

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

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- 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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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 people 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.

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