

**End-of-life care in a Swedish county**  
**- patterns of demographic and social conditions, clinical**  
**problems and health care use**

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# ABSTRACT

There is broad consensus in both international and national policy statements that care provided at end-of-life should be different from care provided during other periods of life. There is a need for comprehensive knowledge about the broad population of individuals who access the public health care system during the last period of life. The purpose of this thesis therefore, is to make a contribution to a broader understanding of the nature of end-of-life and end-of-life care for these individuals. The study was undertaken through retrospective examinations of death certificates, medical records and nursing records in a randomly selected sample of adults who accessed the public health care system, and who died in the County of Västra Götaland, Sweden, during 2001. The sample consisted of 229 persons.

The majority of individuals in this study were aged eighty or more at time of death. Men died four years younger, and were significantly more likely to live apart from their partners at time of death, whereas women were significantly more likely to live alone. There were also significant differences in residential environment at time of death, with one-half residing in private homes and the other half in residential care facilities, and this environment was significantly associated with many of the variables analyzed in this study. The group in residential care facilities was, on average, nearly 10 years older than those in private homes. The most common places of death were acute care hospitals and residential care facilities. The less old persons more often died at acute care hospitals whereas the oldest group more commonly died at residential care facilities. The likelihood of inpatient care during last three months of life, including the expected number of hospital admissions, was significantly higher among residents of private homes than among individuals in residential care facilities. However, the presence of mental disorder(s), mainly dementia, was associated with less utilization of both inpatient and hospital-based outpatient care, regardless of residence. Conversely, the likelihood of using outpatient primary care services was significantly higher among residents of residential care facilities than among those in private homes. Factors such as advancing age, ADL-dependency, and living alone increased the likelihood of receiving care at residential care facilities, whereas presence of neoplasm(s) and musculoskeletal disease(s) increased the likelihood of care in a private home. The mean number of all health care services used was 2.67. A wide range of highly prevalent symptoms and problems was identified in the study group, especially among persons who were ADL-dependent. A specific turning point, reflecting onset of the dying process and reorientation of care, was documented in almost three-quarters of the medical or nursing records. Two thirds of these turning points were documented within the last week of life.

Findings from this study provide policymakers, health care providers, and professional caregivers with both a reminder and a framework which may contribute to a more mindful and comprehensive understanding of commonplace end-of-life concerns. It is, in fact, suggested that the public health care system as a whole take greater note of the present situation and that it proactively focus on the development of standards for end-of-life care. Its content should be formulated and based on systematic and detailed insights into the identities of the individuals who utilize the health care system at the end of life, where and from whom they receive care, and most importantly, the nature of their problems and needs. Moreover, steps must be taken to continually audit end-of-life care provided by the public health care system, with an objective to constantly improve the scope, quality, and trustworthiness of its services.

**Keywords:** end-of-life, end-of-life care, demographics, social conditions, health care utilization, places of death, clinical problems, turning point.

## ORIGINAL PAPERS

This thesis is based on papers referenced in the text by Roman numerals I - IV:

- I** Jakobsson, E., Johnsson, T., Persson, L-O., & Gaston-Johansson, F. (2006). End-of-life in a Swedish population: demographics, social conditions and characteristics of places of death. *Scandinavian Journal of Caring Sciences*, 20(1): 10-17.
  
- II** Jakobsson, E., Bergh, I., Öhlén, J., Odén, A., & Gaston-Johansson, F. Utilization of health-care services at the end of life in a Swedish population. (In press in *Health Policy*).
  
- III** Jakobsson, E., Gaston-Johansson, F., Öhlén, J., & Bergh, I. Clinical problems at the end of life in a Swedish population including the role of advancing age and physical and cognitive function. (Submitted for publication).
  
- IV** Jakobsson, E., Bergh, I., Gaston-Johansson, F., Stolt, C-M., & Öhlén, J. (2006). The turning point: clinical identification of dying and reorientation of care. (In press in *Journal of Palliative Medicine*).

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# INTRODUCTION

In Sweden, approximately 95,000 people die each year (Statistiska centralbyrån [SCB], 2006). For many individuals, death is the final event in a complex chain of processes that involve issues related to underlying social and economic factors, lifestyle, and preventive and curative health care. Over time, advances in health care have naturally contributed to a fall in mortality from many conditions around the world (Nolte & McKee, 2003). In Sweden, mortality for most causes of death is also falling, including deaths from circulatory diseases and neoplasms (Socialstyrelsen, 2005a), and most deaths are currently confined to persons of advanced age. In 2003, 38% of deaths in Sweden occurred at the age of 85 years or more (Socialstyrelsen, 2005b), and it has thus been concluded that years of greater health quality have been added to inhabitants' lives even though the population lives longer with disease (Wilhelmsson, 2003). On the one hand, these trends, which are analogous to those in many Western countries (Seale, 2000), can be described as favourable for a modern society, and to be a tribute to modern medicine since a longer healthier life is a comprehensive goal for public health (Socialstyrelsen, 2005b). On the other hand, it also means that the manners of dying in Western countries have changed from being sudden, acute episodes to longer processes, perhaps accompanied by physical and mental deterioration and a wider sense of suffering (Seale, 2000; ten Have & Clark, 2002). This more prolonged end-of-life period presents a challenge to the public health care system, which for the most part, has been designed to respond to acute illnesses (Donaldson & Field, 1998).

End-of-life is regarded as one of the most critical stages of life and, as a society, there is a desire to serve people well and in ways that protect their dignity and give comfort when most needed (Seymour & Ingleton, 2004). Hence, care at end-of-life is an important, common and integral part of care provided by any health care system and, in Sweden, should be treated with the same priority as emergency and curative interventions (Statens offentliga utredningar [SOU] 1995:5). There is, nonetheless, broad consensus among national and international policy statements that care provided at end-of-life should be different from care provided during other periods of life (e.g. Council of Europe, Rec. 2003:12; SOU 2001:6; World Health Organisation [WHO], 2002; WHO, 2004). The previously referenced report (SOU 2001:6), proposes that good care at end-of-life should be realized through further developments of palliative care, and should be offered to every person with such needs. Palliative care should thus be integrated into all types of care, and be provided with the objective to reduce suffering and to maximize well-being and comfort at end-of-life.

Several studies have identified significant concerns with end-of-life care provided by the Swedish health care system, including poor communication about death and dying both among caregivers themselves and between caregivers and patients and their relatives (Nordgren & Ohlsson, 2004); a lack of holistic approaches to patient care, addressing concerns beyond diseases and symptoms (Edvardsson, Sandman, & Rasmussen, 2006; Lindqvist, Widmark, & Rasmussen, 2006); a lack of patients' own involvement in care and care decisions (Ternstedt & Franklin, 2006); a lack of family support beyond specific care-related tasks (Wennman-Larsen & Tishelman, 2002); and a lack of ethical considerations beyond those associated with medical procedures and tasks (Svantesson, Sjökvist, & Thorsén, 2003). Compounding these concerns further, studies have also demonstrated that health care providers themselves often feel inadequate and poorly prepared to manage the concerns among persons near end-of-life (e.g. Berterö, 2005; Friedrichsen & Milberg, 2006; Löfmark, Nilstun, & Bolmsjö, 2005).

In an effort to alleviate suffering at end-of-life, a number of different care models have been developed in several Western countries during the past few decades, including services based at hospitals (e.g. palliative teams and specialized units), private homes (e.g. primary health-care teams and specialist palliative services), and residential hospices (Abu-Saad, 2000; Clark & Seymour, 1999; Higginson, 2005; Lynn, 2000; ten Have & Clark, 2002). The challenges posed are common across country borders since populations of Western countries are increasingly dying at an advanced age with progressive chronic illnesses. A wide range of physical, psychological, social and existential problems thus become increasingly prevalent, and raise additional demand for professional care and treatment. As the demographic patterns and causes of death and disability become increasingly similar in most countries, so are the patterns of necessary resources. Each country, however, must find its own solutions to these challenges, and in each case appropriate to its health care context and culture (Higginson, 2005; ten Have & Clark, 2002).

To date, findings from end-of-life research in Sweden have largely been limited to an understanding of individuals suffering from cancer. A variety of studies have thus placed emphasis on the quality of the end-of-life period as perceived by this subpopulation (e.g. Boström, Hinic, Lundberg, & Fridlund, 2003; Johansson, Axelsson, & Danielsson, 2006; Lundh Hagelin, Seiger, & Furst, 2006; Sahlberg-Blom, Ternstedt, & Johansson, 2001; Sandblom, Carlsson, Sennfalk, & Varenhorst, 2004). A more limited number of studies have focused on the situation for other subgroups, such as the elderly in general and individuals suffering from non-malignant diseases (e.g. Bolmsjö & Hemerén, 2001; Elofsson & Öhlén, 2004; Franklin, Ternstedt, & Nordenfelt, 2006; Nordgren & Sörensen, 2003; Ternstedt & Franklin, 2006).

Other qualitative Swedish studies have shed empirical light on the meaning of care at end-of-life and, although primarily derived from a hospice care perspective, conclude that the character and quality of care provided to seriously ill and dying patients have significant impact upon individuals' sense of dignity and well-being (e.g. Rasmussen, Jansson, & Norberg, 2000; Rasmussen & Sandman, 1998; Öhlén, 2004; Öhlén, Bengtsson, Skott, & Segesten, 2002).

There is a need for comprehensive knowledge about the large population of individuals who access the public health care system during the end-of-life period. This knowledgebase can serve to frame a foundation for both well-reasoned developments and evidence-based improvements in end-of-life care. This thesis thus seeks to contribute to a better understanding of individuals' end-of-life period as well as the care presently received. More specifically, this undertaking describes demographic patterns, concurrent social and health factors, patterns of health care utilization, places of death, and the important turning point which reflects the onset of the dying process and the associated care reorientation in a randomly selected sample of adults who both accessed the public health care system and died in the County of Västra Götaland in Sweden during 2001.

### **Definition of end-of-life**

There is no precise definition of end-of-life. The (U.S.) National Institutes of Health (2005) has, however, concluded that evidence support the following as key components of end-of-life: (1) the presence of chronic disease(s), symptoms or functional impairments which may fluctuate but nevertheless persist; (2) symptoms or impairments resulting from underlying irreversible disease(s) which require formal or informal care, and which can lead to death. Importantly, advanced age and frailty may be surrogates for life-threatening illness. In this thesis, end-of-life has been temporally defined to encompass the last three months of life in a broad but well defined population. This is consistent with Lorentz et al. (2004) who suggest that the correct definition of end-of-life may depend upon its use and context. For research purposes, a few clear definitions of its scope may suffice to permit clear delineation of the denominator population in each study, and to enable comparisons across time and settings.

## A perspective on end-of-life care

There is broad consensus that the aim of care provided to people at end-of-life is a reorientation of care in the direction of palliation with an objective to make a positive difference in these individuals' lives (e.g. Lamont, 2005; Lynn et al. 2002). This approach emphasizes the early recognition, prevention and alleviation of suffering as integral parts of normal and good care (Zimmermann & Rodin, 2004). Hence, the structure of end-of-life care should ideally: (a) be integrated with each level of care, i.e. community and primary care, hospital-based care, and across medical specialities; (b) change from present-day terminal care to encompass a longer end-of-life period; (c) expand from primarily including persons suffering from malignant diseases; (d) emphasize a comprehensive view, including physical, psychological, social and existential concerns. The overall purpose is to relieve suffering in the broadest sense, and to avoid confinement to a special organisation or physical construct. Rhetorically, end-of-life care aims to reduce suffering and to improve quality of life, and the literature illustrates at least three perspectives on paths to its realization: (1) community development and non-clinical approaches to health promotion including a focus on the broad issues of death and dying (Kellehear, 1999; Lloyd, 2000; Skilbeck & Payne, 2005); (2) development of clinical specialists in palliative care (Ahmedzai et al., 2004; George & Sykes, 1997); and (3) adoption of a palliative approach to all health care at end-of-life based on holistic principles (Corner & Dunlop, 1997; Field & Addington-Hall, 2000; Zimmerman & Rodin, 2000).

These perspectives are consistent with nursing beliefs in general. Thus, Kim (2000a) stipulates that nursing is not primarily concerned with disease or disability itself, but with *living* (in its broad sense) under circumstances of health problems and dependency on formal or informal care. More specifically, life during the particular circumstance of end-of-life is only one dimension of normal human living. With this perspective, disease and health problems are not the dominant focus of nursing, but do have to be understood or considered because of their potential impact upon normal life. Further, nursing from this point of view, is a service to people aimed at promotion of health. It is an underlying assumption of this thesis, therefore, that end-of-life care is vigorous, active and not necessarily conceptualized in traditional clinical terms. As a corollary, health at end-of-life is not necessarily absent of disease, functional impairment, symptoms or dependency, but rather a situation in which a sense of well-being and comfort is maximized in its broadest sense (Kellehear, 1999; Lloyd, 2000; Skilbeck & Payne, 2005).

## **Overview of the literature**

The core literature consists of articles on qualitative and quantitative empirical research, topical reviews of end-of-life and associated care (or palliative care), and supplementary articles highlighted by experts in end-of-life research. The literature source is mostly limited to Western countries, that are the USA, Canada, Europe, and Australia/New Zealand, and the overview has been complemented with national statistics when appropriate. With the specific context of end-of-life, the overview comprises demographic and social trends, patterns of illness and associated functional decline, use of health care services, places of death, prevalent symptoms and problems, and the clinical identification of the dying process and associated reorientation of care.

## **Demographic and social trends**

The Swedish population has long been aging. The proportion aged 65 or more has increased from 10% in 1950 to 17% in 2003, and is expected to reach 23% by the year 2050. Between 2004 and 2050, male life expectancy is projected to increase by 5.5 years, from 78.1 to 83.6 years. For women, it is expected to increase by 3.7 years, from 82.5 to 86.2 years. These changes impart increasing demands for resources for both elderly care and traditional health care (SCB, 2003).

Women in Sweden live, on average, longer than men. Among those eighty years or older, women outnumber men by a factor of 1.8. Moreover, many women marry men older than themselves such that elderly women have a high risk of becoming widowed, and in contrast to men, a majority of women thus live alone at the end of life and approach death without a partner. Among those aged 80 or more, 78% of women live in single households compared to only 38% of men (Socialstyrelsen, 2005b; SCB, 2005). Of the 2,563,925 persons registered as living in single households in Sweden during 2003, 465,598 (18%) were aged 75 or more, and of 799,190 identified as cohabitants, 186,452 (23%) belonged to this age group (SCB, 2005). In a study by Tomassini, Glaser, Wolf, Broese van Groenou and Grundy (2005), trends in living arrangements among the elderly were compared among several European countries and the USA, and the proportions of elderly living alone were found to be most prevalent in North western Europe (as exemplified by Sweden and the Netherlands) and least prevalent in southern Europe (as exemplified by Portugal and Italy) and the USA. In this context, it is noteworthy that many who live alone at the end of life are placed in a particularly difficult situation with respect to sources of informal help from children, relatives and friends (Emanuel et al., 1999; Johnson, Gallagher, & Wolinsky, 2004; Visser et al., 2004; Wachterman & Sommers, 2006).

Living alone also implies less access to more extended home care (Fainsinger, Demoissac, Cole, Mead-Wood, & Lee, 2000; Grande, Addington-Hall, & Todd, 1998; Grande, McKerral, Addington-Hall, & Todd, 2003), and thus also increases the likelihood and necessity for institutionalized living at end-of-life (Fainsinger et al., 2000; Jordhøy, et al., 2003; Mustard, Finlayson, Derksen, & Berthelot, 1999; Wachterman & Sommers, 2006).

Sweden has a considerably higher proportion of elderly people living in different types of residential care facilities than both other European countries and the United States (Tomassini et al., 2005). This is consistent with the well known risk that advancing age increases the likelihood of permanent residence in an assisted living facility (Fainsinger et al., 2000; Jordhøy et al., 2003; Mustard et al., 1999; Wang, Mitchell, Smith, Cumming, & Leeder, 2001).

### **Patterns of illness and associated functional decline**

The demographic changes undergone by most Western countries involve a shift in causes of death, from infectious diseases to degenerative conditions (Seale, 2000). Of all deaths in Sweden in 2003, the three most common were related to circulatory diseases (44%), neoplasms (24%), and respiratory diseases (seven percent) (Socialstyrelsen, 2005a). The once familiar and seemingly clear boundaries between being ill and dying have been obscured. Dying can more appropriately be identified as a general condition of old age and gradual deterioration, than as a specific disease-related condition (Lynn et al., 1997; Sloane et al., 2003), and these considerations have implications for individuals' needs at the end of life. Wilson (2002), for example, found that the duration and degree of dependency during the last six months of life increased among both hospitalized and home care clients, and that 74% of these patients experienced progressive dependency prior to death. Clearly, the dying course varied, but dependency was a common pathway for most.

The literature reveals three typical courses of illness which often precede death. One is characterized by a short period of obvious decline prior to death, and is typified by the course of patients with certain neoplasm (Lunney, Lynn, & Hogan, 2002; Lunney, Lynn, Foley, Lipson, & Guralnik, 2005; Lynn, 2001; Teno, Weitzen, Fennell, & Mor, 2001). Other studies have demonstrated that persons dying from neoplasms typically have four or more functional impairments just prior to death (McCarthy, Philips, Zhong, Drews, & Lynn, 2000), and that the need for self-care assistance is highly prevalent among these individuals (Addington-Hall & Karlsen, 1999).

A second course of illness is characterized by long-term disability with periodic exacerbations and an unpredictable time of death, and is exemplified by the course of those suffering from chronic organ system failures such as chronic heart failure and chronic obstructive lung disease (Lunney et al., 2002; Lunney et al., 2005; Lynn, 2001; Teno et al., 2001). One study compared the course of illness between persons who died from neoplasms and those who died from non-malignant diseases, and revealed that persons with non-malignant diseases were much more likely to need assistance for one year or more prior to death. Similarly, this group was also much more likely to have lived in a residential care facility at some period during the year preceding death (Addington-Hall & Karlsen, 1999).

A third course of illness is characterized by deficits in self-care and a gradually failing course towards death, and is usually the result of dementia or age-related frailty (Covinsky, Eng, Lui, Sands, & Yaffe, 2003; Lunney et al., 2002; Lunney et al., 2005; Lynn, 2001). The ability to care for oneself, such as dressing, feeding, waste elimination and personal hygiene, has also been shown to gradually decline with advancing age and during the last year of life (Cartwright, 1993). One study reported that, on average, persons aged 80 or more had 2.4 impairments in activities of daily living prior to death (Somogyi-Zalud, Zhong, Lynn, & Hamel, 2000). Another study compared dependency for activities of daily living among persons with and without cognitive impairments during the three months before death, and those with such impairment(s) were much more likely to be fully dependent even two years before death (Covinsky et al., 2003).

### **Use of health care services and places of death**

Studies of healthy populations have demonstrated that a majority of people prefer to both receive care and die in their private home (e.g. Di Mola & Crisci, 2001; Gott, Seymour, Bellamy, Clark, & Ahmedzai, 2004; Hays, Galanos, Palmer, McQuoid, & Flint, 2001; Wilson, 2000), whereas similar studies among seriously ill persons reveal a more nuanced picture. Thus, seriously ill persons not only express concern over the burden and imposition of care onto others, but also question the ability to receive the same high quality of care in the private home as that expected from hospital-based care (e.g. Fried, van Doorn, O'Leary, Tinetti, & Drickhamer, 1999; Steinhauser et al., 2000; Werkander & Andershed, 2004).

Although health care systems differ among Western countries in many respects, such as health expenditures and available health sector resources (Organisation for Economic Co-operation and Development [OECD], 2006), the physical locale for end-of-life care and death are generally the same: acute care hospitals, residential care facilities, hospices, and private homes. Since life expectancy is rising in Western countries, and since increasingly accompanied by progressive incurable illnesses, there is also a shared expectation of a growing need for community- and home-based care for both chronic diseases and end-of-life needs (Zallman, Sanches, Choi, & Selwin, 2003). With these projections in mind, private home care has received increased attention from both practitioners and researchers in end-of-life care.

Because of its primary role in diagnostic and therapeutic interventions, concern has increasingly been raised that the hospital setting is not perceived as a place devoted to end-of-life care (Taylor, 2004). Moreover, empirical studies have revealed that hospital admissions at end-of-life, especially among frail and elderly individuals, impart not only a risk of distress syndromes such as pressure sores, incontinence and fall injuries (Mecocci et al., 2005) but also a risk of being the subject of medical errors (Staff Myers & Lynn, 2001).

Similarly, the appropriateness of end-of-life care provided at residential care facilities has also been questioned because of a disproportionate focus on rehabilitative and physical needs rather than issues related to death and dying, including a relative lack of competence among staff to manage such end-of-life issues (Cartwright & Kayser-Jones, 2003; Costello, 2001; Katz, Komaromy, & Sidell, 1999; Kayser-Jones et al., 2003; Komaromy, Sidell, & Katz, 2000; Sloane et al., 2003).

The design of a comprehensive health care delivery system, capable of providing comprehensive care at end-of-life, is a frequently debated topic (Murray & Jennings, 2005). Those who remain seriously ill for a long time prior to death, and who typically require many different care settings, pose a particular challenge to the design of any public health care system (Lynn, 2005). Current patterns of resource use for end-of-life care have been demonstrated in a few international studies. Thus, Bird, Shugarman and Lynn (2002) have shown that, during the last year of life, more than 80% of persons studied received inpatient hospital care, and more than 90% received hospital-based outpatient care. Depending on age, care at residential care facilities was provided to between 23 and 53% of the study group, and more than 80% used the services of general practitioners. Home care services were used by more than 40% overall, and by more than 30% of individuals aged 85 or more. And, again depending on age, hospice services were used by between 12 and 19% percent of the study group.

Mukamel, Bajorska and Temkin-Greener (2002) have further shown that, among frail elderly persons, utilization patterns begin to change at approximately six months before death, and that there is a dramatic change during the last month of life when use of hospital-based services increase by almost 250%, while the use of residential care facilities, general practitioner services, and home care increase by 28, 50, and 45%, respectively.

The place and setting of death are important determinants of the quality of life at end-of-life (Tang, 2003), and are also closely associated with next-of-kins' level of satisfaction with care during this period (Vohra, Brazil, Hanna, & Abelson, 2004). Other studies have shown that the place of death varies widely. In samples reflecting persons diagnosed with cancer, the reported proportion of deaths in the home ranged between 16 and 35%, whereas deaths at residential care facilities ranged between eight and 20%. Deaths in hospices and hospitals ranged between 11 and 20% and between 43 and 74%, respectively (Bruera, Sweeney, Russel, Willey, & Lynn Palmer, 2003; Burge, Lawson, & Johnston, 2003a; Gallo, Baker, & Bradley, 2001; Higginson, Jarman, Astin, & Dolan, 1999; Hunt, Fazekas, Luke, & Roder, 2001). Other studies of individuals representing broader populations have similarly reported home deaths to range between 20 and 33%, whereas deaths at residential care facilities and hospitals occurred for between 16 and 20%, and between 50 and 67% of the study groups, respectively (Ahmad & O'Mahony, 2005; Cohen et al., 2006; Mc Namara & Rosenwax, 2006; Solloway, La France, Bakitas, & Gerken, 2005; Weitzen, Teno, Fennell, & Mor, 2003).

### **Symptom and problems**

At end-of-life there are many other concurrent and important determinants of quality of life (Stewart, Teno, Patrick, & Lynn, 1999). For example, studies have shown that functional and cognitive capacity, dependency related to end-of-life suffering, and physical and psychological distress are each of major importance to the dignity perceived at end-of-life (Chochinov et al., 2002; Chochinov, Hack, Hassard, Kristjanson, & Harlos, 2002; Franklin et al., 2006). Qualitative studies of symptom of distress experienced among people living with severe chronic diseases have demonstrated their significant and intrusive effect on not only the individual's everyday life (e.g. Charmaz, 1993; Ekman, Ehnfors, & Norberg, 2000) but also the strength and courage to live while dying from progressive disease(s) (Öhlén, 2000). This emphasizes the importance of both prevention and provision of adequate relief from distress caused by physical and emotional problems. Disturbingly, it has also been documented that the presence of such problems are more often the rule than the exception at end-of-life.

For example, among patients referred to hospice programs, between 27 and 33 different types of such problems were observed at the end of life (Hermann & Looney, 2001; Kutner, Kassner, & Nowels, 2001). Similarly, Nordgren and Sörensen (2003) observed 21 different types of such problems among patients with end-stage heart failure. Conversely, in a sample of patients with a mixture of conditions, Klinkenberg, Willems, van der Wal, and Deeg (2004) found that only nine percent of individuals were free of such symptoms of distress during their last week of life.

A condition of overall deterioration has been described as a common pathway for many persons at end-of-life, and this deterioration causes an increase in the individual's dependency upon others. Lynn et al. (1997) reported that 85% of a sample of older hospitalized patients was extremely ill or disabled during their last three days of life. Similarly, Georges, Onwuteaka-Philipsen, van der Heide, van der Wal and van der Maas (2005) reported that, among a group of patients diagnosed with cancer and short life expectancies, 82% were severely dependent upon others for daily activities, and 29% perceived this dependency to be a severe problem. In a study of patients with severe heart failure, Nordgren and Sörensen (2003) similarly described 49% to be physically limited during the last six months of life. Still other studies also report a significant association between physical deterioration, with a resulting decrease in performance status, and the prevalence of clinical problems (Jordhøy et al., 2001; Mecandante, Casuccio, & Fulfarò, 2000).

A large proportion of individuals at residential care facilities also suffer from not only physical symptoms such as weakness, fatigue, pain and dyspnea (Cartwright, Hickman, Perrin, & Tilden, 2006; Hall, Schroeder, & Weaver, 2002; Parker & De Bellis, 1999; Porock, Oliver, Zweig, Rantz, & Petroski, 2003; Reynolds, Henderson, Schulman, & Hanson, 2002) but also emotional symptoms such as depression and anxiety (Parker & De Bellis, 1999; Reynolds et al., 2002). Still other concerns, such as impaired skin integrity and urinary incontinence, have also been shown to be very prevalent (Mitchell, Morris, Park, & Fries, 2004; Porock et al., 2003; Reynolds et al., 2002). Thus, Hall et al. (2002) found that 53% of the residents studied suffered from at least three symptoms, whereas only eight percent were symptom-free. At these facilities, these problems are also often accompanied by both functional and cognitive impairments (Reynolds et al., 2002).

### **Identification of the dying process and reorientation of care**

In the context of end-of-life care, it is proposed that clinicians should adopt an approach which emphasizes palliation, and thus mandate the early identification, prevention and alleviation of suffering as integral parts of normal and good care

(e.g. Zimmermann & Rodin, 2004). For the clinician, this requires recognition that, while life may continue for a relatively long time, the person is sufficiently ill that death may be imminent (Lynn, 2000). Concern has, however, been raised whether, and if so when, such identification is appropriate, or even desirable, since palliation when applied in its broadest sense can be difficult to mobilize at a time that is very close to actual death (Ellershaw, 2002; Ellershaw & Ward, 2003; Freisinger & Butler, 2000; Lamont, 2005; Plonk & Arnold, 2005). A Swedish Government report (SOU 2001:6) introduces the term *turning point* to identify the clinical recognition of dying and, consequently, a reorientation of the care to be provided. Further, a distinction is made between an early and late phase of this specific and reoriented care mode, each dependent on the timing of the turning point. The early phase is temporally indistinct and simply described as *long*, and the late phase is said to comprise days, weeks or a month. A few studies have subsequently confirmed that, in practice, such turning points are typically identified late, with a delay, or even unexpectedly, even for persons for whom the probability of imminent death is considered high. These considerations impart obvious consequences for the persons' treatment and adjustment to end-of-life care.

Presently, the transition to palliative care is frequently slow and either interrupted by aggressive acute care interventions or delayed until the last few days of the individual's life (Happ et al., 2002; Somogyi-Salud et al., 2000; Travis, Loving, McClanahan, & Bernard, 2001). In part, empirical studies have demonstrated that the identification of dying is difficult since persons typically not only suffer from multiple, concurrent and complex conditions but also experience fluctuating courses of illness (Christakis & Lamont, 2000; Covinsky et al., 2003; Freeborne, Lynn, & Desbiens, 2000; Frick, Uehlinger, & Zuercher Zenklusen, 2003; Lynn, 2000). The identification of dying thus requires an element of tacit knowledge and intuition, and the literature suggests that health performance status together with clinical symptoms and signs are all important clues in this determination (Ellershaw & Ward, 2003; Lamont, 2005; Lynn, 2000). To this end, empirical studies have verified that deterioration of condition, progressive loss of performance, and an increased dependency upon others represent strong signals of impending death (Aune, Herlitz, & Bång, 2005; Chuang, Hu, Chiu, & Chen, 2004; Dendaas, 2002; Llobera et al., 2003; Porock et al., 2005; Vigano et al. 2004). Still other more specific symptoms and signs have also been described as predictors of impending death, including dyspnoea, weight loss, poor appetite, oedema and impaired cognitive function (Vigano et al., 2004; Chuang et al., 2004; Porock et al., 2005).

## **RATIONALE FOR THE STUDY**

It is a principal rationale for this study to delineate characteristics of the population who access the health care system during its last three months of life, and to increase the understanding of both actual and potential problems for this population during this timeframe. Kim (2000b) has proposed that knowledge of certain essential characteristics and experiences during specific situations as aging and end-of-life will significantly contribute to and increase the understanding of the human person. Such essential variables, including age, gender, presence of children, living arrangements and residential status are thus included in this study. From an end-of-life perspective, this information is particularly significant since this knowledge provides the context within which the patient and family seek health care services (Stewart et al., 1999). Further according to Kim (2000b), an understanding of problems that are present in human beings as pathological, or as abnormal deviations from “normal patterns” of healthy living, should be emphasized because they often require some kind of intervention. Thus, although each has an inherent potential to be problematic at the end of life, additional variables such as physical function, cognitive function, presence of chronic diseases, symptoms, and other problems, have also been included in the study. Moreover, this additional information will help to define and identify populations with specific needs, an essential effort in a pursuit to improve care at end-of-life (Lorentz et al., 2004).

A second rationale is to review the patterns of health care resources used during the last three months of life. It is primarily at times and situations of crisis that people become patients and access the health care system, that is when ill, when restricted in the ability to live a normal life, and when in need of specific care (Kollak, 1999). According to Kim (2000b), the health care environment sought has special meaning, both in an empirical and symbolic sense, and a health care environment is always characterized as one that is different from the patient’s ordinary environment, even when care is provided in the patient’s regular home. Moreover, the new or different features of various care environments affect not only the patient, but also the means by which care is provided. In this thesis, the health care environments accessed are of special interest since the environment for end-of-life care must be considered with special reference to this unique time of life.

Thus, Stewart et al. (1999) note that the physical location during the process of dying, including the location of actual death, can strongly affect patients' and families' well-being at end-of-life. It also follows that transfers among different locations of care can be strongly disruptive for both patients and families, and hence strongly and adversely affect well-being during this time.

A third rationale for this study is the illumination of the critical time point, here termed the turning point, at which there is recognition and identification of dying and a reorientation of the everyday care provided. An extensive review has concluded that many concepts of "end-of-life" are in actual use, and none has thus far undergone empirical validation of its potentially defining characteristics (Lorentz et al., 2004). As argued by Kim (2002b), there is a general need to both examine and develop consistent ideas about the complex nature of phenomenon in everyday clinical practice. Nevertheless, it is assumed that end-of-life care emphasizing palliation should gradually begin at the time of diagnosis of an incurable and life-threatening disease, and thereafter broaden its scope toward the illness' final phase, and thus not be confined to any specific type or level of care (Corner & Dunlop, 1997; Field & Addington-Hall, 2000; Zimmermann & Rodin, 2004). As noted by Lorentz et al., (2004), however, if some aspect of clinical care is to turn on such normative definitions, some empirical description and uniformity of the definition is in order.

## **Aims**

The overall aim of this study is to attain comprehensive knowledge about individuals in a Swedish County, who access the health care system during their last three months of life, and thus to make a contribution to a broader understanding of the nature of end-of-life, and end-of-life care for these individuals. Specific objectives include:

- The identification and description of individuals' demographic and social conditions, and places of death (I).
- An exploration of health care resources used by individuals during their last three months of life, and where this care is provided; and an examination of the relationships between health care services used and subjects' characteristics, such as demographics, social conditions, physical and cognitive functions, and prevalent chronic diseases (II).
- A determination of the prevalence of specific clinical problems during the last three months of life, and an examination of their relationship to age as well as physical and cognitive function (III).
- An identification of whether a documented turning point reflecting identification of dying and reorientation of care occurred before actual death; an exploration of the relationships between the turning point as well as the time interval between such point and actual death, and selected demographics, presence of chronic diseases, changes in health performance status and symptoms and signs; and a calculation of the distribution functions of the time interval between the turning point and actual death (IV).

# **METHODS**

## **Design and epistemological considerations**

An epistemological rationale for this study is to determine the frequencies and possible relationships among various factors of interest in a well defined population that is individuals who access the health care system during the last three months of life. This is consistent with the assertion of Kim (2000b) who underscores that such comprehensive knowledge, in the sphere of nursing science, represents one piece of holistic understanding of a patient's situation at end-of-life in a context of health care. This knowledge thus provides a foundation for describing patterns, regularities and tendencies that can be used to frame problems, situations and experiences that, in turn, provide a fuller understanding of the patients. With this rationale, a descriptive and correlational study was designed and undertaken through retrospective examinations of death certificates, medical records and nursing records. The purpose of such a design is to examine the relationships among variables in a situation of short duration. Descriptive and correlational studies are intended to generate rather than test hypotheses, and can be either retrospective or prospective. As in any correlational study, however, a truly representative sample must be selected (Burns & Grove, 2003).

Research and designs focused on end-of-life care have been criticized for typically reporting findings only from specific health care settings or using only samples of persons dying from a specific disease, particularly cancer, thus not permitting generalization beyond a single care setting or specific disease (Carrow, Abernethy, & Fazekas, 2004; George, 2002). Many studies are also biased as a result of poor sampling strategies, (George, 2002). Further criticism of bias also point out that study subjects have been pre-selected from among those already referred to hospices or other programs of specialized palliative care (Grande et al., 1998). A significant part of this criticism is also applicable to Swedish research approaches to this field. For this study, a design was chosen to guard against these aforementioned notions, and thus represents an additional epistemological rationale: (1) a random sample strategy was chosen in order to guarantee external validity, and to permit generalization to the County of Västra Götaland; (2) a broad population context was created, including adults aged 18 or greater who accessed the health care system during the last three months of life; the sample was therefore explicitly not limited to individuals with specific characteristics in terms of age, gender, chronic diseases and similar; (3) the review encompassed the entire continuum of care received during the last three months of life in order to obtain a comprehensive understanding of the person's situation beyond specific health care settings.

## **Inclusion and exclusion criteria**

Criteria for subject inclusion were:

- Died in the County of Västra Götaland during 2001
- Age 18 or greater at time of death
- Used health care services adjusted to the (Swedish) Health and Medical Service Act (Svensk författningssamling [SFS], 1982: 763) during the last three months of life (encompass health care managed by the County Council, and by the Local Governments)

Criteria for subject exclusion were:

- Unexpected death such as sudden death, accidental death and suicide
- Lack of use of health-care services causally related to death
- Lack of access to medical or nursing records

## **Sampling design**

Information about population and death incidence was obtained from publicly available sources. The County of Västra Götaland consists of 49 municipalities and, during 2001, its population was 1,500,857 (755,912 females and 744,945 males). The number of deaths was 15,869, including 8,136 females and 7,733 males (SCB, 2004).

In planning the study, it was assumed that estimations of probabilities and the corresponding 95% confidence intervals (CI) would be the most important results. The sample size of the study was, therefore, determined such that the expected length of a 95% CI of a probability should not exceed 18% for important subgroups (such as gender) of the material. A sample size of 157 persons was thus required (Cochran, 1977).

The sample was initially selected in two steps: first, primary sampling units were chosen with probability proportional to size (PPS), that is proportional to the number of deaths in 10 municipalities in the County of Västra Götaland (municipalities 1-10, Table 1); second, persons within these municipalities were randomly selected proportional to the number of deaths based on the following equation: smallest sample size (157) × deaths in the selected municipality during 2001 (e.g. 4,888 in municipality no. two) / deaths in all selected municipalities (9,144) = smallest number of persons selected in any of the actual municipalities (e.g. at least 84 in municipality no. two) (Cochran, 1977; Dahmström, 2000).

In an effort to assure sufficient representation from the initial sample design, and to guard against an under representative sampling of the County as a whole, a decision was made to include an additional two municipalities (municipality 11 and 12, Table 1). A simple random sample, using the same principles employed for the initial sample, was obtained from the two additional municipalities. As a result, one fourth of the County's 49 municipalities were selected, and the sample is therefore representative of the entire population of the County of Västra Götaland, Sweden.

Two hundred eighty persons were selected in the primary sample. Eighteen were excluded according to study criteria, having died from sudden death, accidents or suicide, or having lacked use of health care services that were causally related to death. Eight were excluded because no health care services were rendered during the last three months of life. Twenty-five persons were excluded because medical or nursing records were inaccessible due to inadequate administrative routines. The final study sample consisted of 229 persons (Table 1).

Table 1: Sampling scheme

Municipalities	Primary sample	Unexpected death	No health-care service adjusted to the Health and Medical Service Act used	Medical or nursing record inaccessible	Study sample
Municipality 1	32	2		9	21
Municipality 2	141	7	5	13	116
Municipality 3	12				12
Municipality 4	3		1		2
Municipality 5	14	3			11
Municipality 6	7	1			6
Municipality 7	5	1			4
Municipality 8	15	1		1	13
Municipality 9	7	1		1	5
Municipality 10	12	1		1	10
Municipality 11	7		2		5
Municipality 12	25	1			24
Total	280	18	8	25	229

## **Procedure**

### **Development of an assessment tool**

As a first step, an assessment tool was developed in order to provide a framework for use as a basis for data selection. The frameworks developed by Donaldson and Field (1998) and Stewart et al. (1999) guided the items chosen for selection from the material, and identify and specify a range of patient- and care-related concepts deemed adequate at the end of life. The assessment tool was developed according to the following process, modified after Schaeffer, Mendelhall and Ott (1996) and Polit and Hungler (1999).

1. Related constructs were clustered together as a basis for separate modules or areas of questioning.
2. Concrete questions were developed for each module with due consideration to the possibility that the nature of the data sources may be limited in precision or scope of content. Some questions were constructed to be closed-ended, and some open-ended. In each module, the tool also included space for qualitative descriptions, that is direct citations from the patients' records.
3. In order to guard against threat(s) to the internal validity (Polit & Beck, 2004), the assessment tool was tested for inter-rater reliability in two different municipalities using 20 and 10 medical and nursing records, respectively. Results from these pre-tests led to revisions, improvements, and re-testing of items until an inter-rater agreement reliability of greater than 85-95% was achieved for the extraction and coding of information onto the developed tool.
4. The assessment tool was also critically evaluated by a panel of experts, consisting of Swedish researchers in the field of end-of-life care, and for the purpose of ensuring both face and content validity. This kind of face validity test is recommended for research in general (Polit & Beck, 2004), and for palliative research in particular (Field, Clark, Corner, & Davis, 2001).

## **Data collection**

Death certificates for each person selected into the study were subsequently obtained from the (Swedish) National Board of Health and Welfare. The place and cause of death, as well as information about the last health care facility used, were surveyed from these certificates. Persons who died from accidents or suicide were excluded at this point.

Information about the persons selected was then requested with respect to pre-death use of health care services, including services operated by either local authorities or the County Council. On the basis of this information, eight persons were excluded according to study criteria due to lack of use of any resource. The data collection for all subjects was then initiated at the site of filing of medical and nursing records. Additional uses of health care facilities were identified in these records, thus permitting an examination and survey of the whole continuum of care during the individual's last three months of life.

Twenty-five persons were excluded during this examination due to missing medical or nursing records. Similarly, persons who suffered sudden deaths were identified and excluded in this process.

A two-phase coding scheme for collected data, data coding and data entry, was developed in accordance with Polit and Hungler (1999), and the data were cleaned of wild-codes and inconsistencies.

## **Variables employed in the study**

### Demographics:

- Age
- Gender

### Social conditions:

- Living arrangements: recorded in study I as lived with partner, children or parents; lived apart from partner; or had no partner and lived alone (never married, divorced or widowed). Recorded in studies II, III and IV as cohabited or lived alone
- Type of residence: private home or residential care facility (defined as a special accommodation such as a home for the elderly, a service apartment, or a nursing home established by local authorities and intended for people with special service and care needs according to The (Swedish) Social Service Law, (SFS 1980: 620)
- Presence of children
- Next-of-kin reported: children, partner, siblings, friends, relatives, nieces and nephews, parents, grandchildren, or none

### Physical and cognitive function:

- Physical function at three months prior to death: functionally independent (ADL-independent) or dependent for activities of daily living, such as dressing, walking, bathing, waste elimination and nutrition (ADL-dependent)
- Cognitive function at three months prior to death: oriented to time, location and person, or permanently disoriented in at least one sphere

### Recorded indications of changes in health performance status:

- Sporadic confinement to bed
- Sporadic need for assistance with self-care, such as personal hygiene, dressing, eating, lavatory visits, and similar
- Sporadic decrease in level of consciousness

Presence of chronic disease(s) at three months prior to death as classified by The International Classification of Diseases and Related Health Problems, ICD 10 (WHO, 2003):

- Circulatory disease(s)
- Neoplasm(s)
- Mental disorder(s)
- Endocrine and metabolic disease(s)
- Respiratory disease(s)
- Musculoskeletal disease(s)

Utilization of health care services during last three months of life:

- Hospital-based inpatient care
- Number of hospital admissions during the last three months of life
- Hospital-based outpatient care
- General practitioner services
- Care in private homes
- Care in residential care facilities
- Number of the aforementioned health care services used

Places of death:

- Acute care hospital
- Residential care facility
- Private home
- Hospice or other place

Clinical problems subjectively experienced or observed by health care professionals during the last three months of life:

- Pain
- Loss of vitality: fatigue, deterioration of condition
- Respiratory problems: breathlessness, pulmonary rattles, cough
- Waste elimination: urinary incontinence, nausea or vomiting, constipation, diarrhoea
- Problems of nutrition: eating disturbances, weight loss, swallowing disturbances
- Skin problems: peripheral oedema, impaired skin integrity
- Disturbances of mood, behaviour and rhythm: anxiety, depression, sleep disturbances

Turning point reflecting identification of dying and reorientation of care:

- Presence of record entries of a turning point, reflecting identification of dying and reorientation of care, that is a change in emphasis from curative, life-extending treatment and rehabilitation, to palliation
- Time interval (days) between the turning point and actual death

## Statistical analyses

### Paper I

In addition to descriptive statistics, estimation of parameters was performed with variance, standard error of the mean (SE), and 95% confidence interval (CI). T-tests were used to compare mean scores of age between genders at time of death, and to compare mean scores of age between those who resided in private homes versus residential care facilities prior to death. One-way ANOVA was used to test the significance of differences in the mean scores of age and living arrangements, age at time of death, and places of death. Tukey's *post hoc* test was further used to ascertain where differences in mean scores occurred. Chi-squared tests for independence were used to explore the relationships between each of gender and living arrangements, gender and children, living arrangements and residence, gender and places of death, living arrangements and places of death, residence and places of death, children and places of death, and reported next-of-kin and places of death.

### Paper II

Descriptive statistics, including frequencies and proportions, were used to describe the use of health care services. In order to calculate the probability of use of certain types of services on the basis of subject characteristics, several analyses were employed. First, relationships between subject characteristics and the use of health care services were explored using Fisher's permutation test (Good, 2001). All significant ( $p \leq 0.05$ ) variables were then entered into five multi-variable models using logistic regression. Finally, the probability of use of each individual health care service was calculated using the derived beta values. In order to estimate the expected number of hospital admissions and the number of all health care services used during the last three months of life according to subject characteristics, additional analyses were employed. These were first tested with Pitman's permutation test. Pitman's test is a non-parametric test not based on ranks, and consists of Fisher's permutation test and Fisher's exact test as special cases (Good, 2001).

Through the use of logistic regression analyses, the expected number of hospital admissions during the last three months was determined based on age and other variables. The expected number of all health care services used was estimated with the same method.

### **Paper III**

Fisher's permutation test and Fisher's exact test (Good, 2001) were used to compare persons with and without clinical problems through correlations with age, physical function and cognitive function. All p-values were two-sided and  $p < 0.05$  was considered to be significant. For percentages, 95% confidence intervals were calculated exactly. In cases where a clinical problem was found to be significantly correlated to more than one variable, multivariable logistic regression analysis was used to assess the relative importance of each variable.

### **Paper IV**

Pitman's test for correlation was first used (Good, 2001) to explore relationships between the presence of a turning point among the sample's subjects and (a) demographics, (b) presence of chronic diseases, (c) changes in health performance status, and (d) symptoms and signs. In this multi-variable context, logistic regression analysis was then used to identify the relative importance of these variables with respect to the identification of a turning point. The probabilities of such identification were then calculated using the resulting beta coefficients. In order to similarly investigate the relationship of the time interval between the turning point and actual death and (a) demographics, (b) presence of chronic diseases, (c) changes in health performance status, and (d) clinical symptoms and signs, Pitman's test for correlation was again first used. Each of median, mean and standard deviation were then calculated for some groups. Distribution functions of this time interval between the turning point and actual death were also calculated.

## **Ethical considerations**

This study underwent customary examination by, and received approval from the Ethics Committee of the Medical Faculty of Gothenburg University, Gothenburg, Sweden (Ö 633-02). Dying persons represent a vulnerable group to study, implying that the decedents' medical and nursing records are very valuable sources of information. The principal ethical concern of this study was the inherent lack of available consent from the individuals studied. The information obtained from records referenced in this study has therefore been treated with utmost respect for the decedents' integrity during both the analytical and the publishing phase. No single person or municipality can be identified from the material, and the questions asked in the assessment tool were adopted with due respect given to the integrity of both decedents and their families.

It is fully recognized that decedents' families and next-of-kin may experience untoward reactions or have misgivings over both the accession and publication of their respective decedent's health care records. While this issue could have been eliminated through consent from family members, these concerns should also be judged against the scientific advantages and value of the manner chosen. After due consideration, a decision was therefore made to not seek consent from the decedents' families because (1) the special circumstance of a bereaved family or next-of-kin (e.g. grief, guilt and so forth) may have increased the risk of missing data, and thus the risk for systematic bias in the sample; and (2) the procedure would have been both very expensive and time-consuming, limiting the scope or even the possibility to undertake the study. Because issues surrounding death, dying, and attendant care are of great interest to health care professionals and the public alike, the advantages of this study as undertaken were judged to exceed the ethical risks and concerns.

# RESULTS

## Sample characteristics

A majority of individuals who accessed the health-care system during the last three months of life died at an advanced age, and the age distribution ranged from 18 and 99 years. The mean age at time of death was 80 years and the median age 83 years. At time of death, approximately one fourth of the study group were aged 75 and below, half were between the age of 76 and 88, and one fourth were aged 89 and above. The relative frequency distribution of age at time of death is shown in Figure 1.

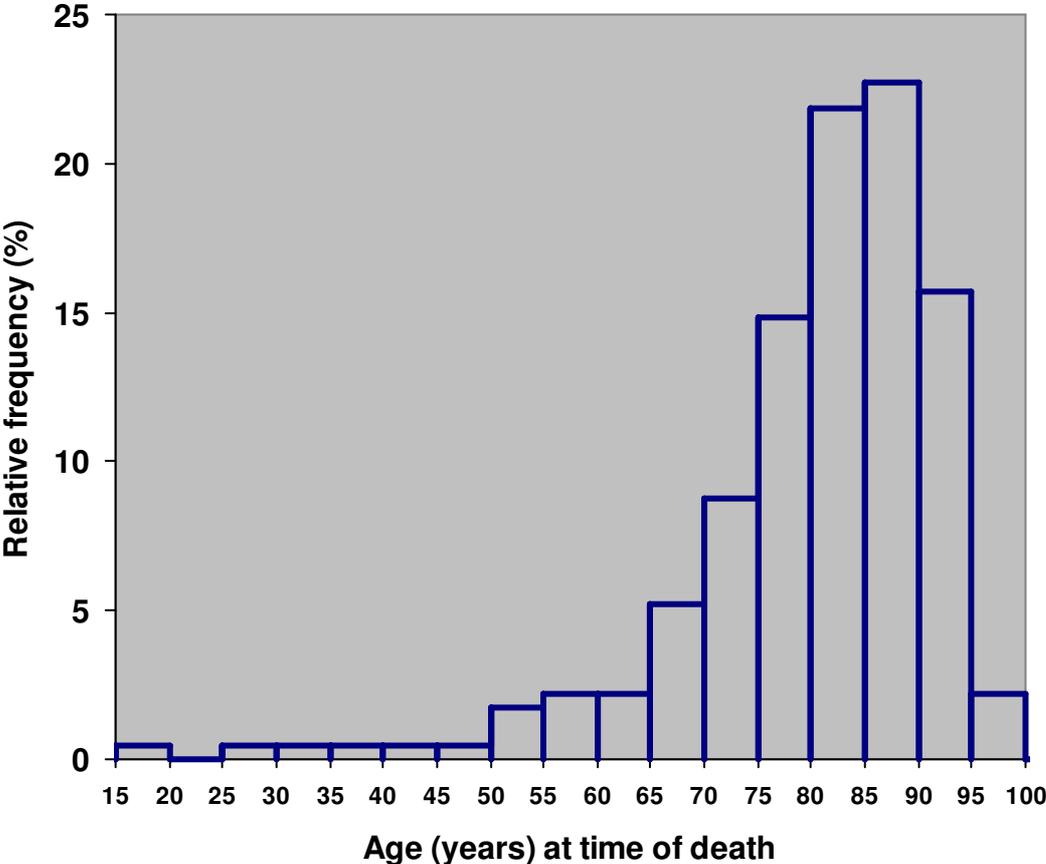


Figure 1: Relative frequency distribution of age at time of death (n = 229)

Approximately 73% of the study group lived alone at time of death, and 27% cohabited with at least one other individual. One-half were residents of private homes at time of death, and the other half lived in residential care facilities. A majority of the study group had children. Next-of-kin, as identified in medical and nursing records, represented not only relatives or members of the individual’s more immediate family, but a small number identified friend(s) or neighbours(s).

At baseline, that is three months prior to death, 52% of the individuals studied were reported to be ADL-independent, and 48% ADL-dependent. Whereas 69% were described as fully oriented, 31% were disoriented to at least one of time, place, and person. As shown in Table 2, almost half were both ADL-independent and fully oriented, and one fourth were both ADL-dependent and disoriented to at least one of time, place and person. Residents of private homes were significantly ( $p<0.001$ ) more likely to be ADL-independent, and significantly ( $p<0.001$ ) more likely to be fully oriented than individuals living in residential care facilities. Specifically, 82% of residents in private homes ( $n=115$ ) were ADL-independent and 86% were fully oriented, whereas among those living at residential care facilities ( $n=114$ ), the corresponding figures were 23% and 53%, respectively.

**Table 2: Relationship between physical function and cognitive function (n=229)**

	ADL-independent (n=120) (% of total)	ADL-dependent (n=109) (% of total)
Fully oriented (n=159)	108 (47)	51 (22)
Disoriented to at least one of time, place, and person (n=70)	12 (5)	58 (25)

The most commonly reported chronic diseases were circulatory diseases (66%), followed by neoplasms (36%), mental disorders (28%), endocrine and metabolic diseases (27%), respiratory diseases (15%), and musculoskeletal diseases (15%). Other chronic diseases were reported including diseases of the digestive system (seven percent), diseases of the genitourinary system (seven percent), diseases of the blood (five percent), diseases of the nervous system (four percent), diseases of the skin (four percent) and diseases of the eye (three percent).

Although 32% of individuals suffered from only one chronic disease, the presence of more than one was common. Relative frequencies of total number of chronic diseases are shown in Figure 2. Thus, an additional 37% of the individuals suffered from two diseases, and the remainder from still more.

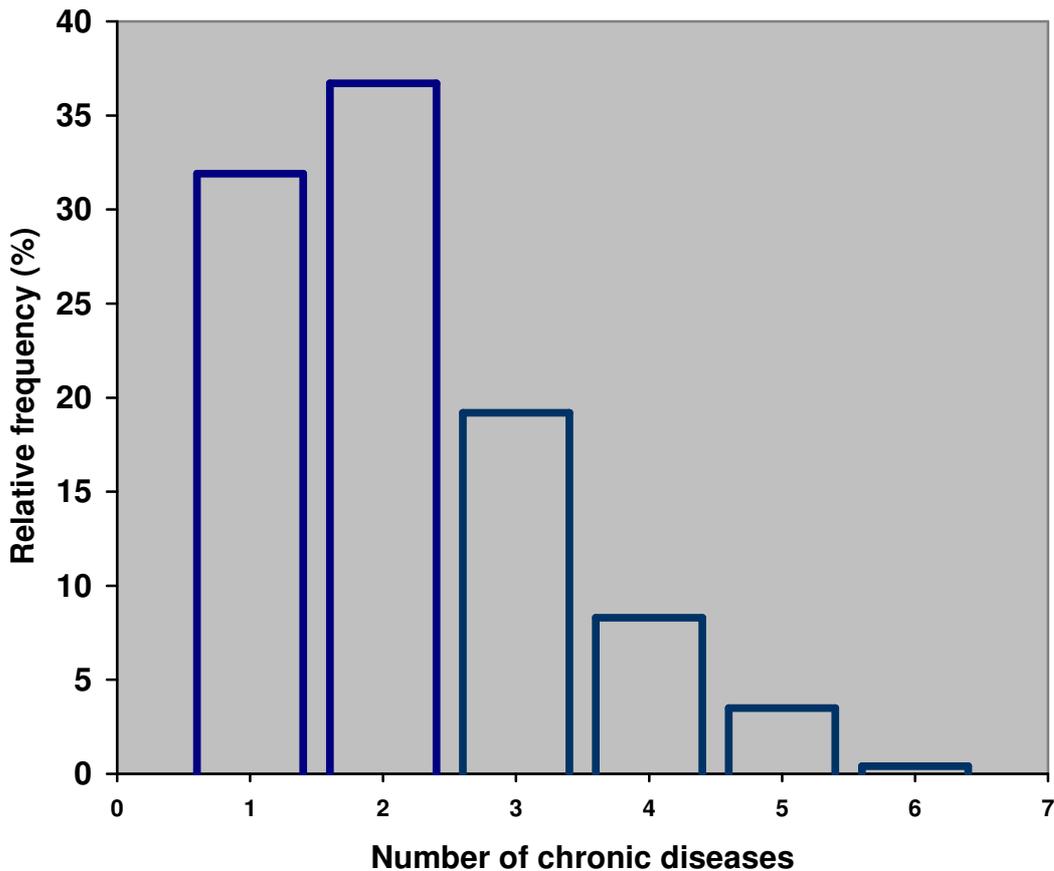


Figure 2: Total number of chronic diseases (n=229)

## Summary of paper I

Significant differences were found between men and women in this study. First, there were significant differences in mean age at time of death ( $p=0.009$ ). On average, men were 78 years and women were 82 years old at time of death. Second, men were significantly ( $p<0.001$ ) more likely than to live apart from their partner, whereas women were more likely to live alone. Among men ( $n=124$ ), 31% cohabited with a partner, 21% had a partner but lived apart, and 48% had no partner and lived alone. Among women ( $n=105$ ), 22% co-habited with a partner, 6% had a partner but lived apart, and 72% had no partner and lived alone.

At time of death, individuals living together with a partner ( $n=62$ ) were nearly 71 years old, those with a partner but living apart ( $n=32$ ) were almost 77 years old and those living alone without a partner ( $n=135$ ) were nearly 80 years old. There was thus a significant ( $p<0.001$ ) difference of nine years between persons living alone and those living with a partner.

Similarly, individuals living in residential care facilities were nearly 10 years older than those residing in private homes ( $p < 0.001$ ), and residents of private homes were significantly ( $p < 0.001$ ) more likely than those living in residential care facilities to be cohabitants, whereas the latter group was more likely to live alone or apart from a partner.

The most common place of death was acute care hospitals, representing 47% of deaths. The next most common were residential care facilities at 42%, followed by private homes at nine percent, and hospices and other places at two percent (Figure 3).

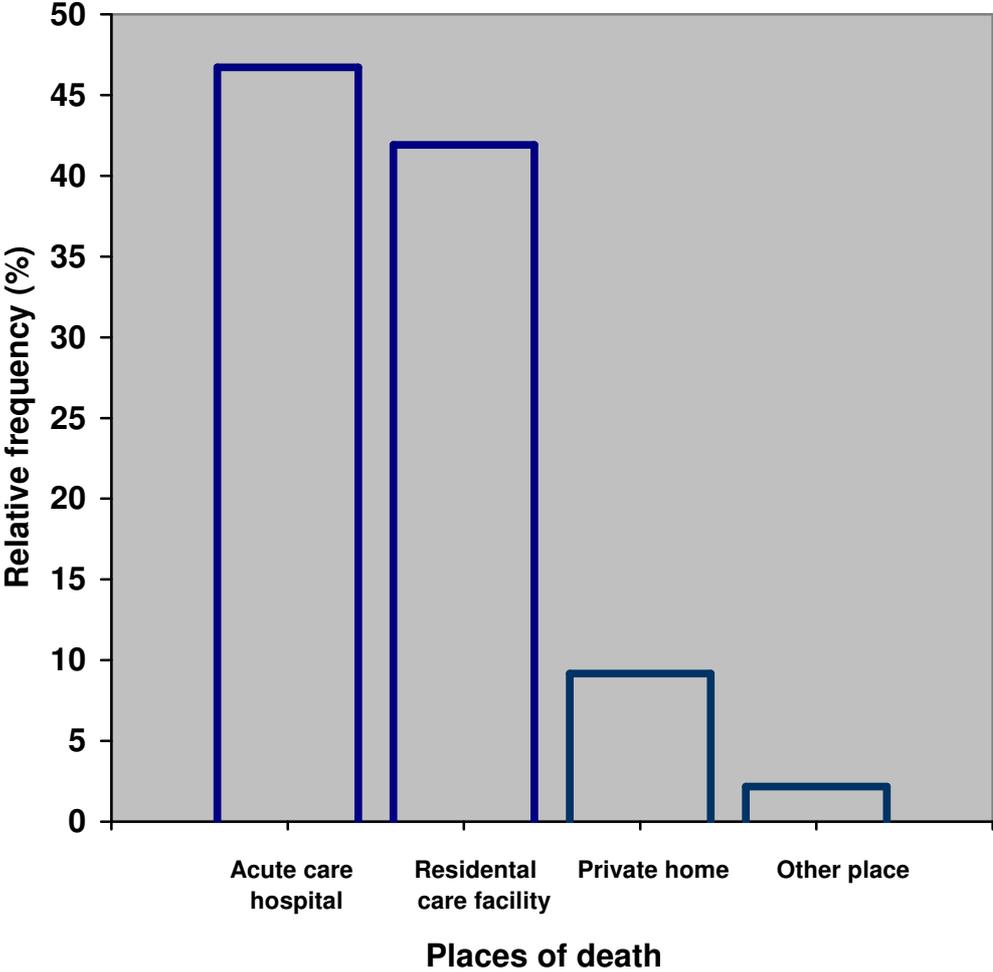


Figure 3: Places of death (n=229)

There were significant ( $p < 0.001$ ) differences in mean age at time of death between individuals who died at acute care hospitals and at residential care facilities. Thus, the mean age among those who died at acute care hospitals was 76 years as compared to 84 ½ years among those who died at residential care facilities. A majority of those living alone at time of death died at residential care facilities followed by acute care hospitals, whereas those who cohabited most commonly died at acute care hospitals followed in frequency by private homes (Table 3).

**Table 3: Relationship between places of death and living arrangements (n=224)**

	Lived alone (n=165) (%)	Cohabited (n=59) (%)
Acute care hospitals (n=107)	65 (39)	42 (71)
Residential care facilities (n=96)	90 (55)	6 (10)
Private homes (n=21)	10 (6)	11 (19)

## Summary of paper II

Hospital care was used by 79%, primary care by 59%, and community care by 72% of the individuals studied. Furthermore, 71% of the study group used between two and three different health care facilities during the last three months of life. Inpatient hospital care was used by almost two thirds of the individuals. Among these individuals the utilization of one clinical department was most common, and departments of internal medicine were used more than twice as often as departments of surgery, followed in order by departments of geriatrics, intensive care and oncology. Use of hospital-based outpatient care (including emergency room visits) was almost as common as inpatient care. Forty-two percent of individuals used both inpatient and outpatient care, whereas 21% did not use any hospital-based services (Table 4).

Table 4: Use of health-care services during last three months of life (n=229)

Variables	Frequency (%)
Hospital-based inpatient care	144 (63)
Number of hospital admissions	
None	85 (37)
One	59 (26)
Two	51 (22)
Three	23 (10)
Four	7 (3)
Five	1 (0.4)
Six	3 (1)
Hospital-based outpatient care including emergency room visits	134 (59)
Utilization of both hospital-based inpatient and outpatient care	97 (42)
General practitioner services	136 (59)
Care at residential care facilities	123 (54)
Care in private homes	67 (29)
Utilization of both care at residential care facilities and care in private homes	25 (11)
Care in hospices and by private care providers	5 (2)
Total number of all health care services used <sup>a</sup>	
One	22 (10)
Two	91 (40)
Three	71 (31)
Four	31 (14)
Five	14 (6)

<sup>a</sup> includes hospital-based inpatient care, hospital-based outpatient care, general practitioner services, care at residential care facilities and care in private homes

There were significant relationships between the use of hospital-based inpatient care and both residence ( $p=0.023$ ) and the presence of mental disorder(s) ( $p=0.023$ ), represented mainly by dementia. Thus, the probability of using hospital-based inpatient care was 82% for residents of private homes and 63% for those who additionally suffered from mental disorder(s). The probability was 57% for those living in residential care facilities, and 32% if also suffering from mental disorder(s).

For the whole study group, the mean number of hospital admissions during the last three months of life was 1.23. This number, however, varied according to age, residence and whether mental disorder(s) were present. The expected number of hospital admissions was substantially greater by a factor of approximately 2.5 among residents of private homes as compared to individuals in residential care facilities who also suffered from mental disorder(s).

Similar significant relationships were also found between the use of hospital-based outpatient care, and both living arrangements ( $p=0.027$ ) and the presence of mental disorder(s) ( $p=0.022$ ). Thus, the probability of using hospital-based outpatient care was 59% for people who lived alone and 36% if also suffering from mental disorders. For cohabitants, the probability was 81%, and 62% if additionally suffering from mental disorder(s).

Fifty-nine percent of the study group used general practitioner (GP) services (41% in combination with either hospital-based inpatient or outpatient care and 18% independently of a hospital). Significant ( $p<0.001$ ) relationships were found between the use of GP services and residence. Thus, the probability of utilization of GP services for persons residing in private homes was 41%, whereas the probability for those living in residential care facilities was 77%.

Seventy-two percent of the study group used care in the home that is in a residential care facility or in a private home. Use of care at residential care facilities was significantly associated with age ( $p<0.001$ ), living arrangements ( $p<0.001$ ) and physical function ( $p<0.001$ ). Thus, the probability of using care at residential care facilities for persons who lived alone, were ADL-dependent, and aged 60, 70, 80 and 90 were 54%, 78%, 91% and 97%, respectively. The corresponding probabilities for ADL-independent cohabitants were 0.5%, 2%, 5%, and 13%, respectively.

Use of care in private homes was significantly associated with the presence of neoplasm(s) ( $p=0.002$ ), musculoskeletal disease(s) ( $p=0.011$ ), and mental disorders(s) ( $p=0.009$ ). The overall probability of using care in private homes was 23%. For the associated subgroups, the probability was 44% for those suffering from neoplasm(s), 45% for those with musculoskeletal disease(s), and nine percent for those diagnosed with mental disorder(s).

The mean number of combined health care services used (i.e. inpatient care, outpatient care, general practitioner services, care at residential care facilities and care in private homes) was 2.67 with a range of 2.00-3.50.

### **Summary of paper III**

A wide range of symptoms and problems was identified in the medical and nursing records. During the last three months of life, these were in the aggregate highly prevalent within the categories of pain, loss of vitality, respiratory problem(s), waste elimination problem(s), problem(s) of nutrition, skin problem(s), and disturbance(s) in mood, behaviour and rhythm. As examples, pain was documented in approximately 84% of the records, fatigue in 76%, deterioration of condition in 68%, and breathlessness in 61%. Similarly, anxiety and depression was documented in 57 and 25% of the records, respectively.

No significant associations was noted between age and clinical symptoms and problems with the exception of cough ( $p=0.042$ ). Thus, the mean age of individuals with cough was lower than individuals lacking this symptom.

Significant relationships were found between physical and cognitive function, and the presence of symptoms and problems. Physical deterioration ( $p=0.013$ ), urinary incontinence ( $p<0.001$ ), constipation ( $p=0.004$ ), impaired skin integrity ( $p=0.002$ ), anxiety ( $p=0.004$ ), and sleep disturbances ( $p=0.003$ ) were all significantly more common among persons with ADL-dependency than among ADL-independent individuals. Similarly, pulmonary rattles ( $p=0.022$ ) and swallowing disturbances ( $p=0.006$ ) were significantly more common among individuals who were disoriented to at least one of time, place and person.

### **Summary of paper IV**

Among the 229 persons included in the study, a turning point reflecting identification of dying and reorientation of care was documented in 70% ( $n=160$ ) of their respective medical and or nursing records. The presence of circulatory diseases ( $p=0.045$ ), sporadic confinement to bed ( $p<0.001$ ), and deterioration of condition ( $p<0.001$ ) each appears to have an independent and significant impact upon the incidence of a turning point. Thus, whereas the overall probability of a documented turning point was 44%, it was 80% among persons reported to be sporadically confined to bed, 76% among persons with presence of a deteriorating condition and 27% among persons with cardiovascular disorders.

For the 160 persons for whom the health care records document a turning point, the time interval between this point and actual death ranged between one and 210 days. Of these turning points, 30% were documented during the last day of life, 33% during the last two to seven days, 19.5% during the last eight to 30 days, 13% during the last 31-90 days, and 4.5% during the last 91-210 days of life. Moreover, the probability of a documented early turning point was

significantly ( $p < 0.001$ ) higher among persons diagnosed with a neoplasm. Conversely, the presence of musculoskeletal disease(s) significantly ( $p = 0.006$ ) increased the probability of a late turning point.

# DISCUSSION

## Discussion of findings

Paper I reveals that the majority of individuals who died during 2001 and who accessed the health care system during last three months of life in the County of Västra Götaland, were aged 80 and higher. This is comparable with findings of another study showing that Sweden has the highest proportion of elderly among the populations of Europe and the USA (Tomassini et al., 2005).

Significant differences were found between men and women with men, on average, having died four years younger than women. Whereas men were overall significantly more likely to live apart from their partners, women were significantly more likely to live alone at time of death. This is consistent with findings of an extensive review, which concludes that differences in longevity in Western countries not only means that women outnumber men but also that women are more likely to experience widowhood, and to face death and dying without a partner beside them (Seale, 2000). Among those living in a residential care facility, however, men are significantly more likely to *live apart* from their partners. Whereas this study does not address the subjective experiences of individuals in this situation, it does call attention to other studies demonstrating that admission to a residential care facility including the “separation” from an often lifelong partner may not only be very traumatic, but may also be associated with coercion, and a constant cause of anxiety for both partners both before, during and after the separation (Davies, Sandberg, & Lundh, 2000; Lundh, Sandberg, & Nolan, 2000; Ryan & Scullion, 2000; Seymour & Hanson, 2002).

One half of the individuals in this study resided in private homes, and the other half lived in residential care facilities at time of death. The latter group was nearly 10 years older than those residing in private homes. It is a well known fact that advancing age increases the likelihood of permanent living in a residential care facility (Fainsinger et al., 2000; Mustard et al., 1999; Wang et al., 2001). While the institutionalization of the elderly has actually decreased during the last decade, Sweden nevertheless has a considerably higher proportion of elderly living in different types of residential care facilities when compared to other European countries and the United States (Tomassini et al., 2005). However, the patterns found in this study are consistent with other international studies (e.g. Cohen-Mansfield, Marx, Lipson, & Werner, 1999; Parker & De Bellis, 1999; Porock et al., 2003; Wallace & Prewst, 2006), and indicate that residential care facilities have become some of the most significant ambient environments of both life and care at end-of-life.

The findings indicate that acute care hospitals and residential care facilities are the most prevalent places of death. Less old individuals in the study group died significantly more often at acute care hospitals, whereas the oldest persons more often died at residential care facilities. This is consistent with findings reported by Socialstyrelsen (2005c) indicating that, between 1997 and 2003, a majority of Swedish residents aged 65 or more died outside hospitals, and this was especially common for those aged 80 or more. Similarly, in an example from one Swedish municipality (Osby), the proportion of deaths at residential care facilities has increased from one-third to one-half during the same time period. Conversely, and as shown in this study, places of death other than acute care hospitals and residential care facilities are uncommon, if not rare. Thus, deaths in private homes were uncommon, representing approximately nine percent of the group, and deaths in hospices were even less frequent at less than two percent. Thus, while the place of death is highly institutionalized with 91% of the group having died in a hospital, hospice or residential care facility, the place of death also reflects continuity for most individuals since 51% died in the same location as their last residence (a private home or a residential care facility). The latter finding contradicts stereotypical views about frail residents of residential care facilities as dying in ambulances or emergency rooms.

International studies have shown that places of death vary widely across the world, and that comparisons among studies are difficult due to both different design and sampling strategies, and different health care systems. Nevertheless, the trend observed in this study is comparable to that of other studies indicating that the vast majority of people still die at acute care hospitals (Ahmad & Mahony, 2005; Cohen et al., 2006; Mc Namara & Rosenwax, 2006; Solloway et al., 2005; Teno et al., 2004; Weitzen et al., 2003). Conversely, the reasons for the low prevalence of home deaths observed in this study are likely many, including an inability for home care programs to match the end-of-life support possible or necessary at a hospital, as well as the inability of such programs to provide the necessary support for an extended period of time (Grande et al., 1998; Grande, Farquhar, Barclay, & Todd, 2004).

Paper II reveal the use of health care services near end-of-life to be both considerable and extensive, and confirms the same high utilization rate reported in other studies (e.g. Barbera, Paszat, & Chartier, 2006; Bird et al., 2002; Kurtz, Kurtz, Given, & Given, 2005; Mukamel et al., 2002). Importantly, this also calls attention to the significance attached to an assignment of end-of-life care in everyday practice.

In the aggregate, a majority of the individuals in this study made use of hospital-based care. This pattern has also been reported in some other studies, demonstrating that the utilization of hospital-based care is substantial at the end

of life (Kurtz et al., 2005; Mukamel et al., 2002; Solloway et al., 2005). It has also been shown in this and other studies that end-of-life care has become a precipitant of referrals to hospital-based care. This phenomenon is true across all medical specialties, and has thus become an increasingly important role for acute care hospitals (Gott, Ahmedzai, & Wood, 2001; Moritze, Nguyen, Lorente, & Desfosses, 1999; Tardy et al., 2002). Indeed, the probability of using hospital-based inpatient care during last three months of life, including the expected number of hospital admissions, was in this study significantly higher among residents of private homes than among those living in residential care facilities. However, the probability of use of any kind of hospital-based care, and of nursing care in private homes, was significantly lower for persons afflicted with mental disorder(s), mainly dementia. This latter finding is contrary to other studies which suggest that persons suffering from advanced dementia are at risk for extensive use of hospital-based care (Albert et al., 1999; Lamberg, Person, Kiely, & Mitchell, 2005; Ramroth, Specht-Leible, Konig, & Brenner, 2006). Hence, acute care provided to these often frail persons at hospitals may, in fact, not represent the ultimate care received during this period. Instead, and consistent with the opinion of others, the findings for this group of individuals may simply reflect a good care policy with respect to the use of hospital-based inpatient care and the associated number of hospitalizations (Mecocci et al., 2005; Staff Myers & Lynn, 2001).

Fifty-nine percent of the individuals in this study used general practitioner (GP) services during their last three months of life, and the probability of using this service was shown to be nearly four times higher for those living at residential care facilities than for residents of private homes. This confirms the findings of other studies which emphasize the role of the general practitioner in the provision of care for this most dependent group of society that is individuals with high levels of disabilities (Goodlin, Jette, Lynn, & Watson, 1998; Kavanagh & Knapp, 1998). With respect to residents of private homes, the continuity of care provided by GPs has previously been shown to be associated with less aggressive treatments at end-of-life, reduced emergency room visits, and fewer in-hospital deaths (Burge, Lawson, & Johnston, 2003b; Burge, Lawson, Johnston, & Cummings, 2003; Hanson, Earp, Garrett, Menon, & Danis, 1999; Leff, Kaffenberger, & Remsburg, 2000;). In contrast to these earlier studies, however, the present study reveals that GP services typically overlap hospital-based care, and were provided without additional hospital-based care to only 18% of the study group.

Taken together, care in private homes and residential care facilities was found to be very common in this study, emphasizing the important role for nurses, social workers, and allied health professionals in the provision of end-of-life care in individuals' homes where a majority of time left is spent (Payne, Seymour, &

Ingleton, 2004). Advancing age, ADL-dependency, and living alone increased the probability of using care at residential care facilities, whereas the presence of neoplasm(s) and musculoskeletal disease(s) increased the probability of using care in private homes. Among those living in residential care facilities, only one-fourth were ADL-independent, and only one-half were fully oriented. Similar to findings of other studies (Covinsky et al., 2003; Lunney et al., 2002; Lunney et al., 2005; Lynn, 2001), this implies that the end of life situation for these residents can be characterized as one accompanied by deficits in self-care, and a decreased ability to look after oneself during daily activities. In this study residential care facilities represent a range of different settings, and life in such facilities both imposes and offers a spectrum of human experiences prior to death. These settings may thus impart a significant change in control, often restricting the persons' abilities and methods to handle important decisions about their own lives. For some, it may represent a form of coercion and discomfort whereas others might deem this to be a setting of safety and greater choice. With these potential contradictions in mind, previous studies have identified several critical issues for improvement at residential care facilities, including better definitions of the needs of the elderly, a more open dialogue about death and dying (Costello, 2001; Katz et al., 1999; Komaromy et al., 2000), and greater competence among staff in the management of symptoms and other concerns when impending death requires more intense monitoring and care (Cartwright & Kayser-Jones, 2003; Erzek, Kraybill, & Hansberry, 1999; Rice, Coleman, Fish, Levy, & Kutner, 2004).

Care in private homes was used by 29% of the individuals in this study, and findings indicate that nursing care in private homes was mainly "disease related", perhaps implying that home care is limited to an exclusive groups of persons. Home care finds its justification from two principal foci: 1) a benefit to the patient, based on the assumption that care in the home increases quality of life; and 2) a desire of society to minimize in-hospital care (Thomé, Dykes, & Hallberg, 2003). In line with these assumptions, the findings of this study identify a need to expand the availability of home care to other groups of patients, especially at the end of life. Complementary care models, such as home-based palliative care programs, have not only been shown to yield increased satisfaction and an increase in end-of-life care in the private home, but also a decrease in both hospital deaths and the need for hospital-based care (Barbera et al., 2006; Brumley, Enguidanos, & Cherin, 2003; Fassbender et al., 2005; Higginson et al., 2003; Hughes et al., 2000; Mörch, Timpka, & Granéus, 1999; Stuart, D'Onofrio, Boatman, & Feigelman, 2003).

The types of services delivered in these programs vary widely, and there is a tendency of reporting mainly positive outcomes from their use (Higginson et al., 2003). Some studies, however, have critically evaluated the effects of different

kinds of palliative home care programs. Thus, Milberg and Strang (2000) have identified a need for improvements in a specific palliative home care program in Sweden, recognizing a need for more regular physician visits, greater staff continuity, and a longer period of respite for family and bereavement visits. Other studies have also identified a need for better family support by professional caregivers, including an extension of their competence beyond that of basic care related tasks (Grande et al., 2004; Wennman-Larsen & Tishelman, 2002).

The mean number of health care services and settings used (among inpatient care, outpatient care, general practitioner services, care at residential care facilities, and care in private homes) was in this study found to be 2.67 with a range of 2.00-3.50. Noteworthy is that one of the highest expected numbers (3.47) was found among those both lived in residential care facilities and suffered from endocrine and metabolic disease(s), mainly diabetes. Individuals suffering from diabetes have not received much attention within the context of palliative care, even though it is well known that diabetes substantially increases utilization of health care resources, principally because of the burden of associated co-morbidities (e.g. Fahlman, Lynn, Doberman, Gabel, & Finch, 2006; Natarajan & Nietert, 2004; Struijs, Baan, Schellevis, Westert, & van den Bos, 2006). Finally, the expected total number of health care services used during the last three months of life was higher among those living in residential care facilities than among residents of private homes. Other studies (e.g. Bird et al., 2002; Mukamel et al., 2002) have made similar observations, and this finding may signal a need to re-define the focus of end-of-life care at these facilities. Representing a core element of good end-of-life care, our findings thus reflect a need for good continuity both within and across health care settings (Ferrell, 2005; National Consensus Project for Quality Palliative Care, 2004).

In paper III, a wide range of symptoms and problems were identified and shown to be highly prevalent during the last three months of life, and many were especially prevalent among ADL-dependent individuals. Several problems, such as weakness/fatigue and nutritional problems often mediated by reduced appetite or anorexia, may be inevitable parts of the dying process (Silveira, Kabeto, & Langa, 2005) since well-documented as highly prevalent at end-of-life across many sample characteristics and designs. Other problems, such as pain, dyspnea, constipation, depression, anxiety and sleeping disturbances are all considered to be both preventable and treatable (Silveira et al., 2005). Despite their differences, many disease states manifest similar symptoms and problems at end-of-life (WHO, 2004). Hence, even though the many differences in study design, sample selections, and instruments used make comparisons among studies difficult, the findings in this study are congruent with many others in demonstrating that a range of distressing and readily identifiable problems

constitute a common pathway for many individuals at end-of-life (e.g. Hickman, Tilden, & Tolle, 2001; Kutner, Kassner, & Nowels, 2001; Nordgren & Sörensen, 2003; Parker & De Bellis, 1999; Strömngren et al., 2002; Tramner et al., 2003). Thus, taken together, this and many other studies reflect and report a range of unmet needs at the end of life.

Nearly one half of the study group was ADL-dependent, 31% were disoriented to at least one of time, place, and person, and 26% met both of these criteria. There were also significant relationships between physical and cognitive function, and the presence of specific clinical problems during the last three months of life. Thus, overall clinical deterioration, urinary incontinence, constipation, impaired skin integrity, anxiety and sleep disturbances were significantly more common among people who were ADL-dependent. Similarly, pulmonary rattles and swallowing disturbances were significantly more common among persons disoriented in at least one sphere. In the aggregate, the relationships among the clinical variables studied characterizes these individuals' situations at end-of-life to be ones of frailty, vulnerability, and a high degree of dependency upon the health care system, confirming the findings of other studies (e.g. Cartwright, 1993; Levenson, McCarthy, Lynn, Davis, & Phillips, 2000; Somogyi-Salud et al., 2000). Moreover, while many persons in this frail population endure and suffer from highly complex problems, it is also well known that the care received is not always proportional to the actual needs (e.g. Parker & McLeod, 2002; Travis et al., 2001).

In paper IV, the documentation of a turning point, reflecting recognition of dying and reorientation of care, was identified in slightly less than three-quarters of medical or nursing records. The presence of cardiovascular disorder(s) decreased the probability of finding a documented turning point, whereas confinement to bed and the presence of a deteriorating condition increased this probability. These findings, together with findings from others, suggest that a general physical deterioration, rather than specific disease related factors, represents the best clinical prognostic criterion for impending death (Aune et al., 2005; Chuang et al., 2004; Dendaas, 2002; Llobera et al., 2003; Porock et al., 2005; Vigano et al. 2004). Thus, the probability of finding a documented turning point for individuals with cardiovascular disease(s) was as low as 27%. These findings are consistent with, and enhance previous reports indicating that life expectancy is difficult to estimate among persons with cardiovascular diseases. Indeed, since death is less predictable for this group, actual death may often seem sudden and unexpected for the individual patient (Addington-Hall & Higginson, 2001; Freisinger & Butler, 2000; Goldstein & Lynn, 2006; Kirkpatrick & Kim, 2006; Skilbeck & Payne, 2005). These findings also call attention to studies demonstrating that, among persons with cardiovascular disorders, very few have discussed end-of-life issues and

preferences with their physician(s) even though a majority indicate a desire to partake in decisions about such issues (Edmonds, Karlsen, Khan, & Addington-Hall, 2001; Laakkonen, Pitkala, Strandberg, Berglind, & Tilvis, 2005; Murray et al., 2002).

Two thirds of the turning points were documented within the last week of life. The probability of an “early” documented turning point was higher among those diagnosed with neoplasm(s), whereas the probability of a “late” turning point was higher for individuals suffering from musculoskeletal diseases. The former finding underscores the common stereotype that the course of illness for persons with neoplasm(s) represents a “model of dying”. This “model” has, in turn, given rise not only to the hospice entity (Goldstein & Lynn, 2006), but also to an understanding that, in contrast to other conditions, neoplasms cause a predictable course of dying during the last few months of life (Lunney et al., 2002; Lunney et al., 2005; Lynn, 2001; Teno et al., 2001). The end-of-life course for the individuals who suffer from musculoskeletal diseases may thus be perceived as the opposite of the course of neoplasms, that is a chronic and “nonfatal” illness. Nevertheless, some empirical data has demonstrated that musculoskeletal disorders not only place a great burden on the individual, but also are also associated with a quality of life that is fully comparable to that of many other chronic conditions, including neoplastic disorders (Salaffi, De Angelis, Stancati, , Grassi, 2005).

Overall results from this study also indicate that the documentation of a turning point, when present, was generally quite late in the study group as a whole, albeit with a range of one to 210 days. Thus, for nearly one third of the individuals, the turning point was not documented until the last day of life, and for another nearly two thirds, the turning point was only identified during the last week. Moreover, the probability of finding a documented turning point earlier than thirty days before death was as low as 17%. These, as well as findings of others, indicate that in clinical practice, the identification of the dying process appears to typically be late, delayed, or even unexpected, even for individuals for whom the probability of near-term death is unequivocally high. The consequences of such a late turning point may include unnecessarily aggressive or even inappropriate treatments (Happ et al., 2002; Somogyi-Salud et al., 2000; Travis. et al., 2001). As a further consequence, the demarcation between care directed at cure and rehabilitation, and care aimed at relief of suffering, becomes unclear. The lack of an identified turning point, or its delay until very close to death, may thus also mean that individuals die with unnecessary pain and distress due to invasive and ineffective therapies rather than in comfort, based on care modalities that emphasize palliation (Higginson, 2005; Seymour & Ingleton, 2004).

## **Strengths' and limitations**

The retrospective design of this study uniformly identified and included fatally ill persons, thus eliminating data loss due to the dying individual's poor condition. Such data loss is typically a significant problem with use of prospective end-of-life studies, often resulting in the introduction of bias into sampling designs (George, 2002; Klinkenberg et al., 2004).

It was neither the nature nor primary aim of this study to encourage evaluative analyses, for instance to measure good end-of-life care or to measure quality of life at the end of life. Instead, this study was primarily designed to ascertain and describe the conditions for a population accessing the health care system during its last three months of life, and to do so through a determination of the prevalence of certain variables and their possible statistical relationships. Frequencies and associations therefore merely represent indices, which highlight the importance and call attention to the phenomenon in question. As a result, this study will generate new hypotheses rather than test existing ones, and may also pave the way for more rigorous and better controlled study designs (Polit & Beck, 2004).

The findings of any study must be interpreted in the context of the inherent strengths and limitations of the data sources used. In this study, data was derived from retrospective reviews of death certificates, medical records and nursing records. Although data from such health care records is noted to have already been collected and recorded for another purpose (Polit & Beck, 2004; Övretveit, 1998) the advantages of its use for research purposes are several, including (1) time and cost savings; (2) an ability to examine trends over time; (3) a minimization of respondent bias; (4) a lack of reliance upon respondents' participation; and (5) the routine nature of care providers entries into health care records (Polit & Beck, 2004). Moreover, all documented care was delivered in accordance with the Swedish Health and Medical Service Act. The data sources used in this study therefore include documentation by physicians, nurses, and others engaged in the care of the selected persons, and represent many and different health care services and settings. In their entirety, these multiple data sources thus contribute to form a comprehensive view and understanding of the status and situation for each member of the group studied.

Conversely, whereas these data sources reflect the study group's experiences at end-of-life, many important outcomes of end-of-life care are not captured, including the patients' and families' subjective evaluation of their situation. Hence, findings in this study provide information which may affect subjective experiences and evaluations, and which can be further examined through other approaches.

It is also well known that documentation in health care records may lack detailed descriptions of, for example, symptoms experienced and functional status (Bogardus, Towle, Williams, Desal, & Inouye, 2001; Idvall & Ehrenberg, 2002). Such detail was also sparse or even absent in the records reviewed in this study. Consequently, a decision was made to only identify the presence or absence of symptoms, and to do so as a single time point measurement. A closely related concern is the degree to which the documented content corresponds to the individuals' actual reports and experiences, especially since some studies have found such levels of concordance to be low or poor. Thus, problems have typically been shown to be more prevalent in patients' self-reports than in physicians' and nurses' documentation (e.g. Bogardus et al., 2001; Ekman and Ehrenberg, 2002). If so, the prevalence of symptoms and problems found in this study may merely be "the top of the iceberg".

The relationships identified among variables in this study are merely those between two or more research variables examined in a specific situation, in this case among individuals who accessed the health care system during their last three months of life (Burns & Grove, 2003). Thus, while the study identifies several significant relationships among the variables studied, and because many variables is only measured at a single point in time during a three month period, temporal relationships cannot be determined. Similarly, where relationships and associations are found, there is no implication of a causal relationship. Nevertheless, knowledge of variables' frequent coexistence provides a framework for a better understanding of experiences at end-of-life, and constitutes a rationale for further research.

According to Polit and Beck (2004), selection bias is the most common threat to the validity of any study, specifically bias due to a non-random selection of subjects. In this study, individuals were randomly selected through the PPS sampling method previously described, thus assuring its external validity. The sample is representative of the population who accesses the health-care system during last three months of life in the County of Västra Götaland and the findings may therefore not be *statistically* generalized to other parts of Sweden. More important than statistical generalization, however, is the concept of applicability that is the validity of findings in other parts of Sweden, or other countries. Since health care structures as well as demographic, social, and morbidity patterns are similar, the observations from this study may thus be applicable elsewhere, and be useful as a basis for both national and international comparisons. As mentioned previously, there are many shared challenges to end-of-life care across Western countries. Increasingly, people in these countries are dying from progressive chronic illnesses at an advanced age, and the patterns of needs may consequently be similar in these countries as well (Higginson,

2005; ten Have & Clark, 2002). However, whereas findings from this study confirm those of others with respect to both patterns and relationships in Western countries, there is a notable difference in the extent to which palliative services have been developed both within and across European countries, including Sweden. Thus, the internationally recognized “Swedish hospital-based home care model”, which has its origin and dominant practice in the (Swedish) County of Östergötland (Clark, ten Have, & Janssens, 2002), is not practiced in the County of Västra Götaland from which this study derives its data.

## IMPLICATIONS

The home often represents an individual’s point of familiarity and comfort. The findings of this study shed empirical light on the nature and patterns of many of the characteristics of persons living in private homes as well as those living in residential care facilities. With the assumptions that end-of-life care needs are increasing, and since it is assumed that the private home care setting is preferred by both individuals and society, the present high reliance on hospital-based care should be reversed. Moreover, the scope of private home care must be broadened to also encompass support and services to assist informal caregivers. As suggested by Kellehear (1999), this support may include ways to promote a sense of control over everyday life issues, information and education about death and dying, social support and assistance with the attendant interpersonal reorientation, thus facilitating the adjustment to life and lifestyle changes.

For the oldest group, this study also demonstrates a high reliance upon residential care facilities as a place of residence, care, and dying, making these facilities among the most significant contexts at the end of life. To date, end-of-life care has been criticized for lack of progressing sufficiently to transform conditions for the elderly to a meaningful degree (Hallberg, 2006; Seale, 1998). Accordingly, the goals of end-of-life care may require adjustment(s) in order to adequately meet the needs of the population living at residential care facilities, to include broader goals, the promotion of non-institutionalized living, and perhaps a different professional approach (Hallberg, 2004; Hockley & Clark, 2002; Lloyd, 2000) As Kellehear (1999) suggests, the services provided in these facilities by those professionals who work with dying individuals may also need both greater acknowledgement and enhancement. It is thus suggested that a critical audit of the frameworks for care at end-of-life represents an important issue for both policymakers and health care providers. More specifically, such reviews of services rendered at both residential care facilities and private homes should focus on alternative organizations, practice methods, and overall staff competence.

This study also underscores the often debated question of how to design a comprehensive health care delivery system that will meet the most needs, for most of the time, and for the most people at end-of-life (Murray & Jennings, 2005). Currently, end-of-life has been characterized as an indistinct zone of chronic illnesses, and as this study demonstrates, for many people this indistinct zone is not accompanied by any specific health care resource, such as a hospice. Individuals who are very ill for a prolonged time before death, and who therefore need many care settings, thus pose a challenge to the design of a public health care system (Lynn, 2005). And, indeed, this study indicates that people use an entire spectrum of health care services during their last time of life. These findings thus emphasize not only the responsibility of both policymakers and professional care providers to create coordinated and integrated models of end-of-life care, but also the need for updated evidence-based guidelines and pathways for end-of-life care both *within* and *among* different care settings.

The *nature* of end-of-life care provided by the public health care system is also an issue in need of further attention. There is widespread belief that end-of-life care should be improved through implementation of palliative approaches, and as integral parts of all public health care (e.g. Corner & Dunlop, 1997; Council of Europe, Recommendations, 2003; Field & Addington-Hall, 2000; SOU 2001:6; Zimmerman & Rodin, 2004). Findings from this study further emphasize the need for such approaches, since many both prevalent and preventable symptoms and problems were identified. For the individual care provider, this means careful attention to symptoms and signs, frequent assessments, and the use of care methods primarily aimed to relieve suffering and to promote subjective comfort and well-being during the end-of-life period. The heretofore ubiquitous treatment paradigm of the establishment of a diagnosis followed by disease-defined therapy thus requires modification for care provided to individuals at the end of life (Corner & Dunlop, 1997; Field & Addington-Hall, 2000; Skilbeck & Payne, 2005; WHO, 2004; Zimmermann & Rodin, 2004). Care services should therefore be available on the basis of needs in terms of symptoms and problems, as well as their effectiveness in meeting those needs, rather than on the basis of diagnoses (WHO, 2004). The prevalence and patterns of health concerns shown in this study, including those related to both physical and cognitive function, constitute areas for further development and refinement of palliative care. As a starting point, the findings can be used across all health care settings as a framework for more substantial discussions of these real and important issues.

In this study, the time of recognition and documentation of the critical turning point, reflecting the identification of dying and reorientation of care was, on the whole, late. This finding has important implications for both the manner and

content of care provided since palliative care, when applied in its broadest sense, can be difficult to mobilize very close to actual death (Ellershaw, 2002; Ellershaw & Ward, 2003; Freisinger & Butler, 2000; Lamont, 2005; Plonk & Arnold, 2005). It is a common perception in clinical practice that palliative care is relevant only during the last few weeks of life, when no other treatments are feasible, and that such care can only be delivered by specialized palliative care teams (WHO, 2004). Hence, both the content and timing of palliative care is a crucial question raised by the findings of this and other studies. Indeed, WHO (2004) has declared that people experience many different problems during years of illness, and need help throughout that time rather than at some easily identified point just before death. It clearly follows that a concept of palliative care that is only provided or offered at the end of life clearly not does meet the needs of many common situations. Instead, palliative care must be developed and implemented as an interventional model to be offered, together with potentially curative treatment, to meet the needs of *all* aging populations as well as those of younger people experiencing life-threatening illnesses. Put differently, palliative care should be a natural and integral part of *all* care, rather than an alternative form of care (Zimmermann & Rodin, 2000). With this frame of reference, findings from this study offer practitioners, managers and policymakers new perspectives on everyday practice.

Finally, findings from this study provide policymakers, health care providers, and professional caregivers with both a reminder and a framework which may contribute to a more mindful and comprehensive understanding of commonplace end-of-life concerns. It is, in fact, suggested that the public health care system as a whole take greater note of the present situation, including perhaps the creation of an “end-of-life movement”, and that it proactively focus on the development of standards for end-of-life care. Its content should be formulated and based on systematic and detailed insights into the identities of the individuals who utilize the health care system at the end of life, where and from whom they receive care, and most importantly, the nature of their problems and needs. Moreover, steps must be taken to continually audit end-of-life care provided by the public health care system, with an objective to constantly improve the scope, quality, and trustworthiness of its services. Once brought to the forefront of open debate, the subject of care at end-of-life raises many new as well as some previously debated questions, each of which needs to be addressed. For example, should end-of-life care in the context of public health care services primarily focus on issues of *death* and *dying*, or help individuals to *live* with life-limiting disease(s)? And does good end-of-life care reflect the implementation of a palliative approach and specialized palliative care teams, or the further development of good holistic care in general? The need for an open and society-wide discussion of these important questions is now overdue.

## **FUTURE DIRECTIONS**

The extensive research approach employed in this study may constitute grounds for more intensive research approaches of both a qualitative and quantitative nature. For example, there is a need for increased knowledge about the manner and degree to which social conditions, such as living alone, affect individuals' experiences at end-of-life. Thus, very little is known about their effect upon preferences for residence, place of care and place of death. Similarly, the living situation for men and women appears to be different in ways not already discussed. Thus, women at an advanced age typically experience end-of-life without a partner. And, as a closely related matter, the conditions arising from being separated from a partner at the end of life, and the frequently associated transfer to a residential care facility are crucial issues in need of further research, especially when undertaken involuntarily. Indeed, the support necessary before, during, and after such transitions requires considerably more definition. Still other questions ask how the experiences of death and dying among others (e.g. spouses, friends etc.) affect widowed individuals, and how such individuals manage and prepare themselves for their own eventual end. Finally, there is a more general need to explore both the nature and meaning of end-of-life, end-of-life care, palliation and palliative care among different types of everyday health care practice. Although normative views of these concepts are well documented, this may not be the case for perceptions among those professionals who provide the range of actual care in many different health care settings.

As provided by the public health care system, the development and improvement in end-of-life care is preferably implemented by action research strategies (e.g. Holter & Kim, 1995). This approach would encompass a range of systematic investigations which, in the aggregate, not only aim to contribute to the knowledgebase but also to solve practical problems.

## CONCLUSIONS

Drawn from the mainstream population of the County of Västra Götaland, Sweden, this study includes individuals who died within the health-care system during 2001, and makes a contribution to a broader understanding of the nature of end-of-life and end-of-life care. The main findings include that:

- The majority of individuals who accessed the health care system during last three months of life and died in the County of Västra Götaland during 2001 were aged 80 or more.
- Significant differences were found between men and women and, on average, men died four years younger than women. At time of death, men were significantly more likely to live apart from their partners, and women were significantly more likely to live alone.
- Residential environments differed significantly at time of death, with one-half of the group residing in private homes, and the other half living in residential care facilities. Each location had a significant association with many of the variables analyzed in this study. On average, individuals living in residential care facilities were nearly ten years older than residents of private homes.
- The most prevalent places of death were acute care hospitals and residential care facilities. Less old individuals significantly more often died at acute care hospitals, whereas the most old died significantly more often at a residential care facility.
- The probability of using hospital-based inpatient care during the last three months of life, including the expected number of hospital admissions, was significantly higher for residents of private homes than for those living in residential care facilities. The presence of mental disorder(s), mainly dementia, however, decreased the probability of using either outpatient or hospital-based inpatient care, regardless of residence.
- The probability of using general practitioner services was significantly lower for residents of private homes than for those living at residential care facilities.

- Several factors, including advanced age, ADL-dependency and living alone, increased the probability of using care at a residential care facility, whereas the presence of neoplasm(s) and musculoskeletal disease(s) increased the probability of using care in a private home.
- The mean number of total health care services used (among inpatient care, outpatient care, general practitioner services, care at a residential care facility, and care in a private home) was 2.67 with a range 2.00-3.50 depending on residence, presence of neoplasm(s), endocrine and metabolic disease(s) or mental disorder(s).
- A wide range of symptoms and problems was identified as highly prevalent during last three months of life, and many were especially common among ADL-dependent individuals.
- A documented turning point, reflecting an identification of dying and reorientation of care, was discovered in slightly less than three-quarters of medical and or nursing records. The presence of cardiovascular disorder(s) decreased the probability of an identification of a turning point, whereas confinement to bed and presence of a deteriorating condition increased the probability of such a point having been documented.
- Two thirds of turning points were documented within the last week of life. The probability of an early documented turning point was higher for persons suffering from neoplasms, whereas the probability of a late turning point was higher for individuals diagnosed with musculoskeletal disease(s).

In conclusion, the study revealed two general groupings of individuals during the last three months of life. The less old persons resided in a private home at time of death, and often but not always, lived together with a partner. These individuals were typically ADL-independent, cognitively intact and, for the most part, utilized health care at acute care hospitals and, less often, in their own home. The second group, comprising the oldest old, typically lived alone and at a residential care facility, and was more likely to be ADL-dependent and cognitively impaired. Most of this second group used health care at the residential facility, complemented by care from a general practitioner. Both groups suffered from a wide range of chronic diseases, and the prevalence of symptoms and problems was high in both groups. Reorientation of care toward palliation generally occurred late for both groups.

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## REFERENCES

- Abu-Saad, H. H. (2000). Palliative care: an international view. *Patient Education and Counselling*, 41(1), 15-22.
- Addington-Hall, J., & Higginson, I. (2001). Introduction. In J. Addington-Hall & I. Higginson (Eds.), *Palliative Care for Non-Cancer Patients* (pp. 1-9). Oxford: Oxford University Press.
- Addington-Hall, J. M., & Karlsen, S. (1999). Age is not the crucial factor in determining how the palliative care needs of people who die from cancer differ from those of people who die from other causes. *Journal of Palliative Care*, 15(4), 13-19.
- Ahmad, S., & O'Mahony, M. S. (2005). Where older people die: a retrospective population-based study. *Quarterly Journal of Medicine*, 98(12), 865-870.
- Ahmedzai, S. H., Costa, A., Blengini, C., Bosch, A., Santz-Ortis, J., Ventafridda, V., & Verhagen, S. C., on behalf of the international working group convened by the European School of Oncology. (2004). *European Journal of Cancer*, 40(15), 2192-2200.
- Albert, S. M., Costa, R., Merchant, C., Small, S., Jenders, R. A., & Stern, Y. (1999). Hospitalization and Alzheimer's disease: results from a community-based study. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences*, 54(5), M267-271.
- Aune, S., Herlitz, J., & Bång, A. (2005). Characteristics of patients who die in hospital with no attempt resuscitation. *Resuscitation*, 65(3), 291-299.
- Barbera, L., Paszat, L., & Chartier, C. (2006). Indicators of poor quality end-of-life cancer care in Ontario. *Journal of Palliative Care*, 22(1), 12-17.
- Berterö, C. District nurses' perceptions of palliative care in the home. (2002). *American Journal of Hospice and Palliative Care*, 19(6), 387-397.
- Bird, C. E., Shugarman, L. R., & Lynn, J. (2002). Age and gender differences in health-care utilization and spending for Medicare beneficiaries in their last year of life. *Journal of Palliative Medicine*, 5(5), 705-712.

- Bogardus, S. T., Towle, V., Williams, C. S., Desal, M. M., & Inouye, S. K. (2001). What does the medical record reveal about functional status? A comparison of medical records and interview data. *Journal of General Internal Medicine, 16*(11), 778-736.
- Bolmsjö, I., & Hemerén, G. (2001). Interviews with patients, family and caregivers in amyotrophic lateral sclerosis: comparing needs. *Journal of Palliative Care, 17*(4), 236-240.
- Boström, B., Hinic, H., Lundberg, D., & Fridlund, B. (2003). Pain and health-related quality of life among cancer patients in final stage of life: a comparison between two palliative care teams. *Journal of Nursing Management, 11*(3), 189-196.
- Bruera, E., Sweeney, C., Russel, N., Willey, J. S., & Lynn Palmer, J. (2003). Place of death of Houston area residents with cancer over a two-year period. *Journal of Pain and Symptom Management, 26*(1), 637-643.
- Brumley, R. D., Enguidanos, S., & Cherin, D. A. (2003). Effectiveness of a home-based palliative care program for end-of-life. *Journal of Palliative Medicine, 6*(5), 715-724.
- Burge, F., Lawson, B., Johnston, G., & Cummings, I. (2003). Primary care continuity and location of death for those with cancer. *Journal of Palliative Medicine, 6*(6), 911-918.
- Burge, F., Lawson, B., & Johnston, G. (2003b). Family physician continuity of care and emergency department use in end-of-life care. *Medical Care, 41*(8), 992-1001.
- Burge, F., Lawson, B., & Johnston, G. (2003a). Trends in the place of death in cancer patients, 1992-1997. *Canadian Medical Association Journal, 168*(3), 265-270.
- Burns, N. & Grove, S. K. (2003). *The Practice of Nursing Research. Conduct, Critique and Utilization* (4<sup>th</sup> rev. ed.). Philadelphia: Elsevier Health Sciences.
- Cartwright, A. (1993). Dying when you're old. *Age and Ageing, 22*(6), 425-430.
- Cartwright, J. C., Hickman, S., Perrin, N., & Tilden, V. (2006). Symptom experiences of residents dying in assisted living. *Journal of the American Medical Directors Association, 7*(4), 219-223.

Cartwright, J., & Kayser-Jones, J. (2003). End-of-life care in assisted living facilities. Perceptions of residents, families and staffs. *Journal of Hospice and Palliative Nursing*, 5(3), 143-151.

Charmaz, K. (1993). *Good Days bad Days. The Self in Chronic Illness and Time*. New Brunswick: Rutgers University Press.

Chochinov, H. M., Hack, T., Hassard, T., Kristjanson, L. J., McClement, S., & Harlos, M. (2002). Dignity in the terminally ill: a cross-sectional, cohort study. *The Lancet*, 360(9350), 2026-2030.

Chochinov, H. M., Hack, T., McClement, S., Kristjanson, L., & Harlos, M. (2002). Dignity in the terminally ill: a developing empirical model. *Social Science & Medicine*, 54(3), 433-443.

Christakis, N. A., & Lamont, E. B. (2000). Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. *British Medical Journal*, 320(7233), 469-473.

Chuang, R. B., Hu, W.Y., Chiu, T. Y., & Chen, C. Y. (2004). Prediction of survival in terminal cancer patients in Taiwan: constructing a prognostic scale. *Journal of Pain and Symptom Management*, 28(2), 115-122.

Clark, D., & Seymour, J. (1999). *Reflections on Palliative Care*. Milton Keynes: Open University Press.

Clark, D., ten Have, H., & Janssens, R. (2002). Palliative care service development in seven European countries. In H. ten Have & D. Clark (Eds.), *The Ethics in Palliative Care. European Perspective* (pp.34-51). Milton Keynes: Open University Press.

Cochran, W. G. (1977). *Sampling techniques* (3<sup>rd</sup> rev. ed.). New York: Wiley.

Cohen, J., Bilsen, J., Hooft, P., Deboosere, P., Wal, G. V., & Deliens, L. (2006). Dying at home or in an institution. Using death certificates to explore the factors associated with place of death. *Health Policy*, 78(2-3), 319-329.

Cohen-Mansfield, J., Marx, M. S., Lipson, S., & Werner, P. (1999). Predictors of mortality in nursing home residents. *Journal of Clinical Epidemiology*, 52 (4), 273-280.

Corner, J., & Dunlop, R. (1997). New approaches to care. In D. Clark, J. Hockley & S. Ahmedzai (Eds.), *New Themes in Palliative Care* (pp. 288-302). Milton Keynes: Open University Press.

Costello, J. (2001). Nursing older dying patients: findings from an ethnographic study of death and dying in elderly care wards. *Journal of Advanced Nursing*, 35(1), 59-68.

Council of Europe. (2003). Recommendations Rec. (2003) 12 of the Committee of Ministers to member states on the organisation of palliative care.

Covinsky, K. E., Eng, C., Lui, L. Y., Sands, L. P., & Yaffe, K. (2003). The last 2 years of life: Functional trajectories of frail older people. *Journal of the American Geriatrics Society*, 51(4), 492-498.

Currow, D. C., Abernethy, A. P., & Fazekas, B.S. (2004). Specialist palliative care needs of whole populations: a feasibility study using a novel approach. *Palliative Medicine*, 18(3), 239-247.

Dahmström, K. (2000). *Från datainsamling till rapport. Att göra en statistisk undersökning*. Lund: Studentlitteratur.

Davies, S., Sandberg, J., & Lundh, U. (2000). The entry to a nursing home. Residents and relatives experiences. In A. M. Warnes, L. Warren & M. Nolan (Eds.), *Care Services for Later Life. Transformations and Critiques* (pp. 152-170). London: Jessica Kingsley Publishers.

Dendaas, N. R. (2002). Prognostication in advanced cancer: nurses perceptions of the dying process. *Oncology Nursing Forum*, 29(3), 493-499.

Di Mola, G., & Crisci, M. T. (2001). Attitudes toward death and dying in a representative sample of the Italian population. *Palliative Medicine*, 15(5), 372-378.

Donaldson, M. S., & Field, M. J. (1998). Measuring quality of care at the end of life. *Archives of Internal Medicine*, 158(2), 121-128.

Edmonds, P., Karlsen, S., Khan, S., & Addington-Hall, J. (2001). A comparison of the palliative care needs of patients dying from chronic respiratory diseases and lung cancer. *Palliative Medicine*, 15(4), 287-295.

- Edvarsson, D., Sandman, P-O., & Rasmussen, B. (2006). Caring or uncaring – meanings of being in an oncology environment. *Journal of Advanced Nursing*, 55(2), 188-197.
- Ekman, I., Ehnfors, M., & Norberg, A. (2000). The meaning of living with severe chronic heart failure as narrated by elderly people. *Scandinavian Journal of Caring Sciences*, 14(2):130-136.
- Ekman, I. & Ehrenberg, A. (2002). Fatigued elderly with chronic heart failure: do patient reports and nurses recordings correspond? *International Journal of Nursing Terminologies and Classifications*, 13(4), 127-136.
- Ellershaw, J. (2002). Clinical pathways for care of the dying: an innovation to disseminate clinical excellence. *Journal of Palliative Medicine*, 5(4), 617-621.
- Ellershaw, J., & Ward, C. (2003). Care of the dying patients: the last hours or days of life. *British Medical Journal*, 326(7379), 30-34.
- Elofsson, L-C., & Öhlén, J. (2004). Meanings of being old and living with chronic obstructive pulmonary disease. *Palliative Medicine*, 18(7), 611-618.
- Emanuel, E. J., Fairclough, D.L., Slutsman, J., Alpert, H., Baldwin, D., & Emanuel, L.L. (1999). Assistance from family members, friends, paid care givers and volunteers in the care of terminally ill patients. *New England Journal of Medicine*, 341(13), 956-963.
- Ersek, M., Kraybill, B. M., & Hansberry, J. (1999). Investigating the educational needs of licensed nursing staff and certified nursing assistants in nursing homes regarding end-of-life. *The American Journal of Hospice and Palliative Care*, 16(4), 573-582.
- Fahlman, C., Lynn, J., Doberman, D., Gabel, J., & Finch, M. (2006). Prescription drug spending for Medicare choice beneficiaries in the last year of life. *Journal of Palliative Medicine*, 9(4), 884-893.
- Fainsinger, R. L., Demoissac, D., Cole, J., Mead-Wood, K., & Lee, E. (2000). Home versus hospice inpatient care: discharge characteristics of palliative care patients in an acute care hospital. *Journal of Palliative Care*, 16(1), 29-34.
- Fassbender, K., Fainsinger, R., Brenneis, C., Brown, P., Braun, T., & Jacobs, P. (2005). Utilization and costs of system wide palliative care in Alberta, 1993-2000. *Palliative Medicine*, 19(7), 513-520.

- Ferrell, B. (2005). Overview of the domains of variables relevant to end-of-life care. *Journal of Palliative Medicine*, 8(Suppl. 1), S 22-29.
- Field, D., & Addington-Hall, J. (2000). Extending specialist palliative care to all? In D. Dickenson, M. Johnson & J. Katz (Eds.), *Death, Dying and Bereavement* (pp. 91-106). London: Sage Publications Ltd.
- Field, D., Clark, D., Corner, J., & Davis, C. (2001). Introduction. In D. Field, D. Clark, J. Corner & C. Davis (Eds.), *Researching Palliative Care* (pp. 1-10). Milton Keynes: Open University Press.
- Franklin, L-L., Ternstedt, B-M., & Nordenfelt, L. (2006). Views on dignity of elderly nursing home residents. *Nursing Ethics*, 13(2), 130-146.
- Freeborne, N., Lynn, J., & Desbiens, N. A. (2000). Insights about dying from the SUPPORT project. The study for understand prognoses and preferences for outcome and risk treatments. *Journal of the American Geriatrics Society*, 48(5 Suppl.), S199-205.
- Freisinger, G. C., & Butler, J. (2000). End-of-life care for elderly patients with heart failure. *Clinics in Geriatric Medicine*, 16(3), 663-674.
- Frick, S., Uehlinger, D. E., & Zuercher Zenklusen, R. M. (2003). Medical futility: predicting outcome of intensive care unit patients by nurses and doctors – a prospective comparative study. *Critical Care Medicine*, 31(2), 456-461.
- Fried, T. R., van Doorn, C., O’Leary, J. R., Tinetti, M. E., & Drickamer, M.A. (1999). Older person’s preferences for site of terminal care. *Annals of Internal Medicine*, 131(2), 109-112.
- Friedrichsen, M., & Milberg, A. (2006). Concerns about losing control when breaking bad news to terminally ill patients with cancer: physicians perspective. *Journal of Palliative Medicine*, 9(3), 673-682.
- Gallo, W. T., Baker, M. J., & Bradley, E. H. (2001). Factors associated with home versus institutional death among cancer patients in Connecticut. *Journal of the American Geriatrics Society*, 49(6), 771-777.
- George, L. Research design at the end of life research: state of science. (2002). *The Gerontologist*, 43(Spec. No. 3), 86-98.

George, R., & Sykes, J. (1997). Beyond cancer? In D. Clark, J. Hockley & S. Ahmedzai (Eds.), *New Themes in Palliative Care* (pp. 239-254). Milton Keynes: Open University Press.

Georges, J. J., Onwuteaka-Philipsen, B. D., van der Heide, A., van der Wal, G., & van der Maas, P. J. (2005). Symptoms, treatment and "dying peacefully" in terminally ill cancer patients: a prospective study. *Supportive Care in Cancer*, 13(3), 160-168.

Goldstein, N., & Lynn, J. (2006). Trajectory of end-stage heart failure –the influence of technology and implications for policy change. *Perspectives in Biology and Medicine*, 49(1), 10-18.

Good, P. (2000). *Permutation Tests* (2<sup>nd</sup> rev. ed.). New York: Springer Verlag.

Goodlin, S. J., Jette, A. M., Lynn, J., & Wasson, J. H. (1998). Community physicians describe management issues for patients expected to live less than twelve months. *Journal of Palliative Care*, 14(1), 30-35.

Gott, M. C., Ahmedzai, S. H., & Wood, C. (2001). How many inpatients at an acute hospital have palliative care needs? Comparing the perspectives of medical and nursing staff. *Palliative Medicine*, 15(6), 451-460.

Gott, M., Seymour, J., Bellamy, G., Clark, D., & Ahmedzai, S. (2004). Older people's views about home as a place of care at the end of life. *Palliative Medicine*, 18(5), 460-467.

Grande, G. E., Addington-Hall, J. M., & Todd, C. J. (1998). Place of death and access to home care services: are certain groups at a disadvantage? *Social Science & Medicine*, 47(5), 565-579.

Grande, G. E., Farquhar, M. C., Barclay, S. L., & Todd, C. J. (2004). Valued aspects of primary palliative care: content analysis of bereaved carers' descriptions. *The British Journal of General Practice*, 54(507), 772-778.

Grande, G. E., McKerral, A., Addington-Hall, J. M., & Todd, C. J. (2003). Place of death and use of health services in the last year of life. *Journal of Palliative Care*, 19(4), 263-270.

Hall, P., Schroeder, C., & Weaver, L. (2002). The last 48 hours of life in long-term care: a focused chart audit. *Journal of the American Geriatrics Society*, 50(3), 501-506.

Hallberg, I. R. (2004). Death and dying from older peoples point of view. A literature review. *Aging Clinical and Experimental Research*, 16(2), 87-103.

Hallberg, I. R. (2006). Palliative care as a framework for older people's long-term care. *International Journal of Palliative Nursing*, 12(5), 224-229.

Hanson, L. C., Earp, J. A., Garrett, J., Menon, M., & Danis, M. (1999). Community physicians who provide terminal care. *Archives of Internal Medicine*, 159(10), 1133-1138.

Happ, M. B., Capezuti, E., Strumpf, N. E., Wagner, L., Cunningham, S., Evans, L., & Maislin, G. (2002). Advance care planning and end-of-life care for hospitalized nursing home residents. *Journal of the American Geriatrics Society*, 50(5), 829-835.

Hays, J. C., Galanos, A. N., Palmer, T. A., McQuoid, D. R., & Flint, E. P. (2001). Preference for place of death in a continuing care retirement community. *The Gerontologist*, 41(1), 123-128.

Hermann, C., & Looney, S. (2001). The effectiveness of symptom management in hospice patients during the last seven days of life. *Journal of Hospice and Palliative Nursing*, 3(3), 88-96.

Hickman, S. E., Tilden, V. P., & Tolle, S. W. (2001). Family reports of dying patients' distress: The adaptation of a research tool to assess global symptom distress in the last week of life. *Journal of Pain and Symptom Management*, 22(1), 565-574.

Higginson, I. J. (2005). End-of-life care: lessons from other nations. *Journal of Palliative Medicine*, 8(Suppl 1), S-161-173.

Higginson, I. J., Finlay, H. G., Goodwin, D. M., Hood, K., Edwards, A. G., Cook, A., Douglas, H. R., & Normand, C. E. (2003). Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? *Journal of Pain and Symptom Management*, 25(2), 150-168.

Higginson, I. J., Jarman, B., Astin, P., & Dolan, S. (1999). Do social factors affect where patients die: an analysis of 10 years of cancer deaths in England. *Journal of Public Health Medicine*, 21(1), 22-28.

Hockley, J., & Clark, D. (2002). Conclusion. In J. Hockley & D. Clark (Eds.). *Palliative Care for Older People in Care Homes* (pp. 182-186). Milton Keynes: Open University Press.

Holter, I. M., & Kim, H. S. (1995). Methodology for critical theory. Critical action research. In A. Omery, C. E. Kasper & G. G. Page (Eds.), *In Search of Nursing Science* (pp. 220-231). California: Sage Publications Inc.

Hughes, S. L., Weaver, F. M., Giobbie-Hurder, A., Manheim, L., Henderson, W., Kubal, J. D., Ulasevich, A., Cummings, J., & Department of Veterans Affairs Cooperative Study Group on Home-Based Primary Care. (2000). Effectiveness of team managed home-based primary care: a randomized multicenter trial. *The Journal of the American Medical Association*, 284(22), 2877-2885.

Hunt, R. W., Fazekas, B. S., Luke, C. G., & Roder, D. M. (2001). Where patients with cancer die in South Australia, 1990-1999: a population based review. *The Medical Journal of Australia*, 175(10), 526-529.

Idvall, E. & Ehrenberg, A. (2002). Nursing documentation of postoperative pain management. *Journal of Clinical Nursing*, 11(6), 734-742.

Johansson, C-M., Axelsson, B., & Danielson, E. (2006). Living with incurable cancer at the end of life –patients perceptions on quality of life. *Cancer Nursing*, 29(5), 391-309.

Johnson, R. J., Gallagher, T. J., & Wolinsky, F. D. (2004). The influence of the end of life on the extent of informal help received by older adults. *Research on Aging*, 26(2), 259-283.

Jordhøy, M. S., Fayers, P., Loge, J. H., Saltnes, T., Ahlner-Elmqvist, M., & Kaasa, S. (2001). Quality of life in advanced cancer patients: the impact of sociodemographic and medical characteristics. *British Journal of Cancer*, 85(10), 1478-1485.

Jordhøy, M. S., Saltvedt, I., Fayers, P., Loge, J. H., Ahlner-Elmqvist, M., & Kaasa, S. (2003). Which cancer patients die in nursing homes? Quality of life, medical and sociodemographic characteristics. *Palliative Medicine*, 17(5), 433-444.

Katz, J., Komaromy, C., & Sidell, M. (1999). Understanding palliative care in residential and nursing homes. *International Journal of Palliative Care*, 5(2), 58-64.

Kavanagh, S., & Knapp, M. (1998). The impact on general practitioners of the changing balance of care for elderly people living in institutions. *British Medical Journal*, 317(7184), 322-327.

- Kayser-Jones, J., Schell, E., Lyons, W., Kris, A. E., Chan, J., & Beard, R. L. (2003). Factors that influence end-of-life care in nursing-homes: the physical environment, inadequate staffing, and lack of supervision. *The Gerontologist*, 43(Spec. No. 2), 76-84.
- Kellehear, A. (1999). Health-promoting palliative care: developing a social model for practice. *Mortality*, 4(1), 75-82.
- Kim, H. S. (2000a). An integrative framework for conceptualizing clients: a proposal for a nursing perspective in the new century. *Nursing Science Quarterly*, 13(1), 37-44.
- Kim, H. S. (2000b). *The nature of Theoretical Thinking in Nursing*. (2<sup>nd</sup> rev. ed.). New York: Springer Publishing Company.
- Kirkpatrick, J. N., & Kim, A. Y. (2006). Ethical issues in heart failure – overview of an emerging need. *Perspectives in Biology and Medicine*, 49(1), 1-9.
- Klinkenberg, M., Willems, D. L., van der Wal, G., & Deeg, D. J. H. (2004). Symptom burden in the last week of life. *Journal of Pain and Symptom Management*, 27(1), 5-13.
- Kollak, I. (1999). Nursing and its science in historical perspective. In H. S. Kim, & I. Kollak (Eds.), *Nursing Theories: Conceptual and Philosophical Foundations* (pp. 189-204). New York: Springer Publishing Company.
- Komaromy, C., Sidell, M., & Katz, J. T. (2000). The quality of terminal care in residential and nursing homes. *International Journal of Palliative Nursing*, 6(4), 192-200.
- Kurtz, M. E., Kurtz, J. C., Given, C. W., & Given, B. A. (2005). Utilization of service among elderly cancer patients – relationships to age, symptoms, physical functioning, comorbidity, and survival status. *Ethnicity & Disease*, 15(Suppl. 2), S17-22
- Kutner, J. S., Kassner, C. T., & Nowels, D. E. (2001). Symptom burden at the end of life: hospice providers' perception. *Journal of Pain and Symptom Management*, 12(6), 473-480.
- Laakkonen, M-L., Pitkala, K. H., Strandberg, T. E., Berglind, S., & Tilvis, R. S. (2005). Older people's reasoning for resuscitation preferences and their role in the decision-making process. *Resuscitation*, 65(2), 165-171.

- Lamberg, J. L., Person, C. J., Kiely, D. K., & Mitchell, S. L. (2005). Decisions to hospitalize home residents dying with advanced dementia. *Journal of the American Geriatrics Society*, 53(8), 1396-1401.
- Lamont, E. B. (2005). A demographic and prognostic approach to defining the end of life. *Journal of Palliative Medicine*, 8(Suppl. 1), S12-21.
- Leff, B., Kaffenberger, K. P., & Remsburg, R. (2000). Prevalence, effectiveness, and predictors of planning the place of death among older persons followed in community-based long term care. *Journal of the American Geriatrics Society*, 48(8), 943-948.
- Levenson, J. W., McCarthy, E. P., Lynn, J., Davis, R. B., & Phillips, R. S. (2000). The last six months of life for patients with congestive heart failure. *Journal of the American Geriatrics Society*, 48(5 Suppl.), S101-109.
- Lindqvist, O., Widmark, A., & Rasmussen, B. H. (2006). Reclaiming wellness – living with bodily problems, as narrated by men with advanced prostate cancer. *Cancer Nursing*, 29(4), 327-337.
- Llobera, J., Esteva, M., Benito, E., Terrasa, J., Rifa, J., Pons, O., & Maya, A. (2003). Quality of life for oncology patients during the terminal period. Validation of the HRCA-QL index. *Supportive Care in Cancer*, 11(5), 294-303.
- Lloyd, L. (2000). Dying in old age: promoting well-being at the end of life. *Mortality*, 5(2), 171-188.
- Lorenz, K., Lynn, J., Morton, S. C., Dy, S., Mularski, R., Shugarman, L., Sun, V., Wilkinson, A., Maglione, M., & Shekelle, P. G. (2004). End-of-Life Care and Outcomes. Evidence Report/Technology Assessment No. 110. (Prepared by the Southern California Evidence-based Practice Center, under Contract No. 290-02-0003.) AHRQ Publication No. 05-E004-2. Rockville, MD: Agency for Healthcare Research and Quality.
- Lundh Hagelin, C., Seiger, A., & Furst, C-J. (2006). Quality of life in terminal care –with special reference to age, gender and marital status. *Supportive Care in Cancer*, 14(4), 320-328.
- Lundh, U., Sandberg, J., & Nolan, M. (2000). I don't have any other choice: spouses' experiences of placing a partner in a care home for older people in Sweden. *Journal of Advanced Nursing*, 32(5), 1178-1186.

- Lunney, J. R., Lynn, J., Foley, D. J., Lipson, S., & Guralnik, J. M. (2005). Patterns of functional decline at the end of life. *The Journal of the American Medical Association*, 289(18), 2387-2392.
- Lunney, J. R., Lynn, J., & Hogan, C. (2002). Profiles of older Medicare decedents. *Journal of the American Geriatrics Society*, 50(6), 1108-1112.
- Lynn, J. (2000). Learning to care for people with chronic illness facing the end of life. *The Journal of the American Medical Association*, 284(19), 2508-2511.
- Lynn, J. (2005). "Living Long in Fragile Health: The New Demographics Shape End of Life Care," *Improving End of Life Care: Why Has It Been So Difficult? Hastings Center Report, Special Report*, 35(6), S14-S18.
- Lynn, J., Nolan, K., Kabcenell, A., Weissman, D., Milne, C., & Berwick, D. M. (2002). Reforming care for persons near the end-of-life: The promise of quality improvement. *Annals of Internal Medicine*, 137(2), 117-122.
- Lynn, J. (2001). Perspectives on care at the close of life. Serving patients who may die soon and their families: the role of hospice and other services. *The Journal of the American Medical Association*, 285(7), 925-932.
- Lynn, J., Teno, J. M., Philips, R. S., Wu, A. W., Desbiens, N., Harrold, J., Claessens, M. T., Wenger, N., Kreling, B., & Connors, A. F. (1997). Perceptions by family members of the dying experience of older and seriously ill patients. *Annals of Internal Medicine*, 126(2), 97-106.
- Löfmark, R., Nilstun, T., & Bolmsjö, I. A. (2005). From cure to palliation: staff communication, documentation and transfer of patient. *Journal of Palliative Medicine*, 8(6), 1105-1109.
- McCarthy, E. P., Philips, R. S., Zhong, Z., Drews, R. E., & Lynn, J. (2000). Dying with cancer: patients function, symptoms, and care preferences as death approaches. *Journal of the American Geriatrics Society*, 48(5 Suppl), S110-121.
- McNamara, B., & Rosenwax, L. (2006). Factors affecting place of death in Western Australia. *Health & Place*, (In press).
- Mecocci, P., von Strauss, E., Cherubini, A., Ercolani, S., Mariani, E., Sening, U., Winblad, B., & Fratiglioni, L. (2005). Cognitive impairment is the major risk factor for development of geriatric syndromes during hospitalization: Results from the GIFA study. *Dementia and Geriatric Cognitive Disorders*, 20(4), 262-269.

- Mercandante, S., Casuccio, A., & Fulfaro, F. (2000). The course of symptom frequency and intensity in advanced cancer patients followed at home. *Journal of Pain and Symptom Management*, 20(2), 104-112.
- Milberg, A., & Strang, P. (2000). Met and unmet needs in hospital-based home care: qualitative evaluation through open-ended questions. *Palliative Medicine*, 14(6), 533-534.
- Mitchell, S. L., Morris, J. N., Park, P. S., & Fries, B. E. (2004) Terminal care for persons with advanced dementia in the nursing home and home care settings. *Journal of Palliative Medicine*, 7(6), 808-816.
- Moritze, V., Nguyen, D. T., Lorente, C., & Desfosses, G. (1999) Descriptive epidemiological survey on a given day in all palliative care patients hospitalized in a French university hospital. *Palliative Medicine*, 13(2), 105-117.
- Mukamel, D. B., Bajorska, A., & Temkin-Greener, H. (2002). Health-care service utilization at the end of life in a managed program integrating acute and long term care. *Medical Care*, 40(12), 1133-1148.
- Murray, S. A., Boyd, K., Kendall, M., Worth, A., Benton, T. F., & Clausen, H. (2002). Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. *British Medical Journal*, 325(7370), 929-938.
- Murray, T. H., & Jennings, B. (2005). "The Quest to Reform End of Life Care: Rethinking Assumptions and Setting New Directions," *Improving End of Life Care: Why Has It Been So Difficult? Hastings Center Report, Special Report*, 35, S52-S57.
- Mustard, C., Finlayson, M., Derksen, S., & Berthelot, J. M. (1999). What determines the need for nursing home admission in a universally insured population? *Journal of Health Service Research and Policy*, 4(4), 197-203.
- Mörch, M., Timpka, T., & Granéus, A-K. (1999). Thirty years experience with cancer and non-cancer patients in palliative home care. *Journal of Palliative Care*, 15(3), 43-48.
- Natarajan, S., & Nietert, P. J. (2004). Hypertension, diabetes, hypercholesterolemia, and their combinations increased health care utilization and decreased health status. *Journal of Clinical Epidemiology*, 57(9), 954-961.

National Consensus Project for Quality Palliative Care. A consortium of the American Academy of Hospice and Palliative Medicine, The Center to Advance Palliative care, Hospice and Palliative Nurses Association, Last Acts Partnership, and National Hospice and Palliative Care Organization. (2004). National Consensus Project for Quality Palliative Care: Clinical Practice Guidelines for Quality Palliative Care, Executive summary. *Journal of Palliative Medicine*, 7(5), 611-624.

National Institutes of Health. (2005). State-of-the-science Conference statement. Improving end-of-life care. Final statement.

Nolte, E., & McKee, M. (2003). Measuring the health of nations: analysis of mortality amenable to health care. *British Medical Journal*, 327(7424), 1129–1132.

Nordgren, L., & Olsson, H. (2004). Palliative care in a coronary care unit: a qualitative study of physicians and nurses perceptions. *Journal of Clinical Nursing*, 13(2), 185-193.

Nordgren, L., & Sörensen, S. (2003). Symptoms experienced in the last six months of life in patients with end-stage heart failure. *European Journal of Cardiovascular Nursing*, 2(3), 213-217.

Organisation for Economic Co-operation and Development (OECD). OECD Health Data 2006: Statistics and Indicators for 30 Countries. <http://www.oecd.org/health/healthdata>, September 2006.

Parker, D., & De Bellis, A. (1999). A profile of dying residents in South Australian nursing homes. *International Journal of Palliative Nursing*, 5(4), 162-170.

Parker, D., & McLeod, A. (2002). Assessment of need in care homes. In J. Hockley & D. Clark (Eds.), *Palliative Care for Older People in Care Homes* (pp. 34-51). Milton Keynes: Open University Press.

Payne. S., Seymour, J., & Ingleton, C. (2004). Introduction. In S. Payne., J. Seymour & C. Ingleton (Eds.), *Palliative Care Nursing. Principles and Evidence for Practice* (pp. 1-12). Milton Keynes: Open University Press.

Plonk, W. M., & Arnold, R. M. (2005). Terminal care: the last weeks of life. *Journal of Palliative Medicine*, 8(5), 1042-1054.

Polit, D. F., & Beck, C. T. (2004). *Nursing Research: Principles and Methods* (7<sup>th</sup> ed.). Philadelphia: Lippincott.

Polit, D. F., & Hungler, B. P. (1999). *Nursing Research: Principles and Methods* (6<sup>th</sup> ed.). Philadelphia: Lippincott.

Porock, D., Oliver, D. P., Rantz, M., Mehr, D., Madsen, R., & Petroski, G. (2005). Predicting death in nursing home: development and validation of the 6-month Minimum Data Set mortality risk index. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences*, 60(4), 491-498.

Porock, D., Oliver, D. P., Zweig, S. C., Rantz, M., & Petroski, G. F. (2003) A profile of residents admitted to long-term care facilities for end-of-life care. *Journal of the American Medical Directors Association*, 4(1), 16-22.

Ramroth, H., Specht-Leible, N., Konig, H. H., & Brenner, H. (2006). Hospitalizations during the last month of life of nursing home residents: a retrospective cohort study from Germany. *Biomedical Chromatography: Health Service Research*, 8(6), 70.

Rasmussen, B. H., Jansson, L., & Norberg, A. (2000). Striving for becoming at home in the midst of dying. *American Journal of Hospice and Palliative Care*, 17(1), 31-43.

Rasmussen, B. H., & Sandman, P-O. (1998). How patients spend their time in a hospice and in an ontological unit. *Journal of Advanced Nursing*, 28(4), 818-828.

Reynolds, K., Henderson, M., Schulman, A., & Hanson, L. C. (2002) Needs of the dying in nursing homes. *Journal of Palliative Medicine*, 5(6), 895-901.

Rice, K. N., Coleman, E. A., Fish, R., Levy, C., & Kutner, J. S. (2004). Factors influencing models of end-of-life care in nursing homes: results of a survey of nursing home administrators. *Journal of Palliative Medicine*, 7(5), 668-675).

Ryan, A. A., & Scullion, H. F. (2000). Nursing home placement: an exploration of the experiences of family carers. *Journal of Advanced Nursing*, 32(5), 1187-1195.

Sahlberg-Blom, E. Ternestedt, B-M., & Johansson, J-E. (2001). Is good quality of life possible at the end of life? An explorative study of the experiences of a group of cancer patients in two different care cultures. *Journal of Clinical Nursing*, 10(4), 550-562.

Salaffi, F., De Angelis, R., Stancati, A., & Grassi, W. (2005). Health-related quality of life in multiple musculoskeletal conditions: a cross-sectional population based epidemiological study. II. The MAPPING study. *Clinical and Experimental Rheumatology*, 23(6), 829-839.

Sandblom, G., Carlsson, P., Sennfalk, K., & Varenhorst, E. (2004). A population-based study of pain and quality of life during the year before death in men with prostate cancer. *British Journal of Cancer*, 99(6), 1163-1168.

Scheaffer, R. L., Mendelhall, W., & Ott, L. (1996). *Elementary Survey Sampling* (5<sup>th</sup> ed.). Belmont California: Duxbury Press.

Seale, C. (2000). Changing patterns of death and dying. *Social Science & Medicine*, 51(6), 917-930.

Seale, C. (1998). *Constructing Death. The Sociology of Dying and Bereavement*. Cambridge: Cambridge University Press.

Seymour, J. E., & Hanson, E. (2001). Palliative care and older people. In M. Nolan, S. Davies & G. Grant (Eds.), *Working With Older People and Their Families* (pp. 99-119). Milton Keynes: Open University Press.

Seymour, J., & Ingleton, C. (2004). Transitions into the terminal phase. Overview. In S. Payne, J. Seymour & C. Ingleton (Eds.), *Palliative Care Nursing. Principles and Evidence for Practice* (pp. 189-217). Milton Keynes: Open University Press.

Silveira, M. J., Kabeto, M. U., & Langa, K. M. (2005). Net worth predicts symptom burden at the end of life. *Journal of Palliative Medicine*, 8(4), 827-837.

Skilbeck, J. K., & Payne, S. (2005). End of life care: a discursive analysis of specialist palliative care nursing. *Journal of Advanced Nursing*, 51(4), 325-334.

Sloane, P. D., Zimmermann, S., Hanson, L., Mitchell, C. M., Riedel-Leo, C., & Custis-Bule, V. (2003). End-of-life care in assisted living and related residential care settings: comparison with nursing homes. *Journal of the American Geriatrics Society*, 51(11), 1587-1594.

Socialstyrelsen. (2005a). Dödsorsaker 2003. Socialstyrelsen, Epidemiologiskt centrum 2005:7.

Socialstyrelsen. (2005b). Folkhälsorapport 2005. Socialstyrelsen, Epidemiologiskt centrum.

Socialstyrelsen (2005c). Var dör de äldre – på sjukhus, särskilt boende eller hemma? En registerstudie.

Solloway, M., La France, S., Bakitas, M., & Gerken, M. (2005). A chart review of seven hundred eighty-two deaths in hospitals, nursing homes and hospice/home care. *Journal of Palliative Medicine*, 8(4), 789-796.

Somogyi-Zalud, E., Zhong, K., Lynn, J., & Hamel, M. B. (2000). Elderly persons last six months of life: findings from the hospitalized elderly longitudinal project. *Journal of the American Geriatrics Society*, 48(5 Suppl), S131-139.

Staff Myers, S., & Lynn, J. (2001). Patients with eventually fatal chronic illness: their importance within a national research agenda on improving patient safety and reducing medical errors. *Journal of Palliative Medicine*, 4(3), 325-332.

Statens offentliga utredningar (SOU). (2001). Döden angår oss alla - värdig vård i livets slutskede. Slutbetänkande från Kommittén om vård i livets slutskede. Statens offentliga utredningar SOU 2001:6, Socialdepartementet.

Statens offentliga utredningar (SOU). (1995). Vårdens svåra val. Slutbetänkande av Prioriteringsutredningen. Statens offentliga utredningar SOU 1995:5, Socialdepartementet.

Statistiska centralbyrån (SCB). (2004). Befolkningsstatistik 2003. Stockholm.

Statistiska centralbyrån (SCB). (2005). Statistisk årsbok för Sverige 2005. Stockholm.

Statistiska centralbyrån (SCB). (2006). Statistisk årsbok för Sverige 2006. Stockholm.

Statistiska centralbyrån (SCB). (2003). Sveriges framtida befolkning 2004–2050. Reviderad befolkningsprognos. Stockholm.

Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., McIntyre, L., & Trulsky, J. A. (2000). Factors consider important at the end of life by patients, family physicians, and other care providers. *The Journal of the American Medical Association*, 284(19), 2476-2482.

Stewart, A. L., Teno, J., Patrick, D. L., & Lynn, J. (1999). The concept of quality of life of dying persons in the context of health care. *Journal of Pain and Symptom Management*, 17(2), 93–108.

Struijs, J. N., Baan, C. A., Schellevis, F. G., Westert, G. P., & van den Bos G. A. (2006). Comorbidity in patients with diabetes mellitus: impact on medical health care utilization. *Biomedical Chromatography: Health Service Research*, 4(6), 84.

Strömgren, A. S., Goldschmidt, D., Groenvold, M., Petersen, M. A., Jensen, P. T., Pedersen, L., Hoermann, L., Helleberg, C., & Sjogren, P. (2002). Self-assessment in cancer patients referred to palliative care: a study of feasibility and symptom epidemiology. *Cancer*, 94(2), 512-520.

Stuart, B., D'Onofrio, C. N., Boatman, S., & Feigelman, G. (2003). CHOICES: promoting early access to end-of-life care through home-based transition management. *Journal of Palliative Medicine*, 6(4), 671-683.

Svantesson, M., Sjökvist, P., & Thorsén, H. (2003). End-of-life decisions in Swedish ICUs. How do physicians from the admitting departments reason? *Intensive and Critical care Nursing*, 19(4), 241-251.

Svensk författningssamling (SFS). (1982). Hälso- och sjukvårdslag. Svensk författningssamling 1982:763.

Svensk författningssamling (SFS). (1980). Socialtjänstlag. Svensk författningssamling 1980:620.

Tang, S. T. (2003). When death is imminent: where terminally ill patients prefer to die and why. *Cancer Nursing*, 26(3), 245-251.

Tardy, B., Venet, C., Zeni, F. Bethet, O., Viallon, A., Lemaire, F., & Bertrand, J. C. (2002). Death of terminally ill patients on a stretcher in the emergency department: a French speciality? *Intensive Care Medicine*, 28(11), 1625-1628.

Taylor, V. (2004). Acute hospital care. In S. Payne, J. Seymour & C. Ingleton (Eds.), *Palliative Care Nursing. Principles and Evidence for Practice* (pp. 108-125). Milton Keynes: Open University Press.

Ten Have, H., & Clark, D. (2002). Introduction: the work of the Pallium project. In H. ten Have & D. Clark (Eds.), *The Ethics in Palliative Care. European Perspective* (pp.1-12). Milton Keynes: Open University Press.

- Teno, J. M., Clarridge, B. R., Casey, V., Welch, L. C., Wetle, T., & Mor, V. (2004). Family perspective on end-of-life care and the last place of care. *The Journal of the American Medical Association*, 291(1), 88-93.
- Teno, J. M., Weitzen, S., Fennell, M. L., & Mor, V. (2001). Dying trajectory in the last year of life: does cancer trajectories fit other diseases? *Journal of Palliative Medicine*, 4(4), 457-564.
- Ternstedt, B-M., & Franklin, L-L. (2006). Ways of relating to death: views of older people resident in nursing homes. *International Journal of Palliative Nursing*, 12(7), 334-340.
- Thomé, B., Dykes, A. K., & Hallberg, I. L. (2003). Home care with regard to definition, care recipients, content and outcome: systematic literature review. *Journal of Clinical Nursing*, 12(6), 860-872.
- Tomassini, C., Glaser, K., Wolf, D. A., Broese van Groenou, M. I., & Grundy, E. (2005). Living arrangements among older people: an overview of trends in Europe and in the USA. *Population Trends*, 115, 24-34.
- Tramner, J. E., Heyland, D., Dudgeon, D., Groll, D., Squires-Graham, M., & Coulson, K. (2003) Measuring the symptom experience of seriously ill cancer and noncancer hospitalized patients near the end-of-life with the memorial symptom assessment scale. *Journal of Pain and Symptom Management*, 25(5), 420-429.
- Travis, S. S., Loving, G., McClanahan, L., & Bernard, M. (2001). Hospitalization patterns and palliation in the last year of life among residents in long-term care. *The Gerontologist*, 41(2), 153-160.
- Vigano, A., Donaldson, N., Higginson, I. J., Briera, E., Mahmud, S., & Suarez-Almazor, M. (2004). Quality of life and survival prediction in terminal cancer patients: a multicenter study. *Cancer*, 101(5), 1090-1098.
- Visser, G., Klinkenberg, M., van Groenou, M. I., Willems, D. L., Knipsheer, C. P., & Deeg, D. J. (2004). The end-of-life: informal care for dying older people and its relationship to place of death. *Palliative Medicine*, 18(5), 468-477.
- Vohra, J. U., Brazil, K., Hanna, S., & Abelson, J. (2004). Family perceptions of end-of-life care in long-term care facilities. *Journal of Palliative Care*, 20(4), 297-302.

- Wachterman, M. V., & Sommers, B. D. (2006). The impact of gender and marital status on end-of-life care: evidence from the National Follow-Back Survey. *Journal of Palliative Medicine*, 9(2), 343-352.
- Wallace, J. B., & Prevst, S. S. (2006). Two methods for predicting limited life expectancy in nursing homes. *Journal of Nursing Scholarship*, 38(2), 148-153.
- Wang, J. J., Mitchell, P., Smith, W., Cumming, R. G., & Leeder, S. R. (2001). Incidence of nursing home placement in a defined community. *The Medical Journal of Australia*, 174(6), 271-5.
- Weitzen, S., Teno, J. M., Fennell, M., & Mor, V. (2003). Factors associated with site of death: a national study of where people die. *Medical Care*, 41(2), 323-335.
- Wennman-Larsen, A., & Tishelman, C. (2002). Advanced home care for cancer patients at the end of life: a qualitative study of hopes and expectations of family caregivers. *Scandinavian Journal of Caring Sciences*, 16(3), 240-247.
- Werkander, C., & Andershed, B. (2004) Good palliative care: how and where? The patients' opinions. *Journal of Hospice and Palliative Nursing*, 6(1), 27-35.
- Wilhelmson, K. (2003). Longer life-better life? Studies on mortality, morbidity and quality of life among elderly people. (PhD thesis). Departments of Social Medicine and Geriatric Medicine, Institute of Community Medicine. Göteborg University, Göteborg Sweden.
- Wilson, D. M. (2000). End-of-life care preferences of Canadian senior citizens with caregiving experience. *Journal of Advanced Nursing*, 31(6), 1416-1421.
- Wilson, D. M. (2002). The duration and degree of end-of-life dependency of home care clients and hospital inpatients. *Applied Nursing Research*, 15(2), 81-86.
- World health organisation Europe. (2004). *The solid facts. Palliative care*. World Health Organisation, Copenhagen.
- World health organisation. (2003). *International statistical classification of diseases and related health problems* (10<sup>th</sup> rev. ed.). World Health Organisation, Geneva.

World Health organisation. (2002). *National cancer control programmes: policies and managerial guidelines* (2<sup>nd</sup> ed.). World Health Organisation, Geneva.

Zallman, L., Sanches, J., Choi, H., & Selwin, P. (2003). Unmet need for chronic diseases and end-of-life care at urban family centers in the Bronx, NY. *Family Medicine*, 35(9), 637-642.

Zimmermann, C., & Rodin, G. (2004). The denial of death thesis: sociological critique and implications for palliative care. *Palliative Medicine*, 18(2), 121-128.

Öhlen, J. (2000). Att vara i en fristad – berättelser om lindrat lidande inom palliativ vård. (Akademisk avhandling). Institutionen för vårdpedagogik, Göteborgs universitet. Göteborg, Sverige.

Öhlén, J., Bengtsson, J., Skott, C., & Segesten, K. (2002). Being in a lived retreat –embodied meaning of alleviated suffering. *Cancer Nursing*, 25(4), 318-325.

Öhlén, J. (2004). Violation of dignity in care-related situations. *Research and Theory for Nursing Practice*, 18(4), 371-385.

Övretveit, J. (1998). *Evaluating Health Interventions*. Buckingham: Open University Press.

**THESES FROM INSTITUTE OF HEALTH AND CARE SCIENCES,  
SAHLGRENSKA ACADEMY AT GÖTEBORG UNIVERSITY**

Doctoral theses:

Skärsäter, I. (2002). The importance of social support for men and woman, suffering from major depression – a comparative and explorative study.

Ahlberg, K. (2004). Cancer-Related Fatigue – experience and outcomes.

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