

Diagnostic Assessment & 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

All authors declare no conflict of interest.

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<https://doi.org/10.1016/j.dadm.2017.10.006>

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institutional care, which was offered in nursing homes and in 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

Table 1
Description of the study population

	1998–2000	2001–2003	2004–2006	2007–2009	2010–2012	2013	Total
N*	61,861	84,083	100,994	105,572	112,059	38,087	520,656
N with dementia	13,617	20,615	26,537	30,935	35,429	12,901	140,034
% with dementia	22.0	24.5	26.3	29.3	31.6	33.9	27.9
Age, mean	85.4	85.6	85.8	86.2	86.7	87.0	86.0
Age group (%)							
70–79	18.9	18.9	19.9	15.2	12.9	12.9	15.8
80–89	54.0	51.4	51.4	53.5	52.8	51.0	52.4
90+	27.1	29.7	30.7	31.3	34.2	36.1	31.7
Age group (men, %) [†]							
70–79	28.2	29.7	28.8	24.3	20.6	19.8	24.8
80–89	54.6	51.0	52.1	57.0	57.7	57.1	55.2
90+	17.2	19.3	19.2	18.7	21.7	23.1	20.0
Age group (women, %) [‡]							
70–79	14.9	14.2	12.7	10.7	9.0	9.2	11.5
80–89	53.7	51.5	51.1	51.7	50.4	47.7	51.1
90+	31.4	34.3	36.2	37.6	40.6	43.1	37.5

*Number of those who died at the age of 70 years or older: all those who died in years 1998 and 2002–2013, and a 40% random sample from years 1999 to 2001.

[†]Men N = 45,689.

[‡]Women N = 94,345.

mean age at the time of death was 87.2 years old (not shown in the table), with the maximum age being 111 years. The mean age of men was 84.0 (not shown in the table), with a maximum of 109 years.

The proportion of persons dying at the age of 90 years or over out of all those who died increased from 27.1% to 36.1% during the years of study (Table 1). Concurrently, the proportion of those who died at the age between 70 and 79 years decreased. The increase in the oldest age group was most notable in women: in 2013, 43.1% (31.4% in 1998–2000) of women and 23.1% of men (17.2% in 1998–2000) died at the age of 90 years or older.

The primary care hospital was the most common place of death for people aged 70 years with dementia in Finland: 39.8% of deaths occurred there in 2013 (Table 2). The second most common place was sheltered housing with 24-hour assistance where approximately every fourth person with dementia died (24.7%). Approximately every fifth person with dementia died in a nursing home (20.5%). Fewer than every tenth died at home (8.1%). Adding specialized care hospitals to primary care hospital, 46.7% of the people with dementia died in hospital. When nursing home and sheltered housing with 24-hour assistance were totaled up, 45.2% died in an LTC facility.

Dying at home or hospital was more common for men and those who died at the age of 70–79 years than for women and older age groups, while the oldest patients and women died more often at an LTC facility (Table 2). This finding did not change when the year of death and the other diagnoses were taken into account in the logistic regression analysis (Table 3).

Dying in hospital was common yet decreased notably during the study years: when specialized care hospitals and primary care hospital were totaled up, 71.2% in 1998,

but 46.7% in 2013, died in hospital. This decrease was caused by the decrease in primary care hospital deaths (64.0% in 1998–2000 and 39.8% in 2013). The decrease applied to all age groups (Fig. 1) and both genders (men; 74.3%–54.9%, women; 70.0%–42.2%, respectively, not shown in the tables). Death at specialized care hospitals did not change during the study period (7.2% in 1998–2000, 6.9% in 2013) in any age group (Fig. 1), for neither men nor women (not shown in the tables). The likelihood of dying in a hospital decreased consistently by the study year when age, gender, and other diagnoses were taken into account (Table 3).

The rate of dying at home did not change notably during the study years: 7.7% in 1998 and 8.1% of older people with dementia in 2013 died at home (Fig. 1). This was true for both genders (men; 8.6% to 9.2%, women; 7.2% to 7.5%, respectively, not shown in the tables). When age, gender, and other diagnoses besides dementia were adjusted for, the likelihood of dying at home decreased by study years but increased again to the same level in 2013 than in 1998–2000 (Table 3).

The most notable change occurred in sheltered housing with 24-hour assistance: the proportion of deaths was eight times higher in 2013 (24.7%) than in 2001–2003 (2.8%) (Fig. 1). The increase was highest among those who died at the age of 90 years or older (3.4% in 2001–2003 to 27.9% in 2013), but the increase was high also in other age groups: in the group 80–89, deaths in sheltered housing increased from 2.9% to 23.4%, and in the group 70–79 from 1.9% to 20.2% (Fig. 1). The increase also was true for both genders, although higher in women (from 3.2% to 27.9%, not shown in the tables) than in men (from 2.0% to 18.6%, not shown in the tables). The frequency of patients dying in a nursing home did not change during the study period

Table 2
Frequency distribution of the deceased with dementia at the place of death in 2013

Death place (%)	Home	Specialized care hospitals	Primary care hospital	Nursing home	Sheltered housing with 24-hour assistance
All	8.1	6.9	39.8	20.5	24.7
Mean age	85.5	84.5	85.8	87.3	87.5
Age group					
70–79	9.0	9.6	43.0	18.1	20.2
80–89	8.3	7.5	41.9	18.9	23.4
90+	7.6	5.2	35.7	23.7	27.9
Gender					
Men	9.2	9.8	45.1	17.1	18.6
Women	7.5	5.3	36.9	22.3	27.9

(20.7% in 1998–2000, and 20.5% in 2013) in men or women. There was a slight increase among the 70–79 age group, but no increase was observed among the older age groups. In the multivariate model, there was no clear time trend, but the likelihood of dying at nursing home was higher in years 2001–2003 and 2004–2012 than in the beginning or at the end of the study period.

4. Discussion

Hospital has been the predominant place of death for people with dementia in Finland. Dying in a primary care hospital that offers both primary hospital care and LTC is still most common, but it has decreased notably as is the place of death between 1998 and 2013. Dying in specialized care hospitals was relatively infrequent. A new form of LTC facility, sheltered housing with 24-hour assistance, was initiated in 2000, which has become an important place of death for people with dementia. The proportion of deaths in a nursing home or in a private home remained unchanged.

Our study showed that end-of-life care for people with dementia is moving from institutional care to noninstitutional LTC in Finland. The change in the service structure that decreased the institutional LTC and increased the available noninstitutional LTC has inevitably influenced this development. One of the primary goals of health and social care in Finnish policies is helping old people to stay at home or in a home-like environment as long as possible [16]. Furthermore, when increasing numbers of people are diagnosed with dementia and die with dementia, the question of which place offers the most peaceful and high-quality environment for the last period of life is of increasing significance. Studies imply that the design of the physical environment is an important factor in dementia care [17]. Sheltered housing with 24-hour assistance, a care facility that offers round-the-clock LTC in noninstitutional settings, was introduced in the 1990s in Finland. It provides an environment that is considered more home-like than institutional nursing home [18] and can therefore be beneficial for people with dementia [17,19–21]. Hospital settings are considered inadequate for

Table 3
The association of the place of death with age, gender, and the year of death among people with dementia

Place of death	All (N = 14,0003)	Home	Specialized care hospital	Primary care hospital	Nursing home	Sheltered housing with 24-hour assistance
		(N = 8873)	(N = 11,235)	(N = 76,684)	(N = 30,609)	(N = 12,489)
		OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)
Gender (%)						
Men	45,689 (32.6)	Ref	Ref	Ref	Ref	Ref
Women	94,345 (67.4)	0.69 (0.66–0.72)*	0.56 (0.54–0.58)*	1.10 (1.07–1.12)*	1.24 (1.20–1.27)*	1.24 (1.18–1.29)*
Age at death (%)						
70–79	22,170 (15.8)	Ref	Ref	Ref	Ref	Ref
80–89	73,414 (52.4)	0.80 (0.75–0.85)*	0.73 (0.69–0.77)*	0.94 (0.91–0.97)*	1.17 (1.12–1.22)*	1.39 (1.31–1.48)*
90+	44,450 (31.7)	0.66 (0.62–0.70)*	0.45 (0.43–0.48)*	0.83 (0.81–0.86)*	1.58 (1.51–1.65)*	1.73 (1.63–1.85)*
Year of death (%)						
1998–2000	13,617 (9.7)	Ref	Ref	Ref	Ref	Ref
2001–2003	20,615 (14.7)	0.70 (0.64–0.76)*	0.99 (0.91–1.08)*	0.90 (0.86–0.95)*	1.10 (1.04–1.16)*	Ref
2004–2006	26,537 (19.0)	0.69 (0.64–0.75)*	1.17 (1.09–1.27)*	0.80 (0.77–0.84)*	1.05 (1.00–1.11)	1.57 (1.42–1.74)*
2007–2009	30,935 (22.1)	0.71 (0.66–0.77)*	1.09 (1.01–1.18)*	0.70 (0.67–0.73)*	1.10 (1.04–1.16)*	2.62 (2.38–2.87)*
2010–2012	35,429 (25.3)	0.85 (0.79–0.91)*	1.02 (0.95–1.11)	0.47 (0.45–0.49)*	1.16 (1.10–1.22)*	5.83 (5.34–6.36)*
2013	12,901 (9.2)	1.01 (0.92–1.10)	0.90 (0.82–0.99)*	0.34 (0.32–0.35)*	0.99 (0.93–1.05)	10.97 (10.01–12.02)*

NOTE. Odds ratios (ORs) and 95% confidence intervals with binary logistic regression models. Statistically significant odds ratios are with * mark significant at $P < .05$. Adjusted for comorbidity, including 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.

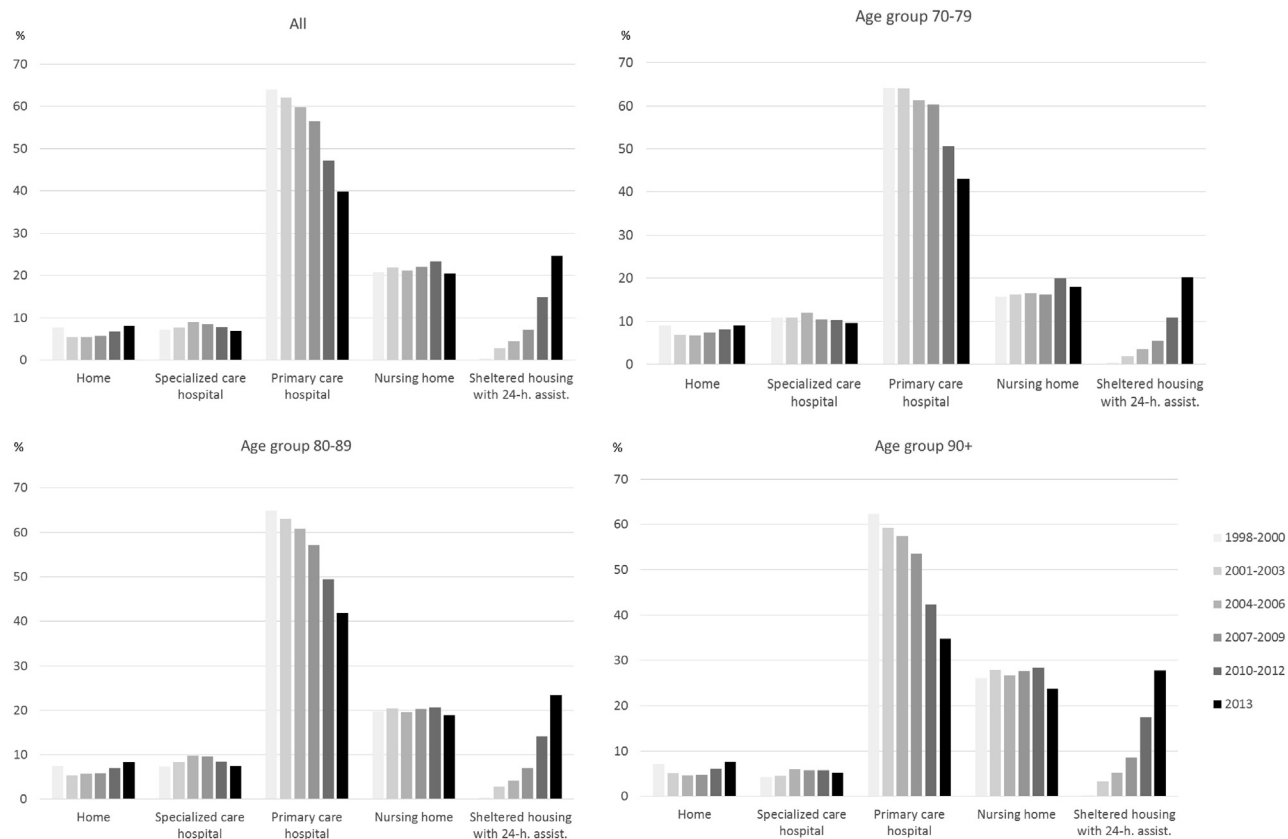


Fig. 1. The places of death (%) between 1998 and 2013. The whole study population and age groups of 70–79, 80–89, and 90+.

end-of-life care for people with dementia [23]. Lehmus et al. [24] found that family members thought that patients in an LTC care facility (sheltered housing with 24-hour assistance) in Finland received higher quality end-of-life care than those who died in a hospital. Thus, the decreasing number of deaths in hospital and increasing number of deaths in LTC facility during the study years may suggest an improvement in the end-of-life care setting. Even if an increasing number of people with memory disorders live and are cared for at their homes [15], its importance as a place of death did not change. The end-of-life care at the patient’s own home is valued higher than hospital care [25], but in reality, caring for people with dementia at home until the end of their lives may be difficult and it may have negative effects on informal caregivers’ mental and physical health [26,27].

The places of death of people with dementia differ between countries, although the LTC settings seem to be the most frequent places of death for the people with dementia in Europe and North America [23]. In a study of five European countries from the early 2000s, dying at home was even rarer in the UK and the Netherlands than in Finland. Dying in hospital was rare for people with dementia in the Netherlands but quite common in the UK [9], where dying in hospital was close to the level of hospital deaths in Finland. In the UK population-based prospective study, of the oldest old (aged over 85 years) who were community dwelling a year before death, a majority

had cognitive impairment (one-quarter had mild/moderate, one-third had severe). Those oldest old most frequently died at the acute hospital. Just only 8% died in the community [7]. The ratio of dying in hospital of people with dementia in the UK used to be one of the highest proportions in Europe in 2003 [9]. However, this trend toward hospital death in dementia reversed during the last decade (2001–2010) [28]. The hospital deaths started to decrease in 2006, and residential care home deaths had been increasing (0.60% per year) due to the growing of care home bed provision. Even though, the hospital deaths in UK remained rather high ratio [28] and were about as frequent as in Finland.

Place of death from Alzheimer’s disease in the United States also has changed in the last decades. Nursing home or LTC facility is still most likely the end-of-life place between in 1999 to in 2014; however, during this period, the percentage of death in a medical facility or nursing home declined. By contrast, the death at home increased from 13.9% in 1999 to 24.9% in 2014 [29]. The causes behind those changes are not clear, but the report [29] suggested the influence of financial effect. The increasing number of dementia is crucially affecting government budget at social and health care expenditure on LTC in many countries [30,31]. It causes serious problems in the practice of social and health care such as resulting in lack of sufficient professional care for all patients [30].

Sheltered housing with 24-hour assistance is not without problems. A study found that in Finland, sheltered housing facilities had a higher number of end-of-life care transitions, especially hospital admissions, than traditional nursing homes [32]. There are few studies on what causes the end-of-life care transitions. Some reasons could include symptoms that are too difficult to be treated outside hospitals, such as falls, pneumonia, or hip fractures [33,34]. In addition, previous care transition studies found that dementia is not always recognized as a terminal illness [25,35,36]. This might cause unnecessary hospitalizations with aggressive or insufficient treatments at the end of life [35].

Even if sheltered housing with 24-hour assistance is considered more home-like, in reality, the arrangements vary and are often rather similar to institutional care sites in Finland. The notable difference between nursing homes and sheltered housing with 24-hour assistance is funding. Institutional care funding is strictly regulated and as such is fairly identical across the country, whereas nationwide rules for funding sheltered housing are nonexistent leading to variable fees that are often higher than in institutional care for old people themselves. While the rent of service housing is partly covered by the reimbursement of the Social Insurance Institution, and the municipality covers most of service fees for the less affluent people, many services that are included in nursing home care have to be paid out of the residents' own pockets [22]. More research is needed on the quality of end-of-life care in sheltered housing and to what extent the unregulated user fees affect the residents' ability to purchase different services.

In the United States, hospice care for people with dementia has been considered as effectively supporting the maintenance of function and comfort at end of life. An American study of place of death among people with dementia noted that most deaths (older than 65 years) occurred in nursing homes (66.9%) in 2001 [27]. However, palliative and hospice care has become more common in the United States than in other countries, after which deaths at home related to dementia increased to 22.8% in 2009 from 19.9% in 2000 among Medicare beneficiaries [36] and the ratio of Alzheimer's decedents died at home increased from 13.9% in 1999 to 24.9% in 2014, with an additional 6.1% who died in a hospice facility in 2014 [29]. In Finland, both hospices and hospice-like care at home are rare. According to Finnish care guideline, every health care facility should have the ability to offer palliative care. LTC facilities are also expected to offer end-of-life care for those who are dying [37]. Because of rapidly increasing longevity in Finland, the number of people dying with dementia is expected to increase. Further research should focus on developing adequate care settings at home.

During the study years, the frequency of dementia among those who died at the age of 70 years or older increased from 22.0% to 33.9%. Deaths related to dementia were more common for women than for men. The proportion

of those who died at the age of 90 years or older increased in both genders, suggesting either that people survive longer with dementia or that the onset of dementia is postponed. This applies especially to women, as in 2013, almost a half of women with dementia died at the age of 90 years or older. The older the age, the more often death occurred at a LTC facility, which is likely to lead to an increasing number of deaths in LTC with increasing longevity. In Finland, as in the other Nordic welfare states, the responsibility for social and health care belongs to the state and municipalities rather than the family [38,39]. The rapid increase in longevity and the number of persons with dementia will challenge the current care system due to the financial burden [10,16]. Furthermore, even if the national policy emphasizes staying at home instead of round-the-clock care, this may not be possible for people with dementia. Particularly, the advanced stage of dementia requires more intensive care, which may eventually result in patients being institutionalized [25,33].

This is the first report of the place of death of people with dementia in Finland in the context of a care policy emphasizing noninstitutional care. This analysis, using extensive nationwide data, provided a unique opportunity to study the place of death and the care system in the whole country. The care systems in different countries vary, and often, the data used in previous studies [9] have been based on population samples, not the whole population like in this study, which makes the international comparisons problematic. However, this study has some limitations. Since 2005, the Finnish cause-of-death statistics have adopted an international guideline that limits the use of pneumonia as an underlying cause of death in connection with several chronic diseases. For a person who dies from pneumonia but also suffers from advanced dementia, dementia is selected as the underlying cause of death; before this change, pneumonia may have been registered as the underlying cause [10]. To some extent, this change in diagnostic criteria may have contributed to the increase in dementia as the underlying cause of death in the registers. Yet, in our data, when detecting dementia diagnosis as the cause of death, all causes of death (immediate, underlying, intermediate, and contributing) were taken into account.

In conclusion, since the end of the last century, death of people with dementia has moved from hospital to LTC facility, especially to sheltered housing with 24-hour assistance in Finland. This change is caused by the LTC reform that favors care in sites classified as outpatient facilities but also by increasing longevity. Previous studies imply that LTC facilities are more appropriate places for end-of-life care for people with dementia than hospitals. Yet, there is a lack of research investigating the quality of end-of-life care in this relatively new type of LTC facility. Research on the quality of end-of-life care for people with dementia is urgently needed to determine if the ongoing LTC reform can meet the special needs of people dying with dementia.

Acknowledgments

This study was financially supported by the Competitive State Research Financing of the expert responsibility area of Tampere University Hospital (250241551/Riitta Rantala [Y.M. & M.A.]).

RESEARCH IN CONTEXT

- 1 **Systematic review:** We investigated how the place of death changed between 1998 and 2013 among people diagnosed with dementia in Finland using the data from the Finnish national health and social care registers (total number of 140,034).
- 2 **Interpretation:** This is the first report of the place of death of people with dementia in Finland in the context of a care policy emphasizing noninstitutional care. This analysis, using extensive nationwide data, provided a unique opportunity to study the place of death and the care system in the whole country. We found that since the end of the last century, death of people with dementia has moved from hospital to long-term care facility, especially to sheltered housing with 24-hour assistance.
- 3 **Future directions:** Research on the quality of end-of-life care for people with dementia is urgently needed to determine if the ongoing long-term care reform can meet the special needs of people dying with dementia.

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