



## Diagnostic Assessment &amp; Prognosis

## Changes in place of death among people with dementia in Finland between 1998 and 2013: A register study

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### Abstract

**Introduction:** The place of death is suggested as a quality indicator for end-of-life care. We investigated how the place of death changed between 1998 and 2013 among people with dementia.

**Methods:** Data from the Finnish national health and social care registers were extracted for all people with dementia, who had died at 70 years old during these years ( $N = 140,034$ ). Descriptive analysis and logistic regression analysis were conducted.

**Results:** In 2013, the most common place of death was the primary care hospital (39.8%), followed by nursing home and sheltered housing with 24-hour assistance (20.5%). Dying at home was rare (8.1%). During the study years, dying in the hospital decreased while dying in sheltered housing with 24-hour assistance increased.

**Discussion:** The place of death for people with dementia has changed from institutions to noninstitutional care facilities. Further research on noninstitutional care facilities' ability to provide high-quality care at the end of life is needed.

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### Keywords:

Dementia; End-of-life care; Place of death; Long-term care setting; Sheltered housing with 24-hour assistance

### 1. Introduction

Dementia has become an important cause of disability and death worldwide, mainly because of aging populations and increasing longevity [1–3]. In dementia, the last phase of life is usually dominated by a high level of dependency due to loss of the ability to move, communicate, and even eat and symptoms such as disorientation, restlessness, or aggression [3–5]. The care site that offers end-of-life care for the people with dementia must have staffs with special skills and knowledge of dementia care to respond to patients' needs. The place of death is an indicator of health and social care utilization at the end-of-life and the type of care that is available for patients near the time of death [6–9].

In Finland, the mortality rate due to dementia has more than doubled over the past decades, a trend that shows no deceleration [10]. Research indicates that dementia is an important contributor to the use of long-term care (LTC) [11]. Therefore, researchers predict that the need for LTC especially at the end of life will increase [12]. In Finland, as in several other countries, longevity is increasing, and care systems are undergoing reform simultaneously. Finland, the same as other Nordic countries and UK, offers universal coverage for a wide-ranging variety of health and social services. At the funding structure, the Finnish system is more decentralized and mixed than other Nordic countries. Health and social services are funded mainly by taxes, and partly by user fees. Public primary health care is provided by municipal health centers (the same as primary care hospital in the other countries) [13]. Municipalities are responsible for LTC, which they can either offer in their own care facilities or contracted through other care providers. The recent LTC reform has shifted round-the-clock LTC from institutional care, which was offered in nursing homes and in

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primary care hospitals (health centers in Finland), to noninstitutional LTC, which is offered in sheltered housing with 24-hour assistance, or private homes and now defined as the last residential place till death [14–16]. Sheltered housing with 24-hour assistance in Finland is a rather new system, which provides more home-like environment according to the perception that the people with dementia feel comfortable at home more than at the institution or the hospital [17–21]. The number of sheltered housing with 24-hour assistance facilities has increased notably in the last 15 years [14,15]. In comparison to institutional care facilities, which are mostly publicly owned and funded by tax revenues and regulated user fees, sheltered housing with 24-hour assistance is more frequently owned by private enterprises and not-for-profit NGOs [14,22]. User fees in sheltered housing are unregulated and vary considerably between municipalities and different facilities [22].

Although the number of people with dementia has increased and the care system has changed, there are no previous studies describing the places of death of people with dementia in Finland, nor is there any information about how these have changed in the past decades after the LTC reform. Detailed information on the place of death of people with dementia is highly needed for the planning of end-of-life care for people with dementia. In this study, we analyze the change over time in end-of-life care for people with dementia, using the place of death as an indicator.

The research questions are as follows:

- (1) Where did people diagnosed with dementia die in Finland between 1998 and 2013?
- (2) How do the places of death differ between the age groups of 70–79, 80–89, and 90+, and between men and women?
- (3) How have places of death changed among older people diagnosed with dementia between 1998 and 2013?

## 2. Methods

Data on people with dementia and their places of death were extracted from the Finnish national health and social care registers. The data set included information on all persons who died at the age of 70 years or older in 1998 and between 2002 and 2013 and a 40% random sample of all persons who died at the age of 70 years or older between 1999 and 2001 ( $N = 502656$ ). People with dementia ( $N = 140034$ ) were identified from The Causes of Death register (Statistics Finland) and from The Care Register for Health Care and The Care Register for Social Welfare (The National Institute for Health and Welfare) with ICD10 codes F00 (dementia in Alzheimer's disease), F01 (vascular dementia), F02 (dementia in other diseases), F03 (unspecified dementia), or G30 (Alzheimer's disease).

The information of care use was drawn from The Care Register for Health Care and The Care Register for Social

Welfare. The care registers include information on the use of health center hospitals (i.e., primary care hospital in the other countries), and private, district, general, and university hospitals. Health centers mainly offer primary health care, but they have also offered LTC in their inpatient wards. However, the use of health centers for long-term care has become less frequent in recent years. LTC facilities include nursing homes (institutional LTC) and sheltered housing with 24-hour assistance (housing service, noninstitutional LTC). Information of sheltered housing with 24-hour assistance was available in the registers from 2000 onward.

Study was done as part of the research project New Dynamics of Longevity and the Changing Needs for Services (COCTEL) at the University of Tampere, Faculty of Social Sciences, and Gerontology Research Center. Permission to access register data was obtained from each register official. Information from different national registers was linked with using the personal identity codes that remain unchanged through people's lives. The linking of data was done by Statistics Finland, and the authors had no access to personal identity codes. The research plan was approved by the Ethics Committee of the Pirkanmaa Hospital District.

First, the study population and the age and gender distribution in different study years were described. Then, the frequency of different places of death was analyzed with cross-tabulations with age at the time of death and gender. The association of place of death with age, gender, and the year of death was analyzed with binary logistic regression models. The analyses were adjusted for other diagnoses drawn from the care registers and causes of death register. Data were analyzed using IBM SPSS statistics Windows version 22 (IBM Corp., Armonk, NY, USA).

Place of death was categorized as home, specialized care hospitals (including private, district, general, and university hospitals), primary care hospital (i.e., health center in Finland), nursing home (institutional LTC), and sheltered housing with 24-hour assistance (noninstitutional LTC).

The independent variables were gender, age group at the death (70–79, 80–89, and 90+), year of death from 1998 to 2013, and other diagnoses (cancer, diabetes, psychosis, depressive syndromes or other mental health disorders, Parkinson disease or other neurological diseases, chronic asthma and chronic obstructive pulmonary disease or other respiratory diseases, arthritis or osteoarthritis, hip fracture, stroke, ischemic and other heart disease excluding rheumatic and alcoholic diseases, and other diseases of the circulatory system).

## 3. Results

The frequency of dementia among people who died at the age of 70 years or older increased from 22% to 33.9% between the years 1998 and 2013. The mean age at death of people with dementia increased from 85.4 years to 87.0 years (Table 1). During the whole study period, 67.4% ( $N = 94,345$ ) of the study population was women, whose

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