant, disability status is registered on an annual basis by the designated care staff member (Lagergren, 2004). This method of data collection presents limitations in that the designated care staff member might not submit the information in a timely manner or may omit some information, despite the relatively short time needed of 15 minutes per submission.

Ethical permissions for both sister studies of SNAC-K were obtained from the Karolinska Institute at the outset of the studies. According to this permission, the Care System part requires only oral informed consent to be obtained from the individual at each time of data submission. Lagergren estimates that only 5% of individuals opt out of the Care System part of the study (Lagergren, 2010). No additional ethical permission is necessary to perform analysis of the data, as long as any personal identifying information (name and social number) has been removed beforehand.

4. 5. Study Design Delimitations and Limitations

The fact that the data for this study comes from only one municipality, one which is arguably not representative of the broader population in socioeconomic context, means that a sampling bias may exist and the results of any analyses of these data should be interpreted with caution. Specifically, the level of education, and thus lifetime income, are believed to have been historically higher in this district than some others. However Larsson demonstrates that by 1995 the demand for elder care in Kungsholmen was not significantly different from the rest of the country (Larsson, 2008). Further selection bias may also exist within the Kungsholmen district, because those individuals who have not accessed public eldercare services are not included – these individuals are probably younger and healthier than the study participants. This bias probably attenuates in the older cohorts, but is then likely to be replaced by a mortality bias: those who survive into older ages are probably not representative of the original cohort. However, these limitations are accepted within the context of the purpose of the study, which is to provide a full and rich description of what occurs within a given manifestation of the public eldercare system in Sweden, regardless of whether the individuals served are representative of a broader population.

The narrow inclusion criteria and non-random study design for SNAC-K could be considered delimitations (purposeful limitations) because the intensity of data collection would not be feasible with a larger sample. In addition, variation in the organization of public eldercare across different municipalities means that including participants from other municipalities would

preclude drawing conclusions about system dynamics, unless the sample size were to be large enough to allow for stratified analysis based on location.

4.6. Procedures of Data Analysis

4.6.1. Building the Data Set: Inclusion Criteria

For the purpose of answering questions about the outcome variable Place of Death, a subset of data was extracted which contains information only about the SNAC-K Care System study participants who had died during the calendar years from 2004 through 2012. The first three study years (2001 through 2003) were not included because of significant differences in survey methods. Each study year runs from March 1 of the named year until the end of February of the following year, therefore participants who died in January or February of 2004 are not included in this data set, whereas only those who died in January or February of 2012 are included (the rest of 2012 data was not available at the time of building the dataset). Therefore, a more specific statement of the inclusion criterion is this: those participants who died from March 1, 2004, until February 28, 2012. Deceased individuals with no date of death available were not included, as the year of death is the main independent variable of interest. About 184 individuals were excluded from the analysis for this reason, while 2688 remained in the dataset.

4.6.2. Building the Data Set: Variables of Interest

As place of death analyses have started to become more common, Joachim Cohen and his colleagues in the International Place of Death project have seen a need for standardization of the variables used as covariates in these analyses. In their 2007 article about the quality of data used in place of death analyses, Cohen et al. recommend a minimum set of variables that should be incorporated in any analysis about place of death: place of death (hospital / care home / private home / etc.), age, sex, cause of death, living situation and / or marital status (Cohen, 2007). In

the SNAC-K Care System data, all of these variables except cause of death are available or can be constructed from other variables. The causes of death for each of the included decedents could have been abstracted from linking with hospital administrative data or the Cause of Death Register, but this would have required more time and money than was available for this thesis project. This was the main reason we decided not to conduct an analysis about individual predictors, or 'determinants,' of place of death, but rather to shift our focus to processes happening on the group level.

Since the pathways to end-of-life care in the Swedish eldercare system are strongly determined by use of public eldercare services – for example, those who live in nursing homes generally die in nursing homes – we decided the groups of interest would be divided according to living situation: private home, service housing (similar to 'assisted living' in other countries), general nursing home, or dementia nursing home. It should be noted that the group of decedents living in private homes includes only those that had been approved by a needs-assessor to use the public eldercare system. We did not have access to appropriate data from the municipality to determine the number of Kungsholmen decedents who were not included in the study. However, we can suspect this would be a sizable group, as according to statistics from the National Board of Health and Welfare, the proportion of people 80 years and older using public eldercare was only about 38% in 2011 (Lennartsson, 2012).

As noted before, these non-included individuals would have probably had lesser needs for public care than those who were included, whether that means they had better functional or cognitive ability, or that they had access to other sources of care, namely informal care since privately paid care is almost non-existent in Sweden. All three of these factors (functional ability, cognitive ability, and informal care) are negatively associated with age: each of them declines with increasing age.

Gender also plays a role here, in patterns of disease and survival (Crimmins, 1996), as well as in marriage customs: it is common for older men to marry younger women, thus men tend to have informal care from their wives in their old age and they also more often die before their wives; whereas women are more often widowed and turn to the formal system for care (Lennartsson, 2012). There is also a popular belief that women are better providers of care than men, so in cases where the primary informal care giver is the spouse, men might receive more

and better care than women, thus needing less support from the public eldercare system. Based on these phenomena, we might expect that younger men may be under-represented in our data set, and that there will be more women than men utilizing any given elder care service (Lennartsson, 2012).

Considering the importance of living situation, age, and gender, we decided that these variables should definitely be included as confounders in our statistical models, along with the primary independent variable of passing time (year of death), and the outcome (dependent) variable of place of death. Other variables included in the data set for the purpose of exploratory analysis and descriptive statistics include: marital status, cohabitation status, sex of main care giver, physical functional disability, and cognitive disability.

4.6.3. Statistical Methods Used

The statistical software used will be SPSS. First I will describe the sample in terms of variables of interest, then perform cross-tabulations with the outcome variable POD, as well as correlation analysis to see which variables might be confounders (that is, correlated with both the outcome and the main effect variable), and finally regression analysis to isolate the effect of changes over time. Chi-square tests will be used for testing the statistical significance of differences in the cross-tabulations.

The key variables for this study have all been coded categorically, as described below:

Outcome (dependent) variable:
- o Place of Death = home / nursing home / hospital

Independent covariates:
- o Year of death: 2004, 2005, 2006, 2007, 2008, 2009, 2010, 2011, 2012
- o Age = 65-74, 75-84, 85-94, 95~
- o Sex = male / female = 0 / 1
- o Place of residence = home / service housing / ordinary nursing home / dementia nursing home = 1 / 2 / 3 /4

The main effect variable is Year of death, coded as a categorical variable rather than continuous. This is because we do not expect the difference in effect to be the same from year to year (i.e., we do not expect the distance between each level of the variable to be the same, therefore it should be coded as a categorical variable). Also, we want our regression output to show the magnitude of effect (odds ratio) for each year, and this is exactly what will result if we define year of death as a categorical variable. Whereas coding as a continuous variable would yield one odds ratio for the entire period, assuming this effect is the same each year.

The first set of regression models will be 'univariate': one model for each variable, not adjusted by any other variables. Next I will build a model including the variables that are thought to be confounders with year of death, either because they are identified as significant in the correlation analysis, or because of standard practice. The SPSS method of including variables in the models will be the forced entry method. These models will be run on the entire sample of valid deaths (those with both year of death and POD recorded).

Finally, stratified analyses will be performed based on place of residence, to see if there is any difference in effects between respective subgroups. In practice this means removing the stratifying variable of interest from the regression model, then running this model on subsets of the data, divided according to the categories of the stratification variable. The reason for stratification based on this specific variable is that we expect this variable to not only be a confounder with the outcome variable, but that being in different categories of this variable actually constitutes a different causal mechanism, yielding different effects on the outcome. For example, we expect that those living at home and those living in institutions are subject to different mechanisms pushing them toward or away from hospitals at the end of life. Therefore other changes in other covariates such as the Year of death would affect these subgroups differently, and this warrants running separate regressions.

After running the model on the four separate residence groups, I will check to see if any of the groups have similarity of results. In that case, I will combine these groups, in order to add statistical power and simplify the analysis. It should be noted that the relatively small number of

individuals from the valid sample living in service housing (only 177) will raise questions about statistical power and interpretation of the results for this place of residence group.

In theory, it seems sensible to use the dichotomized version of POR in the final analysis, which would divide the sample into only two groups according to those who were living with or without 24-hour care supervision: POR = home or service housing (1 or 2) and POR = ordinary nursing home or dementia nursing home (3 or 4). This dichotomization reflects the hypothesis that access to 24-hour care is the most operative factor affecting the probability of hospital admission, and thus hospital death.

Before building a regression model to isolate the effect of changes over time, we must decide which kind of regression analysis to perform. The fact that there are three possible values of the outcome variable POD provides multiple choices. I chose to use logistic regression with a dichotomous outcome for POD (0 = home or nursing home, 1 = hospital) for the following reasons:

   a. This approach has been used in similar studies from other settings, so comparison of results may be possible (Houttekier 2011, Andersson 2007).

   b. The causal mechanism we eventually want to explore is the decrease in hospital bed supply, so it makes intuitive sense to also define the outcome effect in terms of hospital utilization. Another way of stating this outcome is POD = 0 for out-of-hospital death, 1 for in-hospital death. This dichotomization can be justified in that a stated preference in favor of, for example, death 'at home,' may in reality just reflect a preference for death 'not in hospital' (Higginson, 2000). It should be noted that this approach will not give us information about the changing relationship between home deaths and nursing home deaths, so that question could be further explored later using another regression model, for example, multinomial logistic regression.

   c. I want to perform the analysis contained in this thesis myself (as opposed to asking the house statistician to do it), and logistic regression is the technique with which I am the most familiar.

For readers unfamiliar with logistic regression, the regression equation is as follows:

$$\ln\left(\frac{\hat{p}}{(1-\hat{p})}\right) = b_0 + b_1 X_1 + b_2 X_2 + \ldots + b_p X_p$$

The left-hand side represents the log-odds of hospital death, p is the probability that a given death occurs in a hospital, each X_p represents one independent covariate, and the corresponding b_p represents the odds of hospital death associated with a given level of the covariate X_p. The output of logistic regression is a set of odds ratios, which represent the change in odds (b_p) of hospital death when the level of a given covariate (X_p) increases by one increment. If the odds ratio is less than 1, the association between the given covariate and risk of hospital death is negative; if it is greater than one, the association is positive.

The results of the aforementioned exploratory, descriptive, and regression analyses are contained in the next chapter.

CHAPTER 5: RESULTS

Before beginning to explore the data, we have some predictions of what we might see, based on knowledge of the Swedish elderly population and the eldercare system:

- There will be more women than men, particularly in the older age groups.
- The most common place of death will be 'in a nursing home.'
- The proportion of hospital deaths will decline over time.

Contents of this chapter:

5.1. Description of the Sample – Exploratory Analysis

5.2. Correlation Analysis – to identify key variables

5.3. Research Question 1: Changes in POD distribution over time, via cross-tabulations

5.4. Research Question 2: Isolating the effect of Year of death, via logistic regressions

      5.4.1. Building the logistic regression models

      5.4.2. Results of the logistic regressions

5.1. Description of the Sample – Exploratory Analysis

Table 4: Frequency distribution of decedents among the four age groups

Age decade	Nr. decedents	Percent (of all decedents)	Cumulative Percent (of all decedents)
65~74	164	6.1	6.1
75~84	601	22.4	28.5
85~94	1404	52.2	80.7
95~	519	19.3	100.0
Total	2688	100.0	

Comment: Deaths in age group 85~94 are the majority (52.2%).

In the entire study sample of 2688 individuals deceased between March 1, 2004 and February 28, 2012, the mean age at death is 87.9 years, ranging from 65 to 106 years. Further

analysis of the mean age at death for each year shows that the mean age has increased from 87.7 in 2004 to 89.2 in 2011 (2012 deaths are not included in this comparison because it only covers 2 months, yielding a much smaller sample and higher variance than the other years).

Table 5: Frequency distribution of decedents among the four residence (POR) categories

Place of residence (POR)	Nr. Decedents	Percent (of all decedents)	Valid Percent (excludes Missing)	Cumulative Percent
At home	1092	40.6	41.1	41.1
Service housing	241	9.0	9.1	50.2
Other nursing home	758	28.2	28.5	78.7
Dementia nursing home	566	21.1	21.3	100.0
Valid Total	2657	98.8	100.0	
Missing values	31	1.2		
Overall Total	2688	100.0		

Comment: Service housing is quite a small subgroup, whereas 49.8% of the sample lived in nursing homes.

Other interesting results of the initial exploration are that older decedents more often lived in nursing homes, whereas younger decedents more often lived at home or in service housing. This is not surprising, as acceptance to nursing homes is needs-tested, meaning that disability is a prerequisite for entry. Since disability is more common in older ages, living in a nursing home – and dying in a nursing home – is more common for older ages.

Also, women outnumber men in the sample by 2.3 to 1. This warrants exploring further cross-tabulations of Sex with the other major variables – Age, Place of residence (POR), and POD – to see if we should suspect different effects for men and women. These cross-tabulations are contained in Table 6.

Table 6: Sex related to key independent variables			
		Sex	
Variable name (% of sample missing values for this variable or POD)	**Number valid deaths**	**Male (%)**	**Female (%)**
Total sample **	2688	30.2%	69.8%
Age group at time of death (0.0%), p=.000 (see Figure 2)	2688		
65~74	164	10.6%	4.2%
75~84	601	32.5%	18.0%
85~94	1404	47.4%	54.3%
95~106	519	9.6%	23.5%
Place of residence (POR) (1.2%), p=.000	2657		
Private home	1092	50.6%	37.0%
Service housing	241	9.0%	9.1%
General nursing home	758	24.6%	30.2%
Dementia nursing home	566	15.8%	23.7%
Place of death (POD) (17.9%), p=.000	2208		
Home	422	23.3%	17.3%
Nursing home	1415	55.9%	67.6%
Hospital	371	20.9%	15.1%

**Row percentages. The rest of the table presents column percentages.

Comments about Table 6

Age by Sex: Most of the decedents in both sexes were in the 85~94 age group: 47.4% of men and 54.3% of women. However the distribution of age at death is clearly different: the next highest proportion of men died in the 75~84 range (32.5%), whereas the next highest proportion of women died in the 95~106 range (23.5%). Thus, in this sample men tend to die at younger

ages than women. This is supported by the results of cross-tabulating in the other direction (not shown in Table 6), to see the distribution of men and women in the sample according to age: men just barely outnumber women (52.4%) in the youngest age group, but the balance shifts in the 75~84 range to favor more women, and in the 85+ range, women are the clear majority.

POR by Sex: Most men within the sample lived at home (50.6%), whereas the women were more evenly spread among private homes, general nursing homes, and dementia nursing homes (37.0%, 30.2%, and 23.7%, respectively). This is probably because men die younger, perhaps with less disability, and certainly with more access to informal support from a spouse (which allows them to stay at home), while greater numbers of women live longer, without a spouse, and with more disability (requiring nursing home support) (Lennartsson, 2012). Service housing dwellers were a 9% minority in both sexes.

POD by Sex: Within both sexes, the majority of decedents died in a nursing home (men 55.9%, women 67.6%). The rest of deaths in both sexes seem to be about evenly divided between private homes and hospitals. Within each POD category, women vastly outnumber men, which is not surprising considering the entire sample contains more than twice as many women as men. In addition, the difference in sex proportion across the different POD categories is relatively small (only about 10 percentage points), but is statistically significant. Whether this difference is due to gender itself, or to some other confounding factor, is not possible to tell from these descriptive statistics.

5.2. Correlation Analysis to identify key variables

Now that we have explored the general relationships among the major variables of Age, Sex, Year of death, Place of residence, and Place of death (POD), our next task is to decide which control variables to include in our regression models of Place of Death with the main effect variable being Year of Death. First we run a correlation analysis to see which other

variables seem to be correlated with both Place of Death and Year of Death. These variables would fulfill the definition of confounders and thus would be good candidates for inclusion in the models.

Referring to the SPSS output in Appendix 3, the correlations with POD range in strength (absolute value) from 0.001 to 0.207, so none of these variables are particularly strongly correlated with POD when looking at them individually. The correlations with Year of death range in strength (absolute value) from 0.005 to 0.250, so again none of these variables are particularly strongly correlated with Year of death, though many of them have stronger relationships than they do with POD.

The variables that have a statistically significant correlation with both POD and Year of death, as seen by one or two stars after the correlation coefficient, are as follows: Place of residence, and Sex of main care giver. It should be noted that Sex of main care giver is significant, despite the relatively small valid sample size. HOMEalone also has a relatively small valid sample size, yet the strength of correlation is similar to that of Place of residence, and it has a highly significant and relatively strong correlation with Year of death, so I argue to consider including it in the model. Age and Sex do not appear to be correlated significantly with both POD and Year of death, but they will be included in the model nonetheless, as this is standard practice. So the full set of covariates emerging from the correlation analysis is as follows: Year of death, Place of residence, Age, Sex, and possibly Sex of main care giver and HOMEalone (living alone).

In the next section, I look more deeply into the relationships between POD and each of the relevant variables in the dataset through cross-tabulations.

5.3. Research Question 1: Changes in POD distribution over time, via cross-tabulations

Table 7 shows the distribution of Place of Death over the study period, as well as related to other key variables. When aggregated over the entire period, 19% of decedents died at home, 64% died in a nursing home, and 17% died in a hospital. However the data clearly shows this
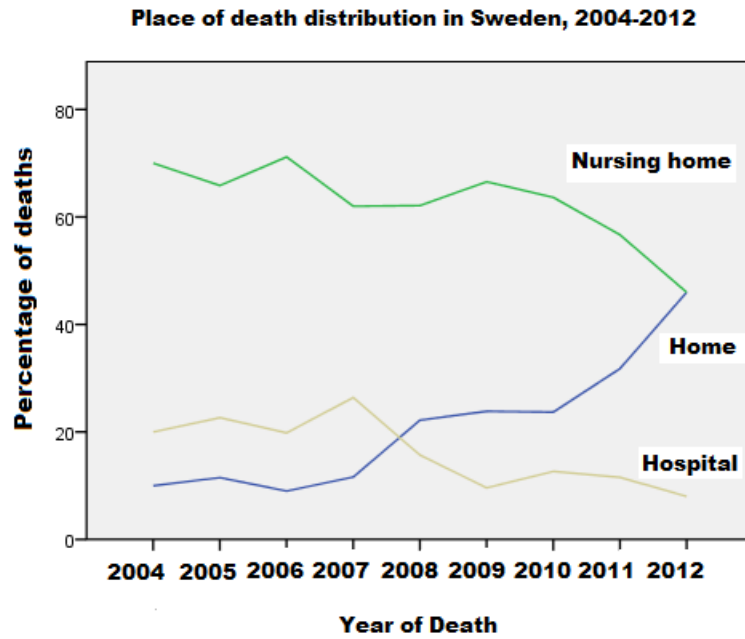
distribution has been changing over time from 2004 to 2011: home deaths have increased from 10% to 32%, nursing home deaths have decreased from 70% to 57%, and hospital deaths have decreased from 20% to less than 12%. These differences are significant at p=0.000 in the chi-square test for difference. I do not quote the results from 2012 because the sample size is small and likely to be biased, for example due to seasonal differences in mortality. Figure 1 shows the proportions of POD plotted over time.

The cross-tabulations in Table 7 also show differences in place of death according to age and place of residence. Comparing younger and older age groups, the younger deaths were more likely to occur in the hospital or at home, whereas the older deaths were more likely to occur in a nursing home. This is because older individuals are more likely to live in a nursing home. Figure 2 is a plot of the proportions of POD according to age.

In terms of place of residence, those living in private homes were much more likely than any other group to die in a hospital. Those living in nursing homes (both types) had almost 100% probability to die in a nursing home – we can conclude that nursing home residents who died "at home" were either by accident or by special arrangement. Those living in service housing were about equally as likely to die at home as those living in private homes, but much more likely to die in a nursing home. The source of the latter difference is not readily apparent, but is probably related to differences in disability status or access to informal care: as an artefact of the needs-testing the system, those living in service housing should have greater needs in one or both areas than those living in private homes. Beyond these interesting differences between groups, the results about nursing home deaths are also somewhat surprising, because a substantial percentage of individuals not officially living in nursing homes end up dying in a nursing home (17% of home dwellers, 52% of service housing dwellers). This means that these individuals transferred to a nursing home and died there before their place of residence was updated, which implies that this process happened rather quickly.

For the full set of cross-tabulations of POD with all variables of interest, please see Appendix 5.

Table 7: POD related to key independent variables				
		Place of Death		
Variable name (% of sample missing values for this variable or POD **)	**Number valid deaths**	**Hospital (%)**	**Nursing Home (%)**	**Home (%)**
Total sample (17.9% missing POD)	2208	16.8%	64.1%	19.1%
Year of death (17.9%), p=.000 (see Fig. 1)				
(only 10 months) 2004	240	20.0%	70.0%	10.0%
2005	287	22.6%	65.9%	11.5%
2006	222	19.8%	71.2%	9.0%
2007	250	26.4%	62.0%	11.6%
2008	293	15.7%	62.1%	22.2%
2009	281	9.6%	66.5%	23.8%
2010	308	12.7%	63.6%	23.7%
2011	277	11.6%	56.7%	31.8%
(only 2 months) 2012	50	8.0%	46.0%	46.0%
Age group at time of death (17.9%) p=.000 (see Fig. 2)				
65~74	129	25.6%	37.2%	37.2%
75~84	475	17.9%	57.5%	24.6%
85~94	1158	17.6%	66.1%	16.3%
95~106	446	11.0%	73.8%	15.2%
Sex (0.0%), p=.000				
Male	657	20.9%	55.9%	23.3%
Female	1551	15.1%	67.6%	17.3%
Place of residence (POR) (18.6%), p=.000				
Private home	804	39.9%	17.3%	42.8%
Service housing	177	6.8%	52.5%	40.7%
General nursing home	694	2.9%	96.8%	0.3%
Dementia nursing home	512	1.8%	98.0%	0.2%
Place of residence (POR) dichotomized (18.6%), p=.000				
Independent	981	33.9%	23.6%	42.4%
Care home	1206	2.4%	97.3%	0.2%
Living alone (37.7%) p=.061				
No	135	33.3%	21.5%	45.2%
Yes	332	33.1%	31.3%	35.5%

** 17.9% of the sample are missing a value for POD, the main outcome variable, therefore any cross tabulations with POD will show missing values of at least 17.9%.

Figure 1: % Valid Deaths in each location according to Year of death**

Place of death distribution in Sweden, 2004-2012

**See Table 7 for exact percentages

Figure 2: % Valid Deaths in each location according to Age group (10-year increments)**

Place of death distribution according to Age
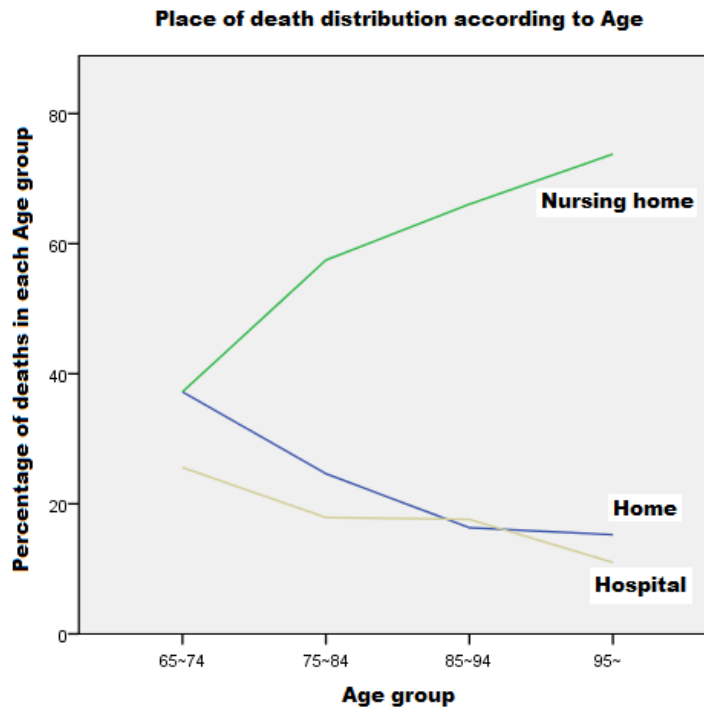
**See Table 7 for exact percentages

5.4. Research Question 2: Isolating the effect of Year of death, via logistic regression

<u>5.4.1. Building the logistic regression models</u>

Having explored our data set fairly extensively, we can now choose the covariates for our logistic regression models with more confidence. The outcome variable is the Place of Death (POD), coded as 1 for 'hospital death' or 0 for 'residential death' (see explanation in Section 4.6.3). The main effect variable is Year of death, coded as a categorical variable rather than continuous (see explanation in Section 4.6.3). The correlation analysis presented in section 5.2 provided evidence for the inclusion of Place of residence, Sex of main care giver, and Living alone as control variables. A further exploration of the variable Sex of main care giver can be found in Appendix 4. However, both Sex of main care giver and Living alone have a high percentage of missing values, so including them in the regression model would result in a much smaller valid sample size than if they were not included as covariates. Therefore, I will check to see if a very much difference in results occurs between the models where they are included and not included. If the difference is minimal, then I will keep the simpler model (for the sake of parsimony and increasing the valid sample size). Age group and Sex will also be included, as this is standard practice.

As previously described in the Methods chapter, first I will run several unadjusted models, containing only one independent variable at a time, to see what the effect of each variable looks like before adjustment by other variables. Next I will build a model including the control variables that were identified as significant confounders in the correlation analysis (see Section 5.2 and Appendix 3), by way of the forced entry method. This method includes all variables in the model simultaneously rather than stepwise according to their statistical significance. This model will be run first on the entire sample of valid deaths -- those with both year of death and POD recorded. Then I will stratify the sample according to the decedent's place of residence (see explanation in Section 4.6.3) and run the model again on these four groups to see if any groups have similar enough results to allow combining groups. It should be noted that the variable 'Living alone' is not applicable for nursing home residents, so it will not be included when running the model for the subgroup of nursing home decedents.

When interpreting the results of the logistic regression models in Table 8, let us remember that the outcome variable is coded as hospital death (1) versus residential death (0), and the primary covariate of interest is Year of death. Odds ratios greater than / less than 1 indicate higher / lower odds of death in that category compared to the reference category. After controlling for age, sex, and place of residence, a significant "protective effect," or negative association, of time can be seen from 2008 through 2011, where the odds ratios for hospital death versus residential death are 0.54, 0.31, 0.50, and 0.35. These odds ratios seem to decrease overall (from 0.54 to 0.35), which may indicate an increasingly "protective effect," meaning that as Year of Death increases, the already low odds of Hospital Death decrease even further (an increasingly negative association of time). Again, the results from 2012 are questionable due to smaller sample size and possible seasonal effect of including only two months. In the full model (second column of Table 8), living in an institution also shows significant and highly protective effects (0.12, 0.04, 0.02), which leads into the final research question about the difference in effects according to place of residence.

In order to explore the difference in effects according to place of residence, I stratified the sample into four groups according to place of residence: private home, service housing, ordinary nursing home, and dementia nursing home. The results for those living in private homes (POR=1) and ordinary nursing homes (POR=3) are shown in Table 8, columns 3 and 4. An odds ratio of 0.00 with 95% confidence interval (0.00) indicates that no hospital deaths occurred in the given category (in these cases, the given year). The results for the other two strata, those living in service housing and dementia nursing homes, are not shown. This is because the service housing group showed no trends or significant differences in any variable (perhaps because of the small sample size), and the results for the dementia nursing home group were un-interpretable (odds ratios equal to extremely high numbers, a phenomenon which may be explained by a zero in the denominator of the odds ratio, indicating that no hospital deaths occurred in the reference category). For further explanation of the logistic regression setup and general meaning of the results, please see Section 4.6.3.

The odds ratios for the private home group (Column 3) show a significant and possibly increasing protective effect of time from 2008 onward. It should be noted that the magnitude of effects in this group is very similar to those in the model before the stratified analysis, so we might conclude that the bulk of the effect originates from this group. This is supported by the fact that the results for each of the other three residence groups show no trends over time or significant differences in any of the included variables.

Table 8: ORs for Outcome: Hospital Death(1) v. Non-hospital Death(0)							
Model:	Bivariate ("Unadjusted")		With Significant Confounders		Stratified: POR=1 Home, n=804		Stratified: POR=3 Nurs. Home, n=694
Indep. Vars.	OR (95% CI)	Sig	OR (95% CI)	Sig	OR (95% CI)	Sig	OR (95% CI)	Sig
Year of death							
2004	reference		reference		reference		Reference
2005	1.171 (0.77, 1.78)		1.01 (0.59, 1.72)		1.08 (0.59, 1.99)		1.49 (0.36, 6.23)
2006	.989 (0.63, 1.56)		0.94 (0.53, 1.67)		1.05 (0.55, 2.03)		0.41 (0.04, 3.75)
2007	1.435 (0.94, 2.19)		1.14 (0.67, 1.94)		1.22 (0.66, 2.27)		1.53 (0.33, 7.19)
2008	.745 (0.48, 1.16)		**0.54** (0.31, 0.92)	*	**0.53** (0.29, 0.98)	*	1.52 (0.32, 7.16)
2009	**.425** (0.26, 0.71)	*	**0.31** (0.17, 0.56)	*	**0.26** (0.13, 0.52)	*	0.00 (0.00)
2010	**.580** (0.37, 0.92)	*	**0.50** (0.29, 0.87)	*	**0.44** (0.23, 0.84)	*	1.35 (0.32, 5.63)
2011	**.522** (0.32, 0.85)	*	**0.35** (0.20, 0.62)	*	**0.39** (0.21, 0.74)	*	0.31 (0.03, 2.82)
2012	.348 (0.12, 1.01)		**0.18** (0.06, 0.57)	*	**0.20** (0.06, 0.65)	*	0.00 (0.00)
Age group							
65~74	reference		reference		reference		reference
75~84	0.63 (0.40, 1.00)		0.97 (0.58, 1.64)		1.09 (0.62, 1.89)		0.39 (0.03, 4.62)
85~94	**0.62** (0.41, 0.95)	*	1.36 (0.84, 2.22)		1.45 (0.87, 2.43)		1.27 (0.15, 10.77)
95~106	**0.36** (0.22, 0.59)	*	0.94 (0.53, 1.67)		1.00 (0.53, 1.88)		0.12 (0.01, 2.17)
Sex							
Male	reference		reference		reference		reference
Female	**0.67** (0.53, 0.85)	*	0.87 (0.66, 1.16)		0.90 (0.66, 1.23)		1.19 (0.40, 3.55)
Place of residence							
Home (1)	reference		reference				
Service housing (2)	**0.11** (0.06, 0.20)	*	**0.12** (0.06, 0.22)	*			
Ordinary Nursing Home (3)	**0.04** (0.03, 0.07)	*	**0.04** (0.02, 0.06)	*			
Dementia Nursing Home (4)	**0.03** (0.01, 0.05)	*	**0.02** (0.01, 0.05)	*			
Living alone							
Cohabit	reference						
Alone	0.99 (0.65, 1.52)				***		

(*) significant at p = 0.05   (***) Living alone is not included in the model because of its small valid sample size, but including it in the model reveals noteworthy age and gender effects.

CHAPTER 6. DISCUSSION AND CONCLUSIONS

Based on guidelines published in the British Medical Journal (Docherty & Smith, 1999), this Discussion chapter will be structured in the following way:

1. Statement of principal findings
2. Strengths and weaknesses of this study
3. Strengths, weaknesses, and results in relation to other studies
4. Meaning of the study: possible mechanisms and implications for clinicians or policymakers
5. Unanswered questions and future research
6. Conclusion: Key take-aways of this study

6.1. Statement of principal findings

Many interesting points arose from the data analysis, but in this section I will focus on those findings directly related to the research questions:

1. What is the distribution of place of death among the participants of our study population for each year, 2004~2012? Has the distribution changed significantly over these years?
3. After adjusting for the most important individual factors, is there an association between year of death and place of death, 2004~2012?
   a. Does the association between year of death and place of death differ for individuals who live in private homes versus in nursing homes?

6.1.1. RQ1: Changes in the distribution of POD over the years 2004~2012

When aggregated over the entire period (including two months in 2012), 19% of decedents died at home, 64% died in a nursing home, and 17% died in a hospital (see Table 7). From 2004 to 2011, home deaths increased from 10% to 32%, nursing home deaths decreased from 70% to 57%, and hospital deaths decreased from 20% to less than 12%.

6.1.2. RQ2: Association between Year of death and Place of death, 2004~2012

Logistic regression was used to isolate the effect of time on the decline in hospital deaths. After controlling for age, sex, and place of residence, a significant protective effect of time (negative association) can be seen from 2008 through 2011, where the odds ratios for hospital death (coded as '1') versus residential death (coded as '0') are 0.54, 0.31, 0.50, and 0.35 (see Table 8). These odds ratios seem to decrease overall, which indicates a potential increasing protective effect (i.e., an increasingly negative association between time and hospital death). In this model (second column of Table 8), living in an institution also shows significant and highly protective effects (0.12, 0.04, 0.02), which leads into the final research question about the difference in effects according to place of residence.

6.1.3. RQ2a: Difference in effects for private home dwellers v. nursing home dwellers

A stratified analysis was performed according to the variable Place of residence, with the four subgroups being residence in a private home, service housing, an ordinary nursing home, or a dementia nursing home. The odds ratios for the private home subgroup show a significant and increasing protective effect of time from 2008 onward. In other words, for those decedents who were living in private homes, the passage of time was negatively associated with hospital death. The magnitude of effects in this group is very similar to those in the model before the stratified analysis, so we might conclude that the bulk of the effect originates from this group. This is

supported by the fact that the results for each of the other three residence groups show no trends over time or significant differences in any of the included variables.

6.2. Strengths and weaknesses of this study

The biggest strengths of this study are the use of place of death statistics that differentiate between deaths 'at home' and 'in a nursing home,' detailed information about the decedents' places of residence prior to death, and the analysis of changes over time on a year-by-year basis. Several other relevant variables are also contained in the dataset, but the extent of missing values warrants checking for selection bias in these variables.

The biggest weaknesses of this study are also related to the quality of data in the main variables of POD, POR, and Year of death. The first inclusion criterion was information about the Year of death, which led to the exclusion of 6.1% of the original sample of decedents (184 out of 2872).

The second inclusion criterion of information about the place of death led to the exclusion of another 17.8% of those whose year of death was known. Currently the SNAC-K Care System study coordinators do not consider this to be a serious limitation or selection bias, as it seems unlikely that these 17.8% are missing a recorded POD for any reason other than random mistakes or random omissions by the care staff members who submit the data. However, I believe this warrants further investigation, as it seems plausible that those decedents who change care environments just before death may be more likely to have an unrecorded POD.

Finally, the data about the place of residence (POR) is problematic because it is recorded in two separate variables (one for the needs assessor's decision, and one for the actual place of residence), and there can be a lag in documentation when an individual changes residences. This lag may have been magnified by the method of building the data set for this thesis, which was to merge only the annual-level data. Using the monthly data updates would probably yield more accuracy in the place of residence, albeit the process is much more time-consuming.

In terms of external validity, it bears reminding that the sample consists of all public eldercare recipients in one district of Stockholm. As such, caution should be taken when generalizing to other elderly populations (even in Sweden) for three reasons:

1) The study sample excludes those individuals not needing public eldercare (either because of good health or because their care needs are met by some other source). If the sample were to include the entire elderly population in this location, we would expect a greater proportion of home deaths and hospital deaths in all years (since nursing home death would not have been an option for the additional individuals). How this would translate into changes over time is unclear, since the causal mechanism is unclear (see Section 6.4).

2) The study sample contains more than twice as many women as men. While this kind of gender imbalance is common in elderly populations, we did not obtain the necessary demographic data about Kungsholmen to determine whether this gender distribution was representative of that of the broader Kungsholmen elderly population during the years under study. Most likely the gender imbalance is less extreme in the broader population.

2) The study sample draws only from a small urban district, which implies better access to hospital care than in rural locations, at least in terms of geographic proximity. However, rural locations may or may not have seen as drastic a decline in hospital bed supply as in urban locations.

6.3. Strengths, weaknesses, and results in relation to other studies

As stated in the previous section, the greatest strength of this study is the use of detailed data about place of death, place of residence, and year of death. Most other studies about place of death do not have the privilege of access to such data.

The results of this study regarding the distribution of POD are difficult to compare with most of the Swedish studies listed in the literature review, because of differences in sample populations or definition of the outcome. However, we can say that the distribution of place of death among hospitals / nursing homes / private homes in the first three years of our data appears to be similar to the results from both Jakobsson's and Andersson's studies, whose data were for the years just previous to ours. Comparing to Åhsberg's results using Swedish national statistics, however, our sample shows a smaller proportion of hospital deaths: 22.6% of 2005 deaths in our sample occurred in hospital, compared to Åhsberg's result of 40% (of elderly deaths in all of Sweden in 2005). This is probably because our sample contains more nursing home dwellers and fewer home dwellers than the general elderly population.

Among the international comparisons, the only populations showing a similarly high concentration of deaths in nursing homes were in Houttekier's study of the dementia populations in England, Scotland, Wales, Netherlands and Belgium. This may just be a coincidence, but it warrants checking our sample to see if the prevalence of dementia is higher than in the general elderly population. While information about diagnoses is not readily available in the SNAC-K Care System data, one special extra component of the study is the evaluation of cognitive impairment, so further analysis based on dementia status could be possible.

The difference between our results and those of most of the remaining Swedish POD studies is due to the fact that they focus on cancer or other causes of death eligible for palliative care – causes of death which appear to lead more often to death in a hospital, hospice, or home, as opposed to death in a nursing home. In contrast, our sample is more representative of the broader elderly population in the sense that it includes deaths from any cause. Among this broader cause of death set, it is clear that deaths in nursing homes are the majority. While we cannot say for certain which causes of death are causing the differences in POD distribution between our sample and the cancer samples, our data does show the effect of age, which is surely intertwined with the effect of cause of death (meaning that certain causes of death are more common in different age groups). Since increasing age is also highly correlated with death in a nursing home (see Figure 2 of Chapter 5), we might expect a noticeable difference in causes of death between those decedents living in and out of nursing homes.

The correlation between age and nursing home enrollment is an artefact of the needs-testing system in Sweden: the two strongest determinants of nursing home enrollment – having dementia and living alone – increase with age. Beyond this, gender is also intertwined with the age and cause of death relationship, as can been seen in the phenomenon of "dead men and suffering women" commonly observed in elderly populations. This implies that elderly populations tend to consist of mostly women, who are often a) widowed – because their husbands die at younger ages – and / or b) suffering from chronic debilitating diseases – because men more often die younger from acute disease, whereas women more often live longer with debilitating disease (Lennartsson, 2012). However, this is only a general observation, and the interaction between age, gender, disability, and mortality is not a simple one and warrants further investigation (Macintyre, 1996). One way to do this with our data would be to link with national register data about healthcare consumption and / or causes of death.

With regard to the research questions about changes over time, the only possible comparator studies are Houttekier 2011, Åhsberg 2012, and to some extent Teno 2013. Similar to our results, all three studies found a decrease in hospital deaths. Houttekier found a "shift from hospitals to care homes" in Belgium, whereas Teno shows the transfer instead from hospital deaths to home deaths in the USA. Our data from Stockholm shows a shift away from both hospital and nursing home deaths toward home deaths. Unfortunately Åhsberg's national data does not allow us to see anything more than a shift from deaths in hospitals toward all other locations.

Finally, in terms of isolating the effects of year of death and place of residence, the only comparator study is Houttekier's 2011 study using Belgian data from 1998 through 2007. After adjusting for other variables, he found a small increase in the effect of year of death over the 10-year study period (toward care home death, away from hospital death), but only in the care home subpopulation. Our study also found an increasing protective effect (away from hospital death) over the 8-year study period, but only in the private home-dwelling subpopulation. Houttekier's proposed explanation for his results was an increased supply of advanced nursing care in care homes, which thereby increased access to death in care homes and decreased the need for transfers to hospitals. Our results have no such clear explanation at present. Possible explanations will be presented in the following section.

6.4. Meaning of the study: possible mechanisms and implications for policymakers

To summarize, the three main results of this study are as follows:

- From 2004 through 2011, a period when the supply of hospital beds declined markedly in Sweden, hospital deaths decreased by almost half (from 20% to 11.6%), while home deaths tripled (from 10% to 32%), and nursing home deaths decreased by almost one-fifth (from 70% to 57%). In other words, 8.4 percentage points of hospital deaths, and 13.3 percentage points of nursing home deaths have shifted to the home death category, which has seen an increase by 21.8 percentage points (arithmetic discrepancy due to rounding).

- After controlling for age at death, sex, and place of residence, dying in the years 2008 through 2011 had a significant protective effect against hospital death (i.e., there was a negative association between the passage of time and hospital death).

- When looking at each place of residence group separately, it is clear that the bulk of the protective effect (against hospital death) from dying later in the period (2008 through 2011) is concentrated in the population that was residing in private homes prior to death.

Without additional data related to factors such as individual preferred place of death, cause of death, hospital discharge less than 2 weeks before death, or changes in local hospital bed supply, we cannot say what is causing this shift toward home death or whether it is a positive or negative development. However, these results may provide support for the hypothesis that the reduction of hospital bed supply has had a major impact on the end-of-life care of urban elderly persons using public care, since the probability of hospital death has declined at the same time that the supply of hospital beds has declined. If this is the case, we might expect to see an even greater impact of declining bed rates on the excluded population, since we would expect them to have a higher utilization of end-of-life hospital care (as other forms of care would be harder for them to access quickly than for those already enrolled in the system).

Some possible alternative explanations for the decline in hospital deaths among the study sample are listed below. Since the intention of this section is to inform policies which affect all

elders (not just the minority partaking in public eldercare), I also speculate how these alternative mechanisms might have different effects for those individuals who are not beneficiaries of the public eldercare system (and thus would be excluded from our study sample).

1) More people are discharged from the hospital just before death (a possible consequence of the 1992 Ädel-reform). This phenomenon would be expected to affect public eldercare users more strongly than those outside the system (see Chapter 1).

2) End-of-life (palliative) healthcare at home has become more available, thus reducing the need for end-of-life care in hospitals. We might expect that public eldercare users would have easier access to these options than those outside the system.

3) Attitudes and behaviors around death have shifted in favor of home death, thus increasing utilization of previously-existing home care options and reducing hospital deaths. Again, those in the public eldercare system would probably have better access to these options.

4) The distribution of causes of death has changed in favor of diseases which can be cared for out of hospital at the end of life. Such a substantial transition is unlikely to occur in only eight years. The National Board of Health and Welfare reports that in recent decades, deaths from circulatory disease and cancers have decreased (at different rates for men and women), while COPD deaths have doubled and dementia deaths have quadrupled (Danielsson, 2012).

5) In other settings, socioeconomic status has been shown to affect utilization of hospital care. Recent research about Swedish elderly from 1992 until 2002 shows a smaller proportion of individuals who had been manual workers, balanced by more non-manual workers (Fors, 2008). However more evidence is needed for the period in our study. It would be good to investigate if the overall level of education has changed, as one study from Belgium found that lower education correlates with less access to palliative care and physician visits at the end of life (Bossuyt, 2011). Therefore higher education overall could potentially lead to the fewer overall hospital deaths seen in the present study.

6) Provision of informal care (from spouses or otherwise) has increased in quality or quantity, thus reducing the need for end-of-life hospital care. Such a change in informal

care could result from changes in partnership patterns, intergenerational dynamics, labor force participation of middle-aged daughters, or social policies regarding elderly persons. Such a change might have more impact on non-users of the public eldercare system, since informal care is their only source of care beyond the medical system.

Considering the apparent decline in the proportion of nursing home deaths as well, the final explanation about increased informal care seems plausible, since this would protect against nursing home entry and thus nursing home death. According to Lennartsson, informal care has indeed been increasing, and nursing home beds decreasing, as a result of changing social policies. Budget cuts have lead to a purposeful cutting of not only hospital beds, but also of nursing home beds, and even home help care, such that the burden of care for elders has shifted back to families, particularly lower class women (Lennartsson, 2012). This means that the trend toward home deaths is perhaps not only a matter of individual choice, but also of blocked access to nursing homes.

While we cannot pinpoint the exact causes of the shift toward more home deaths, we can say with more certainty that this information is important for policymakers to consider at present. Currently public eldercare in Sweden is being reorganized and municipal authorities are becoming increasingly responsible for not only the social care of elderly citizens, but also their health care – and dying care – as this study illustrates. When planning for the future, these municipal authorities should consider the fact that technological advancement allows for more and more health services to be provided in the home, possibly with less cost and/or greater benefit than inpatient care, and that the published surveys to date indicate that most people prefer to die at their place of residence, when possible. These two phenomena could indicate that both the 'demand' and the cost-effectiveness of home healthcare and home death will increase in the future, regardless of cuts in the supply of hospital care. However, truly evidence-based planning would require more evidence about the costs and benefits of healthcare and dying care in private homes and nursing homes, as opposed to in hospitals. We also know very little at present about the preferences of the Swedish population about the circumstances around death, including the place of death.

6.5. Unanswered questions and future research

As previously stated in discussing the limitations of the data, I would like to see if the results change if we use a dataset based on the monthly data updates rather than the annual data that was used. At that point I would also like to investigate if there are any patterns, and thus bias, in the missing values for variables such as cohabitation and the sex of the main care giver. With this data we would also like to conduct further regression analyses using different definitions of the outcome variable, for example a new logistic regression of home deaths versus institutional deaths, to see if the trend toward home deaths might be the underlying cause, rather than the trend away from hospital deaths (which is illustrated in this thesis). Another example is a multinomial logistic regression – which allows more than two levels of the outcome variable – in order to detect not only the relationship between hospital deaths and residential deaths, but also the relationship between the two subcategories of residential deaths (private home versus nursing home).

Additionally, we would like to link the SNAC-K Care System data to the Swedish national hospital discharge register (also known as the Inpatient Care Register), in order to explore further questions such as:

- Are there predictors (often called 'determinants') of the Place of Death, after controlling for the primary diagnosis?

- Have near-death discharges increased since the Ädel reforms, as suggested by both Åhsberg and Lennartsson?

Finally, I would like to eventually utilize the newly-established Swedish Register for Palliative Care (SRPC) to look at these questions from a national perspective. The greatest advantage of the SRPC with regard to studying place of death outcomes is that the outcome is defined in terms of achieving the preferred place of death, so no assumptions need be made about the "goodness" of the different locations for place of death. The ideal would be to link the SRPC with data about the hospital bed supply and palliative home care supply in different municipalities, in order to look directly at the effects of changes in supply, rather than using time as a proxy for these changes. Based on the results of the current study, where home deaths have

increased at the same time as hospital bed supply has decreased, it is likely that the availability of different end-of-life care options is a major predictor of the place of death for those not living in a nursing home.

6.6: Conclusion: Key take-aways of this study

Over the study period, the place of death distribution has shifted significantly: the proportion of deaths in hospitals and nursing homes has dropped while the proportion in private homes has increased from 10% to 32%. The bulk of this effect seems to be emerging from the subgroup of individuals living in private homes, whose odds of dying in hospital have decreased over time, and thus their odds of dying at home or in a nursing home have increased. Those living in other types of residence showed no significant changes in place of death over time.

The policy implications of these results are substantial in that dying in private homes is a growing trend among elderly persons, which warrants careful planning and regulating to ensure that these individuals receive timely, good quality care, and that this care is equally accessible to all. The importance of these implications is magnified when considering the projected growth of the elderly population in the coming decades, along with the expectation that the home death trend is even stronger in the subpopulation of elderly persons who are not enrolled in public eldercare (and thus excluded from this study). Finally, our finding that those who live in nursing homes, or 'special accommodation,' almost always die there highlights the need for guaranteed availability of palliative care services in these settings.

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Registrering – SNAC vardsystem Löpnummer

Uppgiftslämnare:

Namn	Befattning	Period (ÅÅ-MM)
		200 -
Vårdgivare (om flera, ange huvudsaklig utförare)	Telefon	

Uppgiften avser: Ny person ☐1 Ändring ☐2 Avslut ☐3
(Gå till Avslutad längst ner på sidan)

Nuvarande bostad: Vanlig ☐1 Servicehus ☐2 Demensboende ☐3 Övrigt Säbo ☐4
reg. *svc. housing* *dementia inst* *other special housing*

Samtycke: Ja ☐1 Datum: _____ Till: _____
Nej ☐2 (om annan än uppgiftslämnaren ovan)

Samtycket är lämnat av personen själv ☐1 Efter hörande av närstående/god man ☐2

Personuppgifter:

Utomnordisk härkomst: Ja ☐1 Pers.nr: | | | | | | | - | | | | |

Land: _____

Civilstånd: Änka/änkling ☐1 Skild ☐2 Gift ☐3 Ogift ☐4

Ensam-/samboende: Ensamboende ☐1 Samboende ☐2

Sammanbor med: Make/maka/sambo ☐1 Anna person ☐2

Sammanbor med person som har varaktig vård/omsorg? Nej ☐0 Ja ☐1 Pers.nr: | | | | | | | | | | |

Avslutad: Insats t.o.m: _____ HSL ☐1 Rehab ☐2
Enhet: _____ Säbo ☐3 Övrig SoL ☐4
Kod

Avslutsorsak: ☐1 Flyttat till: _____ (SDF´s betalningsansvar upphör)
☐2 Avsäger sig
☐3 Ej längre i behov av insatsen
☐4 Avslag
☐5 Inlagd geriatrisk klinik, akutsjukhus etc.

Avliden den _____ I hemmet ☐6 I särskilt boende ☐7 På sjukhus ☐8
☐9 Annat: _____

Återtagit samtycke: ☐1 den _____

Bostadens anpassning till funktionshinder (vanligt boende och servicehus, EJ Säbo med heldygnsomsorg)

		Nej 0	Ja 1			Nej 0	Ja 1
Trösklar borttagna	91	☐	☐	Badkar ersatt med dusch	93	☐	☐
Badrum tillgängligt för rullstol	92	☐	☐	Förekomst av s.k. spisvakt	94	☐	☐

Bostaden är tillgänglig utifrån för person (vanligt boende och servicehus, EJ Säbo med heldygnsomsorg)

				Nej	Ja
som är rullstolsburen	(hiss och ramp finns om det behövs)	97	☐	☐
med svåra rörelsehinder	(hiss, fåtal trappsteg)	98	☐	☐
med lätta rörelsehinder	(hiss, trappa högst ett våningsplan)	99	☐	☐

Standard i särskilt boende med heldygnsomsorg (EJ servicehus)

		Nej 0	Ja 1			Nej 0	Ja 1
Egen WC	100	☐	☐	Enbäddsrum	103	☐	☐
Egen dusch/bad	101	☐	☐	Tvåbäddsrum	104	☐	☐
Kokmöjligheter	102	☐	☐	Flerbäddsrum (3 boende eller fler)	105	☐	☐

Hjälp för dagligt liv från andra (dvs ej biståndsbedömd)

Får regelbunden hjälp av:		Service / IADL					Omvårdnad / PADL			
		Saknas/ ej aktuellt (IADL-PADL) 8	Aldrig 0	Sällan 1	Flera ggr/v 2	Dagl. 3	Aldrig 0	Sällan 1	Flera ggr/v 2	Dagl. 3
Individuval informal care										
Make/maka/partner	106	☐	☐	☐	☐	☐	116 ☐	☐	☐	☐
Annan person	107	☐	☐	☐	☐	☐	117 ☐	☐	☐	☐

Kön på huvudsaklig hjälpare	114	Kvinna ☐1	Man ☐2	124	Kvinna ☐1	Man ☐2
(Om sammanboende) samman- bor med huvudsaklig hjälpare	115	Nej ☐0	Ja ☐1	125	Nej ☐0	Ja ☐1

if cohab, is main caregiver

Personligt vårdberoende

Service / IADL		obero-ende 0	delvis bero-ende 1	bero-ende 2	Omvårdnad / PADL		obero-ende 0	delvis bero-ende 1	bero-ende 2
Städning	135	☐	☐	☐	Bad och dusch	140	☐	☐	☐
Matinköp	136	☐	☐	☐	Av- och påklädning	141	☐	☐	☐
Transport, allmänna kommunikationer	137	☐	☐	☐	Toalettbesök	142	☐	☐	☐
Matlagning	138	☐	☐	☐	Förflyttning (inkl. upp- stigning/sänggående)	143	☐	☐	☐
Tvätt	139	☐	☐	☐	Födointag	144	☐	☐	☐

Övrigt personligt vårdberoende pga.

		Nej 0	se anvisn. sid 3-4 1	2	3			Nej 0	se anvisn. sid 4 1	2	3
Rörelsehinder (fys.)	145	☐	☐	☐	☐	Svårhanterligt beteende	154	☐	☐	☐	☐
Urininkontinens	146	☐	☐	☐	☐	Smärta	155	☐	☐	☐	☐
Avföringsinkontinens	147	☐	☐	☐	☐	Yrsel	156	☐	☐	☐	☐
Synnedsättning	148	☐	☐	☐	☐	Urinkateter	157	☐	☐	☐	☐
Hörselnedsättning	149	☐	☐	☐	☐	Trycksår	158	☐	☐		
Oro, otrygghet	150	☐	☐	☐	☐	Kroniskt sår	159	☐	☐		
Nedstämdhet	151	☐	☐	☐	☐	Behov av särskild tillsyn eller särsk. vårdinsatser	160	☐	☐		
Kognitiv nedsättning	152	☐	☐	☐	☐						

Katz: 153   A ☐1   B ☐2   C ☐3   D ☐4   E ☐5   F ☐6   G ☐7   Ö ☐8

Behov av särskilda sjukvårdsinsatser

		Nej 0	se anvisn. Sid 4-5					Nej 0	Ja 1
			1	2	3				
Läkemedel	162	☐	☐	☐	☐	Näring via sond	167	☐	☐
APO-dos	163	☐	☐			Näring intravenöst	168	☐	☐
Smärtbehandling	164	☐	☐	☐	☐	Blodtransfusion	169	☐	☐
Injektionsbehandling	165	☐	☐	☐	☐	Dialysbehandling	170	☐	☐
Provtagning	166	☐	☐			Omläggning av sår	171	☐	☐

Beslut enligt SoL

		Nej 0	Ja 1	Enhet	Kod
Matdistribution/matlåda ...	173	☐	☐	------------	
Hemhjälp Service/IADL ...	174	☐	☐	------------	
Hemhjälp Omvårdn./PADL	175	☐	☐	------------	
Hemhjälp kväll	176	☐	☐	------------	
Hemhjälp natt	177	☐	☐	------------	
Dagverksamhet	178	☐	☐	------------	
Trygghetslarm	180	☐	☐		
Korttidsboende:	181	☐			

Avgiftsgrupp .... 184 _____
(hemtjänst/dagverksamhet)

Hemtjänst Timmar/vecka: 185 _____

Dagverks. Dagar/vecka: 188 _____

Hemvårds-/Anhörigbidrag 189 _____ kr/mån

Kod

Avlastning/Växelvård   ☐1 Enhet: _____

Övrigt korttidsboende   ☐2 Enhet: _____

From -------------   Tom -------------

Särskilt boende: 194 ☐   Enhet: _____

Inriktning   Servicehus ☐1   Demensboende ☐2   Övrigt Säbc ☐3

Beslut enligt LSS   Nej ☐0   Ja ☐1

Pågående insatser enligt HSL

Ifylls av sjukvårdspersonal men EJ vid särskilt boende med heldygnsomsorg.

Inga HSL-insatser ☐244

Inskriven i hemsjukvårdens verksamhet ☐245   Enhet: [____]

		Nej 0	Ja 1	I organisationen kring patientens vård finns		Nej 0	Ja 1	Antal besök/mån
				Läkare	256	☐	☐	----------------
Hemsjukvård, dag	249	☐	☐	Sjuksköterska ..	260	☐	☐	----------------
Hemsjukvård, kväll	250	☐	☐	Undersköterska	264	☐	☐	----------------
Hemsjukvård, natt	251	☐	☐	Annan personal	268	☐	☐	----------------
Hemsjukvård timmar/månad	252	------------		Verksamheten ansluten till 272	Sjukhus ☐		Primärvård ☐	

Pågående rehabilitering

Ingen rehabilitering ☐273   Enhet: [____]

		Rehabiliteirng i egna boendet - Säbo			Rehab. utanför hemmet / Rehab-enhet		
		Nej 0	Ja 1	Antal Besök/månad	Nej 0	Ja 1	Antal Besök/månad
Rehabilitering av	111	☐	☐	------------	☐	☐	------------
Sjukgymnast/sjukgym.biträde	111	☐	☐	------------	☐	☐	------------
Arbetsterapeut/arbetster.bitr.	111	☐	☐	------------	☐	☐	------------
Annan	111	☐	☐	------------	☐	☐	------------

Var: _____

Åtgärd:		Nej 0	Ja 1	Åtgärd:		Nej 0	Ja 1
Bedömning	111	☐	☐	Handledning	111	☐	☐
Träning	111	☐	☐	Behandling	111	☐	☐

SNAC-K Care System study design and phenomena measured (published on www.snac-k.se)

Study design and outline of the protocol

In the care system perspective there is a systematic longitudinal, individual-based collection of data concerning the operations of the long-term care services system – volume and character of services provided in relation to disability and other factors influencing needs. Starting from a baseline survey, all contacts between older persons and the care system in the involved areas are recorded. This includes the provision of acute care, geriatric hospital care, home health care, and home services. Additionally, information on housing and received informal or privately-funded care is collected. The care system perspective and the population perspective are joined through those elderly persons who participate in both parts of the study. Thereby, information collected from different sources can be checked.

Through this systematic data collection using the same design and basic study protocol, a reliable, comparable, longitudinal database is built up. This database enables practitioners as well as researchers in the field to study, analyse and draw conclusions concerning a multitude of important questions that are of importance to the living conditions of frail elderly people.

The care-system-part-protokolls are essentially the same in all four areas. Data consist of continuous recording of each (substantial) change in the provision of public long-term care and services for all persons 65 years or older lignin the area. This means that a record is made, when a person is granted home help services, long-term home health care or rehabilitation or special housing. A record is also made when care services for some reason is discontinued and a special notification is made in case of death.

The protocol of the SNAC care systems part contains the following items:

A. Demography

- Age, gender, marital status, current housing, cohabitation

B. Housing and living arrangements

- Adaption of current housing to disability
- Accessibility of current housing in relation to restrictions in mobility
- Standard in special housing for frail elderly
- Access to informal care

C. Functioning

- Functional disability (IADL, ADL)
- Mobility
- Incontinence – urine and feaces
- Communication – hearing and eye-sight
- Anxiety and insecurity

- Cognitive dysfunction
- Pain
- Dizziness
- Chronic wounds
- Behaviour problems
- Special care needs – pain treatment, nutrition through sond, dialysis…

D. Decided provision of care services according to the Social Services Act

- Home help, hrs/week
- Help in the evenings
- Help at night
- Day centre (n:o of days/week)
- Daily activities for demented patients
- Short-term dwelling
- Special housing for frail elderly persons
- Home care allowance
- Alarm
- Aids

E. Provision of care services according to the Health Service Act

- Home health care (visits of doctors, nurses; n:o per month)
- Home rehabilitation (by physiotherapeut or occupational therapeut)
- Rehabilitation in day hospital care

APPENDIX 3:

Table 9: Abbreviated SPSS Output of Correlation Analysis for POD and Year of death

		YEARofdeath	Place of death
YEARofdeath	Pearson Correlation	1	-.207[**]
	Sig. (2-tailed)		.000
	N	2688	2208
Place of death (POD)	Pearson Correlation	-.207[**]	1
	Sig. (2-tailed)	.000	
	N	2208	2208
SEX	Pearson Correlation	-.024	.001
	Sig. (2-tailed)	.208	.949
	N	2688	2208
Place of residence (POR)	Pearson Correlation	.039[*]	.051[*]
	Sig. (2-tailed)	.045	.016
	N	2657	2187
COGNITIVE DISABILITY	Pearson Correlation	.011	.046[*]
	Sig. (2-tailed)	.602	.043
	N	2220	1903
IADLdependence	Pearson Correlation	-.042[*]	.005
	Sig. (2-tailed)	.049	.813
	N	2230	1910
PADLdependence	Pearson Correlation	-.005	-.028
	Sig. (2-tailed)	.802	.229
	N	2226	1907
SEX OF MAIN CARE GIVER	Pearson Correlation	-.235[**]	.090[*]
	Sig. (2-tailed)	.000	.039
	N	587	525
AGEdecade	Pearson Correlation	.046[*]	.035
	Sig. (2-tailed)	.018	.105
	N	2688	2208
MARRIED	Pearson Correlation	.072[**]	-.033
	Sig. (2-tailed)	.001	.140
	N	2270	1940
HOMEalone	Pearson Correlation	-.250[**]	.051
	Sig. (2-tailed)	.000	.274
	N	648	467

Correlation is significant at the 0.01 level (2-tailed).[**]   Correlation is significant at the 0.05 level (2-tailed).[*]

Other Cross tabulations based on Correlation results

The correlation analysis showed an unexpected significant correlation between Sex of main care giver and POD, so we want to look deeper to see if this correlation seems legitimate.

Table 12: Cross-tabulation of POD and Sex of main care giver

Place of death (POD) * SEX OF MAIN CARE GIVER Crosstabulation

% within Place of death (POD)

| | | SEX OF MAIN CARE GIVER | | | Total |
		FEMALE	MALE	BOTH	
Place of death (POD)	At home	97.3%	1.3%	1.3%	100.0%
	At nursing home	87.1%	8.4%	4.6%	100.0%
	At hospital	85.7%	8.9%	5.4%	100.0%
Total		88.4%	7.4%	4.2%	100.0%

Comment: Among those who died at home, 97.3% had a female main care giver, as opposed to 87.1% of nursing home decedents, and 85.7% of hospital decedents. This begs the question: what is the proportion of decedents with female main care givers in the entire sample?

Table 13: Frequency distribution of Sex of main care giver (entire sample)

SEX OF MAIN CARE GIVER

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	FEMALE	519	19.3	88.4	88.4
	MALE	46	1.7	7.8	96.3
	BOTH	22	.8	3.7	100.0
	Total	587	21.8	100.0	
Missing	System	2101	78.2		
Total		2688	100.0		

Comment: We only have data about 21.8% of the sample to approximate an answer to the above question, but the result is still interesting: the proportion of all decedents (who have a date of death on record) with a female main care giver is 88.4%. So the 97.3% proportion among home deaths is notably above the average. A large difference can also be seen in the Table 2 cross tabulation with POD, which shows that among those with a female main care giver, 15.7% died at home, as opposed to only 2.6% of those with a male main care giver. It is hard to draw any

solid conclusions from this without knowing the exact definition of a main care giver, particularly in the nursing home setting, and disentangling any decedent gender effect (those who die at home with a female main care giver could be mostly men living with their wives), but these numbers may support the hypothesis that females provide more or better care.

Full set of Cross-tabulations with Place of Death

Table 10: System variable (1)		**Place of Death**		
Variable name (% of sample missing value for this variable or POD)	Total deaths	Home (%)	Nursing home (%)	Hospital (%)
Year of death (17.9%) p=.000 (see Figure 1)				
(only 10 months) 2004	240	10.0%	70.0%	20.0%
2005	287	11.5%	65.9%	22.6%
2006	222	9.0%	71.2%	19.8%
2007	250	11.6%	62.0%	26.4%
2008	293	22.2%	62.1%	15.7%
2009	281	23.8%	66.5%	9.6%
2010	308	23.7%	63.6%	12.7%
2011	277	31.8%	56.7%	11.6%
(only 2 months) 2012	50	46.0%	46.0%	8.0%

Table 11: Living situation variables (5)		**Place of Death**		
Variable name (% of sample missing value for this variable or POD)	Total deaths	Home (%)	Nursing Home (%)	Hospital (%)
Place of residence (POR) (18.6%) p=.000				
Private home	804	42.8%	17.3%	39.9%
Service housing	177	40.7%	52.5%	6.8%
General nursing home	694	0.3%	96.8%	2.9%
Dementia nursing home	512	0.2%	98.0%	1.8%
Place of residence (POR) dichotomized (18.6%) p=.000				
Independent	981	42.4%	23.6%	33.9%
Care home	1206	0.2%	97.3%	2.4%
Living alone (37.7%) p=.061				
No	135	45.2%	21.5%	33.3%
Yes	332	35.5%	31.3%	33.1%
Married (27.8%) p=.02				
Yes	282	24.1%	59.2%	16.7%
No	1658	16.5%	69.1%	14.4%
Sex of main care giver (80.5%) p=.137				
Female	464	15.7%	73.9%	10.3%
Male	39	2.6%	84.6%	12.8%
Both	22	4.5%	81.8%	13.6%

Table 12: Individual health variables (6)			Place of Death	
Variable name (% of sample missing value for this variable or POD)	Total deaths	Home (%)	Care home (%)	Hospital (%)
Age group at time of death (17.9%), p=.000 (see Figure 2)				
65~74	129	37.2%	37.2%	25.6%
75~84	475	24.6%	57.5%	17.9%
85~94	1158	16.3%	66.1%	17.6%
95~106	446	15.2%	73.8%	11.0%
Sex (0.0%), p=.000				
Male	657	23.3%	55.9%	20.9%
Female	1551	17.3%	67.6%	15.1%
Cognitive disability (29.2%), p=.000 (see Figure 4)				
None	768	29.8%	46.1%	24.1%
Mild	451	14.9%	72.7%	12.4%
Severe	412	6.8%	88.3%	4.9%
Very Severe	272	1.1%	95.6%	3.3%
Dementia status (Cognitive disability dichotomized) (29.2%), p=.000				
No	1219	24.3%	55.9%	19.8%
Yes	684	4.5%	91.2%	4.2%
PADL dependence (Personal Activities of Daily Living) (29.1%), p=.000 (see Figure 5)				
None	331	36.0%	30.8%	33.2%
Minimal	202	24.3%	44.1%	31.7%
Slight	198	25.8%	57.1%	17.2%
Moderate	132	12.9%	77.3%	9.8%
Severe	313	14.4%	76.0%	9.6%
Complete	731	6.8%	90.6%	2.6%
IADL dependence (Instrumental Activities of Daily Living) (28.9%), p=.000 (see Figure 6)				
None	14	28.6%	28.6%	42.9%
Minimal	47	48.9%	34.0%	17.0%
Slight	56	33.9%	23.2%	42.9%
Moderate	94	37.2%	21.3%	41.5%
Severe	134	29.9%	41.0%	29.1%
Complete	1565	13.4%	76.6%	10.0%