

Mari Aaltonen,<sup>1</sup> Leena Forma,<sup>1</sup> Jutta Pulkki,<sup>1</sup> Jani Raitanen,<sup>1,2</sup> Pekka Rissanen,<sup>1</sup> Marja Jylha<sup>1</sup>

**To cite:** Aaltonen M, Forma L, Pulkki J, et al. Changes in older people's care profiles during the last 2 years of life, 1996–1998 and 2011–2013: a retrospective nationwide study in Finland. *BMJ Open* 2017;7:e015130. doi:10.1136/bmjopen-2016-015130

► Prepublication history for this paper is available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2016-015130>).

Received 11 November 2016  
Accepted 30 August 2017



CrossMark

<sup>1</sup>Faculty of Social Sciences (Health Sciences) and Gerontology Research Center, University of Tampere, Tampere, Finland

<sup>2</sup>The UKK Institute for Health Promotion Research, Tampere, Finland

**Correspondence to**  
Dr Mari Aaltonen;  
mari.s.aaltonen@uta.fi

## ABSTRACT

**Objectives** The time of death is increasingly postponed to a very high age. How this change affects the use of care services at the population level is unknown. This study analyses the care profiles of older people during their last 2 years of life, and investigates how these profiles differ for the study years 1996–1998 and 2011–2013.

**Design** Retrospective cross-sectional nationwide data drawn from the Care Register for Health Care, the Care Register for Social Care and the Causes of Death Register. The data included the use of hospital and long-term care services during the last 2 years of life for all those who died in 1998 and in 2013 at the age of  $\geq 70$  years in Finland.

**Methods** We constructed four care profiles using two criteria: (1) number of days in round-the-clock care (vs at home) in the last 2 years of life and (2) care transitions during the last 6 months of life (ie, end-of-life care transitions).

**Results** Between the study periods, the average age at death and the number of diagnoses increased. Most older people (1998: 64.3%, 2013: 59.3%) lived at home until their last months of life (profile 2) after which they moved into hospital or long-term care facilities. This profile became less common and the profiles with a high use of care services became more common (profiles 3 and 4 together in 1998: 25.0%, in 2013: 30.9%). People with dementia, women and the oldest old were overrepresented in the latter profiles. In both study periods, fewer than one in ten stayed at home for the whole last 6 months (profile 1).

**Conclusions** Postponement of death to a very old age may translate into more severe disability in the last months or years of life. Care systems must be prepared for longer periods of long-term care services needed at the end of life.

## INTRODUCTION

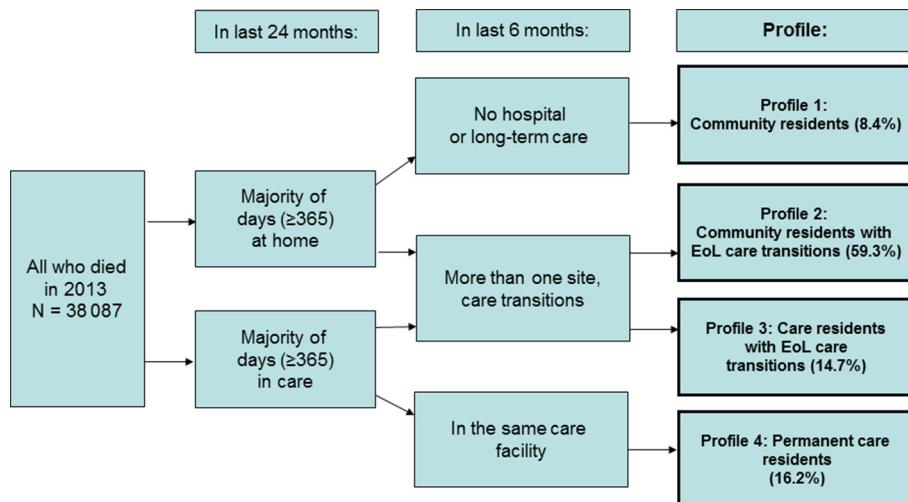
Driven mainly by longer average lifespans, population ageing creates significant new challenges for health and social service systems worldwide.<sup>1 2</sup> Findings on health trends and the development of healthy life expectancy vary, but what is constant is that,

## Strengths and limitations of this study

- The major strength of this study is the availability of information on all round-the-clock care use and days lived at home during the last 730 days of life for everyone who died at age 70 or older in 1998 or in 2013 in Finland.
- The size and reliability of the study population provides a unique study composition that enables the identification of the older populations' care profiles at the national level, and clearly reveals how those profiles have changed between the study years.
- The data lacked information on functional ability, availability of informal care and formal home care, all of which are important contributors to care use.
- Detailed information on which care sites people actually moved between could not be identified.

on average, physical and cognitive capabilities will decline with increasing old age and approaching death.<sup>3–7</sup> The use of care services<sup>8–10</sup> and care transitions, that is, movements between care sites,<sup>11–13</sup> are thus naturally more frequent at the end of life (EoL) than earlier. Declining old-age mortality has postponed the EoL period and death to older ages, thereby producing new challenges for medical services and long-term care.

In response to the increasing need for care and rising costs induced by population ageing and longer life, several countries have reallocated resources from institutional care to support for living at home with home help or in home-like care facilities.<sup>14–17</sup> Finland is no exception. Since the late 1990s, the provision of traditional institutional long-term care has decreased, while the availability of service housing with 24 hours assistance, classified as community long-term care, has increased.<sup>18</sup> This change has coincided with an increase in the modal age of death from



**Figure 1** The four care profiles. End of life (EoL) refers to the last 6 months of life.

83 to 86 years and a doubling in the number of people aged 85 or older.<sup>19</sup>

Although the impacts of higher age and the closeness of death on care use are well known, we still lack a good understanding of patterns of care use among older people. We have virtually no information about how these care patterns will be affected by the ongoing reform of care services. In this study, we took advantage of existing nationwide care registers to investigate (1) care profiles in the last 2 years of life for the entire population who died at the age of 70 or older in Finland in 1998 or in 2013 and (2) the changes in these profiles between 1998 and 2013, a period during which long-term care was reformed.

## METHODS

### Data

The data for the study were drawn from national registers and included the use of hospital and long-term care services during the last 2 years of life for all people who died in 1998 (n=34 116) and in 2013 (n=38 087) at the age of 70 or older in Finland. Information on the use of care services for the last 730 days for each individual was obtained from the Care Register for Health Care and the Care Register for Social Care (National Institute for Health and Welfare). These registers include information on all care use delivered in all round-the-clock care facilities. The information in the registers is filled for everyone, thus there is practically no missing information. The decision to focus on the last 2 years of life was based on the knowledge that the use of different care services increases most sharply during this period.<sup>8,9</sup> The Causes of Death Register (Statistics Finland) provides the date of death and all causes of death (immediate, underlying, intermediate and contributing causes) as stated on each individual death certificate. Datasets were linked using personal identity codes (PICs) that remain unchanged throughout the person's lifetime. The researchers had no access to the PICs. Permission to access the registers was obtained from each registrar. The research plan

was approved by the Pirkkamaa Hospital District Ethics Committee (Decision R08192).

The diagnoses were identified in the care registers and the Causes of Death Register and were categorised according to the International Classification of Diseases (ICD10): dementia (F00–F03, G30), cancer (C00–C97), diabetes (E10–E14), psychosis, depressive symptoms or other mental health disorders excluding dementia (F04–F99), Parkinson's disease or other neurological diseases (G00–G99 excluding G30), chronic asthma and chronic obstructive pulmonary disease (COPD) or other respiratory diseases (J00–J99), hip fracture (S72), stroke (I60–I69), ischaemic and other heart diseases excluding rheumatic and alcoholic heart diseases (I20–I25, I30–I425, I427–I52), and other diseases of the circulatory system (I00–I15, I26–I28, I70–I99).

### Care services

The care services used and the amount of time spent outside care facilities was followed for 730 days prior to each individual's death. The round-the-clock care services studied here included primary care hospital (health centre inpatient wards offering short-term hospital care and institutional long-term care); specialised care hospital (university hospitals and central, district and private hospitals); nursing homes (institutional long-term care) and service housing with 24 hours assistance (community long-term care). Service housing with 24 hours assistance (also known as sheltered housing with 24 hours assistance) represents a relatively new form of round-the-clock long-term care facilities and differ from nursing homes. Most nursing homes are publicly owned, while more than half of the service housing facilities with 24 hours assistance facilities are owned by the private sector or non-governmental organisations. Municipalities offered care in publicly owned nursing homes previously, however, in recent years, they have increasingly purchased services from privately owned service housing that provides 24 hours assistance. The eligibility for long-term care placement either in a nursing home or in service

housing with 24 hours assistance is needs based. Service housing facilities are considered more home-like than nursing homes, but the former are expected to provide care for similar health conditions and resident groups as the latter, namely, nursing homes do. The municipalities hold the main responsibility for the funding of nursing home care, and in addition the residents pay an income-based monthly fee for care and residence. On the contrary, in service housing with 24 hours assistance the fees which the residents pay out of pocket vary, thus the funding is not as regulated as it is for nursing homes.<sup>20</sup>

People were classified as living at home when they were not in any of the above described care facilities. However, we have no data on the use of informal care or formal home care services. The 1998 study population refers to people who died in 1998: their care use thus took place during 1996–1998. The 2013 study population refers to people who died in 2013 and whose care use took place during 2011–2013.

### Key concepts

*Use of care* refers to the number of days stayed in different round-the-clock care facilities in the last 2 years of life. *Care transition* is defined as moving from one's home to a care facility or from one care site to another or a home discharge for at least one night. *Care profile* refers to the whole trajectory of days stayed at different sites and the frequency of care transitions in the last 24 months. The concept EoL refers here to the final 6 months of life.

### Identification of profiles

Based on earlier findings by our research group<sup>9 20 21</sup> and others,<sup>6–8 22</sup> we considered being in round-the-clock care versus living at home and the experience of care transitions as the most important descriptors of patterns of care during the last years of life. Therefore, we first categorised each individual into a group by using two criteria (figure 1): (1) whether the decedent had lived the majority of time in the last 2 years of life in round-the-clock care ( $\geq 365$  days) or at home ( $\geq 365$  days) and (2) whether or not the decedent had any care transitions during the last 6 months of life (ie, EoL care transitions).

Based on these criteria, we constructed four care profiles. The first profile consisted of people who lived most of the time in the last 2 years at home and had no transitions to care facilities in the last 6 months. The second profile included those who lived most of their last 2 years at home and had care transitions in the last 6 months. The third profile comprised people who lived most of the time in round-the-clock care and had EoL care transitions. The fourth profile included people who lived most of the time in round-the-clock care and stayed the last 6 months in the same care facility. These categories covered 97.8% and 98.6% of all individuals who died in 1998 or in 2013, respectively. Individuals who did not fall into any of these categories (2.2% in 1998 and 1.4% in 2013) were designated as 'unclassified' and thus excluded from further analysis.

**Table 1** Description of the study population, care transitions and days in round-the-clock care\*

Year of death (n)	1998 (34 116)	2013 (38 087)
Age at death, mean†	82.4	84.3**
Age (%)‡		
70–79	36.4	27.2**
80–89	46.8	46.7**
90+	16.8	26.1**
Gender (%)‡		
Men	40.8	43.5**
Women	59.2	56.5**
Diagnoses (%)*‡		
Dementia	21.7	33.9**
Cancer	23.1	25.8**
Diabetes	13.8	16.1**
Mental disorders	7.1	6.4**
Neurological	10.1	11.6**
Respiratory	43.6	45.5**
Hip fracture	7.3	6.1**
Stroke	22.8	19.9**
Ischaemic heart disease	55.3	53.2**
Other circulatory disease	27.7	41.2**
Number of diagnoses, mean	2.3	2.6**
§		
Number of transitions, mean (median)¶		
In last 24 months	7.8 (5.0)	7.9 (5.0)
In last 6 months	3.2 (2.0)	3.3 (2.0)**
Days in care, mean (median)¶		
Last 24 months in total	220.3 (82.0)	257.4 (93.0)**
Primary care hospital	103.1 (22.0)	65.0 (18.0)**
Specialised care hospital	20.2 (7.0)	14.0 (4)**
Nursing home	96.6 (0)	63.5 (0)**
Service housing with 24 hours assistance	na	113.2 (0)**
Days at home, mean (median)¶	509.7 (648.0)	472.6 (637.0)**

All those who died at age 70 or older in 1998 and 2013.

\*The Causes of Death Register, The Care Register for Health Care, and The Care Register for Social Welfare.

†p Value refers to independent samples t-test between 1998 and 2013.

‡p Value refers to  $\chi^2$  test by crosstabs between 1998 and 2013.

§Includes the above mentioned diagnoses.

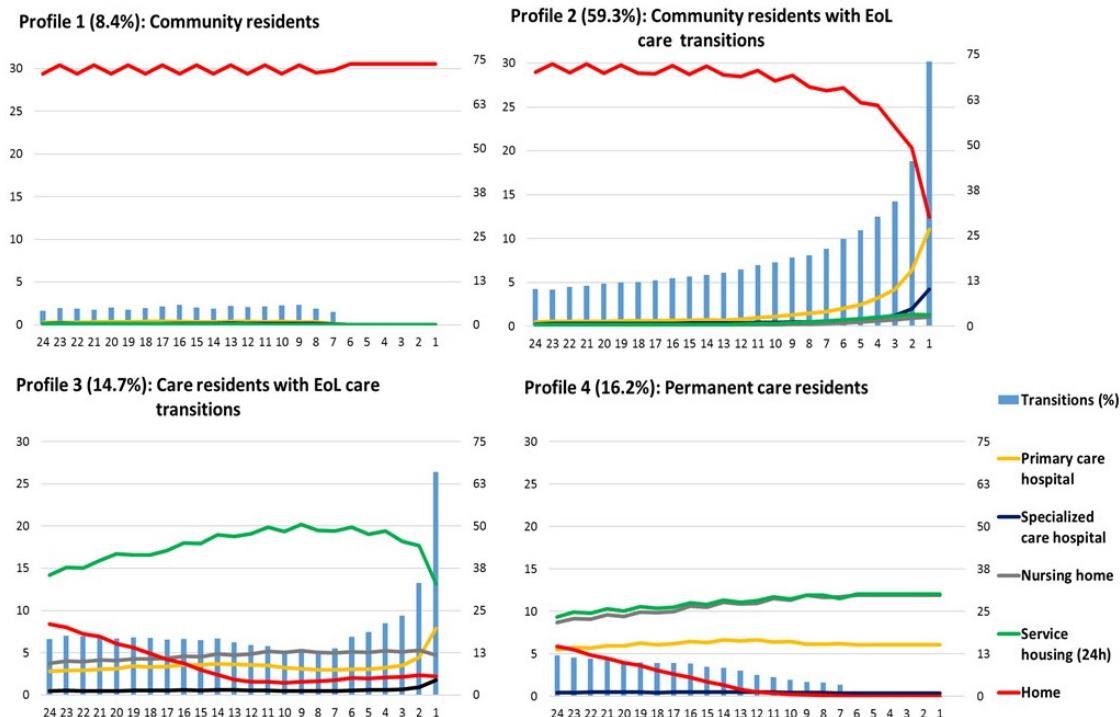
¶p Value refers to Mann-Whitney U test between 1998 and 2013.

\*\*p<0.001.

na, information not available.

### Statistical analysis

The characteristics of the different profiles were described by age, gender, diagnostic groups, number of care transitions in the last 2 years and in the last 6 months, and number of days in care during the last 2 years. First,



**Figure 2** Profiles 1–4 in 2013. Right scale: proportion (%) of people who had transitions 24 months to 1 month before death. Left scale: average number of days in different care facilities or at home 24 months to 1 month before death. EoL, end of life.

the study population was categorised into four different profiles and described among those who died in 2013. Second, the profiles were identified among those who died in 1998. Third, the profiles in 1998 and 2013 were compared.  $\chi^2$  tests were performed to compare the proportion of different age groups, men, women and the proportion of people with different diagnoses in different profiles for these years. Independent sample t-tests were performed to compare the mean age and mean number of diagnoses for the different profiles between 1998 and 2013. Mann-Whitney U tests were conducted to compare the number of transitions in the last 2 years and the last 6 months, and the number of days in care for the different profiles. The data were analysed using IBM SPSS Statistics V.22. Profile figures were constructed using Excel (Microsoft Office 2013).

## RESULTS

The number of people who died at age 70 or older totalled 34 116 in 1998 and 38 087 in 2013. The average age at death was 82.4 years in 1998, and 84.3 years in 2013 (table 1). The proportion of women in the sample was lower in 2013 (56.5%) than in 1998 (59.2%). The proportion of those with dementia, cancer, diabetes, Parkinson's disease or other neurological diseases, chronic asthma and COPD or other respiratory diseases, and other diseases of the circulatory system, in last 2 years of life, was higher in 2013 than in 1998. Hip fracture, stroke, ischaemic and other heart diseases, and mental disorders decreased between the study years. The average number of diagnoses in the last 2 years of life and the number of

care transitions in the last 6 months of life increased. The total number of days in care per capita increased due to the increase in days in service housing with 24 hours assistance; the number of days in other care facilities decreased between the study years, as the number of days lived at home also decreased.

The four care profiles constructed in 2013 were: (1) community residents (8.4% of the whole study population); (2) community residents with EoL care transitions (59.3%); (3) care residents with EoL transitions (14.7%) and (4) permanent care residents (16.2%) (figure 2). In all profiles, the average age, the proportion of those who died at age 90 or older and the proportion of men were higher in 2013 than in 1998.

Profile 1, community residents, was equally prevalent in both study years. Older people in this group made little use of care services, especially care provided in long-term care facilities (table 2). All of the older people in this group stayed at home for the last 6-month period. This profile was the youngest of all the profiles although the average age and the proportion of those who died at the age of 80 or older increased. Profile 1 was the only one with a male majority. The number of diagnoses was lower (average 1.8) than in the other profiles, although the number was higher in 2013 than in 1998. Over half had ischaemic heart disease and one-third had other circulatory diseases.

Profile 2, community residents with EoL care transitions, was the single biggest profile and accounted for over half the study population, although the profile was less prevalent in 2013 than in 1998 (table 2). People in

**Table 2** Description of profiles

	Profile 2: Community residents with EoL care transitions						Profile 3: Care residents with EoL care transitions			Profile 4: Permanent care residents		
	1998	2013	1998	2013	1998	2013	1998	2013	1998	2013	1998	2013
<b>Year of death</b>												
% of population (n)	8.5 (2889)	8.4 (3207)	64.3 (21 951)	59.3 (22 568)	10.5 (3574)	14.7 (5610)	14.5 (4958)	16.2 (6176)				
<b>Population</b>												
Age, mean*	79.4	81.1**	81.4	83.2**	85.2	86.8**	86.3	87.8**				
Age (%)†												
70–79	55.2	44.9**	41.7	32.0**	19.5	15.0**	16.8	12.9**				
80–89	37.0	41.2**	45.9	47.7**	54.6	48.2**	49.9	44.6**				
90+	7.8	13.9**	12.4	20.3**	25.9	36.8**	33.3	42.5**				
Gender†												
Men	51.4	57.6**	45.2	48.3**	31.1	34.5**	23.9	27.0**				
Women	48.6	42.4**	54.8	51.7**	68.9	65.5**	76.1	73.0**				
Number of diagnoses, mean*	1.5	1.8**	2.4	2.7**	2.7	3.0**	2.3	2.3				
Diagnoses (%)†												
Dementia	5.7	10.8**	12.0	20.4**	40.8	59.3**	56.5	70.4**				
Cancer	7.0	8.9**	31.0	36.4**	12.9	13.3	6.5	8.1*				
Diabetes	8.9	12.1**	15.0	17.9**	16.0	17.8*	10.0	10.1				
Mental disorders	5.9	8.2**	6.3	5.8*	10.4	8.4*	8.5	5.6**				
Neurological	3.9	5.6*	9.8	11.7**	15.8	14.8	11.9	11.3**				
Respiratory	14.9	19.9**	43.8	48.0**	52.9	56.7**	51.3	39.9**				
Hip fracture	1.2	1.5	6.7	6.1*	15.8	10.5**	7.4	4.7**				
Stroke	12.0	10.3*	22.1	19.2**	28.6	25.9*	27.0	21.5**				
Ischaemic heart disease	74.2	66.5**	57.7	57.7	52.5	51.3	37.4	34.0**				
Other circulatory disease	25.8	35.8**	30.6	46.4**	25.7	41.2**	18.1	25.0**				
<b>Description of profiles</b>												
Number of transitions,‡ mean (median)												
In last 2 years	1.8 (0)	1.6 (0)**	9.7 (7)	9.9 (7)	8.3 (6)	9.1 (6)**	2.5 (0)	2.7 (0)				
In last 6 months	0	0	4.5 (3)	4.7 (4)**	2.8 (2)	3.4 (3)**	0	0				
Days in care,‡, mean (median)												
Primary care hospital	14.8 (0)	10.4 (0)**	78.7 (53)	77.5 (52)**	610.9 (665)	645.0 (728)**	672.5 (730)	688.2 (730)**				
Specialised care hospital	5.7 (0)	5.9 (0)	42.1 (20)	43.7 (24)**	128.0 (41)	84.1 (24)**	398.7 (461)	148.9 (0)**				
Nursing home	3.5 (0)	2.4 (0)**	23.6 (0)	16.2 (9)**	23.2 (5)	14.5 (3)**	14.4 (0)	11.0 (0)**				

Continued



Table 2 Continued

Year of death	Profile 1: Community residents		Profile 2: Community residents with EoL care transitions		Profile 3: Care residents with EoL care transitions		Profile 4: Permanent care residents	
	1998	2013	1998	2013	1998	2013	1998	2013
Service housing	na	1.4 (0)	na	10.7 (0)	na	424.8 (521)	na	266.9 (0)
Home	715.2 (730)**	719.6 (730)**	651.4 (677)	652.5 (680)**	119.1 (65)	84.6 (2)**	57.5 (0)	41.8 (0)**

EoL, end of life, refers to the last 6 months of life.

Number of diagnoses: mean number of major diagnostic groups in Causes of Death register, Care Register for Health Care and Care Register for Social Welfare.

Diagnoses: prevalence by profiles in 1998 and in 2013 in Causes of Death register, Care Register for Health Care and Care Register for Social Welfare.

\* $p < 0.005$ , \*\* $p < 0.001$ .

\*p Value refers to independent samples t-test between 1998 and 2013.

†p Value refers to  $\chi^2$  test by crosstabs between 1998 and 2013.

‡p Value refers to Mann-Whitney U test between 1998 and 2013.

na, information not available.

this profile lived mainly at home, and most of their round-the-clock care use was clustered in their last few months of life. The average number of days in care facilities during the last 2 years was only 77.5 days, indicating that people mostly spent less than 3 months in care. The use of long-term care services was infrequent. The number of care transitions was higher than in other profiles and increased from 1998 to 2013. This was the second youngest profile yet the proportion of people aged 90 or older increased especially. Profile 2 was almost equally common among men and women. The number of diagnoses was rather high and increased from 1998 to 2013. The most common diagnosis was cardiovascular disease, followed by respiratory diseases. Cancer was clearly more frequent in this profile than in the other profiles and increased over time: over one-third of the people in this profile were diagnosed with cancer.

The number of care residents with EoL care transitions (profile 3) increased from 1998 to 2013 (table 2). Long-term care use was frequent, especially service housing with 24 hours assistance. People increasingly moved from long-term care to hospital as death approached. The care transitions were rather high and increased from 1998, but they were still lower than in profile 2. Profile 3 was dominated by women and people aged 80 or over. The average number of diagnoses increased from 1998 to 2013. The prevalence of both dementia and respiratory diseases was over 50%, and was higher in 2013 than in 1998.

The number of permanent care residents (profile 4) increased somewhat over time (table 2). This was the oldest profile: the average age of death was 87.8 years, and 42.5% were aged 90 or older. The days lived in care facilities were also the highest of all in this profile: permanent care residents spent no more than approximately 1 month at home. The number of care transitions was rather low, and they did not change between the study years. The average number of diagnoses also remained unchanged. The majority were women, and three in four of the permanent care residents had dementia. The prevalence of dementia increased notably between the study years.

## DISCUSSION

In this study of Finnish people who died at the age of 70 or older in 1998 and 2013, we constructed four care profiles in the last 2 years of life. One of the main findings was that the majority of older people lived outside care facilities until the very last months of life. This, however, became less frequent over the study period, and the care profiles with high levels of care service use became more prevalent. The proportion of those who lived majority of the time in care and had care transitions in the last 6 months of life increased in particular. These changes in older people's care profiles occurred simultaneously to when the Finnish healthcare policy has promoted de-institutionalisation of care and emphasised living at home as long as possible. Therefore, the

care in last 2 years of life has developed in the opposite direction to what the recommendations for care policy suggested.

The number of people who died at a very old age with dementia, and with multi-morbidity, increased between the study years. It is likely that increasing longevity and morbidity contributed to the increase in care profiles that showed high levels of care use.<sup>9 22–25</sup> Lunney *et al*<sup>6 7</sup> identified four EoL functional decline trajectories: the frailty group, cancer group, sudden death and organ failure group. The patterns of functional decline illustrate the level of independence and the need for care near the time of death; the sudden death and the cancer group were the most independent, while the frailty group was the least independent and used long-term care services the most. In our study, profiles 1 and 2 likely include the sudden death and cancer groups, respectively, represented in Lunney's study, while profiles 3 and 4 share characteristics that are in common with the frailty group that is dominated by very old people and women. The changes in care service use at the EoL and in the study population do imply that the proportion of those who belong to the frailty group at the EoL has increased between the study periods.

The increase in the percentages and the numbers of people aged 90 or older and those with dementia were highest in the care profiles 3 and 4. However, these numbers increased in all the profiles, even among those who lived at home until their last months. We do not know the functional status of these individuals or how independently they managed in their everyday lives, but there is no evidence that the functional capacity of people aged 90 or over has improved in the past decade.<sup>26</sup> It is possible then that increasing numbers of the very old and frail are living their last months of life mainly at home. If this is true, more resources will need to be made available to home care services to ensure there is a sufficient supply of professionals trained in the care of older people with dementia and complex chronic conditions.

Further, more resources and greater effort will probably have to be invested in informal care, which is usually provided by family members or friends.

Patterns of care use reflect not only the changes occurring in the population structure, but also the ongoing reform of the service system. Between the two study years, the emphasis of long-term care in Finland shifted from institutional care to community long-term care offered in service housing with 24 hours assistance. Our finding of an increase in the number of older people categorised in profile 3, including EoL care transitions, suggests that increasing use of service housing may have led to a higher number of care transitions near the time of death, a result supported by our previous study.<sup>20</sup> Our results also showed a decline in hospital days and an increase in the number of diagnoses. In previous studies, both the shorter periods of hospital care<sup>27</sup> and the increased number of diagnoses<sup>28</sup> were identified as underlying causes of the more frequent care transitions. There are few studies on what

causes transitions from service housing with 24 hours assistance to hospitals.<sup>29 30</sup> Some of the reasons include symptoms that are too difficult to be treated outside hospitals, such as severe falls or hip fractures. Transitions of these kinds of cases to hospitals are likely to indicate adequate care. Yet, a higher number of care transitions may also be indicative of poor coordination of care for those suffering from complex chronic conditions.<sup>1</sup> The growing number of transitions, particularly close to death, may also jeopardise the quality of care and quality of life, especially in the most vulnerable patient groups, such as those with cognitive impairment.<sup>31</sup> Better coordination of care and improved management of hospital admissions and discharges are essential conditions for a well functioning and ageing friendly service system.<sup>1</sup> When health and social care services are reorganised to cope with an increasing number of older clients, it is important to give careful thought to the unintended consequences of those changes.

Rather than trying to identify causal relationships between individual characteristics and care use, this study provides greater insight into ongoing demographic changes and how these changes are reflected in actual care use at the population level. The greatest strength of this research is in its use of extensive and reliable register data that enabled a retrospective follow-up on all older people who died in 1998 and in 2013. Finnish care registers are considered highly reliable<sup>32</sup> for providing accurate information on care service use and individual characteristics. The information on care use, care transitions and personal characteristics, such as age, gender and diagnoses, are available for everyone; thus there are practically no missing data in these registries. A rough classification, based on previous research findings, was made on the basis of days stayed in care and EoL care transitions. It revealed clear differences between the four profiles in age, gender and frequency of different diagnoses. Retrospective EoL care studies are not without critique due to the observation time decided in advance, which does not vary between the study subjects, and the problems in drawing associations between the subject characteristics and the observed care.<sup>33</sup> Yet, the purpose of our study was not to establish any prospective care use trajectories for different diagnoses, or to evaluate clinical care pathways typical for specific diseases. The main goal of this paper was to present a realistic view of the extent of care service use in the last 2 years of life in the older population during the time when death is increasingly postponed to higher ages, and major care reforms are conducted to reduce institutional care and increase living at home. Such a nation-wide, retrospective study provides extensive information about the extent and the specific services that are being used in this population during the last years of life, that is, during the time period when care use is usually at its highest,<sup>8–10</sup> as well as to what extent service use has changed over a certain time period.

One of the weaknesses of this study is that our data provided no information on functional ability or the

availability of informal care or formal home care services, which affect the need for and use of round-the-clock care. In some cases, informal care may substitute for formal round-the-clock care services, and vice versa.<sup>34</sup> Based on our results, we can only comment on round-the-clock care service use occurring outside private households. More detailed information on which care sites people move between would give beneficial information on the current care arrangements near the time of death; however, these single care transitions could not be identified in this study. The results of this study are based on comparisons made between two time periods, and therefore, any assumptions of linear trends in development between 1998 and 2013 should be made with caution. It is possible that changes in diagnostic practices have contributed to the increases seen in some of the diagnostic groups studied. For example the diagnostics of dementing diseases has improved during the past 20 years and it cannot be excluded that the registers are therefore likely more accurate reporting these diseases at the end of our study period than in the beginning. However, we are not able to investigate the development of such diagnostic practices in this particular study.

Despite these shortcomings, this article provides novel and reliable information on ongoing trends in the patterns of care of an old population living their last years of life. The demographic change and the care policies that now prefer home care over institutional care are not just a Finnish phenomenon; thus, the results of this study should be taken seriously in the care planning for other societies as well. As for increasing longevity, the key question is whether this change is accompanied by either a compression or an expansion of morbidity.<sup>1,25</sup> In either case, the EoL period is inevitably characterised by morbidity and disability. Even if morbidity and the onset of chronic conditions, such as dementia, are further postponed,<sup>35</sup> the increasingly high age at which this period is lived and experienced means there will probably be a continued growing need for care for a longer period of time before death. In other words, it is possible that people will be able to enjoy an increasing number of healthy years, while at the same time having their last years of life be characterised by a longer period of serious disability than ever before.

## CONCLUSIONS

Most older people continue to live in their homes until the last months of their lives. This pattern of care is in line with current care recommendations, which emphasise the benefits of living in a private home, and care provided in non-institutional settings. Yet, living the most of the last 2 years of life in long-term care settings, increased from 1996–1998 to 2011–2013. The reasons behind this development should be studied further. Increasing age at the time of death, and an increase in multi-morbidity, especially dementia, might have contributed to the increase in care use near the time of death. It is, therefore, important

to bear in mind that living at home until close to death may present new problems and challenges for the older people themselves as well as for their care providers, especially when those last years and months of life are increasingly lived at a very old age, and with multi-morbidity. The care systems must be prepared for the challenges of more severe disability as well as for longer periods of long-term care as needed at the end of life.

**Acknowledgements** This study was conducted as part of the project New Dynamic of Longevity and the Changing Needs for Services (COCTEL).

**Contributors** MA designed and conducted the analysis in collaboration with MJ, JR, LF, JP and PR. JR was responsible for data construction. MA prepared the first draft of the manuscript and MJ, LF, JP, JR and PR gave critical comments to the study compositions, revised the text draft and approved the final version.

**Funding** The research was supported by the Academy of Finland (grant number 287372).

**Competing interests** None declared.

**Ethics approval** The research plan was approved by the Pirkanmaa Hospital District Ethics Committee, Finland.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data sharing statement** No additional data are available.

**Open Access** This is an Open Access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>

© Article author(s) (or their employer(s) unless otherwise stated in the text of the article) 2017. All rights reserved. No commercial use is permitted unless otherwise expressly granted.

## REFERENCES

1. Rechel B, Grundy E, Robine JM, et al. Ageing in the European union. *Lancet* 2013;381:1312–22.
2. Christensen K, Doblhammer G, Rau R, et al. Ageing populations: the challenges ahead. *Lancet* 2009;374:1196–208.
3. Lentzner HR, Pamuk ER, Rhodeniser EP, et al. The quality of life in the year before death. *Am J Public Health* 1992;82:1093–8.
4. Guralnik JM, LaCroix AZ, Branch LG, et al. Morbidity and disability in older persons in the years prior to death. *Am J Public Health* 1991;81:443–7.
5. Smith AK, Walter LC, Miao Y, et al. Disability during the last two years of life. *JAMA Intern Med* 2013;173:1506–13.
6. Lunney JR, Lynn J, Foley DJ, et al. Patterns of functional decline at the end of life. *JAMA* 2003;289:2387–92.
7. Lunney JR, Lynn J, Hogan C. Profiles of older medicare decedents. *J Am Geriatr Soc* 2002;50:1108–12.
8. Martikainen P, Murphy M, Metsä-Simola N, et al. Seven-year hospital and nursing home care use according to age and proximity to death: variations by cause of death and socio-demographic position. *J Epidemiol Community Health* 2012;66:1152–8.
9. Forma L, Rissanen P, Aaltonen M, et al. Age and closeness of death as determinants of health and social care utilization: a case-control study. *Eur J Public Health* 2009;19:313–8.
10. Pot AM, Portrait F, Visser G, et al. Utilization of acute and long-term care in the last year of life: comparison with survivors in a population-based study. *BMC Health Serv Res* 2009;9:139.
11. Menec VH, Nowicki S, Blandford A, et al. Hospitalizations at the end of life among long-term care residents. *J Gerontol A Biol Sci Med Sci* 2009;64A:395–402.
12. Lambreg JL, Person CJ, Kiely DK, et al. Decisions to hospitalize nursing home residents dying with advanced dementia. *J Am Geriatr Soc* 2005;53:1396–401.
13. Menec VH, Nowicki S, St John PD. In-region versus out-of-region hospitalizations at the end of life among older rural residents: the relationship between personal and system-related factors. *J Gerontol A Biol Sci Med Sci* 2011;66:1328–35.

14. Schon P, Lagergren M, Kareholt I. Rapid decrease in length of stay in institutional care for older people in sweden between 2006 and 2012: results from a population-based study. *Health Soc Care Community* 2016;24:631–8.
15. Connolly S, Gillespie P, O'Shea E. Estimating the economic and social costs of dementia in Ireland. *Dementia* 2014;13:5–22.
16. Hernandez M. Assisted living and residential care in oregon: two decades of state policy, supply, and medicaid participation trends. *Gerontologist* 2007;47:118–24.
17. de Meijer C, Bakx P, van Doorslaer E, et al. Explaining declining rates of institutional LTC use in the Netherlands: a decomposition approach. *Health Econ* 2015;24 Suppl 1:18–31.
18. National institute for health and welfare. Statistical yearbook of social welfare and health care. [http://www.julkari.fi/bitstream/handle/10024/125386/URN\\_ISBN\\_978-952-302-286-7.pdf?sequence=1](http://www.julkari.fi/bitstream/handle/10024/125386/URN_ISBN_978-952-302-286-7.pdf?sequence=1) (accessed 18 Mar 2016).
19. Official Statistics of Finland (OSF) (2016) Deaths by age and gender 1980–2014. [http://pxnet2.stat.fi/PXWeb/pxweb/fi/StatFin/StatFin\\_vrm\\_kuol/020\\_kuol\\_tau\\_102.px/table/tableViewLayout1/?rid=443f0829-a747-4dc9-a0df-2c351d1e02d7](http://pxnet2.stat.fi/PXWeb/pxweb/fi/StatFin/StatFin_vrm_kuol/020_kuol_tau_102.px/table/tableViewLayout1/?rid=443f0829-a747-4dc9-a0df-2c351d1e02d7) (accessed 18 Mar 2016)
20. Aaltonen M, Raitanen J, Forma L, et al. Burdensome transitions at the end of life among long-term care residents with dementia. *J Am Med Dir Assoc* 2014;15:643–8.
21. Aaltonen M, Rissanen P, Forma L, et al. The impact of dementia on care transitions during the last two years of life. *Age Ageing* 2012;41:52–7.
22. Nihtila EK, Martikainen PT, Koskinen SV, et al. Chronic conditions and the risk of long-term institutionalization among older people. *Eur J Public Health* 2008;18:77–84.
23. Chen JH, Chan DC, Kiely DK, et al. Terminal trajectories of functional decline in the long-term care setting. *J Gerontol A Biol Sci Med Sci* 2007;62:531–6.
24. Banaszak-Holl J, Fendrick AM, Foster NL, et al. Predicting nursing home admission: estimates from a 7-year follow-up of a nationally representative sample of older Americans. *Alzheimer Dis Assoc Disord* 2004;18:83–9.
25. Chatterji S, Byles J, Cutler D, et al. Health, functioning, and disability in older adults-present status and future implications. *Lancet* 2015;385:563–75.
26. Jylha M, Enroth L, Luukkaala T. Trends of functioning and health in nonagenarians: the vitality 90+ study. *Annual Review of Gerontology and Geriatrics* 2013;33:313–32.
27. Unruh MA, Trivedi AN, Grabowski DC, et al. Does reducing length of stay increase rehospitalization of medicare fee-for-service beneficiaries discharged to skilled nursing facilities? *J Am Geriatr Soc* 2013;61:1443–8.
28. Abarshi E, Echteld M, Van den Block L, et al. Transitions between care settings at the end of life in the Netherlands: results from a nationwide study. *Palliat Med* 2010;24:166–74.
29. Vantaja K, Seinela L, Valvanne J. Elaman loppuvaiheen sairaalasiirrot ja hoidon suunnittelu tehostetussa palveluasumisessa tampereella 2011. Available only in Finnish. *Gerontologia* 2015;29:61–74.
30. Lehto V, Seinela L, Aaltonen M. Tehostetun palveluasumisen asukkaiden siirrot - taustatekijät ja siirtojen syyt. Available only in Finnish. *Gerontologia* 2015;29:12–23.
31. Gozalo P, Teno JM, Mitchell SL, et al. End-of-life transitions among nursing home residents with cognitive issues. *N Engl J Med* 2011;365:1212–21.
32. Sund R. Quality of the finnish hospital discharge register: a systematic review. *Scand J Public Health* 2012;40:505–15.
33. Bach PB, Schrag D, Begg CB. Resurrecting treatment histories of dead patients. A study desing that should be laid to rest. *JAMA* 2004;22:2765–70.
34. Pickard L. Substitution between formal and informal care: a 'natural experiment' in social policy in Britain between 1985 and 2000. *Ageing Soc* 2012;32:1147–75.
35. Ngandu T, Lehtisalo J, Solomon A, et al. A 2 year multidomain intervention of diet, exercise, cognitive training, and vascular risk monitoring versus control to prevent cognitive decline in at-risk elderly people (FINGER): a randomised controlled trial. *Lancet* 2015;385:2255–63.