

MARI AALTONEN

Patterns of Care in the Last Two Years of Life

Care transitions and places
of death of old people





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ACADEMIC DISSERTATION

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ACADEMIC DISSERTATION

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For my sons Jere and Jasper

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- I Aaltonen M, Forma L, Rissanen P, Raitanen J, Jylhä M. (2010). Transitions in health and social service system at the end of life. *European Journal of Ageing* 7 (2), 91-100.
- II Aaltonen Mari, Rissanen Pekka, Forma Leena, Raitanen Jani, Jylhä Marja. (2012). The impact of dementia on care transitions during the last two years of life. *Age and Ageing* 41 (1), 52-57.
- III Aaltonen Mari, Forma Leena, Rissanen Pekka, Raitanen Jani, Jylhä Marja. (2013). Effects of municipality factors on care transitions. *Scandinavian Journal of Public Health* 41 (6), 604-615.
- IV Aaltonen Mari, Raitanen Jani, Forma Leena, Pulkki Jutta, Rissanen Pekka, Jylhä Marja (2014) Burdensome Transitions at the End of Life Among Long-Term Care Residents with Dementia. *Journal of the American Medical Directors Association* 15 (9), 643-648.

Abstract

In old age people have more disabilities and diseases than at a younger age which increases the need for and use of different care services. With approaching death people use more care services than at the earlier stages of life. Besides the age and closeness of death, the use of care among old people is associated with gender, morbidity and service supply. When people use different services they might move from one care facility to another, or have several readmissions from home. What is not known, however, is what the patterns of care are, including the frequency of care transitions across the care settings, and the places of death. The aim of this study was to discover the frequency and type of care transitions in the last two years of life, the places of death, how dementia affects the number of care transitions, and how age, gender, municipality of residence, and different care sites contribute to the number of care transitions in the last two years of life.

The data were collected from The Care Register for Health Care, The Care Register for Social Welfare, and The Causes of Death Register. Data included all those who died at the age of 70 or older in the years 1998, 2002-2008, and a 40% random sample of those who died during the years 1999-2001. Care transitions could be followed for 730 days preceding death for each individual. The care services included in analyses were health center inpatient wards, general hospitals, university hospitals, and residential care including nursing homes and sheltered housing with 24-hour assistance.

The number of different types of care transitions varied between individuals in the last two years of life. Yet, it was common for care transitions to become more frequent in the last six months. Most persons lived at home before their final months. Fewer than one in five stayed in care for the entire last two years, and over a half of them were people with dementia. Almost half of the study population died in a health center inpatient ward and it was the most frequent place of death, followed by a general hospital, a nursing home and a private home. People died less frequently in a university hospital or in sheltered housing with 24-hour assistance.

The number of transitions varied according to age and gender. The oldest old people (aged 90 or over) and women had fewer care transitions in their last two years than men and the youngest old people (age range 70–79). The oldest people and

women died more frequently in residential care or in a health center inpatient ward than the younger old and men, who died more frequently in specialized care hospitals or at home. Frequency of different types of care transitions varied according the municipality of residence, the highest variation being in moves involving specialized care hospitals.

Of those who lived at home two years before death, people diagnosed with dementia had more care transitions than those without a dementia diagnosis when age, gender and other diagnoses were taken into account. Of those who were in residential care two years before death, people with dementia had fewer care transitions during the last two years than those without dementia. Of those who were in residential care three months before death about one tenth had burdensome transitions in their last three months of life. Burdensome transitions were more frequent for those who lived in sheltered housing with 24-hour assistance than for those who lived in nursing homes.

In conclusion, the variation in care transitions and places of death was extensive. An increase in the number of care transitions during the final months was true for both those who lived at home and for those who were staying in a care facility. People most frequently moved to health center inpatient wards, which are highly important end-of-life care providers. The care patterns including care transitions and places of death vary according to age, gender, dementia diagnosis, municipality of residence, the year of death and the care site where the person stayed prior to death. Care offered in different care sites is often an adequate response to the care needs of individuals, but several transitions between care sites might cause disadvantages or compromise the continuum of care. The number of avoidable or burdensome transitions could be decreased through early care planning and by increasing end-of-life care capability in different care facilities.

Tiivistelmä

Vanhat ihmiset käyttävät hoitopalveluja elämän lähestyessä loppuaan enemmän kuin aikaisemmassa vaiheessa elämäänsä. Palvelujen käytön tiedetään vaihtelevan muun muassa iän, sukupuolen, sairastavuuden ja palvelujen tarjonnan mukaan. Terveystilan muuttuessa ihmiset liikkuvat sosiaali- ja terveyspalvelujärjestelmässä eri palveluntarjoajien välillä. Toistaiseksi ei kuitenkaan tiedetä miten usein ja minkä palvelujen välillä ihmiset liikkuvat, missä he kuolevat, ja millaiset tekijät vaikuttavat hoitopaikkojen ja kodin välisiin siirtymiin. Tässä tutkimuksessa tutkittiin kuinka yleisiä ovat siirtymät kodin ja erilaisten hoitopaikkojen välillä kahden viimeisen elinvuoden aikana, missä ihmiset kuolevat, miten dementia-diagnoosi vaikuttaa erilaisten siirtymien yleisyyteen, ja miten erilaisten siirtymien määrät vaihtelevat iän, sukupuolen, asuinkunnan ja hoitopaikan mukaan.

Tutkimuksen aineisto poimittiin Tilastokeskuksen ja Terveystilan ja hyvinvoinnin laitoksen rekistereistä. Aineisto sisälsi kaikki vuosina 1998, 2002–2008 70-vuotiaana tai sitä vanhempana kuolleet ja 40 prosentin satunnaisotoksen saman ikäisinä vuosina 1999–2001 kuolleista. Aineistosta pystyttiin seuraamaan jokaisen tutkitavan tapauksen liikkumista palvelujärjestelmässä viimeisten 730 vuorokauden aikana. Tutkitavat palvelut sisälsivät hoidon terveyskeskuksen vuodeosastolla, vanhainkodeissa, tehostetussa palveluasumisessa, yleissairaaloissa (sisältäen alue- ja keskussairaalat sekä yksityiset sairaalat) sekä yliopistollisessa sairaalassa.

Ihmisten liikkuminen sosiaali- ja terveyspalvelujärjestelmässä oli hyvin vaihtelevaa. Sekä siirtymien määrä että mihin siirryttiin vaihteli yksilöiden välillä paljon. Siirtymien määrä kasvoi viimeisten kuuden kuukauden aikana ja oli korkeimmillaan viimeisen kuukauden aikana. Ennen viimeisiä elinkuukausia suuri osa vanhoista ihmisistä asui kotona. Vähemmän kuin joka viides oli hoidossa koko kahden viimeisen elinvuoden ajan, heistä yli puolet oli dementiaa sairastaneita ihmisiä. Yleisin kuolinpaikka oli terveyskeskus jossa kuoli lähes puolet suomalaisista vanhoista ihmisistä. Seuraavaksi yleisimpiä kuolinpaikkoja olivat yleissairaala, koti ja vanhainkoti. Yliopistollisessa sairaalassa ja tehostetussa palveluasumisessa kuoltiin kaikkein harvimmoin.

Siirtymien määrä vaihteli iän ja sukupuolen mukaan. Vanhimmat ihmiset (vähintään 90-vuotiaat) ja naiset siirtyivät harvemmin kuin miehet tai nuoremmat

(70–79 -vuotiaat). Vanhimmat ihmiset ja naiset kuolivat nuorempia ja miehiä useammin pitkäaikaishoitoa tarjoavissa hoitopaikoissa, nuoremmat ja miehet vanhimpia ihmisiä ja naisia useammin erikoissairaanhoidossa tai kotona. Siirtymien kohteet vaihtelivat asuinkunnan mukaan, suurin vaihtelu oli siirtymien määrässä erikoissairaanhoidoon.

Kaksi vuotta ennen kuolemaa kotona asuneet, muistisairauksia eli dementiaa sairastaneet ihmiset siirtyivät dementiaa sairastamattomia useammin kodin tai eri hoitopaikkojen välillä kun ikä, sukupuoli ja muut diagnoosit otettiin huomioon. Dementiaa sairastavat ihmiset, jotka asuivat kaksi vuotta ennen kuolemaa pitkäaikaishoitoa tarjoavissa hoitopaikoissa, siirtyivät dementiaa sairastamattomia harvemmin. Dementiaa sairastavista noin joka kymmenes koki kuormittaviksi luokiteltavia siirtymiä. Kuormittavia siirtymiä kokivat todennäköisemmin ne, jotka asuivat tehostetussa palveluasumisessa kuin ne, jotka asuivat vanhankodeissa.

Tutkimuksen tulosten perusteella voidaan todeta, että vanhojen ihmisten hoitopolut sisältävät hyvin erilaisen määrän siirtymiä eri hoitopaikkoihin. Siirtymien määrä vaihtelee iän, sukupuolen, dementiadiagnoosin, asuinkunnan, kuolinvuoden ja hoitopaikkojen mukaan. Yleistä oli kuitenkin se, että hoitoon siirtyminen lisääntyy huomattavasti elämän viimeisinä kuukausina niin niillä, jotka asuvat kotona, kuin niillä, jotka ovat jo hoidossa. Yleisimmin ihmiset siirtyivät viimeisten kuukausien aikana terveyskeskuksen vuodeosastolle, joka onkin tärkeä elämän loppuvaiheen hoidon tarjoaja. Monet siirtymät ovat tarpeellisia, mutta vältettävissä olevia tai kuormittavia siirtymiä tulisi vähentää esimerkiksi hoidon suunnittelun ja eri hoitopaikkojen tarjoamien palvelujen ja hoitovalmiuksien lisäämisellä.

1 Introduction

The general population is ageing and the number of very old persons is increasing. The time of death is postponed to a high age and people living their last phase of life are older than previously. Old persons, who are living the last phase of their lives, usually have diseases and chronic conditions (Smith et al. 2013) that increase their use of care services (Larsson et al. 2008, Pot et al. 2009, Martikainen et al. 2012). Disability and multi-morbidity are common in old age and require care offered by several care providers (Abarshi et al. 2010). Thus people move, i.e. have care transitions, between different care settings or their home. These care transitions, especially hospitalizations, become increasingly frequent near the time of death (Van den Block et al. 2007a Menec et al. 2009, Abarshi et al 2010). The older people are at the time of death, the more vulnerable they usually are: for example dementia, a common disease in people who reach a very high age, makes people more dependent on other people than those without cognitive impairment, especially at the advanced stage of the illness (Meeussen et al. 2012). This sets specific requirements for the care offered at the last stages of life; care transitions can represent an adequate response to a person's care needs but they can also increase the risk for the person of experiencing harmful events or poorly coordinated care (Sachs et al. 2004, Volicer et al. 2005).

What is not known is what the patterns of care, described by care transitions in the last years or months of life and the places of death, are at the population level. This study offers insight into how people aged 70 or older are moving across the care settings in their last two years of life. The more detailed research questions were the following: 1) What is the frequency of care transitions in the last 24 months of life and how do age, gender and municipality of residence affect the number of transitions 2) Which are the places of death 3) What is the impact of dementia on the frequency of care transitions and 4) How frequent are transitions classified as burdensome for people with dementia, and does that frequency vary by the year of death or by the long-term care setting.

The ageing of the general population presents a challenge to health and social care systems that requires improvements in how hospital and long-term care are organized (Rechel et al. 2013). For example, in Finland, as in many other countries,

there is an ongoing shift from institutional care to homelike services. Hence the knowledge of the care patterns in the last years or months is highly important in order to plan and provide adequate care services which correspond to the actual needs of those living their last phase of life, and to guarantee a good quality of life until the end.

This study applies the concepts and previous findings of gerontology and health services research. The study was conducted as part of the comprehensive research project New Dynamic of Longevity and the Changing Needs for Services (COCTEL). It is constituted of four original research articles plus a summary.

2 Old age, health and the use of care

2.1 Ageing of the population

The number of people who reach old age is increasing. In 2014, 13.1% of the whole population in Finland was aged 70 years or older, but in 2060 the number is predicted to be 22.3% (Official Statistics of Finland 2015a). Simultaneously, the people who reach old age can expect to live longer: in 1986 for people who had reached the age of 70 life expectancy was 12.4 years, but in 2013 it was 16.0 (Official Statistics of Finland 2014a). This means that the number of very old people is growing: in Finland in 2014 about 40 000 had reached the age of 90, but in the year 2060 the number is predicted to be around 200 000 (Official Statistics of Finland 2015a). Gender difference in life expectancy has been narrowing, but the difference still persists and women outlive men: in Finland in the year 2013 the life expectancy for men who reached the age of 70 was 14.3 years and for women 17.3 years. (Official Statistics of Finland 2014a).

The reduction in old age mortality has been shifting the time of death to very old age (Figure 1). Figure 1 demonstrates how in 1980 the number of deaths was highest around the age of 75, but in 2012 the highest peak in deaths was around 85 years. This indicates that the end of life, the time usually accompanied by severe illness, is increasingly lived in a very old age.

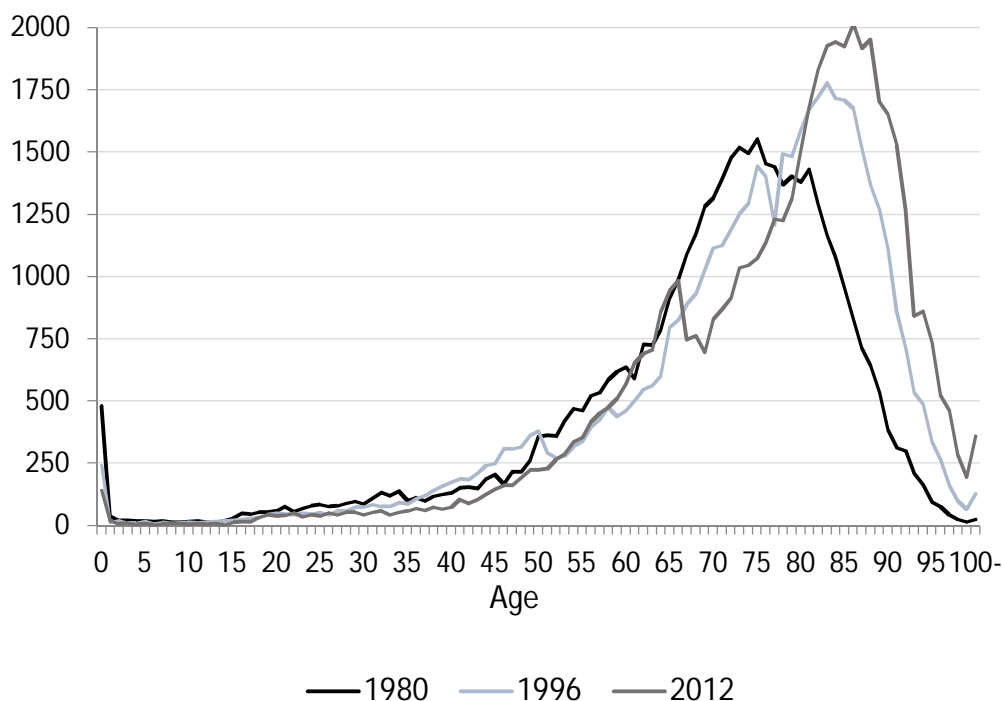


Figure 1. Number of deaths in Finland in 1980, 1996, and 2012. (Source: Official Statistics of Finland 2013a).

2.2 Disease and functioning in old age

Functional limitations and chronic conditions become more frequent with increasing age. Common diseases and chronic conditions include cardiovascular diseases, cancer, arthritis, diabetes, stroke, diseases of the respiratory system, and memory disorders (Christensen et al. 2009, Prince et al. 2015). In Finland in 2013 the most common causes of death for people who died at the age of 65 or older were diseases of the circulatory system, cancer and dementia. This applied to both genders though cancer was more common in men and dementia in women. (Official Statistics of Finland 2014b).

The older people are the more common are functional limitations. Even among old people increasing age is associated with the increasing likelihood of disabilities

and functional problems (Guralnik et al. 1991, Parker et al. 2008, Smith et al. 2013). The ability to cope with basic activities of daily living (ADL) declines with increasing age, and, of all old people, those aged over 85 are found to have more problems with ADL (Guralnik et al. 1991, Vaarama 2004) than younger old people. However, there are inconsistent findings regarding the effect of increasing old age in connection with the number of chronic conditions. Stenholm et al. (2015) found that the number of chronic conditions was higher in the age groups of 80-89 and 90 or over than with people aged 60-79, indicating that the oldest people often have more multi-morbidity than do younger old people. However, in the oldest old, i.e. people aged 90 or older, the multi-morbidity and the mean number of chronic conditions did not increase with increasing age (Jylhä et al. 2013).

Women suffer from disability more frequently than men (Newman and Brach 2001, Parker et al. 2008, Crimmins et al. 2011, Smith et al. 2013). Crimmins et al. (2011) found that women had worse functioning and higher disability rates than men when age was taken into account and women had more nonfatal diseases like hypertension, depressive syndromes, and arthritis, while men had heart diseases, strokes and lung diseases. Newman and Brach (2001) showed that women had more comorbidity and chronic health problems than men, but even with the same amount of comorbidity women had more disability than men. When age was taken into account women survived a longer time with the same level of functioning as did men, indicating that women survive for a longer time with disability than men (Tiainen et al. 2013). Jylhä et al. (2013) found that in 2010 men and women aged 90 or older reported good self-rated health equally often though women had more diseases and disabilities than men.

High age does not inevitably translate into illness and low functional ability: the people who live the last years or months of their lives have a higher number of chronic conditions and disabilities than those who are of the same age but not in the last phase of life (Guralnik et al. 1991, Smith et al. 2013). Differences in functional ability are associated with functional trajectories at the end of life. This variety in functional trajectories is demonstrated in Lunney et al. (2002, 2003) who identified four different main functional trajectories at the end of life in a population-based study on people aged 65 or older: sudden death, terminal illness, organ system failure and general frailty. The most common was the frailty trajectory with a prolonged period of functional decline (included 47% of the study group), dominated by women aged 80 or over who were diagnosed most often with dementia and stroke. The terminal illness trajectory (22%) was identified as the trajectory of cancer patients with a high functional ability until the final months of life, along with a steep

slope in functional decline at the very end of life. This trajectory was more common for people who died at a younger old age (approximately 77 years), and was equally common for both genders. The people identified in the organ failure trajectory (16%) had a more gradual decline in functioning than cancer patients when the time of death approached. They were diagnosed with congestive heart failure or chronic obstructive pulmonary disease. Over a half of the people in this group were women, and the mean age was 80 years. The sudden death trajectory, with no functional decline before death, appeared only for 7% of the people, and was dominated by men at a younger old age (73 years) (Lunney et al. 2002). Chen et al. (2007) found similar trajectories in nursing home residents with dementia, cancer and organ failure. People with dementia were more functionally disabled and for a longer period preceding death than those with cancer and organ failure. Those with cancer and organ failure did not experience a decline in ADL abilities until their last months.

One of the most important contributors to cognitive and functional decline in old age is dementia. Old age is a major risk factor in dementia, hence dementia becomes more frequent with increasing age (Fratiglioni et al. 2000, Corrada et al. 2008). The term “dementia” subsumes several underlying brain disorders causing problems with memory, language and thinking, thus people with dementia are also referred to as people with memory disorders (Erkinjuntti et al. 2010). According to Alzheimer’s Association (2013) dementia is an umbrella term describing a variety of incurable conditions causing gradual cognitive and functional decline. The most important condition causing dementia is Alzheimer’s disease (Lobo et al. 2000, Alzheimer’s Association 2013). The most important risk factor of Alzheimer’s disease is old age, and it is estimated to cover from 60 to 80% of dementia cases. Other major conditions causing dementia are frontotemporal dementia, vascular cognitive impairment, and dementia with Lewy bodies. (Alzheimer’s Association 2013).

The frequency of dementia diagnoses differs between men and women. A larger proportion of women than men is found to have Alzheimer’s disease and other dementias (Seshadri et al. 1997, Fratiglioni et al. 2000, Corrada et al. 2008). Women live to an older age than men and the gender difference with respect to dementia is assumed to be based on different life expectancy rather than on gender itself (Hebert et al. 2001). In Finland in 2013 dementia was a more frequent primary cause of death for women aged 65 or older (22.3%) than for men (12.4%) (Official Statistics of Finland 2014b). However, the gender difference exists in people in the same age: Corrada et al. (2008) demonstrated that in people aged 90 or older 45% of women and 28% of men were diagnosed with dementia. In addition, Fratiglioni et al. (2000)

also showed that the gender difference is growing wider with increasing age. Martikainen et al. (2010) reported in the year 2010 that in the age group of 65-69 years 1.8% of men and 1.4% of women suffered from memory disorders in Finland, but in the age group of 85-89 years the corresponding figures were 21.5% in men and 28.5% in women.

2.3 The use of care

In old age people with different diseases or chronic conditions use more care services than during their earlier phases of life. Andersen & Newman (2005) identify illness as the most immediate cause of care use. People who live the last years or months of their lives have a higher number of chronic conditions and disabilities than those who are of the same age but not living the last phase of life (Guralnik et al. 1991, Smith et al. 2013). Thus when the time of death is approaching, the increase in chronic conditions and disabilities contributes to the need for and use of care (Pot et al. 2009): the care use is found to increase towards the end of life (Forma et al. 2009, Larsson et al. 2008, Pot et al. 2009).

Among old people the use of care varies according to the age-related level of functional impairment. Problems with the instrumental activities of daily living (IADL), and especially problems with the basic activities of daily living (ADL), more common in people over the age of 85, are associated with a growing need for permanent care (Vaarama 2004). Mehdizadeh (2002) studied health and long-term care-use trajectories and found that younger old people (average age 79) were more often able to live in the community while older old people (average age 81-83) were more frequently residents in long-term care, or needed multiple visits to nursing homes and hospitals.

Even near the time of death care use varies according to age. At the time of death the oldest people more frequently had cognitive limitations and functional restrictions than did the younger old, hence the use of nursing home care was much higher in the oldest persons during their last years than for younger persons (Martikainen et al. 2012, Lentzner et al. 1992). Also Pot et al. (2009) found age-related differences in the use of care in the last year of life: the younger old used more acute care services while older old people used more long-term care. Lunney et al. (2002) found an age-related decrease in hospital deaths, suggesting that the oldest old (≥ 85) receive less hospital care than younger old people (65-74 years) near

death, indicating that the oldest and most frail people more often received nursing home care than younger people.

The use of care differs by gender: in old age, women are more often institutionalised (Grundy and Jital 2007, Luppa et al. 2009). Bird et al. (2002) argued that the differences in care use by gender are primarily explained by age, but in age-adjusted analyses Martikainen et al. (2012) showed that women used both hospital and nursing home care more than men. Increasing age increases the risk of institutionalization for both genders, though the effect seems to be higher for women (Luppa et al. 2009). This is supported by Kaspers et al. (2013), who demonstrated how in the last three months of life women were more likely to be institutionalized than men, when age was taken into account. The higher institutionalization rates for women is likely explained by the higher disability rates of women. Women often outlive men and thus have spousal care less often than men (Newman and Brach 2001). Informal care plays an important role in the care of old people. Having a partner can enable access to care (Pot et al. 2009), but it also decreases or postpones the need for formal care and institutionalization (Nihtilä and Martikainen 2008): living with a spouse and being married are important factors in reduced risk of institutionalization (Grundy and Jital 2007, Luppa et al. 2009, Wong et al. 2010). Kelly et al. (2010) found that the median length of stay in a nursing home varied from men's 3 months to women's 8 months before death. They also found that the length of a nursing home stay at the end of life was in proportion to social support and varied by an approximately 4-month shorter stay in a nursing home for those who were married than for those unmarried.

Different end-of-life functional trajectories, together with the age- and gender-related factors, are contributing to the end-of-life care. Pot et al. (2009) found that in the last year of life the high average number of chronic conditions, cancer and heart disease were strongly associated with the use of hospital care, while functional limitations and low physical performance were associated with the use of institutional care. People with cancer and people with dementia usually represent the opposite functional trajectories at the end of life, thus their care use also differs. Those with cancer had better functional ability and mobility a year before death than non-cancer decedents (Teno et al. 2001), and they had lower prevalence of disability than people with other health conditions (Smith et al. 2013). Martikainen et al. (2012) found that when the time of death was close, those with cancer used less nursing home care and experienced a steep downward slope from no inpatient care to inpatient care in hospitals at the end of life, a finding that reflects the steep decline in functional ability when death is imminent.

The progressive nature of dementia imposes different requirements on care than for example cancer: the illness trajectory of dementia often depicts a situation where at the beginning of the illness people are able to cope with moderate help provided in a private home. However, changing care needs require an increasing amount of help and, in addition to the increasing functional decline, conditions like pneumonia and eating problems were found to be common in people with dementia in the last six months of life (Mitchell et al. 2009). In the advanced stage of dementia people are often admitted in round-the-clock long-term care: and it is well known that people with dementia are at a higher risk of institutionalization than those without dementia (Aguero-Torres et al. 2001, BanaszakHoll et al. 2004, Nihtilä et al. 2008). Institutionalization is associated with functional decline, but it is not the only predisposing factor; BanaszakHoll et al. (2004) showed that dementia had a strong effect on institutionalization, not only as a consequence of functional impairment but because of behavioral problems.

Besides the individual factors, care use is associated with the characteristics of the care service system (Andersen and Newman 2005, Klinkenberg et al. 2005, Pot et al. 2009) that affects the availability of different services. Availability refers to geographical access to care and to the service structure that determines when people gain entry to the care system and what happens to an individual after entering the system (Andersen & Newman 2005). Pritchard et al. (1998) showed that fewer hospital beds were related to lower hospital use in the US. Geographical distance and the urban level of an area are related to differences in access to care and service supply between regions: Chan et al. (2006) showed that residents living in rural areas in the US had longer distances to travel for specialized care and were found to rely more often on general-practice doctors than residents of urban areas. In Canada the old people who lived in a region with more physicians per capita were more likely to remain in that area till death and less likely to be hospitalized in another region (Menec et al. 2011). The different service structures with varying care practices in different countries are likely contributing to the findings concerning hospital care use by people with dementia; in two studies from the US, Kelley et al. (2012) found that dementia was associated with fewer days in hospital, and Burton et al. (2001) found an association with less medical service use by individuals with dementia compared to those without dementia. Instead in Guijarro et al. (2009) the length of a hospital stay in Spain was longer for people with dementia than for those without dementia. However, as with the majority of the old population, people with dementia are often hospitalized during the last three months of life (Lamberg et al. 2005, Meeussen et al. 2012).

2.4 Changing health trends

The research findings regarding the development of old people's health are somewhat inconsistent and differ between studies conducted in different countries (Chatterji et al. 2015). In general, the common perception is that during past decades mortality and severe disability in old people has declined while the number of diseases and especially chronic diseases has increased (Crimmins 2004, Christensen et al. 2009, Crimmins and Beltrán-Sánchez 2011). The incidence with respect to many major conditions has not changed over time but mortality has decreased, thus the number of people living with these conditions has increased (Crimmins and Beltrán-Sánchez 2011, Christensen et al. 2009). Crimmins and Beltrán-Sánchez (2011) draw the conclusion that diseases are less lethal than earlier, hence people live longer lives with chronic conditions that often cause functional decline and disability prior to the time of death. In addition, the possible health improvements are not consistent in all age groups: Christensen et al. (2009) found that in the younger old (<85) most of the studies of health trends show postponement in disability despite the increase in chronic diseases. However, the results for people aged 85 or older are less consistent (Christensen et al. 2009). In Finland self-rated health, chronic morbidity (Koskinen et al. 2012a) and functioning (Sainio et al. 2012, Tuulio-Henriksson et al. 2012, Koskinen et al. 2012b) showed improvement in people aged 75 or older between the years 2000 and 2011. Yet, Jylhä et al. (2013) found that in people aged 90 or older the changes in mobility did not show any time trend in Finland, and the proportion of people who reported good health decreased between the years 2001 and 2010. Parker et al. (2005) in Sweden showed either no change in several diseases or actually an increase in health problems such as depression, hypertension, fatigue and mobility limitations in people aged 77 or older between the years 1992 and 2002.

One major concern with respect to the future is the frequency of dementia that can affect the need for and use of care services. Different scenarios concerning the future prevalence of dementia have been posited. Scenarios regarding a possible decrease in dementia are based on a reduction of different risk factors and diseases such as circulatory disorders, which are found to be associated with the incidence of dementia (Jagger et al. 2006, Barnes and Yaffe 2011). However, the frequency of dementia is expected to increase along with the increase of old people (Ferri et al. 2005). An extensive increase in the number of people with dementia is expected to occur in developed countries, but even more so in developing countries (Ferri et al. 2005, Brookmeyer et al. 2007).

In Finland, the number of people with dementia has been growing in recent decades. Figure 2 shows a noteworthy and continuing increase in dementia as the underlying cause of death between the years 1969 and 2011. The proportion of men who live to a very old age is growing and dementia is also becoming more frequent in men. Besides the actual increase in the number of people with dementia, changes in diagnostic criteria and practices can also add to the number of people diagnosed with dementia (Wu et al. 2014). The Causes of Death register uses The International Classification of Diseases. This register changed from ICD8 to ICD10 between 1969 and the present day (Official Statistics of Finland 2005). Although the ICD10 has been in use since 1996, the changes in coding cannot be considered the underlying reason for the increase in dementia cases over the past two decades. In 2005, the Causes of Death Register adopted the WHO guideline that limits the use of pneumonia as an underlying cause of death; if a person has both pneumonia and dementia, dementia is considered to be the statistical underlying cause of death (Official Statistics of Finland 2013b). This change can explain at least some of the increase of dementia as an underlying cause of death after 2005.

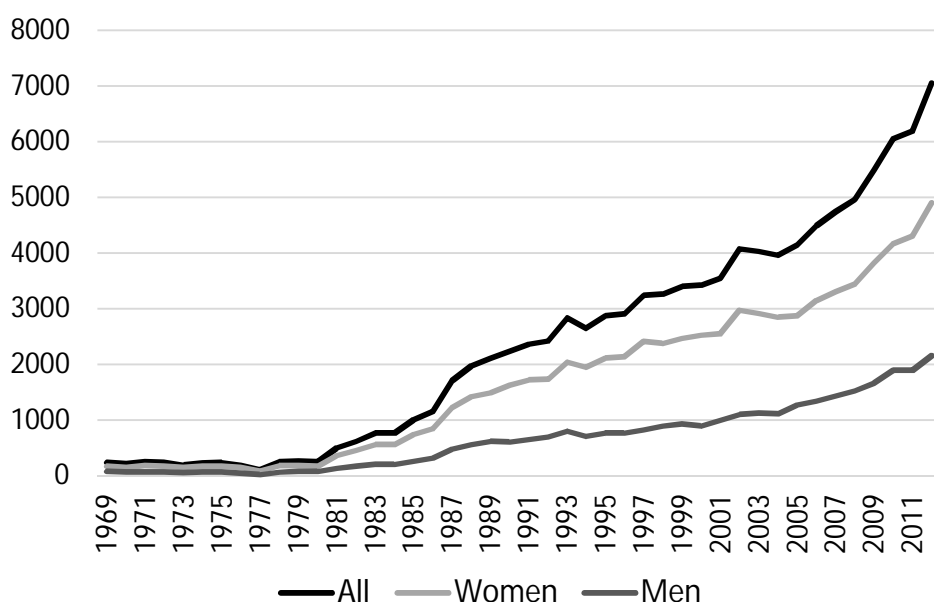


Figure 2. Number of people with dementia or Alzheimer's disease as the underlying cause of death (F01, F03, G30, R54), in Finland in 1969-2011. (Source: Official Statistics of Finland 2014c)

3 Care transitions in the last years of life and the place of death

3.1 Basic concepts

The concept of *care transition*, or *transition in care*, refers to the event when people move between different care settings, or between home and different care settings (Cohen and Pushkar 1999, Van den Block et al. 2007a, 2007b, Abarshi et al. 2010, Gozalo et al. 2011, Teno et al. 2013). A care transition has been described as “a change in setting or location of care” (Abarshi et al 2010). In Kahn and Angus (2011) the transition of care is described as a situation “when a patient moves across care sites within the health system”. Transitions can take place between care facilities, but also between a care facility and a home or other residence (Brock et al. 1996). Transition is also referred to as a transfer (Kaspers et al. 2013) or as a move between different care settings (Cohen and Pushkar 1999), and the concepts of hospitalization (Menec et al. 2009) and discharge (Wong et al. 2010) also describe care transitions. In Geary and Schumacher (2012) care transition was defined as a hospital discharge or moving from one health care setting to another; however, they were not seen as single events, but as processes occurring within the context of multiple relationships between different actors and life situations. In research, the concept of transition can also refer to a situation where a person does not necessarily physically change location; Burge et al. (2005) define transition in care as a change in a service provider, regardless of the actual moves of the person. In this study the concept of care transition refers to a change of care location, i.e. a change in a care facility, or moving from a private home to a care facility, or from a care facility back home.

An older population with multiple health conditions often has several care needs and uses services provided in different care settings. This can cause several care transitions when people move from one care facility to another to visit different specialists. All of these care transitions constitute a *care pathway*. In Abarshi et al. (2010) this continuum is called a trajectory which “is the pathway of care settings a patient lived in”. A care pathway can be seen according to Abarshi et al (2010) or Cohen and Pushkar (1999); as a result of sequential transitions between different care facilities. The pathway includes all moves which a person undergoes during a

certain period of time, and comprises a continuum of planned or unplanned admissions and discharges caused by single or multiple health conditions. However, the concept of care pathway can also be seen in a different light: Watts (2012) defined the care pathway as a form of structured clinical pathway, created for organizing, guiding, managing and documenting multi-professional care processes regarding a specific problem within a particular clinical setting. In this study the concept of a care pathway describes the continuum of planned and unplanned care transitions.

The end of life refers to the time period preceding death. Yet, the definition of the end of life varies according to the study aim and the study design; the time frame that reveals aspects of approaching death is different in the use of care, in care practices, and in health. Thus, in previous research different definitions are used according to the purpose of the study.

In research concerning care practices at the end of life, including admissions to care and discharges from care, the end of life usually refers to the last three months or the last 90 days (Brock et al. 1996, Van den Block et al. 2007a, 2007b, Abarshi et al. 2010, Gozalo et al. 2011, Meeussen et al. 2012, Kaspers et al. 2013, Teno et al. 2013). Some studies also focus on the last week (Meeussen et al. 2012) or the last three days (Gozalo et al. 2011, Teno et al. 2013). The last six months are also used (Lamberg et al. 2005, Menec et al. 2009, Kelley et al. 2012). In the studies focusing on the association of death with changes in the use of different care services the time period studied has been the last year (Bird et al. 2002, Pot et al. 2009), the last two years (Forma et al. 2009), the last five years (Larsson et al. 2008) and even the last seven years (Martikainen et al. 2012). In studies concerning the effect of approaching death on functional ability or disability, the last two years (Smith et al. 2013) or the final three years (Guralnik et al. 1991) before death have been used.

The end of life can also be defined without setting any precise time limit determined in months or in years. In such cases, it refers to an individual situation and the end of life begins for example when people are admitted in permanent care (Kelly et al. 2010), or to palliative care (Burge et al. 2005, Lawson et al. 2006) which describes the care at the end of life with the purpose of improving or maintaining the quality of life of the dying person rather than offering curative procedures. When the aim of a study is to reveal how good quality at the end of life or death is constructed, the definition of the end of life varies individually (Kaarbø 2011, Goodman et al. 2013) and in these studies the concept “end of life” refers to the actual dying process: in Kaarbø (2011) the end of life is defined as the ‘immediate time prior to death’. In this study the concept of end of life refers either to the last

24 or to the last three months of life, depending on the study aim of the original article.

3.2 Studies of care transitions

Care transitions constitute one important element of the use of care: entering any care facility necessarily means one care transition. Similarly to the care use in general, care transitions are influenced by individual factors as well as the factors related to the care system. Hence in care transition research the focus is on individual well-being, but in addition it describes the functioning of the care system. From an individual perspective care transitions influence the quality of life even until the end of life. From the care system perspective, transitions demonstrate how care is organized and which care practices are preferred in the service system. In the following literature review of care transitions, studies using the definition of a care transition, but also studies using definitions of a move, a transfer, hospitalization, admittance or discharge, are considered if they are studied within the context of changes in a care site.

An important theme in care transition studies concerns the care patterns at the end of life. Kaspers et al. (2013) and Klinkenberg et al. (2005) focused on people aged 55-85 in general, not in specific patient groups. They studied all transitions between different settings in the last three months of life. Data from the Longitudinal Aging Study Amsterdam (LASA) were used in both studies. Data were collected by employing a questionnaire sent to the proxy respondent in different study waves. Klinkenberg et al. (2005) found that care arrangements three months before death were associated with the end-of-life care transitions and the place of death: people who were residents in nursing homes rarely moved to another care facility, and those who were admitted to hospital during the last three months also often died there. On the other hand, those who were in a private home, or in a residential home with similar access to medical care as those living in a private home, moved more often during the last three months, and the place of death was frequently other than the place where they were staying three months before death. When the years 2000 and 2010 were compared in Kaspers et al. (2013), the proportion of people who had at least one care transition had not changed with respect to time; about a half of the people had transitions in their last three months. Nonetheless, several indicators illustrating health status three months before death seem to reveal that in 2010 more people had poorer health than in 2000. Regardless

of this change in health at the end of life there was no change found in the number of transitions or places of death.

Van den Block et al. (2007a, 2007b), in Belgium, and Abarshi et al. (2010), in the Netherlands, studied care transitions at the end of life by using a mortality follow-back study monitoring care provided for the general population, yet including a majority of people who died at the age of 65 or older. People who experienced a sudden death were excluded. Van den Block et al. (2007a, 2007b) showed that transitions were relatively common in the last three months of life, as over 60% were transferred at least once, most often to hospitals. As with Klingenberg et al (2005), Van den Block et al. (2007a, 2007b) found that transition rates were higher for those who were residing at home three months before death than for those residing in institutions. Abarshi et al. (2010) revealed the variety of different end-of-life care trajectories in the last three months: in the sample of 690 decedents 43 distinct care-setting trajectories were found. Age and gender differences were found to be associated with different transitions; men and people who died at a younger old age (<84) were more likely to have transitions than women and people who died at an older age. Also, multi-morbidity was found to increase the number of transitions. (Abarshi et al. 2010).

People with dementia are a specific group in regard to the end of life. They represent a vulnerable group that might suffer a severe disadvantage during or after care transitions (Sachs et al. 2004, Volicer 2005). The importance of the continuum of care (Sachs et al. 2004), communication with the family members (Lawrence et al. 2011), comfort (Mitchell et al. 2009, Gove et al. 2010), pain and other symptom control (Van der Steen et al. 2011) are emphasized in dementia care at the end of life. Stressful events should be avoided (Lerner 1997) and the aim of the end-of-life care for people with dementia should be to maximize the quality of life and the level of comfort (Gove et al. 2010). Especially in the case of advanced dementia, hospitalizations may be of limited benefit (Mitchell et al. 2009), and transitions can result in undesirable consequences such as mental confusion, causing unnecessary medical treatments (Volicer 2005). However, earlier studies concentrating on people with dementia show that transitions at the end of life are common even in an advanced stage of the disease (Lamberg et al. 2005, Meeussen et al. 2012). Lamberg et al. (2005) found that about one fifth of the people with dementia and who lived in a nursing home were hospitalized in the last six months of life, and about one tenth had an emergency visit without hospitalization. Meeusen et al. (2012) studied the end-of-life care of people with dementia in a nationwide retrospective mortality study in Belgium. They found that in the last three months 41% had at least one care

transition between care settings, and during the final week 14% were transferred at least once. Being institutionalized for a long duration before death and a very old age were associated with lower rates of hospitalization. People who had adequate care plans made at an early phase of the disease were less often hospitalized than those without early end-of-life care planning. (Lamberg et al. 2005).

Gozalo et al. (2011) and Teno et al. (2013) studied burdensome care transitions in the US. Gozalo et al. (2011) defined care transitions as burdensome to people with dementia and who lived in nursing homes if a) those transitions take place during the last three days of life; b) there is lack of continuity in nursing home facilities before and after hospitalization during the last 90 days of life – for example, if the person moves from long-term care facility A to a hospital, and then to long-term care facility B; or c) there are multiple hospitalizations (more than two for any reason, or more than one for pneumonia, urinary tract infection, dehydration or sepsis) in the last 90 days of life. The study group consisted of cognitively impaired people who were residents in a nursing home 120 days before death, were older than 66 years and had extensive or total dependence with respect to all seven activities of daily living. About every fifth person had burdensome transitions, but the results showed wide geographical variation in their frequency, indicating that there were different end-of-life care patterns in different states. In addition, markers showing poor quality of end-of-life care were associated with a higher frequency of burdensome transitions. One cause for burdensome transitions was presumed to be financial incentives (Gozalo et al. 2011), since the unique US reimbursement system might encourage hospitalizing people at the end of life. Teno et al. (2013) studied the frequency of transitions in people with dementia in the years 2000 and 2009. Results showed an increase in the average number of transitions in the last 90 days and in transitions during the last three days, with a slight decrease in multiple hospitalizations in last 90 days.

Some of the care transition studies focus on the implementation and quality of the care process. Before and after people move from one site to another, the continuum of care is challenged (Coleman and Berenson 2004, Van den Block et al. 2007b); thus communication and coordination of care is highly important during the transition (Dubin 2007, Kirsebom et al. 2013). Pieper (2005) describe that older persons with complex needs for medical and long-term care, set requirements for integrated care in regarding to cooperation and coordination of care between different care providers. Potentially avoidable hospitalizations are studied to determine the unnecessary care transitions from nursing homes to hospitals (Givens et al. 2012, Ouslander et al. 2010, Walsh et al. 2012). Transitions back home from a

care facility, i.e. discharges, can cause problems for people and unnecessary rehospitalizations if those transitions are not conducted properly (Berenson et al. 2012). After discharge, old people might go through adverse events which could impair the outcome of care if they lack information about their illness and recovery prognosis (Mistiaen et al. 1997) or medication (Dudas et al. 2001).

Sometimes care transition research reveals characteristics of the service supply sector that affect the different care patterns. Service supply steers itself to where people move, thus regional differences in the service systems can affect the number of transitions and the care facilities to which people move. Differences in hospitalizations have shown that people who lived in rural areas of the US had more hospitalizations from nursing homes than people in urban areas (Coburn et al. 2002, Gessert et al. 2006). Rural-urban differences in discharge rates shown in Coburn et al. (2003) demonstrate that people in urban areas were more often discharged to their home or to low-level care after a hip fracture than people in rural areas who more frequently stayed in nursing homes. The variation in hospitalization practices may also imply differences in financial incentives favoring or disfavoring hospitalizations in different areas (Gozalo et al. 2011, Liotta et al. 2012, Walsh et al. 2012). The ownership of different long-term care facilities has an effect on hospitalizations: Menec et al (2009) in Canada found that for-profit long-term care facilities were associated with a higher number of hospitalizations in the last six months of life than with not-for-profit ones.

3.3 Place of death – the end of the care pathway

The place of death represents the final place in the care pathway, associated with the end-of-life functional and illness trajectory preceding death (Weitzen et al. 2003). In Western countries death has been institutionalized and people often die in hospitals, followed by deaths in long-term care facilities and other institutions (Weitzen et al. 2003, Klinkenberg et al. 2005, Gomes et al. 2012, Broad et al. 2013, Hedinger et al. 2014). Dying at home is often something that is preferred (Tang 2003, Beccaro et al. 2006, Gomes et al. 2013), but it is also a wish that does not come true that frequently.

Places of death vary between different countries due to different service systems (Houttekier et al. 2010, Broad et al. 2013); out of 21 populations the frequency of hospital deaths in the age group of 65 or older was highest in Japan (69%) and Korea (67%) and lowest in New Zealand (34%), while home deaths were most frequent in Cyprus (42%) and in Croatia (41%), and less frequent in Iceland (9%) and Australia

(14%) (Broad et al. 2013). Regardless of the variation between the countries, similar patterns in the factors affecting the place of death exist. In several countries the proportion of people who die in residential care instead of hospital care increases with increasing age, and women die more frequently in a residential care facility than men of the same age (Broad et al. 2013). Hedinger et al. (2014) found similar results: a higher old age and female gender were associated with nursing home deaths in Switzerland. Of Canadian nursing home residents, men were more likely to die in hospital than women (McGregor et al. 2007, Menec et al. 2009). In several European countries the difference in the place of death based on gender was also found in people within the same diagnosis: in people with dementia, men more frequently had a hospital as the place of death than women (Houttekier et al. 2010, Hedinger et al. 2014). In all, people with dementia died more often in a long-term care setting and less often in acute care hospitals or at home than people without dementia (Houttekier et al. 2010, Teno et al. 2013, Hedinger et al. 2014).

The availability of different services is an important determinant of the place of death: a higher number of nursing home beds increased the number of nursing home deaths (Houttekier et al. 2010, Hedinger et al. 2014). Service supply is found to be a more powerful factor than people's own preferences: Pritchard et al. (1998) found that in the US people died most often in those care facilities which were most often available in the area. Klinkenberg et al. (2005) found regional differences in hospital deaths in the Netherlands. Their explanation for this variation was the differences in the availability of hospital care between regions. In addition, the ownership of different long-term care facilities has an effect on hospital deaths: Menec et al. (2009) in Canada found that for-profit long-term care facilities were associated with higher odds of residents dying in a hospital than not-for-profit ones. Several other factors such as lower education, living alone and not having children were associated with a higher number of nursing home deaths (Hedinger et al. 2014).

4 The Finnish health and social care system

4.1 Role and responsibilities of municipalities

In 2015, Finland contains 317 municipalities which differ in population density, in age structure and in the demographic dependency ratio. The proportion of people aged 75 or over is different in different regions, but it is projected to increase in all regions by 2020 (National Institute for Health and Welfare 2014a). The frequency of the common chronic conditions of people aged 75 or over (National Institute for Health and Welfare 2014b) and the age standardized morbidity index (National Institute for Health and Welfare 2014c) vary between the areas. These differences in illness and in the age structure are creating differences in the need for care between the geographic regions and municipalities.

Municipalities are local authorities that are responsible for providing care for their residents. Municipalities have significant autonomy in planning and steering the health and social care services in the way they prefer. They can produce services by themselves, or in conjunction with other municipalities, or they can purchase services from other municipalities, or from the private sector, including not-profit organizations and for-profit enterprises (NGOs). (Vuorenkoski 2008). Municipalities play an essential role in the funding of health and social care services. The services in Finland have traditionally been publicly produced, provided and funded by municipalities and the government which have the right to levy taxes. The public funding covers only a proportion of the services. In 2012 municipalities financed about 36% of the total health care expenditures, the government 25%, the Social Insurance Institution (SII) about 15%, private households 19%, and employers, private insurances etc. around 6% (National Institute for Health and Welfare 2014d). People can buy private services directly, although the private inpatient services, especially long-term care services, are highly expensive and currently only a small proportion of old people can afford to purchase these services by themselves. Depending on the service, the proportion of services funded by municipalities varies. Primary medical care offered in health centers and specialized medical care are about 90% funded by municipalities and less than 10% by private

households, while care for old people is funded by municipalities by 80%, and 20% by private households (National Institute for Health and Welfare 2011).

Municipalities operate under the legislation and national guidelines for older people's care (for example The Ministry of Social Affairs and Health 2008, 2011 and 2013a), which are implemented by The Ministry of Social Affairs and Health. The Act on Care Services for Old People, which came into force in July 2013, is an example of the legislation that affects how care is organized in municipalities (The Ministry of Social Affairs and Health 2013b). The Act on the Arrangement of Social Welfare and Health Care Services is still an ongoing reform. (The Ministry of Social Affairs and Health 2014). In these and in national recommendations and guidelines for health and social care, the equality of access to health and social care is officially valued; the Finnish health and social care recommendations emphasize that everyone is entitled to equal care services, regardless of the municipality of residence or one's wealth, age, gender etc. However, the research findings show different results; increasing socioeconomic differences with regard to access to care and socioeconomic differences in life expectancy are to be found (Manderbacka et al. 2013), as are differences in service provision and access to different care services between the municipalities (Vuorenkoski 2008).

4.2 Hospital and long-term care for old people

Hospital inpatient services in Finland are divided into primary health care and specialized health care. Primary health care is offered in the inpatient wards of the municipal health centers. Municipalities located in the same area are members of the same hospital district and they own and fund that hospital district. Hospital districts are responsible for organizing and providing the specialized health care that is offered in general hospitals, including central and district hospitals, as well as in university hospitals. Each of the 20 hospital districts has one or several hospitals of which one is considered to be the central hospital of the district. Five of the hospital districts have a university hospital as a central hospital that offers secondary care for the residents of the district. The five university hospitals offer the most advanced tertiary care to all residents of Finland. (Vuorenkoski 2008).

Round-the-clock long-term care is offered in nursing homes, sheltered housing with 24-hour assistance and in health centers (Table 1). The nursing homes offer institutional care services and support in everyday living for old people who are not able to manage in their private residence. Sheltered housing with 24-hour assistance,

also known as service housing with 24-hour assistance, is not classified as institutional care, but as a housing service offering long-term care, with the skilled care staff available for 24 hours. Health center inpatient wards are primary care hospital inpatient wards that have also traditionally offered institutional long-term care for chronically ill and frail people. Home care is also classified as long-term care but not as round-the-clock care. (Johansson 2010, Noro et al. 2014).

In 2013 the most common round-the-clock long-term care service for people aged 75 or older was in sheltered housing with 24-hour assistance, followed by nursing homes and the long-term service that was offered in health center inpatient wards. The use of care differs by age: in the age group of those 85 or older the use of any of the round-the-clock long-term care services was higher than for those in the age group of 75 or older. There was a higher number of people and in the age group of 75-84 years who used primary or specialized hospital care than in the age group of 85 or older, but those aged 85 or older had longer average length of stays in hospitals. (National Institute for Health and Welfare 2014e). Forma et al. (2007) showed that in the last 24 months of life the use of health center inpatient care was highly common in all age and gender groups. Any use of long-term care was more frequent in the oldest age group (≥ 90). Over a half of the people in every age and gender group had used general hospital care, except for the oldest women (≥ 90) who used the service less frequently than others. About a third of those who died at the age of 70-79 but less than a fifth of those at the age of 90 or over had stayed in a university hospital.

Table 1. The three types of round-the-clock long-term care for old people in Finland. Source: Forma et al. under review.

	Inpatient ward of health center (LOS≥90 days)	Nursing home		Sheltered housing with 24-hour assistance	
<i>Description</i>					
Type of care ¹	Institutional	Institutional		Housing + closely related services	
Administrative branch	Health care	Social care		Social care	
Producing sector in 2010 ² (%)					
Public	96	87		42	
Private	4	3		26	
Third	-	10		32	
Funding in 2008 ³ (%)		<i>Public</i>	<i>Private</i>	<i>Public</i>	<i>Private</i>
Municipality	84.3	71.6	70.0	na	na
Social Insurance Institution				na	na
Client / household	15.7	28.4	12.0	na	na
Non-profit institutions serving households			18.1	na	na
<i>People living their last 2 years of life⁴</i>					
Patients / residents					
Mean age	84.8	85.5	86.2	85.3	85.5
Women (%)	70.5	67.7	60.7	67.0	68.1
Dementia (%)	53.0	47.4	49.9	46.1	50.8
Users (%) among those who died in					
2002	17.8	23.1	3.5	3.3	4.7
2008	16.7	19.8	2.8	7.4	6.9
Change (%)	- 6.2	- 14.3	- 20.0	+ 124.2	+ 46.8

¹ Ministry of Social Affairs and Health. Decree for outpatient and institutional care 1806/2009

² National Institute for Health and Welfare *Statistical Yearbook on Social Welfare and Health Care 2010*. Helsinki: National Institute for Health and Welfare.

³ Pekurinen et al. 2011 *Sosiaali- ja terveydenhuollon monikanavaisen rahoituksen edut, haitat ja kehittämistraaheet*. Report 4 edn. Helsinki: National Institute for Health and Welfare

⁴ COCTEL data (New dynamic of longevity and the changing need for services)

na = not available

4.3 Changing long-term care

Traditionally, Finnish long-term care has consisted of institutional care offered in nursing homes and in health center inpatient wards. Recently these have been found undesirable because of the institutional environment and because of the high costs of institutional care. Hence, the request is for health center inpatient wards in future to serve only in case of needed short-term primary medical care. Since the 1990s, old people's institutional care has been increasingly replaced by sheltered housing with 24-hour assistance. The service structure and the number of people who use different long-term care services has changed. The use of sheltered housing with 24-hour assistance has increased: in the year 2000 only 1.7% of people aged 75 or older had used the service, but in the year 2013 the proportion was 6.5%. Simultaneously, the number and proportion of people who used nursing home or health center long-term care decreased. (National Institute for Health and Welfare 2014e). Table 1 shows how in the last two years of life the proportion of people who used health center long-term care or nursing home care was higher than the proportion of those who used sheltered housing with 24-hour assistance, although the percentage of users in the latter case had nearly doubled between the years 2002 and 2008, rising to about 14% in 2008. In 2008 about every fourth person had used nursing homes, and less than every fifth had used long-term care offered in a health center inpatient ward, during the last two years of life.

Sheltered housing with 24-hour assistance is classified as a housing service and is regarded as home-like service because people are often entitled to their own room and they can bring some of their personal belongings and furniture with them. Institutional care differs from sheltered housing with 24-hour assistance in its funding. In sheltered housing with 24-hour assistance people pay for a part of the services out of their own pocket. People live in rented accommodation and can apply for financial support for the residential costs from the Social Insurance Institution (SII) that is funded by national taxation. They purchase their own medicines; the drug costs are also covered partly by SII which is similar to the situation for community-dwelling people. On the contrary, in institutional care the municipality is responsible for covering the drug costs and residence is included in the standardized costs of treatment. (The Ministry of Social Affairs and Health 2008, Johansson 2010, Noro et al. 2014).

Another change in long-term care is the shift from the primarily publicly produced services to services produced by private enterprises and not-for-profit foundations and organizations (NGOs), also known as the third sector. In recent

years the public services have been increasingly outsourced to market-based companies (Anttonen and Häikiö 2011); municipalities purchase services for the residents of the municipality from the private sector that includes private enterprises and NGOs. The distribution of long-term care services and funding are shown in Table 1, demonstrating how institutional care is often publicly produced and funded. On the other hand, sheltered housing with 24-hour assistance is more frequently produced by private enterprises and the third sector. Private services (including both private enterprises and the third sector) have been increasingly supplementing public municipal services.

At present the policy guidelines in effect stipulate that old people should stay outside the institutional care settings and live at home with the support of outpatient services, or in non-institutional housing services, as long as possible. Living at home is supported by different efforts. Home care covers home aid and home nursing services. Informal care is partly financially supported by municipalities although the extent of this support varies between different municipalities. Short-term respite care is offered for old people in long-term care settings to support staying at home with the care of the informal caregiver. The purpose of respite care is to prevent or at least delay the shift to permanent long-term care. (The Ministry of Social Affairs and Health 2008, The Ministry of Social Affairs and Health 2013a). During the past decade the proportion of people aged 75 or older who had home care decreased (National Institute for Health and Welfare 2014e), and home care has been increasingly concentrated on people experiencing the greatest need (Kokko and Valtonen 2008).

4.4 Health and social care registers in Finland

The important national registers used in health research in Finland are The Finnish Care Register and The Causes of Death Register. The Finnish Care Register was called The Finnish Hospital Discharge Register until 1994 and included all hospital admissions since 1969. In 1996, data collection of social care began and The Finnish Care Register was divided into two parts: The Care Register for Health Care (HILMO) and The Care Register for Social Welfare (SosiaaliHILMO). The latter include information on the use of housing services and social care institutions. The Finnish Care Register is controlled by the National Institute for Health and Welfare. (Kajantie et al. 2006, National Institute for Health and Welfare 2014 f & g). Statistics Finland holds register information, for example, on population structure and

population structure projections, on births, and the causes of death. The Causes of Death Register holds information on the dates of death and causes of death, including immediate, underlying, intermediate and contributing causes of death, classified according to The International Classification of Diseases (ICD-10). (Kajantie et al. 2006, Official Statistics of Finland 2015b).

Every citizen in Finland has a unique Personal Identity Code (PIC) that remains unchanged throughout life. All information in registers is recorded by using the PIC. Because all register information contains the PIC, it enables reliable linking of individual information recorded in different registers. Early registers contained inaccuracies in the use of the PIC, but since the early 1990s the accuracy has exceeded 99% (Sund 2012).

The Finnish care registers offer a good possibility to conduct comprehensive, nationwide research on care practices for the whole population. Using register-based data is thus efficient when the entire population is to be studied, since collecting the data on the whole population would otherwise be time-consuming or even impossible (Kajantie et al. 2006). Although limitations are also mentioned in Kajantie et al. (2006); the register-based data are secondary data source because information is collected primarily for administrative purposes. The nature of this data constructs methodological differences when compared with research data that are planned and primarily collected for the purpose of considering specific research questions. In register-based research the research questions and the execution of the study have to be formulated on the basis of the information already gathered into registers, or according to variables which can be created on the basis of this existing information, and on the basis of the given structure of the data. In addition, in order to conduct a successful research, a comprehensive understanding of the original function of the data is required.

The reliability of registers was evaluated by Sund (2012) on the basis of previous studies concerning the accuracy of diagnoses, admissions and discharges. The conclusion was that the registers can be considered reliable despite the fact that some inconsistencies were found, in particular with rare diseases. Aro et al. (1990) studied the accuracy of the main diagnoses in different hospitals and found that 96% were accurate. All told, the long history of care registers has enabled the correcting of inconsistencies and technical errors (Sund 2012), and The Finnish Care Register (Sund 2012) and The Causes of Death Register (Kajantie et al. 2006) are considered reliable and substantially accurate.

5 Aims of the study

In this research the main aim was to examine the care patterns, described by care transitions in last two years of life and the places of death, for people aged 70 or older, and separately for people with dementia. The old population and the service system are changing simultaneously. The number of old people is increasing and more people die at a very old age when the disabilities are more frequent. Still, relatively little is known about the care patterns in the old population when the time of death is close; it is known, however, that care transitions and places of death have an effect on the quality of the end of life. The aim therefore was to demonstrate the frequent care patterns at the end of life, and to study how care transitions and the place of death are associated with individual factors, such as age, gender and dementia, and how the care transitions vary according to the municipality of residence, the year of death and in different round-the-clock long-term care facilities.

The research questions were

1. What is the frequency of care transitions in the last 24 months of life for people aged 70 or older? (Articles 1, 2 and 3)
 - How do the frequency and type of transitions differ according to age, gender or municipality of residence?
2. Which are the places of death in people aged 70 or older? (Article 1)
 - How do the places of death vary by age and gender?
3. What is the impact of dementia on the frequency of care transitions? (Article 2)
4. How frequent are transitions classified as burdensome for people with dementia? (Article 4)
 - Does the frequency of burdensome transitions vary by the year of death or by the long-term care setting?

6 Methods and analyses

6.1 The data

Data were derived from comprehensive national registers and included information on the old population and their care use. The data were collected in three different sets, altogether from the years 1998-2008, and included the information on people who died at the age of 70 or older in the study years and the care they received two years (730 days) before death.

The first data set (N 75 578), gathered from the years 1998-2001, consisted of information on all those who died in the year 1998, and a 40% random sample from the years 1999-2001. This data was used in article 1.

The second data set (N 70 366) from the years 2002-2003 was used in articles 2, 3, and 4.

The third data set (N 170 695) from the years 2004-2008 was used in article 4.

The study population was identified by Statistics Finland. Statistics Finland provided information on age, gender, municipality of residence, and the causes of death (including immediate, underlying, intermediate and contributing causes of death). The information on care use was taken from The Care Register for Health Care and The Care Register for Social Welfare, maintained by The National Institute for Health and Welfare. They include information on the use of health centers, central, district and private hospitals, and university hospitals (The Care Register for Health Care), and the use of nursing homes and sheltered housing with 24-hour assistance (The Care Register for Social Welfare). Sheltered housing with 24-hour assistance offer long-term care that is not classified as institutional care but housing service. The Finnish Care Registers contain information on the dates of admissions and discharges. Information on the outpatient care visits was not available in registers. Register data from Statistics Finland and from The Finnish Care Registers were linked by using the unique Personal Identity Codes (PIC). Linking was done in Statistics Finland.

The information about different diagnoses was gathered from The Causes of Death Register and The Care Register for Health Care and The Care Register for

Social Welfare. Diagnosis information included both the main and secondary diagnoses from The Finnish Care Registers and immediate, underlying, intermediate and contributing causes of death from The Causes of Death Register; if a person had a diagnosis recorded in any of the registers, he or she was classified as having that diagnosis. People were identified as having dementia if they had ICD10 codes F00-F03, or G30 (Alzheimer's disease). Other major diagnoses were classified as cancer (C00-C97), psychosis, depressive symptoms or other mental health disorders (F04-F99), Parkinson's disease or other neurological diseases (G00-G99 excluding G30), chronic asthma and COPD or other respiratory diseases (J00-J99), arthritis or osteoarthritis (M05-M06, M15-M19), hip fracture (S72), stroke (I60-I69), ischemic 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).

SOTKANet, used in study three, contains statistical information on welfare and health in Finland. Information is at the municipality level and does not include any individual information. SOTKANet is provided by The National Institute for Health and Welfare and is available via free internet service.

Permission to access register data was obtained from each registrar. The linking of data was done in Statistic Finland, thus the researchers had no access to PICs. The research plan was approved by the Ethics Committee of the Pirkanmaa Hospital District.

6.2 Care transitions in this study

The concept of care transitions refers here to the moves between different care facilities, from a home to a care facility, or from a care facility to a home. The care transition was defined as a change in care provider, and visits to outpatient care or moving between inpatient wards in the same care facility were not included in care transitions. The sequence of all admissions and discharges in the last two years of life constructed one pathway of care including the time stayed outside inpatient care. The place of death was the last place where the person was located on the day of death.

Care facilities to or from which people moved were

- Health center inpatient ward

- General hospital, including central, district and private hospitals

- University hospital

Residential care facilities, including nursing homes and sheltered housing with 24-hour assistance

6.3 The construction of care pathways

To study care transitions and construct individual care pathways, the following variables were used:

The dates of admission

The dates of discharge

The date of death

Pathways of care were constructed according to the sequence of transitions. Transitions could be followed for 730 days preceding death for each individual. The time stayed outside of the round-the-clock care facilities was classified as being at home. The care facilities to or from which people moved were a health center inpatient ward, a general hospital, a university hospital and residential care facilities (including nursing homes and sheltered housing with 24-hour assistance). The final location was classified as the place of death. To be classified as a care transition, a person had to stay overnight in the place to which he/she moved.

The care transition pathways were constructed so that a person could be only in one place during one day, though in reality people moved between different settings during one day. When a person was admitted into a care facility, that day was recorded as an inpatient day in that care facility. When a person was discharged, that day the person was classified as being at home if not admitted to another care facility. If admitted to another care facility, that day was marked as a stay in the new facility.

In care pathways there was one exception from the one-place-in-one-day rule. In order to find out the actual place of death, less than one day stays were taken into account during the last day: there were people who were discharged during the last day from a care facility, and admitted to another during the same day. In that case the place to which the person was admitted, i.e. the latter place, was regarded as the place of death and the last transition was seen as this move during the last day.

An example:

No recordings in care registers until the 2nd of May 2002.

On the 2nd of May admitted to general hospital

Stays there until the 5th of May when discharged back home

Admitted to health center on the 6th of May

Discharged from health center and admitted to general hospital on the 8th of May

On the 10th of May discharged from general hospital and admitted to health center inpatient ward

Dies on the 11th of May in health center inpatient ward

Care transitions in this pathway: home → general hospital → home → health center → general hospital → health center (the place of death). This care transition pathway includes five care transitions; three between home and a care facility, and two between care facilities.

6.4 Statistical analyses

Statistical analyses used in different studies were the following:

- chi-square test, medians, percentages (Article 1)
- negative binomial regression analysis (Article 2)
- multilevel negative binomial regression analysis (Article 3)
- logistic regression analysis (Article 4)

The number of care transitions in total, and between different care facilities or home, were strongly skewed continuous variables and displayed over-dispersion (variance exceeds the mean). Negative binomial regression analyses were used when the outcome variable was the number of transitions in total, or the number of different types of transitions (Hilbe 2008). Analyses and variables in different studies are shown in a more detailed fashion in Table 2. The data included all people who died in the years 1998 and 2002-2008 at the age of 70 or older and thus represented this whole population in those years. Yet the statistical testing was performed when the different years were compared in order to follow the year-to-year change. The Finnish old people included in this study can be seen as a sample of the larger population of old people including old people from other similar countries (also in Forma 2011), or as a part of a theoretically infinite population.

For the years 1998-2001 the service code did not differentiate between a nursing home and sheltered housing with 24-hour assistance; they were thus studied as one group called residential care. Hence, a residential care facility in articles 1-3 refers to round-the-clock long-term care offered in nursing homes or sheltered housing with

24-hour assistance. Different long-term care facilities could be distinguished from the year 2002 onwards and were studied separately in article 4. In addition, in article 4 a group of nursing homes and sheltered housing facilities declaring themselves to be specialized in dementia care were studied as a separate group.

The health center inpatient ward was studied as one care facility which people moved to or moved from. It is a care facility that offers both short-term hospital care (length of stay less than 90 days) and long-term care (length of stay 90 days or more).

Table 2. Data, analyses and variables in 4 articles.

	Article 1	Article 2	Article 3	Article 4
Study years (data set)	1998-2001 (data set 1)	2002-2003 (data set 2)	2002-2003 (data set 2)	2002-2008 (data sets 2-3)
N	75 578	70 366	67 027	18 912
Register	The Finnish Care Register (HILMO) Causes of Death Register	The Finnish Care Register (HILMO) Causes of Death Register	The Finnish Care Register (HILMO) Causes of Death Register SOTKANet Indicator Bank	The Finnish Care Register (HILMO) Causes of Death Register
Study questions	Number of transitions in total, difference by age and gender, and by place of death	Difference in number of transitions between people with and without dementia	Municipal variation in the number and type of transitions	Frequency of burdensome transitions
Analyses	Descriptive: medians, percentages Chi-square test	Negative binomial regression	Multilevel negative binomial regression	Logistic regression
Outcome variables	Places of death Total number of transitions - in last 2 years - in last 6 months Number of different types of transitions	Total number of transitions - in last 2 years - by 24 months	Total number of transitions in last 2 years Number of different types of transitions	Frequency of burdensome care transitions

Explanatory variables/ descriptive variables	(Article 1) Age at death Gender Age and gender groups Places of death	(Article 2) Dementia Gender Age at death Other major diagnostic groups as covariates	(Article 3) <i>Level I</i> Gender Age at death Diagnoses <i>Level II</i> Proportion of 65-year olds Proportion of those living alone Number of inhabitants Tax revenue (€/capita) Total operating health and social expenditure Annual contribution margin Urbanity Support for informal care <i>Level III</i> University hospital in the district	(Article 4) Age at death Gender Year of death Baseline (3 months before death) care facility Other major diagnostic groups as covariates
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Article 1

To construct a general view of care transitions in the last 24 months of life and of the places of death in Finland, descriptive methods were used. The data were divided into six gender and age subgroups: one each for men and women at the ages of 70–79, 80–89, and 90 or over. The proportion of decedents according to the places of death was reported via these six groups. The proportion of people who had any care transitions was calculated, after which the median number of transitions for those who had transitions in the last two years of life was reported. Since the majority of the care transitions were concentrated in the final months, the proportion of people with transitions and the median number of those who had transitions were also reported for the last six months. The proportion of different types of transitions among all of the transitions was reported for the six gender and age groups. Finally, to identify the patterns of transitions by the place of death, the proportion of people having transitions between different care facilities or home, and the median number of all transitions, were reported according to the place of death.

Article 2

The effect of dementia on the number of care transitions in last two years of life were studied for the whole study population and separately according to the baseline site; for those who were at home, or in residential care, two years before death. The influence of dementia, age at death and gender on the number of transitions was analyzed with negative binomial regression analyses. All analyses were adjusted for the other major diagnostic groups. Monthly differences in number of transitions were studied during the 24 final months of life for people with and without dementia, and in different baseline care facilities, all adjusted for age and gender.

Article 3

Differences in the number of transitions between municipalities were examined: these included the total number of transitions in the last two years, and the number of different types of transitions between home and care facilities, and between different care facilities. Because of the hierarchical structure (individual level I, municipal level II, hospital district level III) of the data, a multilevel approach was

employed. The number of care transitions was analysed in random intercept models, adding the explanatory variables sequentially to the models. Three-level analyses were performed to study the significance of explanatory variables at each level, and unexplained variances at levels II and III: 1) Null model (intercept only model), 2) Model 2: municipal level factors, 3) Model 2: model 1+ hospital district level factor, 4) Final model: model 2 + individual level factors.

Article 4

Applying the model suggested by Gozalo et al. (2011) burdensome transitions were defined as 1) any transition to another care facility during the last three days of life, 2) lack of continuity in long-term care, 3) multiple transitions to hospitals (more than two) during the last 90 days of life. The criteria of the study group were having dementia as a cause of death and being in long-term care both six and three months before death. The purpose was to define as accurately as possible those who had advanced dementia in their final months and were, in addition, permanent residents in different long-term care facilities. To study the proportion of potentially burdensome care transitions, the percentages of people having any of these transitions, with all three types studied separately, were reported for the whole population and separately in different baseline care facilities. Logistic regression analysis was used to analyze the likelihood of having at least one of the burdensome transitions (1=yes, 0=no), and all three types separately. Age, gender, year of death, and different baseline care facilities including nursing homes, sheltered housing with 24-hour assistance, and long-term care facilities (nursing homes and sheltered housing) specialized in dementia care as a distinct category were included in analyses as independent variables.

In the following results section, the care patterns in last two years of life, including monthly care transitions and the average number of days spent in different facilities or a home, are shown in figures for the whole study population as well as for people with dementia. The number of care transitions and places of death are shown in all three data sets.

7 Results

7.1 Description of the study population

In the total study population the average age at the time of death was over 80 in all three data sets (Table 3) and it increased during the study years. The proportion of people who died at the age of 70–79 decreased while the proportion of people who died at the age of 90 or over increased. The proportion of men was around 40% and increased slightly during the study years.

Among the persons with dementia the average age at death was around 85 in all three data sets (Table 3). The proportion of people who died at the age of 70–79 decreased while the proportion of people who died at the age of 90 or older increased. The proportion of men was less than one third in all three data sets for people with dementia, but increased during the study years. The proportion of those diagnosed with dementia increased during the study years and was about a fourth of the whole study population in the data set 3.

Table 3. Description of the study population in total, and in people with dementia, in three data sets.

	Data set 1 1998-2001	Data set 2 2002-2003	Data set 3 2004-2008
<i>Total</i> N	75 578	70 366	170 695
Age, mean	82.6	83.0	83.3
Age in three groups %			
70-79	36.1	34.0	32.0
80-89	46.1	45.5	46.4
90-	17.8	20.5	21.6
Gender %			
Men	40.7	40.6	42.4
Women	59.3	59.4	57.6
<i>Dementia</i> N	16 795	17 437	46 619
Proportion of people with dementia %	22.2	24.8	27.3
Age, mean	85.4	85.6	85.9
Age in three groups %			
70-79	19.3	18.5	16.9
80-89	53.3	51.5	51.9
90-	27.4	30.0	31.2
Gender %			
Men	30.2	30.5	32.6
Women	69.8	69.5	67.4

7.2 Care transitions

7.2.1 Care transitions in the whole old population

The number of transitions in the last two years of life varied extensively in every study year from zero to a small number of people with more than a hundred transitions. Of all persons involved, 87.5% had at least one care transition during the last 24 months, and 12.5% remained the entire time in the same site without any transitions. Of those who did not move at all 7.6% stayed the whole time in the same care facility and 4.9% remained at home. (Article 1).

In 1998-2001, the median number of care transitions in those who had a least one transition was seven in the last two years of life (Article 1). The number of transitions increased in the last six months, being highest in the final month (Article 2). In the last six months the median number of transitions was three, and over a half of the people had at least two transitions (Article 1).

When the study years were compared (Table 4), the proportion of those who had no transitions in last two years increased. Of these the proportion of those who were at home the whole time increased from 4.8% (1998) to 5.2% (2008), and those who were in care without transitions the whole time increased from 7.4% (1998) to 8.8% (2008). The proportion of those who had only one care transition, from home to a care facility, decreased. The proportion of those who stayed the whole time in care with transitions, increased from 6.1% (1998) to 9.5% (2008). The median number of transitions did not change in last two years, but the mean number of transitions increased slightly, as did the number of people with at least two transitions in the last six months.

Table 4. Transitions for those who died in 1998 (data set 1), 2002 (data set 2) or in 2008 (data set 3).

	1998 N 34 116	2002 N 35 821	2008 N 34 951
Last 2 years at home, no transitions % ^a	4.8	4.9	5.2*
Last 2 years in care, no transitions % ^a	7.4	9.0	8.8**
Last 2 years in care, transitions % ^a	6.1	8.5	9.5**
One transition in last 2 years, from home to care % ^a	6.6	6.3	5.6**
Transitions, median/mean ^{b, c}			
last 2 years	6 / 8.9	6/8.9	6/8.9 ^{ns}
last 6 months	3 / 3.6	3/3.6	3/3.8**
last 3 months	2 / 2.3	2/2.3	2/2.5**
last month	1 / 1.1	1/1.1	1/1.1 ^{ns}
Transitions, % of those who had 2 or more ^a			
last 2 years	78.9	77.9	78.4 ^{ns}
last 6 months	58.1	57.9	59.0*
last 3 months	47.2	47.1	48.6**
last month	25.3	24.4	26.4**

^a The p-value refers to the chi-square test comparing the years 1998 and 2008

^b Medians, means and percentages for those who had at least one care transition during the last 2 years

^c The p-value refers to the Mann-Whitney-U test comparing the years 1998 and 2008

** p < 0.001, * 0.001 ≤ p < 0.05, ^{ns} not significant

Most of the care transitions occurred between home and a health center, and between home and a general hospital. When people moved between different care facilities instead of being admitted from their home or discharged back home, transitions involving a health center were again the most frequent; people were either discharged from a health center to another care facility, or admitted to a health center from another care facility. In all, transitions between home and care facilities were more common than moving between different care facilities. (Article 1, Article 3).

7.2.2 Age differences in care transitions

The proportion of people who stayed the entire last two years of life at home was highest among those who died at the age of 70-79 years and lowest in those aged 90 or older. People in older age groups more frequently stayed without transitions in a care facility than people from younger age groups. (Article 1)

The older age groups had fewer transitions in their last two years than people who died at a younger age (Article 1-3). When different diagnoses, gender, and residential area factors (the municipal and hospital district factors) were taken into account, the age of 90 or above was associated with a lower number of transitions (Article 3).

A higher age was associated with a higher number of transitions in the last two years among those who lived in a private home two years before death, when gender and diagnoses were taken into account. Instead, among those who were in residential care two years before death a higher age was associated with a lower number of transitions. (Article 2). A similar association of age with transitions was found in residential care residents with dementia, when gender, other diagnoses, the year of death, and the baseline residential care facility were taken into account (Article 4).

People who died at the age of 70-79 more frequently had care transitions between home and a general hospital and home and a university hospital than people who died at an older age. People at an older age more frequently had transitions between home and a health center, home and residential care, residential care and a health center, and between residential care and a general hospital than did younger people. (Article 1). When gender, diagnoses, and residential area factors (the municipal and hospital district factors) were taken into account (Article 3), the differences between age groups persisted (Table 5, Table 6).

Table 5. Association of age and gender with number of transitions between home and different care facilities. Unpublished results related to Article 3.

	Home → health center	Health center → home	Home → general hospital	General hospital → home	Home → university hospital	University hospital → home	Home → residential care facility	Residential care facility → home
Individual level (I)	RR (95% CI)	RR (95% CI)	RR (95% CI)	RR (95% CI)	RR (95% CI)	RR (95% CI)	RR (95% CI)	RR (95% CI)
Age								
0=70-79								
1=80-89	1.24(1.20,1.29)	1.17(1.12,1.22)	0.74(0.72,0.77)	0.63(0.59,0.65)	0.57(0.54,0.59)	0.49(0.46,0.53)	1.64(1.51,1.77)	1.70(1.58,1.83)
1=90+	1.23(1.17,1.29)	1.07(1.02,1.13)	0.45(0.43,0.47)	0.31(0.29,0.33)	0.33(0.30,0.35)	0.22(0.20,0.25)	1.85(1.68,2.05)	1.96(1.79,2.16)
Gender, 0=male 1=female								
	0.97(0.94,1.01)	0.95(0.92,0.99)	0.83(0.80,0.85)	0.76(0.73,0.80)	0.87(0.83,0.91)	0.80(0.75,0.85)	0.76(0.70,0.81)	0.79(0.68,0.88)

Rate ratios (RRs) and 95% confidence intervals from multilevel negative binomial regression models. Adjusted for morbidity, including cancer, dementia, diabetes, psychosis, depressive syndromes or other mental health disorders, Parkinson's 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. Level II and level III results are shown in article 3.

Table 6. Association of age and gender with number of transitions between different care facilities. Unpublished results related to Article 3.

	Health center → residential care	Residential care → health center	Health center → general hospital	General hospital → health center	General hospital → residential Care	Residential Care → general hospital	University hospital → health center	Health center → university hospital
	RR (95% CI)	RR (95% CI)	RR (95% CI)	RR (95% CI)	RR (95% CI)	RR (95% CI)	RR (95% CI)	RR (95% CI)
Individual level (I)								
Age								
0=70-79								
1=80-89	1.77(1.68,1.88)	1.78(1.66,1.90)	0.99(0.94,1.04)	1.09(1.05,1.12)	1.53(1.36,1.71)	1.66(1.51,1.82)	0.94(0.89,0.99)	0.87(0.80,0.95)
1=90+	2.36(2.20,2.54)	2.47(2.28,2.67)	0.68(0.63,0.74)	0.91(0.87,0.96)	1.71(1.47,1.98)	1.96(1.74,2.20)	0.73(0.67,0.78)	0.51(0.44,0.58)
Gender								
0=male								
1=female	1.28(1.21,1.34)	1.35(1.27,1.43)	1.08(1.03,1.14)	1.07(1.04,1.11)	1.01(0.90,1.12)	1.08(1.00,1.17)	1.10(1.05,1.16)	1.10(1.01,1.20)

Rate ratios (RRs) and 95% confidence intervals from multilevel negative binomial regression models.

Adjusted for morbidity, including cancer, dementia, diabetes, psychosis, depressive syndromes or other mental health disorders, Parkinson's 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. Level II and level III results are shown in article 3.

7.2.3 Gender differences in care transitions

A higher proportion of men than women had care transitions in the last two years of life (Article 1, Figure 3); about 90% of men and 86% of women experienced transitions. Of those who had no transitions men more frequently were at home without round-the-clock care during their last two years than women. On the contrary, women more frequently were in care the entire last two years than men.

When different diagnoses, age at death and residential area factors (the municipal and hospital district factors) were taken into account, men had more transitions in their last two years than women (Article 3). The gender difference varied in different age groups: when men and women who had transitions were compared between the three age groups of 70–79, 80–89, and 90 or older, the median number of transitions was higher for men than for women at the age of 80–89 and 90 or older, but there was no difference between genders at the age range of 70–79 years. (Article 1).

Among those who were at home two years before death there was no gender difference in the number of transitions when age and diagnoses were taken into account. Among those who were in residential care two years before death the male gender was associated with a higher number of transitions in the last two years (Article 2). The association of the male gender with a higher number of transitions for residents in residential care was also found among those with a dementia diagnosis, when age, other diagnoses, the year of death, and the baseline residential care facility were taken into account (Article 4).

A higher proportion of men had care transitions between home and a general hospital, and home and a university hospital than did women. A higher proportion of women had transitions between home and a health center and home and residential care. (Article 1). In multilevel analysis when age at death, diagnoses, and residential area factors (municipal and hospital district) were taken into account (Article 3), men were more likely to have transitions between home and care facilities, and women were more likely to have transitions between different care facilities (Tables 5 and 6).

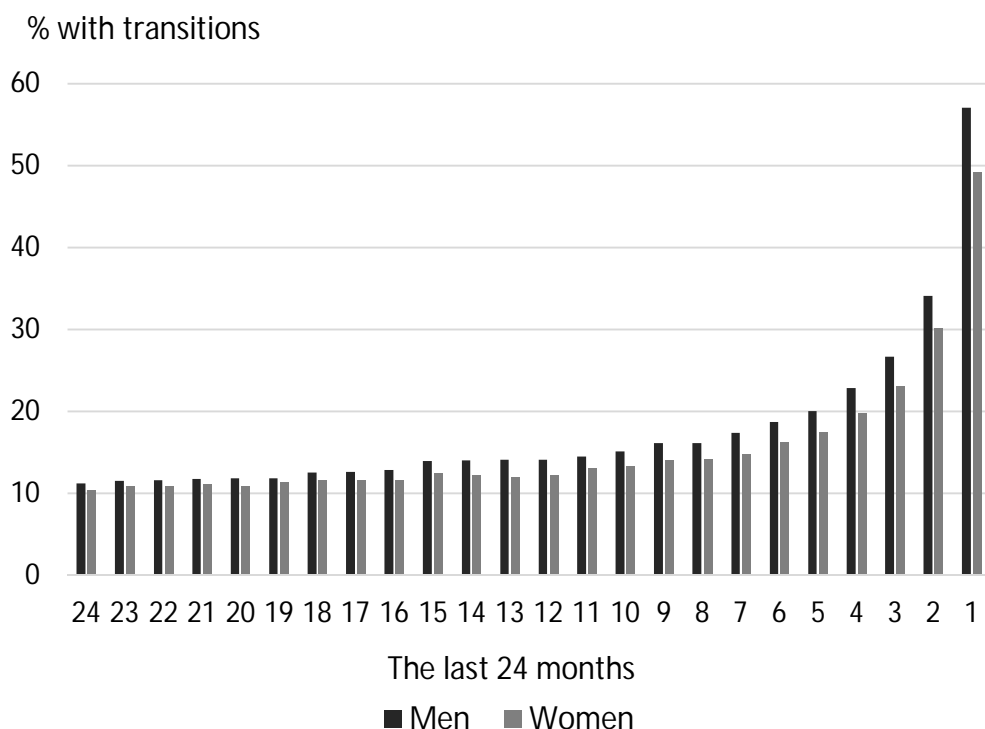


Figure 3. Proportion (%) of men and women with transitions in each of their last 24 months for those who died in 2008.

7.2.4 Municipality of residence and care transitions

The municipality of residence had only a modest association with the total number of transitions in the last two years of life. Transitions were more frequent in semi-urban areas than in urban ones, in municipalities with revenues which covered operating costs, and in municipalities with a higher amount of support for informal care. Most of the individual-level factors had a statistically significant effect on the total number of transitions. (Article 3).

Yet the number of different types of transitions varied between municipalities: the most notable variance was in transitions involving general and university hospitals. The variance in transitions involving general hospital was not explained entirely by the different level of explanatory factors, indicating that even differences between individuals in different municipalities, municipality factors, or the existence of a university hospital in the hospital district did not explain the differences in

transitions to or from general hospitals. Instead, the existence of a university hospital explained most of the variance in transitions to or from a university hospital. The number of transitions to a health center or residential care varied modestly between municipalities. (Article 3).

7.3 Place of death

7.3.1 Places of death in the whole old population

The health center inpatient ward was the most typical place of death for the entire old population: almost a half of all deaths took place there. The second most frequent place of death was a general hospital followed by the home. Only every tenth person died in residential care, and even fewer in a university hospital. (Article 1).

A health center was the most common place of death for all of the study years (Table 7). The proportion of people who died in a general hospital or at home was lower in 2008 than in 1998. In 2008 a university hospital and residential care, especially sheltered housing with 24-hour assistance, were more frequent places of death than in previous years.

Table 5. Place of death for those who died in 1998 (data set 1), 2002 (data set 2), or 2008 (data set 3)

	1998 N 34 116	2002 N 35 821	2008 34 951
Place of death (%)			
Home	16.8	14.3	14.5
University hospital	5.4	6.6	6.8
General hospital	20.4	17.6	15.6
Health center	47.7	49.0	48.8
Residential care	9.7	12.5	14.3
Nursing home	-	11.1	10.6
Sheltered housing with 24 hour assistance	-	1.4	3.7

The number and type of transitions in the last two years varied according to the place of death, as did the days stayed in care. In all, people most frequently moved to or from the site which was to be the place of death. In addition, regardless of the place of death, transitions between home and a health center were frequent. (Article 1, Figure 4).

If the place of death was a home, people most frequently moved between their home and a health center, a general hospital, or a university hospital, respectively. They stayed approximately only 13 days in care in their last two years. For those who died in a university hospital or in a general hospital, the care transitions were the most frequent between home and what was to be the place of death. When the place of death was a university or general hospital, people stayed mostly at home and only 30 or 40 days (median) in any care facility during their last two years. (Article 1, Figure 4).

If the place of death was a health center or residential care, the time spent in care was longer than for those who died in a university or general hospital, or at home. For those who died in a health center the median number of days in care was 154, indicating that those who died in a health center stayed in care about five months of their last two years. They moved most frequently between home and a health center, and home and a general hospital. Also moving between a general hospital and a health center was common. People who died in residential care had a median of 727 days of care. They most frequently had transitions between a health center and residential care, and also between home and residential care or a health center. (Article 1, Figure 4).

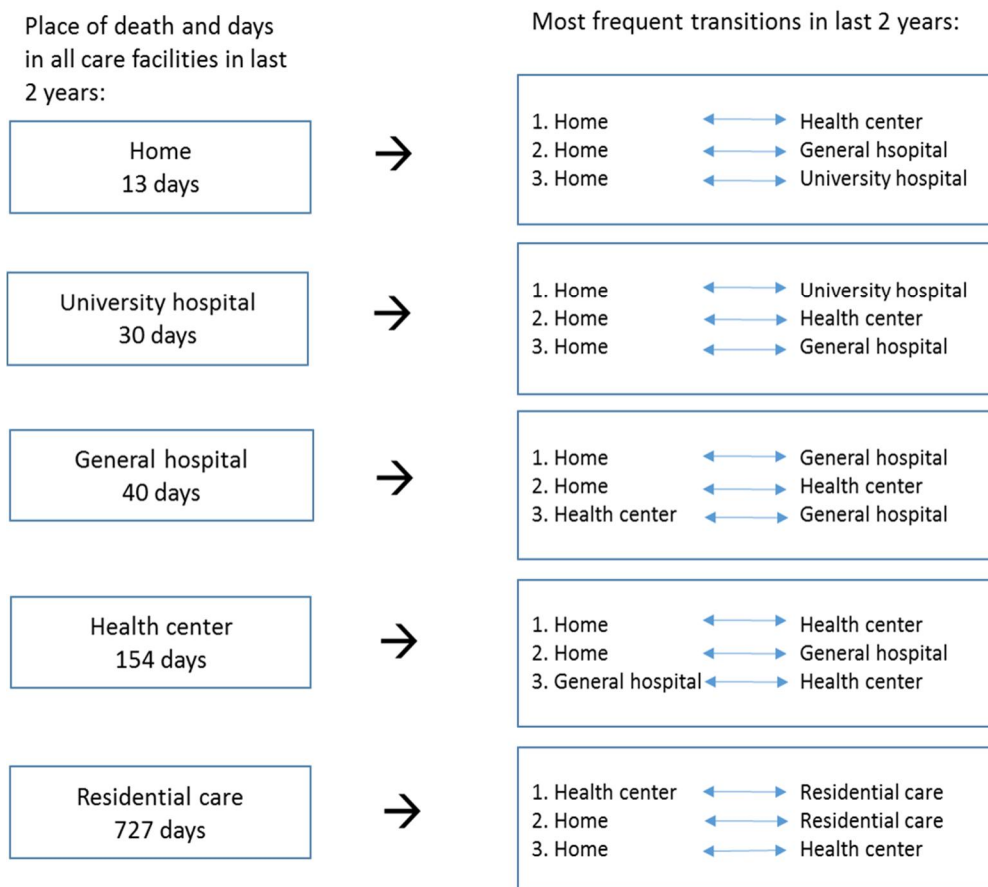


Figure 4. Most frequent transitions by place of death. Days in all care facilities, medians in last two years of life. Years 1998-2001 (Article 1).

7.3.2 Age, gender, and the place of death

A health center was the most frequent place of death in all three age groups for men and women. The higher the age, the more frequent was the place of death a health center or residential care. Those who died at a younger old age more frequently died at home, in a university hospital, or in a general hospital than did the older old people. Women died in a health center or in residential care more often than men who died in a general or university hospital, or at home more frequently than women. When men and women were compared in the same age groups, women still died

more frequently in residential care facilities and health centers than men, and men more frequently died in a general or university hospital or at home. (Article 1, Table 8)

Table 6. Age and gender differences in place of death for those who died in 2008.

Men and women in three age groups	Men 70-79 6483	Men 80-89 7691	Men 90+ 2258	Women 70-79 4132	Women 80-89 10246	Women 90+ 6846
N						
Place of death %						
Home	26.1	15.2	10.6	17.3	10.9	7.1
University hospital	10.1	7.4	4.4	10.0	5.5	3.2
General hospital	19.3	18.4	14.2	19.1	14.6	8.1
Health center	39.2	47.7	52.1	45.8	52.7	54.8
Nursing home	3.8	8.5	13.5	6.0	11.8	20.3
Sheltered housing	1.5	2.8	5.1	1.8	4.5	6.5
Total	100	100	100	100	100	100

7.4 Care transitions for people with dementia

7.4.1 The impact of dementia on care transitions

Every fifth person with dementia had no transitions in the last two years; most of them stayed the whole time in care, and only a small minority at home (Article 2, Table 9). It was almost as common to stay the last two years in care and have care transitions (Table 9). Instead, it was more frequent for people without dementia to stay the whole time at home than for those with dementia (Article 2, Table 9).

For those with dementia who had care transitions the median number of transitions was six during their last two years (Article 2, Table 9). For those without dementia the median number of transitions varied from seven to six in different study years. However, for those who had care transitions in the last two years of life, people with dementia had slightly more care transitions than people without dementia when age, gender and other diagnoses were taken into account (Article 2). As with the whole study population, the number of transitions became more frequent when the time of death approached, and it was the highest during the last month. People with dementia had their last care transition more frequently to a

health center than those without dementia, who moved more frequently to specialized care hospitals. (Article 2).

In those who lived at home two years before death, people with dementia had more care transitions (median 8 in those who had transitions) than people without dementia (median 7 in those who had transitions) in last two years of life. The average number of transitions was higher in the 24-6 months before death, but after that people without dementia had a higher number of transitions. In those who were in a residential care facility two years before death, people with dementia had fewer transitions than people without dementia for every month during the final 24 months. (Article 2).

The proportion of people without transitions among those with a dementia diagnosis was approximately the same for the years 1998, 2002 and 2008 (Table 9). Yet the proportion of those who were in care for the entire two years and who had transitions increased. In people with dementia the number of transitions increased during the study years; those who had transitions, had a significantly higher number in the last 24, six, three, and final months in 2008 than in 1998. The proportion of those with at least two transitions during the last 24, six, three, and final months was significantly higher in 2008 than in 1998. In those without a dementia diagnosis the changes in care transitions in last six months followed approximately the same trend as for those with dementia. Unlike with people with dementia, the proportion of those without transitions in the last two years increased. (Table 9).

Table 7. Transitions for people with and without dementia for those who died in 1998 (data set 1), 2002 (data set 2), and 2008 (data set 3).

	1998		2002		2008	
Dementia/no dementia N	D+ 7408	D- 26 708	D+ 8700	D- 27 121	D+ 10 240	D- 24 711
Last 2 years % ^a						
at home, no transitions	0.8	5.9	0.5	6.3	0.7 ^{ns}	7.0 ^{**}
in care, no transitions	20.0	3.9	20.6	5.2	19.7 ^{ns}	4.3 [*]
in care, transitions	13.6	4.0	16.5	5.9	17.3 ^{**}	6.2 ^{**}
Transitions, median/mean ^{b,c}						
last 2 years	6/8.4	7/9.0	6/8.7	7/8.9	6/9.1 ^{**}	6/8.8 ^{ns}
last 6 months	2/2.6	3/3.8	2/2.8	3/3.9	2/3.0 ^{**}	3/4.0 ^{**}
last 3 months	1/1.5	2/2.5	1/1.7	2/2.5	1/1.9 ^{**}	2/2.7 ^{**}
last month	0/0.7	1/1.2	0/0.7	1/1.2	0/0.8 ^{**}	1/1.3 ^{**}
Transitions , % of those who had 2 or more ^a						
last 2 years	69.3	81.6	71.4	80.0	73.0 ^{**}	80.6 [*]
last 6 months	41.4	62.8	43.9	62.1	47.5 ^{**}	63.7 [*]
last 3 months	30.3	51.9	32.3	51.4	36.7 ^{**}	53.5 ^{**}
last month	14.0	28.4	15.1	27.4	18.7 ^{**}	29.7 [*]

^a The p-value refers to the chi-square test comparing the years 1998 and 2008 for those with dementia, and for those without dementia

^b Medians and means for those who had at least one care transition in the last 2 years

^c The p-value refers to the Mann-Whitney-U test comparing the years 1998 and 2008 for those with dementia, and for those without dementia

^{**}p < 0.001, ^{*} 0.001 ≤ p < 0.05, ^{ns} = not significant

7.4.2 Burdensome transitions

Burdensome care transitions at the end of life were studied for people who had dementia as the cause of death and were residents in a residential care facility during the last six months of life (Article 4). Of study group from the years 2002–2008 (N=18 912) 69.6% were residents in nursing home, 24.9% in sheltered housing with 24-hour assistance, and 5.5% in LTC for people with dementia. Almost a half (42.3%) had at least one care transition in the last 90 days of life, and about one tenth (9.5%) experienced care transitions classified as burdensome. Of different types of burdensome transitions - any transition to another care facility in the last three days of life, lack of long-term care continuity, and multiple transitions to hospitals in the last 90 days of life - multiple hospitalizations in the last 90 days were most frequent;

5.5% of the study group had this type of burdensome transition. Almost as frequent were any transitions in the last three days (4.4%). The lack of continuity in long-term care facilities in the last three months was rare (0.3%). When the other diagnoses were taken into account, burdensome transitions were more common for people who died at a younger age, for men, and for those who were residents in sheltered housing or LTC specialized in dementia care three months before death instead of those who lived in nursing homes; almost every fifth of those who lived in sheltered housing with 24-hour assistance had burdensome transitions, when the corresponding figure for those in nursing home was 6.0%.

7.5 Patterns of care in last 2 years of life

Figure 5 shows the average number of days in care in different care facilities and at home, and the proportion of people with transitions in the last 24 months of life among the whole population of people who died at the age of 70 or older in 2008 (N 34 951). A majority of persons spent most days of their last two years at home. With approaching death the days at home decreased while simultaneously the days in a health center, in a general or a university hospital increased. The frequency of care transitions increased notably during the last six months. In general the transitions and days in care were heavily concentrated in the last six months, and especially in the last three months of life. The average number of days at home, in a nursing home, and in sheltered housing decreased most often when people moved to a health center, but also to other hospitals, before the time of death. The average number of days in a health center was the highest in the final month.

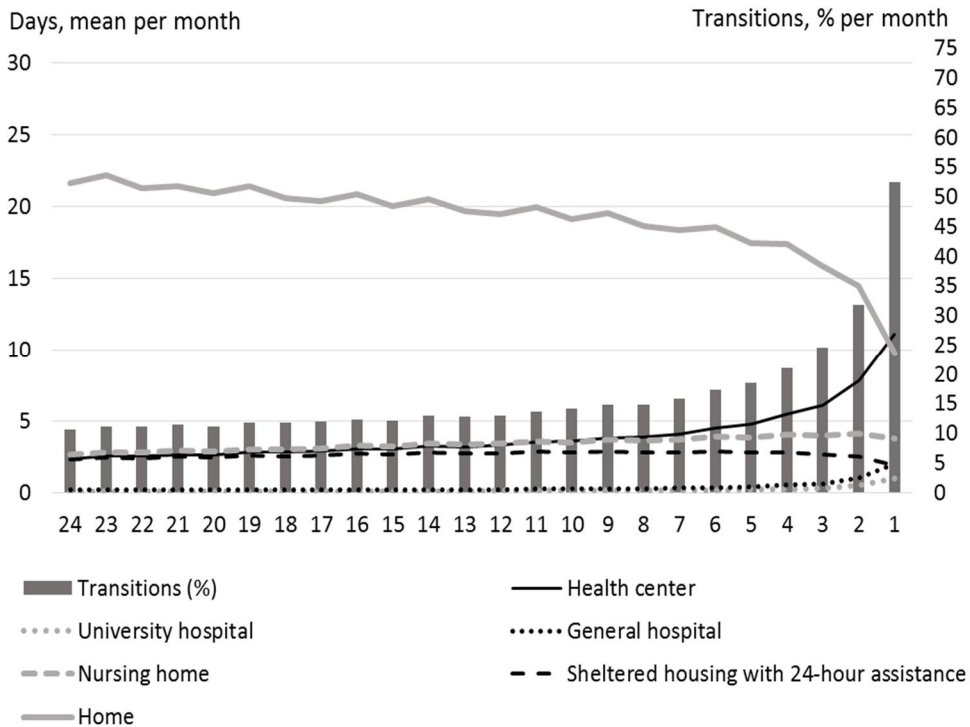


Figure 5. Days in care in different facilities, days at home, and proportion of people with transitions in the last 24 months (month 1 is the last month of life). The whole population of people who died at the age of 70 or older. Days in different care facilities and days at home are the mean values for 24 months (left scale, lines). The percentages are the proportions of people with transitions during 24 months (right scale, bars). Year 2008.

The last two years of people with dementia in 2008 (10 240) are seen in Figure 6. The average number of days at home was lower than in the whole study population. In those with dementia, about a third (37.0%) stayed the entire last two years in a health center, in sheltered housing with 24-hour assistance, or in a nursing home. This group consisted of more than a half of those who stayed their last full years in care in the whole study population. The days at home decreased month by month while the days in a health center and in a nursing home increased. When the time of death was close the proportion of persons with transitions increased, but the proportion was lower and the increase was more gradual than for the whole study population. However, between 24-9 months before death a higher proportion of persons with dementia had transitions than in the whole study population, indicating that those with dementia moved to care at an earlier phase than old people in general.

In the last month of life the average number of days in health center was highest, while the average number of days in sheltered housing, nursing home, and at home decreased when people moved to health center before the time of death.

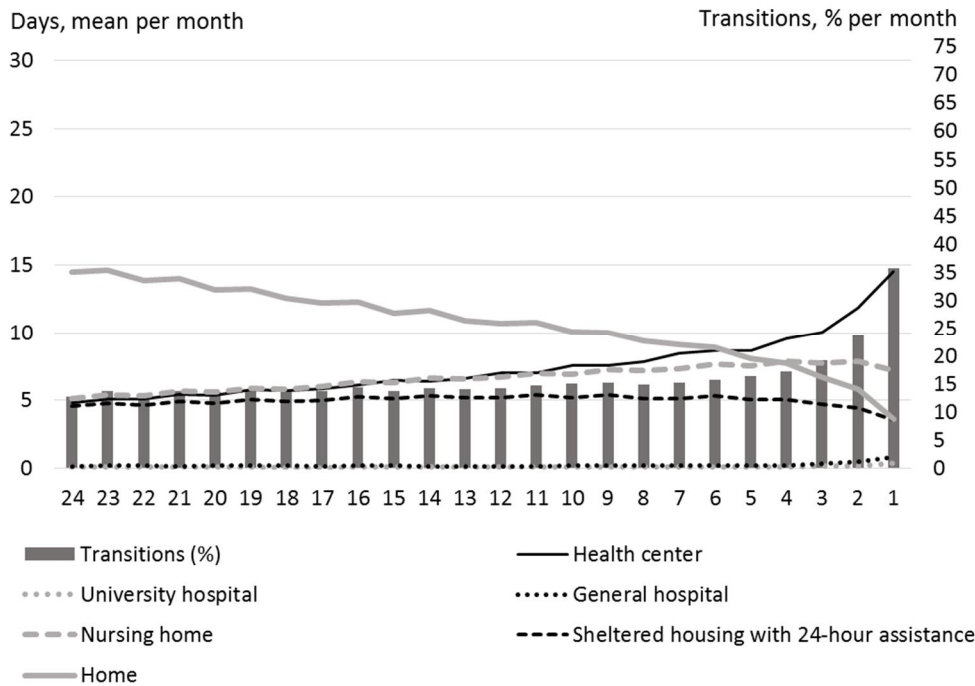


Figure 6. Days in care in different facilities, days at home, and proportion of people with transitions in the 24 last months (month 1 is the last month of life). People with dementia. Days in different care facilities and days at home are the mean values for 24 months (left scale, lines). The percentages are the proportions of people with transitions during 24 months (right scale, bars). Year 2008.

8 Discussion

8.1 Summary of the main results

A minority of the old people stayed in the same place for the entire last two years of life; most of them moved from home to a care facility, or between different care facilities at least once. The majority moved more than once but fewer than ten times in their last two years. People frequently lived most of their days at home until the last six months when the frequency of transitions increased, being the highest in the final month. Most care transitions took place from home to a health center which was the most common place of death, followed by a general hospital, a nursing home and a private home. Where people moved to in their last two years varied between municipalities, yet the municipal factors behind this variation remained for the most part undiscovered.

The number and types of transitions and the places of death varied according to age and gender. The youngest old (aged 70–79) and men stayed at home without transitions the entire final two years more frequently than the oldest old (≥ 90) and women, who more frequently stayed in care the entire last two years. Transitions were more frequent for the youngest old and men than for the oldest old and women. The youngest moved more frequently to or from specialized care hospitals, while the oldest people moved to or from a health center or residential care. Men moved more often between home and care facilities than women who moved instead between different care facilities more frequently than men. The youngest old and men died more frequently in specialized care hospitals or at home while the oldest and women died more frequently in residential care or in a health center.

About one third of the people with dementia spent their entire last two years in care and almost half of them had no transitions in the last two years of life. As with the whole old population, in those with dementia the care transitions were also most frequent in the final month. However, during the last two years they moved to long-term care at an earlier phase than those without dementia. The last transition was more frequently to a health center than for those without dementia who instead moved more frequently to specialized care. About one tenth of the persons with dementia had transitions classified as burdensome. Those in sheltered housing with

24-hour assistance more frequently had burdensome transitions when compared to those in nursing homes.

Between the years 1998 and 2008 the proportion of those without transitions during their last two years increased when the number of those who stayed the two entire years at home, and those who stayed the whole time in the same care facility, increased. The proportion of those who stayed the entire two years in care, with transitions, increased. Transitions in the last six months became more frequent for those who had transitions. The frequency of burdensome transitions did not show consistent changes. During the study years the average age at death, the proportion of people aged 90 or older and the number of people with dementia increased.

8.2 Methodological considerations

8.2.1 The study design

The data included all people who died at the age of 70 or older in the study years 1998 and 2002–2008 and a 40% random sample from the years 1999–2001. A major strength of this study was the extensive data that provided the unique possibility to demonstrate the care patterns for the whole population of people aged 70 or older for a decade.

All care transitions between hospitals, long-term care facilities and homes could be followed during all of the 730 last days of life for each individual, including the final place. Care transitions are different events near death than at an earlier phase of life. It is known that the need for care due to deteriorating health and functioning often starts in last years of life (Pot et al. 2009, Larsson et al. 2008, Smith et al. 2013); however, most previous studies have concentrated on the last three months of life. In this study it was possible to study the care transitions for the entire two years, but also for the last three and six months. It was felt that a time period longer than just a few months would be likely to reveal the care patterns during the time when the effect of approaching death most often starts to show in the health status and in functional ability. Studying care transitions in the final months of life would likely reveal patterns of care at the time of death. Therefore a longer period than just a few months can give more information of the care patterns during the last times of life. Respite care was also included in care transitions: according to the rough estimate in

the first article, respite care would explain only about one percent of all care transitions.

Another strength is that all types of care transitions were included: those to or from home and those between different care facilities. These different types of care transitions represent different events in life: the situation differs if a person is sent to a hospital from home and returns home after receiving hospital care, or if a person moves from one care facility to another.

The comparisons between the years is reasonable because during the whole study period changes have occurred, both in the population and in the care-service system. Information from more recent years would be needed in order to study the latest changes in care patterns.

When a person was not in any care facility, e.g. days in care were not recorded, he or she was classified as staying at home. It is impossible to say if these people were actually staying at their own private home or if they were staying with a relative or a friend, or in a service-housing facility without round-the-clock care.

When care transitions are studied it is important to acknowledge how transitions can pose both advantages and disadvantages, depending on the cause of transition and where and when people move. Care transition research is often criticized for concentrating too much on reduction of readmissions but not enough on the true influence of transitions on people's quality of life and the changes in their health conditions (Geary and Schumacher 2012). Our study design did not permit these themes either. The register data including the whole population of people aged 70 or older did not include information on the quality of life before and after each admission, thus the effect on the quality of life could only be speculated upon previous studies.

8.2.2 The register-based data

The extensive register-based data were linked via the Personal Identity Code (PIC) and drawn from three different registers: The Finnish Care Registers including The Care Register for Health Care (HILMO) and The Care Register for Social Welfare (sosiaaliHILMO), and The Causes of Death Register.

During the study years some of the coding in the registers changed. From the year 2002 onwards a service provider code was available which made the classification of residential care facilities more specific. Before that, nursing homes and sheltered housing with 24-hour assistance could not be separated although it

should be acknowledged that in earlier years the use of sheltered housing with 24-hour assistance was not that common.

A small minority of the study population had two overlapping recordings during the same day. It is possible that these people were first admitted to one care facility and then, during the same day, moved to another. However, we could not be sure how often this actually was the case and which of the recordings might have been incorrectly classified. A person was recorded as being in only one place during one day and these less-than-one-day visits were not classified as care transitions, with an exception being made for the final day.

Another problem was people who had a one-night visit to their home; 4.0% of people in this study were discharged from a care facility and admitted again on the next calendar day. It is possible for a person to be discharged, but develop new symptoms during the night, and be admitted immediately again the next day. However, in some cases there is also the possibility of incorrect recordings, e.g. when a person is not actually discharged. These one night visits constituted only a 1.1% of all transitions and they were classified as care transitions. Sund (2012) has stated that there might be some artificial discharge and admission pairs in cases where patients were discharged during the same day and admitted again the following day; these typically result from administrative changes, and can be considered as minor anomalies in entire registers.

8.2.3 Explanatory variables

Information about the date of birth and the date of death, gender, diagnoses, municipality of residence and where people stayed during the last 24 months was included in the registers. The diagnoses were tracked through the use of The Care Register for Health Care, The Care register for Social Welfare and from The Causes of Death Register. It is likely that people also had other diagnoses that were not recorded in any of these registers during the last two years, thus their effect could not be taken into account in the analyses. However, when the last two years of life are studied, it is likely that the cause(s) of death are to be discovered in the most important diagnoses affecting care near the time of death.

The identification of people with dementia can be considered reliable because the information on dementia was collected from different registers. Because dementia is a progressive, chronic illness it was assumed that even if the first recording was in

the Causes of Death Register, it is highly likely that dementia had affected the person's care use and care transitions for several months before death.

Data were lacking on the stage of illness and functional ability, the availability of informal care and living conditions factors, all of which are important factors affecting care patterns. Information on day-to-day home care is not included in the registers. The information on marital status, children and the socioeconomic factors are in registers, but permission to include such information in the data was not obtained from the registrars because of confidentiality questions.

Though the care register included information on diagnoses, those are not necessarily the same as the cause of admission. Thus, there was no information on the actual causes of transitions listed in the registers.

8.2.4 Statistical analyses

The study population was representative since it consisted of all people who died at the age of 70 or over in the years 1998, 2002-2008, and included a 40% random sample from the years 1999-2001 that has been considered reliable in previous studies (Forma 2011). In article four all people who died in the age of 70 or older in the years 2002–2008, had dementia as one of the causes of death and lived in residential care, were included. Because of the extensive study population the statistical power was sufficient.

The distribution in the number of care transitions was highly skewed and included a large number of zeros. Because of the extensive number of zeros, logarithmic transformations could not be performed. Negative binomial regression analysis was used. This method is used for modelling count variables, usually for over-dispersed (the variance exceeds the mean) count outcome variables (Hilbe 2008) and thus was a suitable method to be applied in articles two and three.

The data used in article three had a hierarchical structure including the individual-municipal-, and a hospital district-level characters. Multilevel negative binomial regression analyses with three hierarchical levels (individual, municipal and hospital district levels) were used to analyse municipal differences in the number of transitions. In multilevel modelling the assumption is that the studied individuals who share the same context, such as the municipality of residence, are influenced by the same municipal-level factors like the age structure in the municipality, urbanity and population density. Yet only a few of the municipal-level factors had a statistically significant effect on the number of transitions in last two years and on

the number of different types of transitions. It is possible the data lacked important municipal-level factors.

The data covered years from 1998 to 2008. The principles regarding how care transitions and places of death were identified remained the same in the different study years. Also the information on age, gender, diagnoses, the year of death and the studied care facilities remained the same. This makes the results from different years comparable.

8.2.5 Ethical considerations

Because register-based data were used, persons belonging to the study population or their relatives were not contacted. The linking of different registers with the Personal Identity Code was done by Statistics Finland. The researchers had no access to the PICs or the researchers had no access to any other information that would have jeopardized the confidentiality of the data. The individuals could not be identified in the extensive data. Permission to use the register-based data was obtained from each of the registrars. The research plan was approved by the Ethics Committee of the Pirkanmaa Hospital District.

8.3 Interpretation of the results

8.3.1 Care transitions

The number of different types of care transitions was dependent on both the individual characteristics such as age, gender and dementia diagnosis, and the service system. The differences in the care patterns between individuals show the heterogeneous needs of care in the large group called 'the old people'. The different illness trajectories typical of different diseases suggest different care needs, thus the pathways of care differ. However, there were also similarities in the patterns of care. The majority of people lived at home until their final months, a result also found in the Netherlands (Kaspers et al. 2013). There were visits to care before the last six months, but for the majority of people the care transitions were more frequent towards the time of death. The increase in care transitions near death was also found in previous studies (Lamberg et al. 2005, Klinkenberg et al. 2005, Van den Block et al. 2007a, Menec et al. 2009, Abarshi et al 2010). It reflects the compression of severe

illness and functional impairment toward the end of life (Lunney et al. 2002) but also the problems in caring old people at the end of life.

In this study the number and types of transitions differed between the age groups. Younger old people more frequently had care transitions than did the oldest people, a result also found in previous studies (Menec et al. 2009, Lamberg et al. 2005, Van den Block et al. 2007a). They more frequently moved between home and specialized care hospitals, while the oldest persons had a higher frequency of transitions between home, residential care and health centers than those in the youngest age group. The higher age people reach, the more common is the functional impairment preceding death (Guralnik et al. 1991, Smith et al. 2013), causing a higher need for care, especially long-term care. This is demonstrated in the greater number of people in the oldest age group who had already stayed in long-term care two years before death, implying they had had at least one care transition before their last two years. However, the impact of age on the number of transitions differed between the baseline sites where people were located two years before death. Among those who were in residential care two years before death, the younger old people were more likely to have care transitions than did the oldest. The older the people were, the more frequently they stayed in the same care facility without transitions. What is not known though whether if the oldest people living in the residential care unit who are in need of hospital care are always admitted there. On the contrary, for those who were at home two years before death the older people had more transitions. This implies that even among those older people who stay at home during the last years, the need of care differs between the age groups, the oldest-old being the most vulnerable group.

As with the results of this study, previous studies revealed that men had more care transitions than women (Abarshi et al. 2010) and were more frequently hospitalized (Van den Block et al. 2007a, Menec et al. 2009). Women more often had moved to a care facility before their last two years and had stayed there the entire remaining time. The ability to live at one's private home is dependent on diseases and functional and cognitive status. Women have a higher level of functional impairment (Crimmins et al. 2011, Newman and Brach 2001) and dementia (Corrada et al. 2008) than men of the same age. Another important factor for the use of long-term care is the availability of informal care, especially with regard to transitions to or from home. Women continue to outlive men and thus are lacking in spousal help. The absence of a spouse is found to increase the need for long-term care (Luppa et al. 2009, Nihtilä and Martikainen 2008). What is not known is whether care offered to same conditions differ according to gender. Among long-term care residents,

hospitalizations at the end of life differ between the genders (Menec et al. 2009, McGregor et al. 2007), a result also found in this study in people with dementia. It is not known what are the underlying reasons for more frequent hospitalizations of men than women with the same diagnosis from the residential care units.

Besides differences in individual needs, the variation in the number and type of care transitions is rooted in differences in the characteristics of the care-service system. Wahlbeck et al. (2008) characterize the Finnish care system as fragmented, where several care providers offer different levels of care for different health problems. The fragmented care system for people with multiple care needs creates a variety of potential care pathways: though the majority of people live at home until their final months of life, they often require several visits to different care providers before their final placement into care. After a visit to a hospital they can be discharged to go home or to a non-acute care setting for a follow-up treatment. In addition, those who were residents in the residential care facilities were often hospitalized before death. Some of these facilities are likely lacking the ability to offer the basic health care and as well a care for the dying person. Givens et al. (2012) and Lamberg et al. (2005) showed that part of the hospitalizations from long-term care was due health conditions that could be treated on-site in long-term care units.

Municipal variation in different types of transitions was found, but only a few of the municipal factors had a statistically significant effect on the number of transitions. The mechanism behind this result is likely to be complex, a conclusion also made in Forma et al. (2011). At least the results reflect the impact of the local service supply. The extensive autonomy of municipalities in organizing care services creates differences in how care is delivered to the residents; because of the highly decentralized system the municipalities can decide how the care services are organized, within the limits of the law (Vuorenkoski 2008). Thus different municipalities may have adopted very different care practices (Kokko and Valtonen 2008). The geographical location of the municipality also has an impact on care transitions; in the north-eastern part of Finland the distances are longer and can create difficulties with regard to access to care (Wahlbeck et al. 2008) or a postponed discharge. Differences in admissions to hospitals do not necessarily mean unequal access to care. It is possible that in those municipalities with less frequent transitions to specialized care there is no specialized care hospital in the municipality or in the immediate proximity, in which case the health centers are able to offer more advanced care. What is not known, though, is if whether older people in different municipalities have an equal access to specialized care if and when necessary.

8.3.2 Place of death

A health center inpatient ward was the most frequent place of death in all three age groups and for all of the study years. There were several possible pathways allowing access to a health center inpatient wards: old people could move from home to a health center just before the time of death, they could be transferred there from a specialized care hospital, they could be moved there from a nursing home or from sheltered housing just before death, or they could have stayed in long-term care in a health center inpatient ward until death. A general hospital was the second most common place of death, followed by a private home and a nursing home. Dying in sheltered housing with 24-hour assistance or in a university hospital was rare. Persons who stayed the majority of their last two years at home usually died in a health center or in specialized care hospitals, or at their home. People who stayed in care for the majority of days in their last two years usually died in residential care or in a health center.

In all, death is frequently institutionalized in Finland, which is similar to the case in many other countries (Klinkenberg et al. 2005, Broad et al. 2013, Hedinger et al. 2014). A systematic literature review by Gomes et al. (2013) found that most of people in the general population prefer dying at home. However, when only old people were studied, many of them preferred dying elsewhere than at home (Gott et al. 2004). In Finland, home deaths were almost as rare as in Iceland or Australia which Broad et al. (2013) found to have the fewest home deaths among people aged 65 or over. This result is confirmed by other studies: the proportion of home deaths was lower in Finland than for example in the in the US (Teno et al. 2013) and in the Netherlands (Kaspers et al. 2013). If the deaths in a health center and in general and university hospitals are all included in the category of hospital deaths, these were the most frequent in Finland (71.2% in 2008) when compared to the 21 nations studied by Broad et al. (2013). However comparisons are complicated by the fact that in Finland, health center inpatient wards also provide long-term care. In all, it is reasonable to say in international comparisons, death at home is rare and death in hospital usual when compared to other European countries and the US.

Age and gender related differences in places of death were previously found in other countries (Broad et al. 2013, Hedinger et al. 2014). It is very likely that different functional trajectories, typical for men and for women and for people at different ages at the time of death (Lunney et al. 2002) have an impact on the type of care preceding death. The differences in functional trajectories suggest differences in care needs and thus in care pathways, which lead to different places of death. In addition,

the different end-of-life hospitalization patterns of men and women, and the younger old and the oldest old (Menec et al. 2009), are likely contributing to the higher number of hospital deaths for men and younger old.

8.3.3 Care transitions for people with dementia

Care patterns including care transitions were somewhat different for people with dementia than for those without it. The greater number of those who were in care two years before death and stayed the whole time in care, and the transitions to care at an earlier phase during the last two years of life, likely reflect the more severe disability for a longer period of time before death in those with dementia than in those without it (Agüero-Torres et al. 2001, Banaszak-Holl et al. 2004).

Among those who lived at home two years before death, people with dementia had more care transitions than those without dementia, resulting in complex care pathways for people with dementia. It is possible that those with dementia who were able to live at home, were at the early stage of illness two years before death. Because of the progressive nature of the disease and the distressing symptoms (Mitchell et al. 2009, Sachs et al. 2004) they developed symptoms requiring several visits to one or several care providers, and thus had multiple care transitions. In those who stayed in residential care two years before death, the ones with dementia had fewer transitions than those without dementia. The underlying reasons behind this difference could not be studied here. In addition, those persons with dementia were more frequently transferred to a health center and less frequently to specialized care near the time of death than those without dementia. In previous study from the US was found that among nursing home residents, acute care at the end of life was more rare for people with dementia than for the others (Li et al. 2013). Results from this study might reflect similar trends in regarding to care practices although we could not demonstrate whether persons admitted in specialized care received more often acute care than those admitted in health center inpatient wards.

The transitions defined as burdensome were not very common in people with dementia in Finland, only about one in ten had burdensome transitions. In the US about one in five had these type of transitions, but the geographical variation implies differences in care practices in the different states (Gozalo et al. 2011). In Finland the care facility where people lived was highly important in the frequency of burdensome transitions: those in sheltered housing with 24-hour assistance three months before death more frequently had burdensome transitions when compared

with those in nursing homes. Burdensome transitions were also more frequent in long-term care facilities specialized in dementia care. The majority of these facilities were classified as sheltered housing with 24-hour assistance, with a specialization in dementia care. It is possible that not all of the sheltered housing units were prepared to care for seriously ill and dying people. In a Finnish study pneumonia was found to be one of the most common causes of hospitalization from sheltered housing with 24-hour assistance (Lehto et al. 2015); pneumonia was one of the causes of hospitalization classified as avoidable (Lamberg et al. 2005, Givens et al. 2012).

8.3.4 Time trends in patterns of care

Several changes in transitions were observed during the study years. First, there was an increase in the rather small proportion of those who stayed the entire last two years of their lives in the same care facility or at home, without undergoing transitions. Second, there was an increase in those who stayed the entire last two years in care but had transitions as they moved to another care facility at least once. In addition the proportion of people who had only moved once, from home to the care site which was to be the place of death, decreased. Third, the number of transitions in the last six months increased for those who had transitions. The increase was more pronounced for people with dementia than in the whole population. Yet, the increase was not due to changes in burdensome transitions because the frequency of those did not show a clear change between the study years 2002 and 2008.

The changes originate with both, the changes in population and the changes in the service system. There could have been health improvements in part of the population which increased the number of people who were able live at home without hospital or long-term care. On the other hand, the care policy has emphasized staying in one's home as long as possible instead of having permanent care placement, thus, there might be more people whose only option is to stay at home. During the study years the age at death and the number of people with dementia increased. Improvements in health and functioning was not found among the oldest old (Jylhä et al. 2013), and there is no evidence that the years immediately before death would be healthier. Some of the people might suffer from functional and cognitive impairment for a longer time than earlier which may have contributed to the increase in those who stayed their entire last two years in care.

Both the policy emphasizing living at home (The Ministry of Social Affairs and Health 2008, 2013) and the change from nursing homes to sheltered housing with 24-hour assistance, in addition to shortening average length of stay in hospital care (National Institute for Health and Welfare 2014e), are likely to have contributed to the increase of care transitions. Forma et al. (2012) found that care transitions in the last year of life are more typical for those in sheltered housing with 24-hour assistance than for those in traditional institutional care. People who basically live at home but have several health problems and high need of help often move several times between home and different care units before a permanent stay in a care facility. With shorter hospital stays, e.g. after surgical operations, another place of care is needed before discharge back home. In some health conditions, yet not in all, the reduction in the length of a hospital stay is found to increase rehospitalization rates (Unruh et al. 2013).

Residential care became a more frequent place of death during the study years. This was mainly due the increase in people who died in sheltered housing with 24-hour assistance without end-of-life care transitions. Yet sheltered housing was still the most rare place of death. Dying in a general hospital decreased the most, home deaths only slightly. Dying in a health center and in a university hospital remained about at the same level. When compared with other countries the time trends in places of death differed in Finland. In the US (Teno et al. 2013) there was an increase in home deaths during the past decade. In the Netherlands the number of home deaths remained at the same level between the years 2000 and 2010 (Kaspers et al. 2013). In these previous studies there has been a decreasing trend in hospital deaths (Teno et al. 2013, Kaspers et al. 2013). A decrease in general hospital deaths also implies a mild decrease in hospital deaths in Finland.

8.4 Policy implications

For most of the people the care transitions were frequent, especially near death. An interpretation of the results could be that people have good access to different care services and the care pathways are as individual as are the individual care needs. However, care transitions pose a challenge to the continuity and coordination of care. If not conducted properly there can be medical errors and miscommunication between the patient and the care specialists, and between the different care specialists, about the medication, symptoms and the rehabilitation of the patient. (Coleman 2003). To maintain the quality of life even until the end of life, unnecessary

care transitions should be avoided. The recognition of avoidable care transitions is difficult, but an effort should be made to improve the capacity of long-term care facilities to care for a dying person and the health conditions that could be cared for in a long-term care setting without necessitating a transfer to a hospital. The reduction of avoidable care transitions would benefit both the service system and the individual. Reducing avoidable care transitions could ensure peaceful death. The potentially avoidable hospitalizations are found to be costly (Jencks et al. 2009, Walsh et al. 2012) thus hospital care would be used only by the people who actually needed it. In Finland the reduction of care transitions and caring people on-site was acknowledged in the Working Group (Ikähoiva) memorandum (The Ministry of Social Affairs and Health 2010) that suggested that the traditional three-level round-the-clock long-term care (including health center inpatient wards, nursing homes and sheltered housing with 24-hour assistance) should shift to one-level care with the care services offering on-site care in one care facility without needing transfers to another care setting. Some of the rehospitalizations from home can also be classified as avoidable hospitalizations if the discharge is not conducted properly, thus home discharge practices and the effect of the length of a hospital stay on rehospitalization rates should be studied.

The introduction of the new service for old people, sheltered housing with 24-hour assistance, might have produced unexpected results like an increase in end-of-life hospitalizations. Though increasing number of people use sheltered housing, it was still a rare place of death. In the US there is evidence demonstrating how hospitalizations at the end of life of people with advanced chronic conditions may represent inappropriate care practices, driven by financial incentives rather than the actual medical need of the patient (Gozalo et al. 2011). In Finland the care service system and its funding is different than in the US and the results from Finland and the US should be compared cautiously. However, financial factors are also likely to be a one contributor to hospitalizations in Finland although the mechanism is different. Anttonen and Häikiö (2011) describe how one motivation behind the change from traditional institutional care to sheltered housing with 24-hour assistance is to speed up marketization since sheltered housing is much more often a privately owned care facility than a nursing home. The underlying causes behind the higher number of care transitions from sheltered housing with 24-hour assistance are yet unknown, and they should be studied further to reveal if there is a difference in end-of-life hospitalization between not-for-profit and for-profit care facilities like in Canada (Menec et al. 2009). Because the residents in sheltered housing with 24-hour assistance can apply for reimbursement for rent from the Social Insurance

Institution which is partly funded by the government, using sheltered housing is also a way to shift part of the financial responsibility from the municipalities to the state. (Anttonen and Häikiö 2011). It is not yet known whether the non-institutional service system creates any real savings if the total care pathway, including hospitalizations, is taken into account in the total costs of care.

Though the problems in care planning are acknowledged, more efforts should be made to improve the coverage of the care planning that could decrease hospitalizations and increase the quality of life near the time of death. Finnish quality recommendations for old people's care (The Ministry of Social Affairs and Health 2013a) stated that current end-of-life care requires improvements due the lack of sufficiently planned palliative care for dying persons. Lehto et al. (2015) found that about a half of the residents in sheltered housing with 24-hour assistance lacked care planning. Yet, the early care planning and adequate palliative treatment goals are found to reduce care transitions at the end of life (Lamberg et al. 2005, Abarshi et al 2010).

Two important changes in the old population occurred during the study years: the number of the oldest people and people with dementia increased. The high age and dementia have a pronounced impact on the need for and use of long-term care. In this study, the last two years had become more care-centered as more people stayed their entire last two years in care. If the development continues, the results of this study suggest that round-the-clock care facilities offering long-term care will have a greater importance as producers of end-of-life care in the future. Martikainen et al. (2012) noted that increasing longevity with a rising trend of dementia is likely to cause a major shift towards higher nursing home care use in the future. If more people live in residential care than earlier, the moving between different care facilities becomes more frequent than earlier, resulting in cooperation and communication between care providers becoming increasingly important.

The increase in care transitions especially for people with dementia is not in line with the dementia care recommendations which emphasize continuity of care (Suhonen et al. 2008, Alzheimer's Disease International 2013) in terms of familiar staff and environment, staff with the knowledge of the progressive illness trajectory of dementia (Sachs et al. 2004) and comfort and symptom control rather than unnecessary acute treatments (Mitchel et al. 2009). People with dementia are more impaired and incapable of decision making than those without dementia at the time of death (Meeussen et al. 2012). However, being able to plan and control the events prior to death and being able to discuss treatment with the care staff were found to

be important in experiencing a good death (Patrick et al 2001). Yet, the ability to do this is rare for people in the late stage of dementia.

To maintain or improve the knowledge of end-of-life care is highly relevant in health centers due its persisting and important role as the final place prior death. Health center inpatient ward was the most frequent place of death in all study years, for people in different age groups, and for men and women. It was also the most frequent care site where people moved to or moved from. Thus, their ability to coordinate and cooperate with other care providers is essential in regarding to the continuum of care.

The regional differences in care transitions might indicate to the differences in care needs, but there is also a possibility of unequal access to care between regions. Revealing the underlying causes of the differences between municipalities in care transitions is problematic. The causes beneath the differences seem to be complicated. If they remain mainly unknown, it will be difficult to develop the care system into a more universal one. The care practices have a tight linkage to the localized care culture in the municipality. Thus it is likely that a change toward a more universal care system in Finland may only come from local authorities and their motivation to standardize the care systems.

Though there were more people in 2008 than in 1998 who stayed their entire last two years in care, the majority of people still stayed at home until the final months of life. Thus it is fair to say that the majority of persons already stay at home 'as long as possible'. Results in this study showed a slight decrease in home deaths. With the increasing number of very old people and with dementia it is likely that home deaths will not become more frequent; it is debatable if the preferred home deaths would even be a realistic or ideal option for the majority of old people. At least a major effort should be made to assure that adequate care is delivered to private homes at the end of life.

9 Conclusions

Care patterns including care transitions in the last two years of life and places of death varied between individuals. This variation is affected by multiple factors such as age at death, gender, dementia diagnosis, the municipality of residence, and the care sites where people stayed. There is no possibility of identifying any typical care pathway, although similarities in care patterns do exist.

Most of the persons in the study population lived at home until the final months of life. During the last six months they increasingly moved to round-the-clock care. In the care policy that emphasizes living in a private home it is important to recognize that most of the old people actually live at home until the very last months of life.

Care transitions were the most frequent in the last six months and they became more frequent during the study years, especially for people with dementia. The underlying cause of this might be in changed care needs of old people, but also in changes in the long-term care system. More emphasis on care planning and improving the capability of long-term care settings to care for dying persons would help to reduce unnecessary hospitalizations.

The importance of the health center inpatient wards did not change during the study years: it was the most common place of death, as almost half of the people died there. People most frequently moved to a health center before death. It is important that the care staff in health centers have adequate knowledge of palliative care treatment for different chronic conditions since they are frequently responsible for end-of-life care.

The number of those who stayed in care their entire last two years and who had transitions, increased between the years 1998 and 2008. Simultaneously the number of people aged 90 or older and the number of people with dementia increased. These changes in the old population contribute to a growing number of those who are in need of round-the-clock care earlier than just prior to death. The time trends in increasing longevity and dementia and their impact on the changes in care patterns should be studied further and for a longer time period to make projections regarding the future care burden.

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Original publications

Transitions in health and social service system at the end of life

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Abstract This study focuses on the amount and types of transitions in health and social service system during the last 2 years of life and the places of death and among Finnish people aged 70–79, 80–89 and 90 or older. The data set, derived from multiple national registers, consists of 75,578 people who died between 1998 and 2001. The services included university hospitals, general hospitals, health centres and residential care facilities. The most common place of death was the municipal health centre: half of the whole research population died in a health centre. The place of death varied by age and gender: men and people in younger age groups died more often in general or in university hospital or at home, while dying in health centres or in residential care homes was more common among women or the very old. Number of transitions varied from zero to over a hundred transitions during the last 2 years. Number of transitions increased as death approached. Men and younger age groups had more transitions than women and older age groups. Among men and younger age groups transitions between home and general or university hospital were common while transitions between home and health centre or residential care were more common to women and older people. The results indicate that municipal health centres have a major role as care providers as death approaches. Differences between gender and age in numbers and types of transitions

were clear. Future research is needed to clarify the causes to these differences.

Keywords Transitions in health and social service system · Place of death · Last years of life · Register study · Ageing

Introduction

Most people use health and social services during the last years of their lives (Pot et al. 2009; Larsson et al. 2008; Forma et al. 2007). Towards the end of life, prevalence rates of disease and disability increase and more markedly in older than in younger people (Guralnik et al. 1991). With advancing age and higher rates of disability and disease the amount of health and social care needed during the period preceding death also increases (Lentzner et al. 1992; Mehdizaleh 2002). With frequent co-morbidity (Guralnik et al. 1991; Mehdizaleh 2002), the likelihood of moving between home and health or social care settings or between different care settings is likely to increase and often these people have complex pathways of care: they go through a combination of various health and social care processes (Mäntyranta et al. 2003). People with the same diagnosis may follow very different pathways of care and experience different numbers of transitions (Cohen and Pushkar 1999). This indicates individuality in care processes, possibly due to co-morbidity and other factors in life.

The final point in the pathway of care is the place of death. According to earlier research, most people prefer to stay at home until the end of life (Beccaro et al. 2006; Tang 2003), although there are also people who would rather die somewhere else, sometimes possibly because they do not want to be a burden on their families (Beccaro et al. 2006).

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Staying at home as long as possible is seen as a way to maintain control over one's life (Eloranta et al. 2008) and the quality of life (Tang 2003). The thought of moving away from one's own home to a care facility at the end of life may cause negative feelings (Lee 1997). Yet most older people in Europe and in North America die somewhere else than at home; nowadays dying is extensively institutionalized and hospitals and long-term care facilities are the common places of death (Ahmad and O'Mahony 2005; Fischer et al. 2004; Jakobsson et al. 2006; Klinkenberg et al. 2005; Van den Block et al. 2007; Wilson et al. 2001).

From the perspective of quality of life, different research findings describe the strengths and weaknesses of different places of death (Mezey et al. 2002), also illustrating the complexity of the concept of the quality of life at the end of life. Transitions may have a negative effect on the quality of life because transitions between settings include the possibility of medical errors or unnecessary treatments (Meier and Beresford 2008), and stress in a patient as consequence of changing location and facing difficulties in the continuum of care (Naylor et al. 2005). However, moving from home to a health or social care facility may be experienced in different ways due to amount and severity of disability (Thomese and Broese van Groenou 2006; Koponen 2003): to some people, it may represent losing some of their autonomy and thus be a negative change, while others may feel insecure when facing deteriorating health at home. In the latter cases moving into institutional care is often a positive or at least a necessary change. For the people themselves, it is not insignificant where they are treated. A familiar place of care is often preferred to an unknown care facility even if the waiting time is longer. (Hirvonen et al. 2006).

The structure and organization of social and health care services greatly influences the likelihood and nature of transitions between the places of care. In Finland, the municipalities are responsible for organizing health and social services for their residents although they do not need to produce these services themselves (see Ministry of Social Affairs and Health 2009). In the last decade some 80% of services for older people have been provided by the public sector (Vuorenkoski 2008). The responsibilities differ between the organizations: municipal health centres provide primary health care and also have inpatient wards where older people receiving long-term care constitute a major patient group. Central and regional hospitals offer specialized care. Among central hospitals there are five university hospitals which provide the most advanced specialized care (Ministry of Social Affairs and Health 2009). One of the main goals in Finnish policies for the elderly is to help older people to stay at home as long as possible and this is supported by formal home care. Residential homes and housing with 24-h assistance are also available (Ministry of Social Affairs and Health 2008).

To ensure the quality and effectiveness of services, well-functioning service chains are required and the different organizational levels should work closely together (Ministry of Social Affairs and Health 2008) but in practice people often meet organizational fragmentation, which may increase the number of transitions between places of care. Improving the integration and seamlessness of care is widely recognized as one of the main challenges in health and elderly care in Finland (Vaarama 2005; Valvanne 2005); more integrated care is also likely to improve client's quality of life (Pieper 2005).

Research on transitions between care facilities is considered critical because multiple transitions are likely to have a negative impact on old people's treatment and wellbeing (Naylor and Keating 2008). In order to maintain the quality of care and quality of life and to organize social and health services in a rational way it is important to have better empirical information of the pathways of care at the end of life.

Yet no extensive research information is available on the pathways of care that older people experience. In health care research, the notion of pathway most often refers to hypothetical optimal chains of treatment or places of care concerning specific individual medical conditions (Atwal and Caldwell 2002; Furåker et al. 2004; Koval and Cooley 2005; O'Donnel et al. 2005; Silvennoinen-Nuora 2004), and research concerning transitions mostly concentrates on certain specific patient groups (Burge et al. 2005; Cohen and Pushkar 1999; Van den Block et al. 2007). However, for most of older people, the decisions on services and the transitions between the places of care are not determined only by individual diseases but by multiple health conditions and disability.

The study is part of a more comprehensive project on 'Costs of Care Towards the End of Life (COCTEL)'. Earlier, we have reported results of utilization of health and social services (Forma et al. 2007, 2009). In this study, we focus on the places of death and the quantity and types of transitions between home and health or social care facilities, or between the care facilities during the last 2 years of life in people aged 70 years and older. The focus is on the last stages of life in old age, not on the treatment of specific disease.

The detailed research questions were:

1. What are the frequencies and types of transitions that people have between home and different care facilities during their last 2 years of life?
2. What are the most usual places of death for people who die at the age of 70 or older?
3. To what extent do places of death and the patterns of transition differ between genders and age groups for people aged 70 or over?

Methods

Data

This study is based on Finnish register data which include information on the utilization of health and social services in the whole country. In Finland, the coverage of population and health registers is exhaustive, and the data can be linked on the basis of the personal identification number. In this study, the sample was identified from the Central Population Register (Statistics Finland) and was linked together with the data from the Care Register for Health Care, the Care Register for Social Welfare and Home Care Census (National Research and Development Centre for Welfare and Health, from 2009 National Institution for Health and Welfare). Our research sample consisted of two subgroups:

1. all those who died in 1998 at the age of 70 or older, and
2. a random sample (40%) of all those who died during the period 1999–2001 at the age 70 or older.

The total sample consisted of 75,578 decedents of whom 44,792 (59.3%) were women and 30,789 (40.7%) were men. The aim was to ascertain the pathways of care including transitions between places and the places of death with a special focus on the last years of life of older people, not end-of-life care for any specific medical condition. Thus, all deaths irrespective of cause are included. The data are described more in detail in Forma et al. (2007).

Data include university hospitals, general hospitals (including central, district and private hospitals), health centres, both private or public residential care facilities (including inpatient wards in nursing home care and sheltered accommodation with 24-h assistance for older people), and home care including both home nursing and home help. The category ‘home’ includes both the individual’s own home with or without home nursing or home help, and living in sheltered accommodation without 24-h formal assistance. From these data, we could monitor admissions to and discharges from health or social care facilities, the duration of stays and also periods of time spent outside care facilities during the 2 years prior to death. Place of death was monitored by tracking the last transition and the place at the time of death.

Analysis

For the analyses, the data were divided into six subgroups: 15,591 men in the age group 70–79 years (20.6%), 12,348 men in the age group 80–89 years (16.3%) and 2,847 men in the age groups 90 years or older (3.8%); 13,398 women

in the age group 70–79 years (17.7%), 22,242 women in the age group 80–89 years (29.4%) and 9,152 women 90 years or older (12.1%).

By transition, we refer to a situation in which a person moves from one place to another, and spends at least one night there: transitions with duration of less than 1 day were excluded. The data were programmed so that transitions are actual moves from one location to another, not a change only of service provider without any change in location (see Burge et al. 2005). Transitions take place between home and health or social care facilities or between different care facilities. We studied the number of transitions during the time period 2 years before death.

Data were analysed using descriptive statistics. Places of death and transitions were studied in six gender and age groups. Distributions in places of death and transitions were compared using chi-square tests. Because of the right-skewed distributions, medians were used. Analyses were performed with SPSS (15.0) statistical software package.

Results

The place of death

For all age and gender groups studied, the most frequent place of death was municipal health centre, where almost half (48.2%) of our subjects died. The second most common place of death was general hospital (19.3%) and the third was private home (16.3%). About 10% died in residential care and only about 6% in university hospital.

There were differences between age groups and between men and women regarding the place of death. General or university hospitals and private home were more common places of death for younger than for older age groups and more common for men than women, whereas older age groups and women more often died in residential care or in health centres. Differences between genders were found in every age group (Fig. 1).

Transitions during the last 2 years of life

In the whole research sample, about 87% (90% of men and 86% of women) had one or more transitions either between home and care facilities or between care facilities during the last 2 years of life, while about 13% had no transitions but stayed in the same place during the whole period (Table 1). In the total sample, about 32% had 1–4 transitions, 30% had at least 10 transitions, and 14% at least 16 transitions during the last 2 years. The maximum was 168 transitions between different care facilities and home. The median number of transitions among those moving at least once was seven. The frequency of transitions

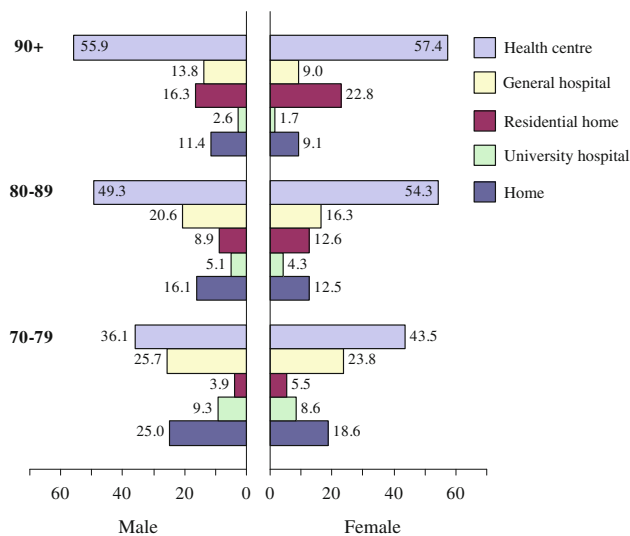


Fig. 1 Place of death among men and women at the ages of 70–79, 80–89 and 90 years or older (all results are given in *percentages*) Results of Chi-Square tests: in both men and in women the differences between age groups were statistically significant ($P < 0.001$). In each age group differences between genders were also statistically significant ($P < 0.001$)

increased as death came closer: between the 24th and the 19th month before death 36% (results not shown), but during the last 6 months as many as 73% moved between

settings. During the last 6 months about 50% of the whole group had 1–4 transitions, 20% had 5–9 transitions, and some 4% had 10 or more transitions (Table 1).

Staying the whole 2 years at home without any transitions was more common in younger age groups in both genders, and it was more common among men than women in each age group, whereas staying the whole time in a care facility without transitions was more common in older age groups and among women. Among women aged 90 years or older, every fifth spent the whole 2 years in the same care facility. Having over 10 transitions was less common in older age groups and among women, but even among the oldest women, where the number of transitions was the smallest, about 19% moved from one place to another at least 10 times during the last 2 years. During the last 6 months the same differences between gender and age persisted: it was more common for men and younger people to have a large number of transitions than for women and older age groups. Men and younger age groups more often spent the last 6 months at home, while 22% of men and 40% of women in the age group 90 years or older spent their last 6 months in a care facility.

Because many people moved many times between the same places, we calculated the proportions of different types of transitions of the total number of transitions in every age and gender group. In the whole sample,

Table 1 Number of transitions during 24 and 6 last months by age and gender (%)

Number of transitions <i>N</i>	Men			Men total 30,789	Women			Women total 44,792	Total 75,581
	70–79 15,591	80–89 12,348	90– 2,847		70–79 13,398	80–89 22,242	90– 9,152		
During last 24 months									
No transitions, 24 months at home	9.2	4.3	2.4	6.6	6.2	3.3	1.5	3.8	4.9
No transitions, 24 months in care facility	2.0	4.5	9.1	3.7	4.6	9.7	20.0	10.3	7.6
1	7.8	7.9	9.7	8.0	8.2	8.6	10.8	9.0	8.6
2–4	22.1	22.2	23.4	22.2	22.0	23.6	24.9	23.4	22.9
5–9	25.4	27.9	28.3	26.7	26.3	27.4	24.2	26.4	26.5
10–15	16.5	17.5	15.0	16.8	17.1	15.5	11.0	15.1	15.8
≥16	17.0	15.7	12.1	16.0	15.6	11.9	7.6	12.0	13.7
Median for those who had transitions	7	7	6	7	7	6	5	6	7
During last 6 months									
No transitions, 6 months at home	15.4	8.3	5.2	11.6	10.9	6.5	4.5	7.4	9.1
No transitions, 6 months in care facility	6.8	13.4	22.3	10.9	11.8	22.4	37.7	22.4	17.7
1	16.5	17.3	19.4	17.1	17.0	17.8	17.2	17.5	17.3
2–4	31.1	34.4	32.9	32.5	32.4	32.7	28.1	31.6	32.0
5–9	23.6	21.7	17.8	22.2	22.3	17.7	11.1	17.7	19.6
10–15	5.8	4.3	2.3	4.9	5.2	2.6	1.3	3.1	3.9
≥16	0.8	0.6	0.1	0.8	0.4	0.3	0.1	0.3	0.4
Median for those who had transitions	3	3	3	3	3	3	2	3	3

Results of Chi-Square tests: in both men and in women the differences between age groups were statistically significant ($P < 0.001$). In each age group differences between genders were also statistically significant ($P < 0.001$)

transitions between home and health centres were the most frequent (Table 2): 18% of all transitions were moves from home to a health centre, and some 16% from a health centre to private home. Transitions from home to a general hospital (15%) and from a general hospital home (10%) were also frequent. Moving between home and a care facility was more common than moving between care facilities.

The most frequent transitions varied somewhat between the age and gender groups. Among younger age groups and men a higher proportion of all transitions took place between private home and general or university hospital and back home than in older age groups and women. In older age groups and among women transitions from home to a health centre or residential care and back home were more typical, although the differences between the genders were less consistent than the differences between age groups. Transitions between health centre and residential care were more common among older age groups and women.

Transitions and the place of death

Next we examined the types and frequencies of transitions according to the place of death. Practically, all of those

who died in university hospital or in general hospital and 91% of those who died in health centres experienced at least one transition during the last 2 years of life (Table 3). Transitions were most rare to people who died in residential care or in their private homes, about 70% of them had transitions, meaning that about one quarter of them spent the whole 2 years in the same place. For those who had moved at least once, the median number of transitions was highest for those who died in a university hospital. Second highest median was for those who died in health centres. The median was lowest for those who died in general hospital, residential care or at home.

When we studied the proportion (%) of people who had different types of transitions (one or more), the most frequent transition during the last 2 years of life was that from home to the facility where death occurred. Yet, also other transitions were frequent, indicating the complex pathways to the final place of care. Regardless of the last place, transitions between private home and health centres were frequent, though for people who died in health centres they were most frequent. Over half of those who died in health centres also experienced a move from a health centre back home, and some 40% came to a health centre not directly from home but from a general hospital. For people who died in university or in general hospital, transition from

Table 2 Proportion of different types of transitions of all transitions between care facilities and home by gender and age group (%)

Type of transitions	Men				Women				Total
	70–79	80–89	90–	Total	70–79	80–89	90–	Total	
Home → health centre	14.6	19.4	21.5	17.1	15.3	20.2	20.6	18.6	17.9
Health centre → home	13.6	17.6	18.5	15.6	14.3	18.4	17.5	16.9	16.3
Home → general hospital	20.1	14.6	9.8	17.0	17.9	12.0	8.2	13.5	15.1
General hospital → home	15.6	10.2	5.8	12.6	13.2	7.3	4.1	8.7	10.4
Home → university hospital	8.3	4.5	2.7	6.3	8.4	4.0	2.5	5.3	5.7
General hospital → health centre	4.4	5.1	5.0	4.7	5.3	6.2	5.6	5.8	5.3
Home → residential care	3.2	5.5	7.9	4.5	2.8	5.6	8.7	5.1	4.9
Residential care → home	3.3	5.7	8.3	4.7	3.0	6.0	9.3	5.4	5.1
University hospital → home	6.2	3.0	1.4	4.5	6.1	2.2	1.1	3.4	3.9
Health centre → residential care	1.2	2.7	4.8	2.1	1.8	4.0	6.2	3.6	2.9
Health centre → general hospital	2.3	2.4	2.0	2.3	2.8	2.7	2.0	2.6	2.5
Residential care → health centre	1.0	2.2	4.1	1.7	1.6	3.4	5.4	3.1	2.5
University hospital → health centre	1.7	1.6	1.6	1.7	2.1	2.1	1.9	2.1	1.9
Residential care → general hospital	0.9	1.6	2.6	1.3	1.1	2.1	2.7	1.8	1.6
General hospital → residential care	0.7	1.3	2.0	1.0	0.9	1.4	1.8	1.3	1.2
Health centre → university hospital	0.8	0.7	0.4	0.7	1.0	0.7	0.5	0.8	0.8
University hospital → general hospital	0.7	0.4	0.2	0.5	0.7	0.3	0.2	0.4	0.5
Other ^a	2.1	1.5	1.4	1.7	1.7	1.4	1.7	1.6	1.5
Total	100	100	100	100	100	100	100	100	100

^a Other includes transitions between health care centres, nursing/residential homes, general and university hospitals, and from general hospital to university hospital, from university hospital or nursing/residential home, and from nursing/residential home to university hospital. In all groups less than 0.5% of transitions were between these facilities

Table 3 Proportions of people who experienced different types of transitions (%) and median number of transitions in the last 24 months by place of death

Place of death	Health centre	General hospital	University hospital	Residential care	Home
Percent of those who had transitions	90.5	99.4	100	71.7	69.7
Percent of people who experienced different types of transitions at least once					
Home → health centre	69.8	40.7	36.1	38.3	49.3
Health centre → home	57.3	39.7	38.1	33.3	56.9
Home → general hospital	45.6	84.1	25.3	24.3	52.4
General hospital → home	30.4	53.1	21.4	14.9	47.9
Home → university hospital	19.5	13.5	83.2	8.4	21.4
University Hospital → home	12.2	10.6	41.0	4.8	18.6
Home → residential care	16.9	10.6	8.7	47.8	11.4
Residential care → home	20.1	12.3	10.4	32.7	21.7
General hospital → health centre	45.8	22.0	5.0	19.6	17.0
Health centre → general hospital	19.3	25.0	2.7	6.3	7.3
Residential care → general hospital	8.3	11.1	2.0	24.9	3.6
General hospital → residential care	5.3	6.1	1.8	25.5	3.7
General hospital → university hospital	1.8	3.6	10.4	0.9	1.5
University hospital → general hospital	2.9	7.7	3.0	1.4	2.2
Health centre → residential care	16.3	7.3	5.6	58.6	7.4
Residential care → health centre	18.7	4.4	3.2	28.7	4.6
Health centre → university hospital	6.5	1.6	17.5	2.1	2.5
University hospital → health centre	16.8	3.3	18.8	7.2	7.2
University hospital → residential care	1.6	0.7	3.0	7.8	1.0
Residential care → university hospital	2.5	0.8	7.2	8.4	1.3
Median for those who had transitions	6	5	7	5	5

home to the hospital in question was clearly the most common. People who died in a general hospital also moved between general hospital and health centre; 22% moved from a general hospital to a health centre and 25% from a health centre to a general hospital. About every fifth and every fourth of those who died in university hospital moved between private home and general hospital. Those who died in residential care facilities had the most diversity in transitions, meaning that many of them had experienced several different transitions. Forty-eight percent were admitted into residential care facilities from their private homes, 59% had transitions from a health centre to residential care facility. Thirty-three percent moved from residential care facilities back home and 29% to a health centre. Approximately one-third of them also moved between home and health centre, and about one-fourth moved from home to a general hospital, and also about fourth moved from a general hospital to a residential care facility. For those who died at home transitions between home and health centre and home and general hospital were most frequent, but every fifth also moved between university hospital and home, from a university hospital to a health centre, or from residential care to home.

When the place of death was a residential care facility or private home, the number of transitions varied by age group: more people in younger age groups had transitions, and they also had more transitions than older age groups. For those who died in general hospital, in university hospital or in a health centre there were no clear differences in the proportion of people who had transitions or in the median numbers of transitions between age and gender groups. Regardless of the place of death, transitions between home and general hospital, between home and university hospital, between university hospital and general hospital and from health centre to university hospital, were more common among younger people. By contrast, regardless of the place of death, transitions between home and residential care facility, and residential care facility and general hospital, were the more common the older the people were. There were only few clear differences between genders in the same age groups; regardless of the place of death transitions between home and general hospital were more common among men, and transitions between health centre and residential care among women. When the place of death was a residential care facility or home, all types of transitions were more common among men than among women in the same age groups.

Discussion

In this study, we focused on places of care and transitions between care settings during the last 2 years of life in more than 75,000 people aged 70 or older. In this group, the number of transitions varied from zero to more than a hundred. Places of death also varied, but for the whole group, health centre was the most common place of death; almost half of all men and over a half of all women died in a health centre. It was also the most common place to move to or to move from. The importance of other places varied by age and gender: men and younger old people died in general hospital, university hospital or at home more often than women and the very old, while dying in a health centre or in a residential care facility was more common in women and the very old.

In Finland, health centres have an important role as the main providers of primary health care. The services include general practice doctors, health care nurses and acute and long-term in-ward care; in some health centres also geriatricians are available. Specialized care is provided by general hospitals and university hospital. (Vuorenkoski 2008). The official health policies prefer health centres to specialized care as providers of care and rehabilitation for old people (Ministry of Social Affairs and Health 1999). However, the care of a dying person differs from other types of care and requires a specific approach (Morrison et al. 2000; Pitorak 2003). Therefore, health centres are facing a very challenging professional task when organizing care ranging from respite care and rehabilitation to terminally ill patients in their final stages.

Differences in service structures and study designs make it difficult to directly compare the places of death in our study with the findings of others. It may be, however, that dying at home is less common in Finland than in some other European countries (Ahmad and O'Mahony 2005; Fischer et al. 2004). According to earlier findings, hospital is the most common place of death, and this was also true for Finland. Taken together, university hospitals, general hospitals and inpatient wards as hospital care in health centres, altogether 57.6 of the deaths occurred in a hospital.

Most of earlier studies on transitions at the end of life focus on the palliative care of cancer patients or have specific exclusion criteria, like excluding sudden deaths. Compared to a study with palliative care patients where the median number of transitions during the last 5 years was one (Burge et al. 2005), the number of transitions in our study seems high. Among people who experienced non-sudden death in Belgium (Van den Block et al. 2007) 26% had two or more transitions during the last 3 months; this is roughly within the same range as our study, where 56% of subjects had two or more transitions during the last 6 months. The Belgian study, however, covered all age groups.

In our study, the total number of transitions was high: 28% of people aged 70 or older had at least 10 transitions during the last 2 years of life, and 13% had more than 15. We did not have information about the causes of the transitions. Partly the numerous transitions may reflect active measures by service providers and their serious attempts to support older people's coping at home. Some of those admitted to care facilities and returning home could result from periods of respite care, specifically planned to support living at home. This would be in accordance with the guidelines of official Finnish policies on old age (Ministry of Social Affairs and Health 1999). We tried to estimate the number of respite care periods by calculating the proportion of several repeated admissions with equally long stays. According to this rough estimate, respite care would explain only about 1.2% of all transitions. One-night stays at home in the middle of a care period possibly indicating home leave from care, cover 3.9% of all transitions. It is plausible that to a large extent they are well justified and in the best interest of the older individual. However, at least in part, the large number of transitions and the complex pathways of care are likely to result from unclear areas of responsibility in social and health care. Information loss and communication problems between different agents (Hauser 2009; Meier and Beresford 2008) and unsuccessful discharges (Mistiaen et al. 1997; Naylor et al. 1999) may contribute to unnecessary moves between different settings.

Our findings reveal a great variety in the pathways of care during the last 2 years of life, and implicate multiple factors underlying these pathways. Younger old people and men had more transitions, especially from home to hospitals, and the place of death was more often general or university hospital than among women and the oldest age groups. The oldest group and women had fewer transitions and more often spent the whole 2 years in a care facility. The oldest women differed most from others in that they had fewer transitions and every fifth of them spent their last 2 years in a care facility. The results support those of earlier research on age differences: hospital care at the end of life is more common among younger age groups (Jakobsson et al. 2006); residential care and longer periods of institutionalisation at the end of life have been more common in the oldest age groups (Ahmad and O'Mahony 2005; Brock et al. 1996; Jakobsson et al. 2006; Larsson et al. 2008).

The variation between genders can be at least partly explained by gender differences in diseases and disabilities (Suominen-Taipale et al. 2006). It is obvious that the patient's diagnosis influences the places of death and number of transitions. Different diseases entail different care needs, e.g. dementia, functional limitations and depressive syndromes are found to predict the use of home

help services and institutionalization (Larsson et al. 2006). Older women are found to have higher prevalence of reported chronic conditions, and it is known that during the period preceding death older women have more problems in functioning than older men (Lentzner et al. 1992). Dementia, for example, is more prevalent among women (Brayne et al. 2006). In Finland in year 2001 almost 70% of all dementia patients in health and social services were patients in residential care (National Research and Development Centre for Welfare and Health 2007). These factors are likely to contribute to longer stays in residential care and fewer transitions, and also to the places of death among women.

Yet medical reasons are not the only factors influencing the pathways of care; social and psychological circumstances are also likely to be important. Living alone, having low income and being very old are associated with institutionalization, while being younger and having a spouse are associated with transition from institution to home (Martikainen et al. 2009). Men have been found to receive informal care and help more often in everyday life than women (Jylhä et al. 2007), which undoubtedly relates to the fact that men are less likely to live alone (Orfila et al. 2006, Suominen-Taipale et al. 2006) and have more often a living spouses as informal help: the probability of not being institutionalized is highest among people who have a spouse, and the relative protective effect of living with a spouse seems to be even stronger in men (Nihtilä and Martikainen 2008).

The major strength of this study is its use of large national registers and the use of personal identification numbers to identify every individual. Every citizen in Finland has a personal identification number as a personal code which remains unchanged throughout his/her life. This enables us to reliably monitor the personal data and individual use of care services from different registers. Our sample included register data on all of those who died in Finland at the age of 70 or older during 1998 and 40% of those of this age who died 1999–2001 and represents well all Finns who died at this age. The responsibilities of different health and social care organizations has not changed and the Finnish health and social service system has not experienced drastic reforms during the last decade (Vuorenkoski 2008) that would jeopardize the validity of our results. Aro et al. (1990) studied the accuracy of the Finnish Hospital Discharge Register by comparing register data with corresponding medical records. The dates of admissions and discharges were 96% accurate, while the speciality field of care was 91% accurate. The majority of problems in accuracy were due to insufficient recording by care professionals and inaccuracy of 1–2 days in exact dates of admissions and discharges. Since that time, the registers have not changed but with developing practices

the coverage and reliability are likely to have improved. In all, the coverage and reliability of the data are good.

A major weakness is that information about informal care is not available in our data. In addition medical history could not be included in this study. These are likely to explain a great part of the variation in transitions and places of death. With these two limitations, the findings of the study must be interpreted with caution. In future, analyses of the pathways of care according to the major causes of death on the one hand, and the different pathways leading to different places of death on the other could improve our understanding of the variation in the patterns of care at the end of life.

In conclusion, places of death and pathways of care in the last 2 years of life among people aged 70 or older are extremely variable and differ between age groups and genders. Some people spend at least the last 2 years of their lives in the same care facility. Most people experience several transitions during their last years and the frequency of these moves increases with approaching death. This means an increasing number of transitions between settings at a time when the patient is perhaps at the most vulnerable stage of his or her life. Although the transitions in part probably reflect an adequate response to diverse health and care needs, it is possible that they also indicate problems in the integration of care, in collaboration between different services, and in the competence of service providers to treat the multiple problems of old age. Better understanding of the factors underlying transitions are needed to evaluate their effects on the quality of the last years of life in old age.

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The impact of dementia on care transitions during the last two years of life

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Abstract

Background: dementia is one of the main challenges to our health and social care. This study compares the number and timing of transitions between care settings in the last 2 years of life among older people with and without dementia.

Methods: data were derived from Finnish national registers, and include all those who died in 2002 and 2003 at the age of 70 or older ($n = 70,366$). Negative binomial regression analyses were used to analyse the impact of dementia on number of transitions among people with and without dementia and to adjust the number for age, gender and other diagnoses.

Results: in the group that lived at home 2 years before death people with a dementia diagnosis had 32% more care transitions than people without dementia, while the group that was in residential care facility 2 years before death people with dementia had 12% fewer moves than those without dementia. The average number of transition was highest in last 3 months of life. People with dementia had their last move more often between care facilities and hospitals offering basic health care than people without dementia.

Conclusion: dementia has a significant impact on the number and type of transitions. As the number of people with dementia increases, the quality and equity of care of these patients in their last years constitute a special challenge.

Keywords: dementia, care transition, end-of-life care, ageing

Introduction

In the next decades the incidence of Alzheimer's disease and other dementias will increase with the increasing

number of older people [1]. Dementia is a significant cause of institutionalisation [2], disability and mortality [3]. In dementia, as in other serious conditions, the greatest need for care usually concentrates on the last years of life. During

this period, older people often move between different care facilities, and age, gender [4] and morbidity [5, 6] are known to affect the number and type of these transitions. In people with dementia, moving from one place of care to another constitutes a special challenge. Regardless of their reasons the transitions include risks [7–9], and the continuum of care is always challenged. Using the comprehensive care registers in Finland, we monitored the patterns of care transitions and compared them between people with and without a dementia diagnosis.

In Finland, the municipalities are responsible for organising health and social services for their residents. These services are funded mainly by taxes, and partly by user fees. University hospitals and general hospitals provide specialised medical care, and municipal health centres offer primary hospital health care in their inpatient wards. Nursing homes and other residential care facilities provide long-term care [10]. Long-term facilities also provide short-term respite care for older people whose permanent residence is their own home [11].

The aim of this study was to identify the number and type of transitions between different care settings, including home, among people with and without dementia during the last 2 years of life. We compared the number of all physical moves between people with and without dementia, not only those necessitated by the treatment of dementia. We also examined the timing of such transitions during the last 2 years of life, and the type and timing of the last transition.

Methods

Data

This study was based on Finnish register data which include information on the utilisation of health and social services in the whole country. Our sample included all those who died in Finland at the age of 70 years or older during the years 2002–2003 ($n = 70,366$). Their admissions to and discharges from care were followed up in the registers retrospectively for 730 days prior to death, by using the personal identification code, which remains unchanged throughout people's life. The data sources are described more detailed in Forma *et al.* [12]. The research plan was approved by the Pirkanmaa hospital district ethics committee. All data were handled according to the ethical norms.

In this study transition refers to a situation when an individual physically moves from one place to another and stays there for at least one night. Outpatient care or moving between different inpatient wards in the same institution is not included. Data include the university and general hospitals providing specialised medical care, health centres providing primary health care services and residential care facilities providing long-term care (nursing homes and sheltered accommodation with 24 h assistance for older people). Data cover the dates of admission to and discharge from care facilities, the duration of stays and periods of time spent outside care facilities.

Identification of individuals with dementia was based on the International Classification of Diseases (ICD10). The dementia group included all decedents whose cause of death (data source Statistics Finland) or cause of hospitalisation during the last 2 years of life (data source National Institute of Health and Welfare) was any of the following ICD-10 codes: F00 (dementia in Alzheimer's disease), F01 (vascular dementia), F02 (dementia in other diseases), F03 (unspecified dementia) or G30 (Alzheimer's disease). We included all causes of death (immediate, underlying, intermediate and contributing, http://www.stat.fi/til/ksyyt/kas_en.html), and both main and side diagnoses in hospital registers. Out of all those with a dementia diagnosis, dementia was noted as a cause of death among 80% of the cases, and as a diagnosis in care registers among 69% (Care Register of Health Care, Care Register of Social Welfare and in the Home Care Census). Forty-nine percent had a mention of dementia in at least two data sources.

Statistical analysis

The number of care transitions was calculated separately for those with and without dementia and also separately for each 3-month period during the last 2 years. Medians were calculated for those with any transitions in 2 years. The type of the last move was calculated separately in both those with and without dementia.

Besides being right-skewed (skewness 3.1), the number of care transitions revealed overdispersion [13], i.e. the variance (73.7) was greater than the mean (7.7). Therefore negative binomial regression models were fitted to estimate the rate ratios (RR) of differences in the number of transitions in people with and without dementia [14]. Models were adjusted for age, gender and other diagnoses. RRs were also reported in percentages [15].

Those who were already in institutional care at the beginning of our follow-up were in a different situation regarding moves from those who were living at home. Therefore, we performed all analyses separately for those who at baseline (730 days before death) were living at home, and for those who were in residential care facilities.

Analyses were performed with SPSS (15.0) software package, and negative binomial regression analyses also with Stata 8.2.

Results

The total number of decedents 70 years old or older in 2002–2003 was 70,366, every fourth (24.8%) having been diagnosed with dementia. The average age of people with dementia was 85 and in people without dementia 82. Of those with dementia 69.5% and without dementia 56.0% were women.

Ten other diagnostic groups were identified: cancer, diagnosed in 9.6% of those with dementia (D+) and in 28.2% of those without dementia (D–), diabetes (D+

13.2%, D– 15.6%), psychoses, depressive symptoms or other mental health disorders (D+ 8.4%, D– 6.7%), Parkinson and other diseases of the circulatory system (D+ 24.5%, D– 33.8%).

Of those with dementia every fifth (20.9%) lived the entire period in the same place without transitions (0.5% at home and 20.5% in a care facility), while of those without dementia the corresponding share was 11.3% (6.3% at home and 5.0% in a care facility) (Table 1).

In both groups the number of transitions varied from 0 to 200. Among those with any care transitions in the last 2 years the median number was six in those with dementia and seven in those without dementia (Table 1). When age, gender and other diseases were adjusted for, people with dementia had 4.2% (RR 1.042) more transitions than people without dementia (Table 2).

In the group living at home at baseline almost everyone had care transitions in the last 2 years of life (Table 1). The median number was eight for those with a dementia diagnosis and seven for those without. When age, gender and other diagnoses were adjusted for, people with dementia had 31.9% (RR 1.319) more transitions than people without dementia (Table 2).

Among people living in residential care facilities at baseline, 70.4% of those with a dementia diagnosis and 80.4% of those without dementia had at least one care transition during their last 2 years of life; the respective median numbers being four and five (Table 1). When age, gender and other diagnoses were adjusted for, people with

dementia had 12.4% (RR 0.890) fewer transitions than people without dementia (Table 2).

The average number of transitions for each 3 months was the higher the closer was the time of death. This was true of both people with and without dementia, and regardless of where they were 2 years before death (Figure 1). In the group living at home at baseline, people with dementia had more care transitions than those without dementia between 24 and 6 months preceding death, but during the last months those without dementia moved more. In the group that was in residential care at baseline, people with dementia had fewer transitions during the whole 2 years than people without dementia.

In the last 3 months of life almost half (48.3%) of all subjects with dementia, 65.4% of those who were at home at baseline and 38.6% of those who were in residential care at baseline, experienced at least one transition. For people without dementia diagnosis, the figures were even higher: 73.6% for the whole group, 65.4% for those living at home at baseline and 58.6% for those in a residential care facility at baseline.

Finally, we compared the types of the last care transition for subjects during the last 3 months of life. For people with dementia, the last care transition was more often (62.5%) between care facilities (rather than from or to own home) than for people without dementia diagnosis (44.4%). In the dementia group, 26.1% moved between residential care and hospitals providing primary care, while 29.0%

Table 1. Number of care transitions in last 2 years of life

	Dementia			No dementia		
	Proportion (%) who had transitions	Median number ^a of transitions (quartiles)	Age (mean)	Proportion (%) who had transitions	Median number ^a of transitions (quartiles)	Age (mean)
All (<i>n</i> = 70,363)	79.1	6 (3,11)	86	88.7	7 (3,12)	82
Men	87.0	7 (4,13)	83	86.8	7 (3,12)	80
Women	75.6	6 (3,10)	87	88.4	6 (3,11)	84
At home at baseline (<i>n</i> = 51,667)	99.0	8 (4,13)	84	92.2	7 (3,12)	81
Men	99.1	9 (5,15)	83	90.7	7 (3,12)	80
Women	98.9	7 (4,12)	86	93.6	7 (3,12)	83
In residential care facility at baseline (<i>n</i> = 12,096)	70.4	4 (2,7)	87	80.4	5 (2,9)	86
Men	75.3	4 (2,8)	85	83.9	5 (3,10)	84
Women	68.9	4 (2,7)	88	78.8	5 (2,9)	87

^aIn those who underwent care transitions.

Table 2. The association of the number of care transitions with dementia diagnosis, age and gender

Number of transitions	All (<i>n</i> = 70,366)		At home at baseline (<i>n</i> = 51,677)		In residential care facility at baseline	
	RR	95%	RR	95%	RR	95%
Dementia (reference = no dementia)	1.042	1.019–1.065	1.319	1.289–1.350	0.890	0.845–0.937
Age	0.992	0.991–0.993	1.003	1.001–1.004	0.981	0.977–0.985
Gender (reference = male)	0.923	0.907–0.940	1.007	0.989–1.026	0.831	0.785–0.880

Negative binomial regression. All analyses adjusted for comorbidity including cancer, diabetes, psychosis, depressive syndromes or other mental health disorders, Parkinson's disease or other neurological diseases, chronic asthma and COPD or other respiratory diseases, arthritis or osteoarthritis, hip fracture, stroke, ischaemic and other heart disease excluding rheumatic and alcoholic diseases and other diseases of the circulatory system.

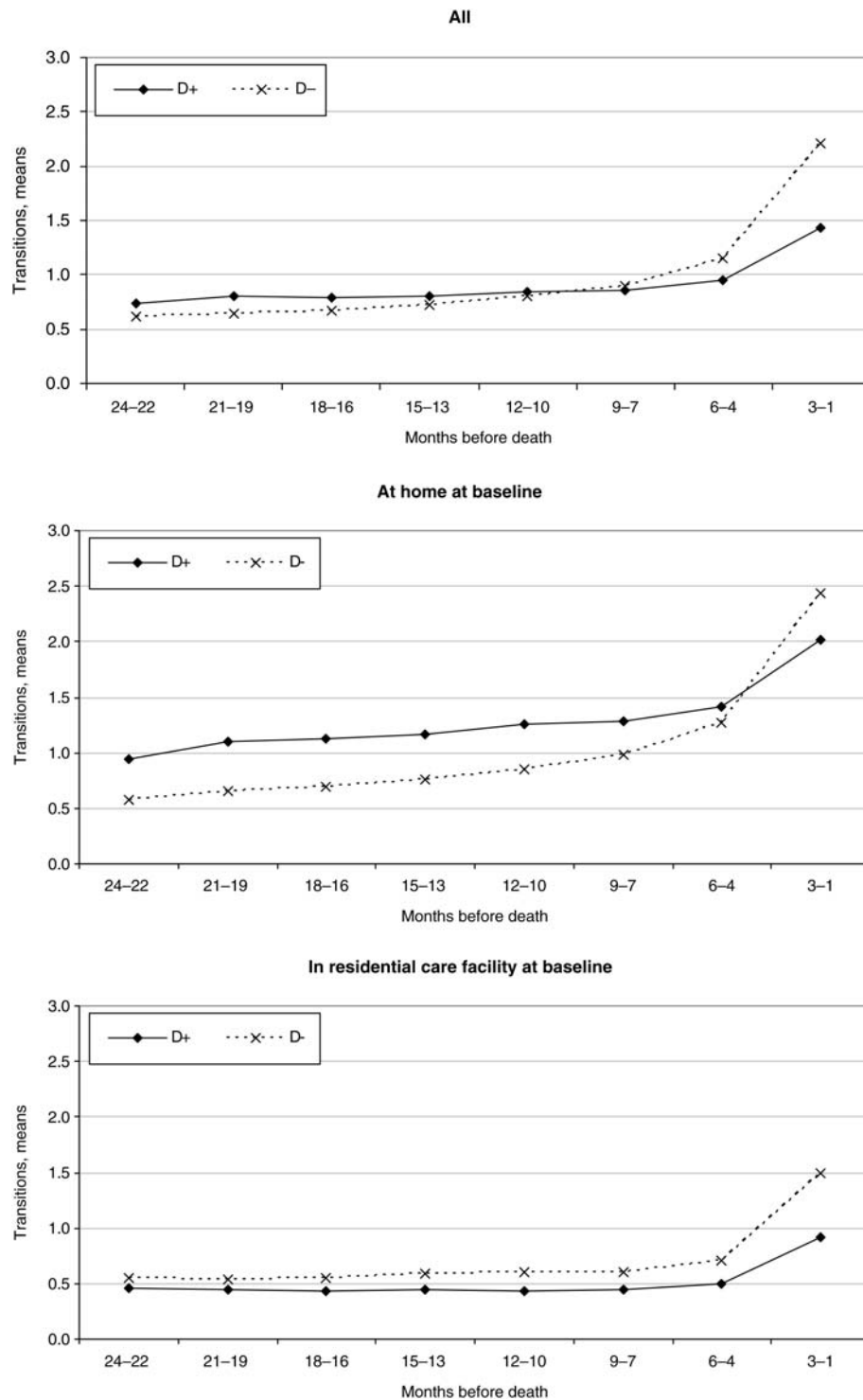


Figure 1. Average number of care transitions during last 2 years. All analyses adjusted for age and sex.

moved between hospitals, the corresponding figures in the non-dementia group being 6.8 and 32.7%. Only 7.4% of those with and 4.9% of those without dementia had transitions between a residential care facility and a hospital providing specialised medical care. In all, the most common destination of the final transition was a hospital providing primary care; this was more frequent for people with (67.4%) than for those without dementia diagnosis

(49.2%), while the latter moved more often to a hospital providing specialised medical care (D- 37.5%, D+ 13.3%).

Discussion

The most striking result in our study was that, after adjusting for age, gender and comorbidity, dementia increased the

number of care transitions almost 32% for older individuals living at home 2 years before death. Among people living in residential care 2 years before death dementia decreased the number of transitions by 12%. Yet, in both groups, the number of transitions increased when death became closer. At the very end of life, people with dementia moved more often to primary care hospitals and less often to specialised hospitals than individuals without dementia.

Our data are not sufficient to explain the large number of care transitions, or the difference between individuals with and without dementia. Nevertheless, it is plausible that the frequency is too high to be consistent with good dementia care, which stresses continuity of care and familiar living environments [16–19]. Dementing diseases are chronic and progressive, leading to great need for care. Therefore, anticipation of increasing needs and advance planning of care are more important than in many other conditions. A Finnish study showed that physicians are more likely to choose active acute care at the end of life for a patient suffering from dementia than for one suffering from cancer [20], although, in advanced dementia, hospitalisations without very specific reasons often lead to negative experiences rather than to demonstrable benefit [16, 21]. Still, our findings and those of others [22] show that people living in residential care are often hospitalised at the final stage of their life.

Comorbidity is common in older age [23]. In our analyses, comorbidity, as well as age and sex, was adjusted for. The prevalence of cancer, lung disease, diabetes, hip fracture, stroke, heart conditions and other circulatory diseases was lower in people with dementia diagnoses than those without. Earlier studies suggest either similar [24, 25], or higher comorbidity in people with dementia [26]. It is possible that the differences in our data are due to under-reporting of other diseases in hospital records, or even to under-diagnosis of other conditions in people with dementia diagnosis [27]. People with dementia are found to have partly different end-of-life care than people without dementia [28]. In our research the difference in the types of last transitions is noteworthy. The register data we used do not allow any conclusions on whether dementia patients were more often than others moved to primary care hospital instead of a specialised hospital because the problems necessitating the transition were different or because similar health problems are treated differently among people with and without dementia.

Besides individual and medical factors, care and care transitions are influenced by service supply and changes in health and social care policy. In Finland, the official goal is to decrease institutional care and encourage people to stay at home as long as possible [29]. From 1995 to 2005, the proportion of older people living in sheltered accommodation increased, while the proportion of those in institutional care and home care decreased. At the same time, the care of the oldest-old in specialised health care increased, but their average length of stay decreased [30]. Here we could not follow the time trends, but it is plausible that the

changes in organisation and practices of care have contributed to the number of care transitions of dementia patients. Hospitalisations of people in residential care during the last months of life may partly reflect the problems of these facilities in the end-of-life care.

To the best of our knowledge, this is the first study to investigate care transitions of people with dementia in a health and social care system by using exhaustive and reliable information on care transitions in the whole country. The accuracy, coverage and reliability of the data in the Finnish care registers are considered good [4]. The apparent weakness in our study is unavailability of information about informal care. Also, we had no information about the time of the dementia diagnosis, the stage of the disease or the functional status of individuals. Obviously, our results from Finland do not necessarily reflect the situation in other countries.

This study showed that in dementia care, moving between care facilities is common during the last years and particularly during the last months of life. Further research is needed to understand the underlying causes. In our view the findings reflect the problems that the service system has in planning and organising adequate care for this particular patient group. With ageing of the population, adequate and equal services for individuals with dementia constitute one of the greatest challenges to health and social services.

Key points

- People with dementia who lived in their own homes 2 years before death moved between care settings or care settings and home three times more often than people without dementia during last 24 months of life.
- People with dementia who lived in a residential care facility 2 years before death had fewer care transitions than people without dementia during the last 24 months of life.
- The number of care transitions among both people with and without dementia increased when death approached.
- People with dementia moved more frequently between primary care hospitals and residential care facilities, while people without dementia moved more frequently to specialised medical care hospitals.

Conflicts of interest

None declared.

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ORIGINAL ARTICLE

Effects of municipality factors on care transitions

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Abstract

Aims: To analyse whether transitions between care settings differ between municipalities in the last 2 years of life among older people in Finland. **Methods:** Data were derived from Finnish national registers, and include all those who died in 2002 and 2003 at the age of 70 or older except those living in very small municipalities ($n=67,027$). Data include admissions and discharges from health and social care facilities (university hospitals, general hospitals, health centres, residential care facilities) and time spent outside care facilities for 730 days prior to death. Three-level negative binomial regression analyses were performed to study the effect of municipal factors on (1) the total number of all care transitions, (2) the number of transitions between home and different care facilities, and (3) transitions between different care facilities. **Results:** The municipality of residence had only a minor effect on the total number of care transitions, but greater variation between municipalities was found when different types of care transition were examined separately. Largest differences were found in care transitions involving specialised care. Age structure, urbanity, and economic situation of the municipality had an impact on several different care transitions. **Conclusion:** The total number of care transitions in 2 final years of life was approximately similar irrespective of the municipality of residence, but the findings imply differences in transitioning specialised care. Potentially, this may suggest inequality between the municipalities, but more detailed studies are needed to confirm the factors underlying these differences.

Key Words: Aged, care transition, health and social services, last 2 years of life, multilevel analysis, municipality, negative binomial regression analysis, specialised care

Introduction

People use more care services at the end of life than in earlier phases of life [1]. They also make more transitions between care facilities, or between care facilities and home [2]. In Finland at least, the pathways of care, i.e. the care facilities to which older people move and the frequency of transitions in the last 2 years of life, vary between older individuals. [3]. Individual characteristics such as age, gender [3,4], and morbidity [5–7] have an impact on care transitions. If individual health needs are expected to determine admissions to and discharges from care and also to determine the appropriate care facility, the role of municipality factors in such transitions should be minor. Hence research on transitions between care settings can also help to clarify whether health and social services are appropriate and equally

accessible to all. From an individual perspective care transitions between home and different care facilities may adversely impact the continuum and outcome of care [8–10], and therefore it is important to study the factors affecting these transitions.

It is plausible that regional characteristics affect care transitions. In Finland the municipalities enjoy significant autonomy over the planning and organisation of health and social services for local residents [11], and therefore the availability and use of these services vary across municipalities [12]. Municipalities are responsible for providing health and social services to residents but they may do so together with other municipalities or may purchase services from NGOs, private companies, or other municipalities. Public primary health care is

provided by municipal health centres, which offer both outpatient and inpatient care. Finland is divided into 20 hospital districts, and every municipality is assigned to one hospital district. Each hospital district has a central hospital that offers specialised secondary care to the district residents. In addition there may also be district and private hospitals, depending on the size of the hospital district. Five of the central hospitals are university hospitals which are located in the country's largest cities. As well as offering secondary care to the residents of their own hospital district, they provide advanced tertiary care to several hospital districts. [12,13]. Institutional long-term care including nursing homes and other residential care facilities is provided by municipal social care services, as well as by private facilities. Long-term care facilities also provide short-term respite care for older people who live permanently in their own home [12,14].

The purpose of this study is to ascertain to what extent care transitions differ between municipalities in last 2 years of life among older people in Finland. The reason we chose to focus on the last 2 years of life was that our previous study implied that among older people, the use of care, and long-term care in particular, begins to increase 2 years before death [15]. Thus our focus is not restricted to the very final stages of life but we consider a longer period of time that is still characterised by a higher need for services. In more detail, we will investigate to what extent: (1) the number of transitions in the last 2 years of life varies between municipalities; and (2) municipal and hospital district factors affect the number of transitions between care facilities, or between care facilities and home.

Methods

Data

This study is based on register data which include individual information on the use of health and social services in the whole country of Finland. The study is part of a research project entitled New Dynamics of Longevity and the Changing Needs for Services (COCTEL II). The study sample was identified from the Causes of Death Register (Statistics Finland) and was linked with data from the Care Register for Health Care and the Care Register for Social Welfare (National Institute for Health and Welfare) using unique personal identity codes. The study population consists of all persons who died in Finland in 2002–03 at the age of 70 or older. The municipal level information was collected from the SOTKANet database [16]. Following a succession of municipal mergers, the number of

municipalities in Finland fell from 448 in 2002 to 416 in 2007. For the purposes of this study we have used the municipality numbers valid at the beginning of 2007 and coded individuals accordingly. The Åland Islands (16 municipalities) and municipalities with 2500 inhabitants or less were excluded because of the small numbers of annual deaths and because of the risk of individuals being identified from the data. Altogether 315 municipalities are included in our analyses covering 95% of persons aged 70 or over who died in Finland in 2002 and 2003 ($n=67,027$). Their use of services and moving between different care settings was monitored retrospectively for 730 days prior to death.

Data include figures for the use of hospitals providing specialised medical care (university hospitals and general hospitals including central, district, and private hospitals) and primary health care services (inpatient wards in public health centres), both private and public residential care facilities providing long-term care (inpatient wards in nursing homes and sheltered accommodation with 24-hour assistance). These data allowed us to monitor admissions to and discharges from health or social care facilities, the duration of stays and periods of time spent outside care facilities. In this study, transition refers to a situation where a person physically moves from one care facility to another, or to or from his/her own home, and stays there at least one night. Outpatient care or moving between wards in the same care facility are not included here as care transitions. The ethics committee of the Pirkanmaa hospital district raised no objections to the study. All registry data were handled in conformity with the principles of ethical research.

Outcome variables

The outcome variables are (1) the total number of transitions (all care transitions between any care settings, including own home), (2) the number of transitions between own home and different care facilities, and (3) transitions between different care facilities, in the last 2 years of life.

Explanatory variables

The models include explanatory variables at three levels. Individual level (level I) factors include age, gender, and diagnoses. The municipal level (level II) includes factors describing the population in the municipality (proportion of inhabitants ≥ 65 years, proportion of those aged ≥ 75 living alone, and the total number of inhabitants), factors describing municipal finances (annual contribution margin, tax revenue, health and social care expenditure, and

Table I. Description of the three-level explanatory variables and the data sources.

	Categories/range	Study population	Data source
Individual level (I)			
Gender	0=man	40.5	Registers ^a
	1=woman	59.5	Registers ^a
Age	0=70-79	36.5	
	1=80-89	45.2	
	2=90+	18.3	Registers ^b
Diagnoses	(0=no, 1=yes)	1=	
	Dementia	25.0	
	Cancer	23.6	
	Diabetes	15.0	
	Mental disorders	7.1	
	Neurological	10.5	
	Respiratory	46.1	
	Arthritis	5.7	
	Hip fracture	7.7	
	Stroke	22.5	
	Ischaemic heart disease	57.2	
	Other circulatory disease	31.4	
Municipal level (II)			
<i>Population factors</i>			
Proportion of 65-year-olds (%)	0=<16	39.5	SOTKANet indicator bank ^f
	1=16-20	38.9	
	2=>20	21.6	
Proportion of those living alone (%) ^c	0=<40	13.4	SOTKANet indicator bank ^f
	1=40-50	56.1	
	2=>50	30.5	
Number of inhabitants	0=2500-4999	10.9	SOTKANet indicator bank ^f
	1=5000-9999	19.2	
	2=10,000-600,000	69.9	
<i>Economic factors</i>			
Tax revenue (€/capita)	0=<2000	20.3	SOTKANet indicator bank ^f
	1=2000-3000	64.2	
	2=>3000	15.5	
Total operating health and social expenditure (€)	0=<2400	39.0	SOTKANet indicator bank ^f
	1≥2400	61.0	
Annual contribution margin ^d	0=<0	9.2	SOTKANet indicator bank ^f
	1≥0	90.8	
Urbanity	0=urban	57.4	Statistics Finland
	1=semi-urban	18.5	
	2=rural	24.1	
<i>Informal care</i>			
Support for informal care (%) ^e	0.1-6.9	2.2 (mean)	SOTKANet indicator bank ^f
Hospital district level (III)			
University hospital in the district	No=0	48.7	Statistics Finland
	Yes=1	51.3	

Values are % or mean, based on individual data ($n=67,027$).

^aStatistics Finland, National Institute for Health and Welfare.

^bStatistics Finland (Causes of Death Register, including immediate, underlying, intermediate and contributing causes of death). National Institute for Health and Welfare (Care Register for Health Care, Care Register for Social Welfare).

^cLiving alone, population aged 75 or older as a proportion (%) of the total population of the same age.

^dAnnual contribution margin. A negative annual contribution margin means revenues are not sufficient to cover operating costs.

^eSupport for informal care, proportion (%) of clients aged 65 or over in the total population of the same age during the year.

^fSOTKANet indicator bank contains extensive statistical information on Finnish municipalities (National Institute of Health and Welfare).

urbanity) and the proportion of people receiving financial support for informal care. These factors describe the situation in 2003. The hospital district level

(level III) has one factor, i.e. the existence of a university hospital in the hospital district. The explanatory variables and data sources are described in Table I.

Modelling strategy

The data have a hierarchical structure: individuals (level I) who live in municipalities (level II) which are nested in different hospital districts (level III) [17]. All outcome variables are strongly skewed continuous variables and display overdispersion (variance exceeds the mean). Therefore, negative binomial regression analysis was used in multilevel modelling [18]. The number of different care transitions was analysed in random intercept models adding the variables listed in Table I sequentially to the models as explanatory variables. Three-level analyses, estimated with second-order penalised quasi-likelihood (PQL), were performed to study the significance of explanatory variables at each level and unexplained variances in levels II and III: (1) Null model (intercept only model); (2) Model 1: municipal level factors; (3) Model 2: model 1 + hospital district level factors; and (4) Final model: model 2 + individual level factors.

To describe the unexplained variation at municipal level (level II, variance between municipalities in the same hospital district) and at hospital district level (level III, variance between hospital districts) in the null model and after the inclusion of different explanatory factors in the models, we represent the random-effects parameters separately [19]. Median rate ratios (MRRs) are also represented to clarify the interpretation of variations. MRR gives the total variance between all municipalities [20]. MRR was calculated as $\exp(0.954 \cdot \sqrt{(\sigma_{hd}^2 + \sigma_m^2)})$ where hd =hospital district, m =municipality. It is equivalent to the median odds ratio and, as such, is the median of the rate ratios between two randomly chosen individuals with identical characteristics taken from two different randomly chosen areas; it is the median of all possible pairwise comparisons between municipalities [20]. MRR value 1 indicates no variation and a high MRR value large variation between areas. Here it describes the increased relative risk of having more transitions in a municipality with high number of care transitions compared to a municipality with low number of care transitions. [21].

First, the outcome variable in the fixed part of the analyses was the total number of care transitions. Then, in order to investigate which types of care transitions are influenced by municipality of residence, different types of care transitions were analysed separately. Since the main interest in this research is the effect of municipal factors, these were the first to be included in the models after the null model. Level II and III fixed-part parameter estimates were transformed into rate ratios (RR) with 95% confidence intervals [17]. Individual-level results are represented

only in the model concerning the total number of transitions in the last 2 years; other individual-level results are discussed in the text. The multilevel package MLwiN 2.19 was used.

Results

Out of all individuals, 83.6% had one or more care transitions during the last 2 years of life. The median was 5 (quartiles 2, 11) and $\text{mean} \pm \text{SD}$ was 7.7 ± 8.6 . The mean number of all transitions per municipality varied from 5.17 to 15.4, the mean of all municipality means was 8.3 ± 1.7 and the median was 8.1 (quartiles 7.2, 9.3). The frequency of care transitions increased with the increasing proximity to death: from 24 to 13 months before death 51% had at least one transition and during the last 3 months of life 67% had at least one transition.

The most frequent transitions between home and a care facility were moves from home to a health centre (48% had at least one such transition), to general hospital (39%), to university hospital (21%), to residential care (16%); and own home from health centre (43%), from general hospital (25%), from university hospital (12%), from residential care (19%). Upon closer examination of different types of transitions between own home and care facilities, the highest mean at the individual level was recorded for transitions from own home to health centre (1.35 ± 2.67) and the lowest for transitions from university hospital to own home (0.29 ± 1.11). At the municipal level, the highest mean (from own home to health centre 1.58) and the lowest mean (university hospital to own home 0.22) were almost the same as at the individual level.

The most frequent transitions between different care facilities were moves to a health centre from a general hospital (26%), from a university hospital (13%), and from residential care (14%), from a health centre to a general hospital (13%), to a university hospital (6%), and to residential care (17%). Altogether, 6% moved from a general hospital to residential care and 8% from residential care to a general hospital. Among different types of transitions between care facilities, the highest mean at the individual level was recorded for transitions from a general hospital to a health centre (0.40 ± 0.82), and the lowest for transitions from a health centre to a university hospital (0.07 ± 0.34). At the municipal level, the highest mean (from a general hospital to a health centre 0.49) and the lowest mean (from a health centre to a university hospital 0.08) were again almost the same as at the individual level.

Table II. Variation in care transitions at municipal and hospital district levels: random-effects parameters for the random intercept models and median rate ratios (MRR) (municipal variation in all hospital districts).

Type of transition	Null model			Model 1 (municipal factors)			Model 2 (hospital district factor)			Final model (individual factors)		
	Level III	Level II	MRR	Level III	Level II	MRR	Level III	Level II	MRR	Level III	Level II	MRR
Total number of transitions	0.014	0.011	1.16	0.012	0.009	1.15	0.012	0.009	1.15	0.007	0.009	1.13
Home→health centre	0.192	0.393	2.07	0.165	0.343	1.97	0.159	0.343	1.97	0.152	0.330	1.94
Health centre→home	0.179	0.363	2.02	0.156	0.319	1.93	0.152	0.318	1.92	0.138	0.308	1.89
Home→general hospital	0.691	0.745	3.14	0.677	0.775	3.16	0.337	0.774	2.73	0.327	0.775	2.72
General hospital→home	0.624	0.769	3.08	0.606	0.709	2.99	0.312	0.708	2.62	0.328	0.760	2.70
Home→university hospital	1.838	0.160	3.85	1.767	0.133	3.72	0.240	0.132	1.79	0.232	0.165	1.82
University hospital→home	2.013	0.162	4.08	1.918	0.121	3.90	0.338	0.121	1.91	0.306	0.151	1.91
Home→residential care facility	NS	0.473	1.96	NS	0.449	1.95	NS	0.449	1.95	NS	0.470	1.92
Residential care facility→home	NS	0.416	1.89	NS	0.394	1.87	NS	0.394	1.87	NS	0.406	1.84
Health centre→residential care	0.066	0.331	1.82	0.059	0.302	1.77	0.051	0.303	1.76	0.050	0.294	1.75
Residential care→health centre	0.119	0.448	2.05	0.109	0.411	1.99	0.089	0.412	1.96	0.085	0.381	1.92
Health centre→general hospital	0.667	0.931	3.34	0.625	0.804	3.13	0.175	0.802	2.57	0.169	0.759	2.51
General hospital→health centre	0.674	1.055	3.51	0.651	0.971	3.37	0.225	0.964	2.83	0.226	0.915	2.77
General hospital→residential care	0.481	1.072	3.28	0.417	0.925	3.02	0.384	0.930	2.99	0.363	0.943	2.97
Residential care→general hospital	0.392	0.784	2.81	0.362	0.699	2.67	0.266	0.703	2.56	0.254	0.708	2.55
University hospital→health centre	3.848	0.563	7.42	3.599	0.495	6.89	0.829	0.484	2.98	0.827	0.504	3.01
Health centre→university hospital	3.173	0.420	6.10	2.929	0.347	5.62	0.585	0.338	2.50	0.591	0.344	2.52

NS=not significant.

Variation in care transitions at municipal level and hospital district level

The MMR of 1.16 in the null model suggests that the municipality of residence had only a minor impact on the total number of care transitions in the last 2 years of life even before any explanatory variables were added to the models (Table II). In the final model which included municipal, hospital district, and individual explanatory variables, the MMR decreased to 1.13, indicating a very small effect of municipality of residence on the total number of transitions.

Greater variation was observed between municipalities when different types of care transitions were examined separately. In transitions involving a general hospital, MMRs were high and varied between 2.51 and 4.08 in null models (Table II). In transitions between a general hospital and own home, a general hospital, and a health centre, and also between a general hospital and residential care, the highest variation was seen at the municipal level, indicating variation between municipalities in the same hospital district. The inclusion of hospital district or individual level factors acted to decrease the municipal variance only

slightly, or not at all. Thus, the variance in transitions involving a general hospital was not explained by the availability of a university hospital.

The MMRs were also high, varying between 3.85 and 7.42 in null models in transitions between own home and a university hospital and between a university hospital and a health centre. However, the very high variance existed at the hospital district level, not at the municipal level, and after the hospital district level factor was included the MMRs decreased notably. However, municipal level variances decreased only slightly, if at all, after all explanatory variables were included in models.

The lowest MMRs were recorded for transitions between own home and a health centre, between own home and residential care facilities and between a health centre and residential care facilities, varying between 1.82 and 2.07 in null models. The variances were higher at the municipal level than at the hospital district level, and municipality variances fell only slightly after all explanatory variables were included in the models.

Effect of municipality factors on the total number of transitions between care settings, and between care settings and own home

When all municipality, hospital district and individual factors were included in models 1–3, the municipality factors emerging as statistically significant were urbanity, annual contribution margin and support for informal care (Table III). Living in semi-urban areas increased the number of care transitions (RR 1.09) compared to urban areas. A positive annual contribution margin in the municipality increased the number of transitions (RR 1.06) when compared to municipalities with a negative annual contribution margin. Increased support for informal care in the municipality brought a slight increase in the number of transitions (RR 1.02).

Almost all individual factors at level I and level III had a statistically significant effect on the number of transitions; being female and 90 years or older decreased and the presence of diagnoses increased the total number of transitions. By contrast, the existence of a university hospital in the hospital district had no significant effect on the total number of transitions.

Effect of municipality factors on different types of transitions

Municipalities with a higher proportion of persons aged 65 or over showed an increased number of transitions between own home and a health centre and

own home and a general hospital, but a reduced number of transitions between own home and a university hospital (Table IV). As regards transitions between different care facilities, a higher proportion of older people in the municipality increased the number of transitions between a health centre and a general hospital, and between a general hospital and residential care, and decreased the number of transitions between a university hospital and a health centre (Table V).

Living in a semi-urban instead of an urban area and living in a municipality with a positive annual contribution margin served to increase the number of transitions between own home and a health centre. Living in a semi-urban area increased the number of moves from a health centre to a university hospital. Municipalities where more than half of the residents over 75 lived alone had a lower number of transitions from residential care to a general hospital. An increase in the proportion of people receiving support for informal care also increased the number of transitions between a health centre and residential care.

Almost all individual factors at level I and level III factors had a statistically significant effect on the number of transitions. Being female and 80 years or older increased transitions between own home and a health centre, own home and residential care, a health centre and residential care, and residential care and a general hospital. Almost all diagnoses increased the probability of all transitions. A dementia diagnosis decreased the likelihood of moving between own home and a general hospital or university hospital, and between a health centre and a general hospital or university hospital. Also, having a stroke decreased the number of moves from a general or university hospital to own home. The existence of a university hospital in the hospital district (level III) greatly increased the number of transitions between own home and the university hospital and between the university hospital and a health centre, while the number of transitions from and to general hospital decreased.

Discussion

This study showed that municipality of residence had only a minor impact on the total number of all care transitions, as indicated by the low MRRs of care transitions [21]. However, municipality of residence did have a distinct impact on certain types of transitions.

Differences between municipalities were greatest in care transitions involving hospitals providing specialised care. The variance in transitions to or from university hospital was mainly explained by the

Table III. Total number of care transitions in last 2 years: three-level negative binomial regression analyses.

	Null model	Model 1	Model 2	Model 3	Model 4	Model 5
Individual level (I)						
Gender (0=man, 1=woman)					0.92	0.91–0.94
Age (years)						
0=70–79, 1=80–89					0.98	0.96–1.00
0=70–79, 1=90+					0.86	0.84–0.89
Diagnoses (0=no, 1=yes)						
Dementia					1.02	1.00–1.05
Cancer					1.84	1.80–1.88
Diabetes					1.35	1.31–1.38
Mental disorders					1.27	1.23–1.31
Neurological					1.45	1.41–1.49
Respiratory					1.44	1.41–1.47
Arthritis					1.45	1.40–1.50
Hip fracture					1.37	1.33–1.41
Stroke					1.12	1.09–1.14
Ischaemic heart dis.					1.36	1.34–1.39
Other circulatory dis.					1.32	1.30–1.35
Municipal level (II)						
65 years (%) (0=<16)						
1=16–20	1.03	0.98–1.08	1.03	0.98–1.09	1.03	0.98–1.07
1=>20	1.04	0.98–1.11	1.04	0.97–1.10	1.03	0.97–1.10
Living alone (%) (0=<40)						
1=40–50	1.02	0.98–1.06	1.02	0.98–1.06	1.01	0.97–1.05
1=>50	0.99	0.92–1.06	0.99	0.92–1.06	0.98	0.91–1.05
Number of inhabitants (0=2500–4999)						
1=5000–9999	1.01	0.97–1.06	1.01	0.97–1.06	1.02	0.97–1.07
1=10,000–600,000	1.04	0.97–1.10	1.03	0.97–1.10	1.06	0.99–1.13
Tax revenue (0=<2000)						
1=2000–3000	0.98	0.93–1.02	0.98	0.62–1.53	0.96	0.92–1.00
1=>3000	0.98	0.87–1.10	0.97	0.87–1.11	0.98	0.87–1.09
Expenditure (0=<2400)						
1=≥2400	1.02	0.98–1.06	0.98	0.98–1.06	1.03	0.99–1.07
Annual contribution margin (0=<0)						
1=≥0	1.06	1.00–1.11	1.06	1.00–1.12	1.06	1.00–1.11
Urbanity (0=urban)						
1=semi-urban	1.08	1.02–1.14	1.08	1.02–1.14	1.09	1.03–1.15
1=rural	1.04	0.97–1.12	1.04	0.97–1.12	1.07	0.99–1.15
Support for informal care (%)	1.02	1.00–1.03	1.02	1.00–1.03	1.02	1.00–1.03
Hospital district level (III)						
University hospital in the district (0=no)						
1=yes			0.98	0.88–1.11	1.02	0.93–1.12

Values are rate ratios (95% confidence intervals).

hospital district level factor: if there was a university hospital in the hospital district, that increased the number of transitions involving the university hospital. This is due to the double role of university hospitals in Finland. For the municipalities in which they are located and those nearby, the university hospital often also serves as a central hospital and provides secondary care. Unfortunately we have no data to make a distinction between secondary and tertiary care needs and therefore we do not know

whether transitions to tertiary care vary between municipalities. However, after the inclusion of the hospital district factor in the model there still remains some unexplained municipal variation, especially in transitions between the university hospital and a health centre. The importance of the local service supply was again demonstrated by the low variances in transitions between own home and a health centre, own home and residential care, and a health centre and residential care. Health centres

Table IV. Number of transitions between home and a care facility: level II and III negative binomial regression analyses.

	Home→health centre	Health centre→home	Home→hospital	General hospital→home	Home→university hospital	University hospital→home	Home→residential care facility	Residential care facility→home
Municipal level (II)								
65 years (%) (0=<16)								
1=16-20	1.13 (0.91-1.41)	1.12 (0.90-1.38)	1.69 (1.21-2.37)	1.71 (1.22-2.38)	0.78 (0.65-0.95)	0.75 (0.61-0.92)	0.94 (0.71-1.24)	0.91 (0.70-1.18)
1=>20	1.46 (1.11-1.92)	1.41 (1.08-1.85)	1.28 (0.89-1.85)	1.33 (0.87-2.01)	0.78 (0.61-1.00)	0.72 (0.54-0.94)	0.84 (0.78-1.20)	0.81 (0.59-1.13)
Living alone (%) (0=<40)								
1=40-50	1.13 (0.95-1.35)	1.11 (0.93-1.32)	1.08 (0.82-1.42)	1.05 (0.81-1.37)	1.03 (0.87-1.22)	1.03 (0.85-1.25)	0.99 (0.78-1.24)	1.03 (0.83-1.28)
1=>50	1.34 (0.95-1.90)	1.32 (0.93-1.84)	0.85 (0.50-1.45)	0.79 (0.47-1.32)	1.03 (0.77-1.37)	1.12 (0.82-1.54)	0.86 (0.56-1.32)	0.86 (0.57-1.28)
Number of inhabitants (0=2500-4999)								
1=5000-9999	1.09 (0.90-1.32)	1.09 (0.90-1.32)	1.04 (0.77-1.39)	1.04 (0.77-1.40)	0.96 (0.79-1.16)	0.91 (0.74-1.14)	0.85 (0.65-1.10)	0.87 (0.68-1.12)
1=10,000-600,000	1.21 (0.91-1.60)	1.24 (0.95-1.64)	1.19 (0.76-1.86)	1.15 (0.75-1.76)	0.94 (0.73-1.22)	0.84 (0.63-1.14)	0.98 (0.77-1.23)	1.01 (0.72-1.42)
Tax revenue (0=<2000)								
1=2000-3000	0.81 (0.74-1.07)	0.91 (0.76-1.10)	1.04 (0.79-1.38)	1.08 (0.81-1.43)	1.03 (0.86-1.23)	0.94 (0.77-1.16)	0.93 (0.73-1.19)	0.87 (0.69-1.09)
1=>3000	1.09 (0.58-2.02)	1.19 (0.68-2.10)	0.51 (0.20-1.32)	0.56 (0.23-1.36)	1.27 (0.80-2.00)	1.22 (0.75-1.97)	0.83 (0.40-1.71)	0.80 (0.41-1.56)
Expenditure (0=<2400)								
1=>2400	1.04 (0.87-1.25)	1.06 (0.89-1.26)	1.11 (0.85-1.43)	1.11 (0.84-1.45)	1.07 (0.91-1.26)	1.07 (0.89-1.29)	1.09 (0.87-1.36)	1.06 (0.86-1.31)
Annual contribution margin (0=<0)								
1=>0	1.37 (1.08-1.74)	1.40 (1.11-1.77)	0.90 (0.63-1.28)	0.97 (0.68-1.39)	1.19 (0.96-1.47)	1.17 (0.92-1.50)	0.77 (0.57-1.05)	0.79 (0.59-1.04)
Urbanity (0=urban)								
1=semi-urban	1.38 (1.07-1.77)	1.40 (1.10-1.78)	1.16 (0.78-1.72)	1.03 (0.70-1.51)	0.95 (0.77-1.17)	0.90 (0.71-1.13)	0.96 (0.70-1.33)	0.99 (0.73-1.32)
1=rural	1.10 (0.79-1.52)	1.15 (0.83-1.57)	1.39 (0.85-2.30)	1.11 (0.68-1.82)	0.91 (0.68-1.21)	0.85 (0.62-1.18)	0.94 (0.62-1.43)	0.96 (0.65-1.41)
Support for informal care (%)	1.03 (0.96-1.10)	1.04 (0.97-1.11)	0.96 (0.85-1.07)	0.96 (0.86-1.07)	0.98 (0.92-1.04)	0.97 (0.90-1.05)	1.02 (0.94-1.12)	1.03 (0.95-1.11)
Hospital district level (III)								
University hospital in the hospital district (0=no)								
1=yes	0.90 (0.59-1.37)	0.93 (0.62-1.40)	0.28 (0.15-0.53)	0.33 (0.18-0.63)	17.37 (10.46-28.87)	17.89 (9.97-32.08)	1.05 (0.79-1.39)	1.01 (0.77-1.34)

Values are rate ratios from the final models (95% confidence intervals).

Table V. Number of transitions between care facilities: level II and III negative binomial regression analyses.

	Health centre→residential care	Residential care→health centre	Health centre→general hospital	General hospital→health centre	General hospital→residential Care	Residential care→general hospital	University hospital→health centre	Health centre→university hospital
Municipal level (II)								
65 years (%) (0=<16)								
1=16–20	1.09 (0.87–1.35)	1.19 (0.92–1.53)	1.58 (1.13–2.23)	1.49 (1.04–2.14)	1.60 (1.05–2.42)	1.52 (1.07–2.14)	0.58 (0.41–0.82)	0.58 (0.40–0.79)
1=>20	1.19 (0.90–1.57)	1.30 (0.94–1.79)	1.78 (1.16–2.72)	1.53 (0.98–2.40)	1.01 (0.59–1.72)	1.08 (0.70–1.69)	0.63 (0.41–0.98)	0.63 (0.41–0.96)
Living alone (%) (0=<40)								
1=40–50	1.04 (0.87–1.25)	1.14 (0.93–1.41)	1.17 (0.89–1.53)	1.14 (0.86–1.52)	0.74 (0.52–1.05)	0.82 (0.61–1.09)	1.18 (0.87–1.60)	1.07 (0.80–1.43)
1=>50	1.04 (0.74–1.46)	1.27 (0.86–1.88)	0.87 (0.51–1.48)	0.89 (0.50–1.57)	0.54 (0.29–1.03)	0.55 (0.32–0.94)	1.19 (0.70–2.03)	1.32 (0.81–2.17)
Number of inhabitants (0=2500–4999)								
1=5000–9999	1.02 (0.83–1.25)	0.98 (0.78–1.24)	0.97 (0.72–1.32)	1.00 (0.73–1.38)	1.07 (0.73–1.58)	1.05 (0.76–1.45)	1.08 (0.77–1.51)	1.11 (0.79–1.54)
1=10,000–600,000	1.18 (0.89–1.57)	1.14 (0.82–1.58)	0.99 (0.64–1.53)	1.11 (0.70–1.77)	1.23 (0.71–2.13)	1.22 (0.79–1.89)	1.01 (0.63–1.61)	1.10 (0.69–1.73)
Tax revenue (0=<2000)								
1=2000–3000	0.84 (0.69–1.01)	0.83 (0.67–1.03)	0.84 (0.63–1.12)	0.89 (0.66–1.21)	1.37 (0.95–1.98)	1.18 (0.87–1.60)	0.99 (0.71–1.38)	0.97 (0.70–1.34)
1=>3000	1.19 (0.67–2.09)	1.07 (0.55–2.05)	0.60 (0.24–1.46)	0.85 (0.33–2.21)	0.69 (0.24–2.00)	0.64 (0.28–1.68)	1.82 (0.81–4.11)	1.28 (0.60–2.73)
Expenditure (0=<2400)								
1=>2400	0.91 (0.77–1.09)	0.94 (0.77–1.16)	0.93 (0.71–1.23)	1.00 (0.75–1.34)	1.04 (0.83–1.31)	1.01 (0.76–1.35)	1.24 (0.91–1.67)	1.29 (0.97–1.72)
Annual contribution margin (0=<0)								
1=>0	0.89 (0.72–0.11)	1.03 (0.78–1.36)	1.03 (0.71–1.49)	1.03 (0.70–1.52)	0.71 (0.45–1.11)	0.76 (0.53–1.11)	1.38 (0.92–2.06)	1.44 (0.97–2.14)
Urbanity (0=urban)								
1=semi-urban	1.06 (0.83–1.37)	1.15 (0.86–1.53)	1.39 (0.94–2.05)	1.34 (0.89–2.03)	0.78 (0.49–1.25)	0.86 (0.58–1.28)	1.33 (0.90–1.96)	1.54 (1.07–2.21)
1=rural	0.88 (0.64–1.22)	0.86 (0.59–1.25)	0.96 (0.56–1.58)	1.05 (0.62–1.79)	1.36 (0.74–2.50)	1.29 (0.77–2.16)	1.36 (0.80–2.29)	1.51 (0.91–2.51)
Support for informal care (%)	1.08 (1.01–1.16)	1.09 (1.01–1.18)	1.03 (0.93–1.15)	1.02 (0.91–1.15)	0.94 (0.82–1.08)	0.98 (0.87–1.10)	0.98 (0.87–1.10)	0.99 (0.89–1.11)
Hospital district level (III)								
University hospital in the hospital district (0=no)								
1=yes	0.86 (0.65–1.13)	0.79 (0.56–1.12)	0.22 (0.14–0.36)	0.23 (0.13–0.39)	0.69 (0.35–1.36)	0.51 (0.29–0.90)	35.23 (13.30–93–33)	28.39 (12.23–65.56)

Values are rate ratios from the final models (95% confidence intervals).

and residential care facilities are widely available care services in all municipalities, and in small municipalities health centres are the only local facilities offering health care.

The greatest variation between municipalities was observed for transitions involving general hospital; transitions between a general hospital and own home, between a general hospital and a health centre, and between a general hospital and residential care. These findings suggest that differences between municipalities within the same hospital district differ in the frequency of admissions of older people to specialised secondary care, either from own home or from some other care facility. The inclusion of explanatory factors in the models, even access to a university hospital, did not decrease the high unexplained variances. This is probably due in part to municipal differences in care organisation [12] and practices; the underlying factors are often historical and based on local policies rather than rigorous analysis of needs. The capability to provide advanced outpatient or inpatient care may vary between general hospitals. The adequacy of home care and rehabilitation may also affect discharge practices and the decision whether people are discharged to their own homes or to another care facility. Local diagnostic practices [22] and factors related to physicians' decision making [23] in different areas have been found to have an effect on care use, and it is possible that these factors vary between municipalities, thereby influencing the frequency of admissions and discharge practices.

Finnish municipalities can be roughly divided into two categories, i.e. urban areas with a growing working age population, and more rural areas with fewer people of working age and with stagnating tax revenue [12]. An older age structure was reflected in most types of transitions: it increased the number of almost all types of transitions, but decreased transitions involving university hospitals located in five of the most urban municipalities. In Finland, official policy has preferred home care to institutionalisation in old age, at least during the past decade [24], and has recommended the reallocation of resources from institutional care to outpatient care [11]. It is possible, although it cannot be confirmed here, that limited health and social service supply in municipalities with an older age structure may put pressure on hospitals to discharge people too early which may lead to readmissions. As for the other municipality level factors, a positive annual contribution margin suggests a better financial situation in the municipality, which may serve to increase inpatient admissions when compared to municipalities in less favourable financial situations, because inpatient care is considered more expensive than outpatient care. Respite care,

offered as an aid to informal caregivers, can partly explain the higher number of care transitions in municipalities with more people receiving support for informal care.

Earlier research has shown that the use of care services varies between municipalities in Finland, but the underlying reasons for this are not clear [25,26]. In some parts of Finland the geographical distances to the nearest general or university hospital are long, complicating both transfers to inpatient care and use of outpatient care. However, the differences seen between municipalities in the same hospital district, especially in moves to a general hospital, imply that not all of the variation is due to distances, but also to differences in care practices between municipalities. We are not in position to investigate the underlying factors in this study, but it is possible that the findings reflect municipal differences, and even inequalities, in access to general hospital or to tertiary care provided by university hospitals. Equal access to care is presented as one of the major motivations behind the Finnish government's current plans for municipal merges. Equity in care, however, is a complex question and cannot be determined without detailed analysis. Basically, differences in care practices do not necessarily indicate unequal delivery of care.

To the best of our knowledge, this is the first study to investigate the effect of municipality factors on transitions between care settings in the last years of life. Earlier research concerning the regional differences from the USA has reported rural-urban differences in hospitalisation [27,28], discharges [27], and overall visits to care [29]. However, the comparisons with earlier research are difficult because of differences in data. The register data used here provide exhaustive and reliable information on transitions in care in the whole of Finland. The personal identity code used in Finnish registers remains unchanged throughout a person's life, and therefore we were able to monitor personal data and individual use of care services from different registers. The accuracy, coverage, and reliability of the data in Finnish care registers are considered good [3,30]. Further research could concentrate on differences in care transitions in imminent death and how the care transitions in different care services vary between municipalities in the last months of life, when care transitions are most frequent [5].

There are also limitations in this study. First, the inclusion in the models of the municipality factors available decreased variation at the municipal level only slightly, if at all, which suggests that there are significant underlying municipality level factors that are not included in our data. Second, our data originates from the past decade. Since the years under study, the priority focus in long-term care has shifted

from nursing home care to housing services, and the mean length of stay in hospital care has decreased. However, the basic structures of health and social services have remained unchanged. It is plausible to believe that the municipal patterns found in this study still exist. Third, research on multilevel negative binomial regression models is fairly recent [18], and in our negative binomial regression analysis including three levels and conducted using MLwiN, the intraclass correlation and random part variance at the individual level cannot be estimated. Due to the lack of information about individual variance, it is impossible to say which have the most significant effect on the variation in the number of care transitions, individual characteristics, or area level characteristics. Yet the statistical significance of almost all individual level explanatory variables suggests that individual factors do indeed have a notable effect on care transitions.

At the end of life, people use more care services than in earlier phases of life and also have more care transitions. Transitions are indeed often an adequate response to care needs, but they may also reflect the difficulties that long-term care units have in meeting the care needs of old people. The number of care transitions in the last 2 years of life among people aged 70+ varies considerably, but findings of this study showed that the municipality of residence had only a minor impact on the total number of care transitions. It did, however, have an impact on certain specific types of transitions. In this study, it remains open whether local care practices or service supply, or municipal factors such as annual contribution margin or age structure, increase the number of unnecessary transitions, or whether problems in service supply in an area can reduce admissions to specialised care even if justified by individual need.

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Conflicts of interest

None declared.

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Original Study

Burdensome Transitions at the End of Life Among Long-Term Care Residents With Dementia



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A B S T R A C T

Keywords:

Care transition
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end of life
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Objectives: The purpose of the study was to examine the frequency of burdensome care transitions at the end of life, the difference between different types of residential care facilities, and the changes occurring between 2002 and 2008.

Design: A nationwide, register-based retrospective study.

Setting: Residential care facilities offering long-term care, including traditional nursing homes, sheltered housing with 24-hour assistance, and long-term care facilities specialized in care for people with dementia.

Study group: All people in Finland who died at the age of 70 or older, had dementia, and were in residential care during their last months of life.

Main outcome measures: Three types of potentially burdensome care transition: (1) any transition to another care facility in the last 3 days of life; (2) a lack of continuity with respect to a residential care facility before and after hospitalization in the last 90 days of life; (3) multiple hospitalizations (more than 2) in the last 90 days of life. The 3 types were studied separately and as a whole.

Results: One-tenth (9.5%) had burdensome care transitions. Multiple hospitalizations in the last 90 days were the most frequent, followed by any transitions in the last 3 days of life. The frequency varied between residents who lived in different baseline care facilities being higher in sheltered housing and long-term specialist care for people with dementia than in traditional nursing homes. During the study years, the number of transitions fluctuated but showed a slight decrease since 2005.

Conclusions: The ongoing change in long-term care from institutional care to housing services causes major challenges to the continuity of end-of-life care. To guarantee good quality during the last days of life for people with dementia, the underlying reasons behind transitions at the end of life should be investigated more thoroughly.

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The proportion of people with dementia will increase rapidly during the coming decades,¹ and end-of-life practices in dementia care concern a significant number of old people and care professionals worldwide. Experts agree that in end-of-life care, the emphasis should be on comfort,² pain and other symptom control,³ continuity of care,⁴ and a familiar living environment⁵ with familiar people.^{4,6,7} However, remaining in a familiar care environment is not

always possible, and end-of-life care transitions, particularly transfers from long-term care facilities to hospitals, are common in this patient group.⁸ These transitions can result in undesirable consequences, such as mental confusion, and can impair the quality of life during the final weeks.^{9,10} Gozalo et al¹¹ introduced the concept of “burdensome transition” to describe potentially harmful transitions between care settings at the end of life among cognitively impaired people in long-term care. According to their definition, transitions are considered burdensome if (1) they take place during the last 3 days of life; (2) there is a lack of continuity of nursing home facilities before and after hospitalization during the last 90 days of life, for example, if the person moves from long-term care facility A to a hospital, and then to long-term care facility B; or (3) there are multiple hospitalizations (more than 2 for any reason, or more than 1 for pneumonia, urinary tract infection, dehydration, or sepsis) during the last 90 days of life.

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These definitions were based on narrative research, and on the expert opinions of geriatricians and palliative medicine specialists.^{11,12}

In Finland, local municipalities are responsible for organizing care for their residents. The municipalities can either provide services themselves, or purchase them from non-governmental organizations (NGOs), the for-profit private sector, or from other municipalities. Long-term care for old people is mainly organized in residential care facilities provided by the social care sector.¹³ Residential care includes traditional institutional care in nursing homes, and services for older people in sheltered housing with 24-hour assistance,¹⁴ which is a fairly new and rapidly growing service. These 2 types of residential care differ by owner, sector, and funding. Most nursing homes are publicly owned; the fees to users are based on residents' income, and cover all of the care services, food, and medication provided in the nursing home.¹³ More than half of sheltered housing with 24-hour assistance is owned by the private sector or NGOs. They are considered more homelike than nursing homes. The funding system is not as closely regulated as it is in nursing homes, and the services covered by the fees vary. In addition to rent for housing, most of the services that are included in nursing home care have to be paid for out of the residents' own pockets in sheltered housing, although partly reimbursed by the Social Insurance. Since the 1990s, political decisions have been taken to diminish the role of institutional care and emphasize housing services or services provided at home.¹⁵ Similar development has occurred in other countries also.^{16,17} In addition, official guidelines have recommended that, instead of people being transferred between care settings, adequate services should be brought to people, if possible.¹⁸ People suffering from memory disorders constitute most residents in all types of long-term care, and their proportion has increased during the past decade.¹⁹ It is not known how changes in the organization of long-term care influence the continuity and transitions of care at the end of life in this group.

Previously, we have found that during 2002–2003 more than a third of older people in Finland with dementia who were in residential care 2 years before their death experienced care transitions during their last 3 months of life.²⁰ In the present study, we applied the concept of “burdensome transition” to investigate the care transitions of residential care residents aged 70 and older with dementia. The purpose was to examine the frequency of burdensome care transitions at the end of life in different types of residential care between 2002 and 2008.

Methods

This study is based on extensive nationwide registry data, which include the use of health and social services in all care facilities in the last 2 years of life in Finland. Data were collected from the Care Register for Healthcare and the Care Register for Social Care (the National Institute for Health and Welfare). The Causes of Death Register (Statistics Finland) includes the date of death and all causes of death as stated on each individual's death certificate. Data were linked by using the individuals' Personal Identity Codes, which remain unchanged throughout people's lives. Permission to access the registers was obtained from each register controller.

The dementia group included all those for whom any cause of death (immediate, underlying, intermediate, or contributing) had any of the following *International Classification of Diseases, 10th Revision* (ICD-10) codes: F00 (dementia in Alzheimer disease), F01 (vascular dementia), F02 (dementia in other diseases), F03 (unspecified dementia) or G30 (Alzheimer disease). A person was classified as a resident in long-term residential care if he or she was in care both 6 months (183 days) and 3 months (91 days) before death, and stayed there for at least 90 days during the last 6 months of life. Other major diagnoses, drawn from the Causes of Death Register and the Care

Registers for Healthcare and Social Care, were cancer (C00–C97), psychosis, depressive symptoms or other mental health disorders (F04–F99), Parkinson disease or other neurological diseases (G00–G99 excluding G30), chronic asthma and chronic obstructive pulmonary disease or other respiratory diseases (J00–J99), arthritis or osteoarthritis (M05–M06, M15–M19), hip fracture (S72), stroke (I60–I69), ischemic heart diseases excluding rheumatic and alcoholic heart diseases (I20–I25, I30–I425, I427–I52), and other diseases of circulatory system (I00–I15, I26–I28, I70–I99).

A care transition was defined as a change of care facility. Visits to outpatient care or moves between inpatient wards within the same care facility were not included in care transitions. Burdensome care transitions were followed up for each day of the last 3 months. We identified 3 types of potentially burdensome end-of-life care transitions (based on Gozalo et al¹¹): Any transition to another care facility during the last 3 days of life (type 1), a lack of continuity in long-term care facilities before and after hospitalization during the last 90 days of life (type 2), and multiple hospitalizations (more than 2) during the last 90 days of life (type 3).

The residential care facilities offering long-term care included nursing homes and sheltered housing with 24-hour assistance (subsequently to be referred to as sheltered housing). A new category, specialist long-term care for people with dementia (subsequently to be referred to as specialist LTC) was available in the care registers after 2006, and was analyzed here as a separate long-term care facility for 2006 to 2008. Specialist LTC includes nursing homes and sheltered housing that, according to their own notification to the register controller, provide special assistance for dementia care. The hospitals to which people were moved were university hospitals and general hospitals that offered specialized care, and health center inpatient wards. Health center inpatient wards are municipal primary-level hospitals run by doctors specialized in general or family medicine. The medical care they offer varies among the municipalities, ranging from coronary recanalization and other minor operations in some rural health centers to basic conservative care and rehabilitation in others.

The frequency (%) of burdensome transitions and their association with different background factors, age at death, gender, the year of death, and the residential care facility at baseline, were analyzed. The care facility at baseline was the facility where an individual was located 91 days before death, and potentially burdensome care transitions were taken into account for 90 days before death. Binary logistic regression models were used. The dichotomized outcome variables were any burdensome transitions and the 3 types of burdensome transition, analyzed separately. Independent variables were age, gender, year of death (2002–2008), and the care facility at baseline, categorized as (1) nursing home, (2) sheltered housing with 24-hour assistance, or (3) specialist LTC for people with dementia. To remove the effect of other conditions on the frequency of burdensome transitions, analyses were adjusted for other major diagnoses classified with ICD-10 codes.

Results

We identified 18,912 residential care residents who died between 2002 and 2008 and who had a dementia diagnosis in the Causes of Death Register. This covers about a third (29.5%) of all dementia cases in the Care Register for Healthcare, the Care Register for Social Care, and the Causes of Death Register. Those decedents not included in the study group did not have dementia registered as a cause of death, or were not in residential care. The average age at death was 87 years and 76% were women. The median number of days in care in the final 6 months was 183 (mean 172); 54.5% of the study group stayed in care for the whole period of the last 6 months. The proportion of

people who had any care transitions during the last 3 months of life, whether classified as burdensome or not, was 42.3% (median 2, average 2.3 in those who experienced transitions).

Between 2002 and 2008 the proportion of people with dementia in residential care increased (Table 1). The distribution of people between the baseline care facilities changed: between 2002 and 2008 it decreased in nursing homes and increased in sheltered housing, and between 2006 and 2008 it increased in specialist LTC (Table 1). The average age, the average number of diagnoses, and the proportion of women did not vary markedly between the baseline care facilities (Table 1) or between the study years (not shown in the tables).

Frequency of Burdensome Care Transitions

During the last 3 months of life, 9.5% ($n = 1798$) of the study group experienced potentially burdensome care transitions (Table 2). Only 0.7% (129 people) experienced 2 different types, and 2 individuals experienced all 3 types of burdensome transition (not shown in the tables). Men, in particular those who died before their 90th birthday, were more likely to have experienced burdensome transitions than women and those who died at the age of 90 or older (Table 2).

Of the 3 types of burdensome transition, the most frequent was multiple hospitalizations (type 3 transition) in the last 90 days of life: altogether 5.5% had such transitions. Almost everyone (97.5%) who had these transitions moved at least once to a health center, 66.2% moved to a general hospital, and 26.4% moved to a university hospital. Altogether 4.4% experienced at least 1 transition in the last 3 days of life (type 1 transition). Almost two-thirds (60.6%) of them moved at least once to a health center, 21.3% to a general hospital, and 8.0% to a university hospital. There were also moves from hospitals to residential care facilities; 8.6% to a nursing home and 3.1% to sheltered housing. In the last 3 days, 6.5% had a transition home. Only 59

people (0.3%) experienced a lack of continuity in residential care facilities during the last 90 days of life (type 2 transition).

Differences in Burdensome Transitions Between the Baseline Care Facilities

Burdensome transitions were experienced more often in sheltered housing (18.3% of people in sheltered housing had at least 1 such transition) and in specialist LTC (14.0%) than in nursing homes (6.0%) (Table 2). When age, gender, year of death, and other diagnoses were taken into account, the likelihood of having at least 1 type of burdensome transition was still higher among people in sheltered housing (odds ratio [OR] 3.14, 95% confidence interval [CI] 2.82–3.49) and specialist LTC (OR 2.61, 95% CI 2.12–3.20) than for those in nursing homes (Table 3). Analyzed separately, all 3 types of burdensome transition followed the same pattern.

Changes Between 2002 and 2008

The proportion of people experiencing burdensome care transitions fluctuated during the study period. It was lowest in 2002–2003 and highest in 2005; after that, the proportion decreased slightly (Table 2). In all 3 baseline care facilities, the proportion of people experiencing burdensome care transitions decreased during the study years: in nursing homes from 6.4% to 5.3%, in sheltered housing from 19.6% to 17.6%, and in specialist LTC from 14.4% to 13.2% (not shown in the tables). In binary logistic regression analyses there were no significant differences in the likelihood of experiencing at least 1 burdensome transition, when the year 2002 was used as a reference (Table 3). In additional analyses, using 2005 as a reference, the likelihood of experiencing at least 1 type of burdensome transition was significantly lower in 2008 (OR 0.80, 95% CI 0.66–0.96, analysis not shown).

Discussion

This study investigated the frequency of potentially burdensome care transitions at the end of life for people who had dementia as the immediate, underlying, intermediate, or contributing cause of death and who lived in long-term residential care, and it examined the association of these transitions with the baseline care facility and the years of death. In all, 9.5% had potentially burdensome care transitions. Most frequent among those were multiple hospitalizations in the last 3 months, followed by any transitions in the last 3 days of life. The frequency varied considerably between different baseline facilities: in sheltered housing and specialist LTC, burdensome transitions were more frequent than in traditional nursing homes. This was true even when age, gender, and other diagnoses were taken into account. During the study years, the number of burdensome transitions decreased in all 3 types of facilities, but simultaneously the use of sheltered housing where the transitions were most common, increased, and the use of nursing homes with fewer transitions decreased. The likelihood of experiencing at least 1 type of burdensome transition fluctuated, and when 2002 was used as a reference, there were no significant differences between the years. Yet there was a slight decrease after 2005, and in 2008, the likelihood of burdensome transitions was significantly lower. Analyses with longer study period are needed to reveal if there is a true decreasing trend in burdensome transitions. In addition, men and people who died at a younger age had burdensome transitions more frequently than women and those who died at an older age, which is consistent with earlier studies showing similar age and gender differences in experiencing any care transitions²¹ or hospitalizations²² among older people.

Table 1
Baseline Characteristics by Care Facility 90 Days Before Death

	All, $n = 18,912$	Nursing Home, $n = 13,159$	Sheltered Housing With 24-h Assistance, $n = 4720$	Long-Term Care for People With Dementia,* $n = 1033$
Age, y, mean	87.2	87.4	86.8	86.6
No. of diagnoses, mean	2.7	2.6	2.9	2.7
Gender, %				
Men	24.5	24.4	24.9	24.1
Women	75.5	75.6	75.1	75.9
Age at death, y, %				
70–79	12.4	12.3	12.7	13.0
80–89	48.9	47.4	52.1	52.9
90+	38.7	40.3	35.2	34.1
Year of death, %				
2002	13.5	15.8	10.3	-
2003	13.3	14.6	12.5	-
2004	13.0	13.6	14.0	-
2005	13.2	13.1	16.3	-
2006	14.4	14.0	14.2	20.8
2007	15.6	14.1	15.1	36.8
2008	17.0	14.8	17.6	42.4
Place of death, %				
Nursing home	54.9	78.0	2.1	1.7
Sheltered housing	10.4	0.1	40.9	0.4
Long-term care for people with dementia	2.6	0.1	0.1	47.4
Health center	26.9	18.1	47.9	42.8
General hospital	2.9	1.9	5.3	4.5
University hospital	0.8	0.6	1.4	1.0
At home	1.5	1.2	2.3	2.2

*Available from 2006 onward. Includes residents in nursing homes ($n = 217$) and sheltered housing with 24-hour assistance ($n = 816$) specialized in dementia care.

Table 2

Percentages (n) of People With the 3 Types of Burdensome Care Transitions by Baseline Characteristics and the Year of Death

Background factors (n)	People With At Least 1 Type of Burdensome Transition (n)	Type 1: Any Care Transitions in the Last 3 Days (n)	Type 2: Lack of Continuity in Long-Term Care Facility (n)	Type 3: Multiple Hospitalizations in the Last 90 Days (n)
All (18,912)	9.5 (1798)	4.4 (841)	0.3 (59)	5.5 (1031)
Age group				
70–79 (2349)	10.9 (255)	5.3 (125)	0.5 (12)	6.2 (145)
80–89 (9250)	11.1 (1028)	4.9 (455)	0.4 (36)	6.5 (604)
90+ (7313)	7.0 (515)	3.6 (261)	0.2 (11)	3.9 (282)
Gender				
Men (4630)	12.2 (565)	5.9 (271)	0.4 (18)	7.1 (329)
Women (14,282)	8.6 (1233)	4.0 (570)	0.3 (41)	4.9 (702)
Year of death				
2002 (2560)	8.9 (228)	4.1 (104)	0.4 (9)	5.3 (135)
2003 (2512)	8.8 (221)	4.5 (113)	0.1 (3)	4.6 (115)
2004 (2455)	9.1 (223)	4.0 (97)	0.2 (6)	5.4 (133)
2005 (2498)	10.7 (268)	5.2 (130)	0.3 (7)	5.9 (148)
2006 (2723)	9.5 (259)	4.2 (115)	0.3 (9)	5.7 (156)
2007 (2955)	9.9 (292)	4.7 (140)	0.3 (10)	5.7 (167)
2008 (3209)	9.6 (307)	4.4 (142)	0.5 (15)	5.5 (177)
Residential care facility at baseline				
Nursing home (13,159)	6.0 (790)	3.4 (449)	0.1 (8)	2.9 (380)
Sheltered housing (4720)	18.3 (863)	6.9 (327)	0.9 (41)	12.0 (568)
Long-term care for people with dementia* (1033)	14.0 (145)	6.3 (65)	1.0 (10)	8.0 (83)

*Available from 2006 onward. Includes residents in nursing homes (n = 217) and sheltered housing with 24-hour assistance (n = 816) specialized in dementia care.

To our knowledge, the criteria of burdensome care transition, introduced by Gozalo et al,¹¹ have been used only in 2 previous studies,^{11,23} both conducted in the United States. Our findings showed a lower frequency of burdensome transitions: in Gozalo et al,¹¹ 19% had burdensome transitions, and in Teno et al,²³ 16.5% had type 1 and 10.7% had type 3. All 3 studies included nationwide information on long-term residents with advanced dementia, and the care transitions were defined in an identical way. In our study, the study sample and the criteria of burdensome transition were similar, but not exactly identical to that of Gozalo et al.¹¹ Their criteria included being resident in a nursing home for 120 days before death, aged more than 66 years, requiring extensive assistance or total dependence with

activities of daily living, and having advanced cognitive impairment. In our data, every person had dementia as the cause of death (63.8% as the underlying cause, 0.3% as the immediate cause, and the rest as the contributing or intermediate cause), and all were in long-term care 6 months before death. Therefore, it is plausible to conclude that most of our cases had advanced dementia at the end of life. Because our data lacked the medical reasons for the transitions, our third criterion for burdensome transitions was not exactly identical to that used by Gozalo et al.¹¹ When compared with Teno et al,²³ whose third criterion was similar to ours, burdensome transitions were still less frequent in our study. In all, it is not likely that the difference in the frequency of burdensome transitions between the United States

Table 3

Associations of Burdensome Care Transitions (1 = yes, 0 = no) With Baseline Characteristics and the Year of Death

Background Factors	People With at Least 1 Type of Burdensome Transition	Type 1: Any Care Transitions in the Last 3 Days	Type 2: Lack of Continuity in Long-Term Care Facility	Type 3: Multiple Hospitalizations in the Last 90 Days
Age group				
70–79 (ref)				
80–89	1.00 (0.86–1.16)	0.87 (0.71–1.08)	0.76 (0.39–1.48)	1.05 (0.87–1.28)
90+	0.69 (0.59–0.82)	0.68 (0.54–0.85)	0.35 (0.15–0.82)	0.73 (0.58–0.90)
Gender				
Men (ref)				
Women	0.73 (0.65–0.82)	0.70 (0.60–0.82)	0.91 (0.51–1.62)	0.74 (0.64–0.85)
Year of death				
2002 (ref)				
2003	0.95 (0.76–1.16)	1.10 (0.83–1.45)	0.30 (0.08–1.12)	0.81 (0.62–1.05)
2004	0.94 (0.77–1.15)	0.93 (0.70–1.24)	0.58 (0.21–1.66)	0.93 (0.72–1.20)
2005	1.05 (0.86–1.27)	1.18 (0.91–1.55)	0.59 (0.22–1.60)	0.91 (0.71–1.17)
2006	0.89 (0.74–1.09)	0.92 (0.70–1.21)	0.67 (0.26–1.74)	0.88 (0.68–1.12)
2007	0.89 (0.73–1.08)	1.01 (0.78–1.33)	0.59 (0.23–1.52)	0.81 (0.63–1.04)
2008	0.84 (0.69–1.02)	0.94 (0.72–1.23)	0.78 (0.33–1.88)	0.77 (0.60–1.00)
Residential care facility at baseline				
Nursing home (ref)				
Sheltered housing	3.14 (2.82–3.49)	1.89 (1.62–2.19)	13.69 (6.37–29.44)	4.08 (3.56–4.69)
Long-term care for people with dementia*	2.61 (2.12–3.20)	1.84 (1.38–2.45)	15.31 (5.68–41.30)	3.04 (2.33–3.97)

Odds ratios (ORs) and 95% confidence intervals with binary logistic regression models. Statistically significant odds ratios are in bold.

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.

*Available from 2006 onward. Includes residents in nursing homes (n = 217) and sheltered housing with 24-hour assistance (n = 816) specialized in dementia care.

and Finland results from differences in study samples or indicators of burdensome transitions.

It is essential, however, to distinguish between hospitalization with medical indications and the burdensome care transitions. Previous research has shown that people with dementia receive less hospital care during the last years of life than those without dementia,²⁴ also when comorbidities are taken into account.^{25,26} This may imply that among people suffering from dementia, medical needs are not always met. However, the concept of burdensome transition refers to potentially avoidable and potentially harmful transition without sufficient medical indication. The importance of avoiding unnecessary care transitions has been highlighted in the Finnish national guidelines on care for older people.¹⁸ Most frequently burdensome transitions were made to health centers, which offer primary-level medical services. It is likely that traditional, publicly maintained nursing homes have a better capability than sheltered housing facilities to care for medical conditions, such as pneumonia, other infections, or symptoms that are common when death approaches, and which do not necessarily require transfer to hospital care.²⁷ In institutional nursing homes, unlike in sheltered housing in general, medical services are usually available and included in the service fee. Reasons for the transition also may be the residential care staff's insufficient knowledge of the illness trajectory of dementia²; previous studies imply that a better understanding among staff of the clinical course of dementia and its terminal phase could help to avoid unnecessary hospitalizations.^{2,28} It is striking, however, that even in specialist LTC the frequency of burdensome transitions was clearly higher than in traditional nursing homes. This result may suggest that a more regulated system is needed for those care facilities announcing themselves as specialized in dealing with dementia. In addition, a few studies suggest that questions of liability and “allowing the patient to die,” and in some cases financial factors, can also be motivators behind the end-of-life care transitions, as the care of a dying person is considered to be costly.⁶

A major strength of this study is the availability of comprehensive and reliable register data,^{29–31} which enabled the identification of all people in residential care with dementia as a cause of death, as well as their care transitions. Our goal was to focus on people with advanced dementia to whom the transitions are most burdensome, and to make the study groups as comparable as possible between the care facilities. Therefore, we included only those who had dementia as a cause of death, and we took the possible effect of other diagnoses into account in analyses. Our data included only permanent long-term care residents; everyone was in residential care 6 and 3 months before death, and most stayed in care the entire last 6 months. A weakness of our study is that the medical reasons for the transitions were not available. For the analysis of the impact of the change in organizing care, the follow-up time (from 2002 to 2008, and from 2006 to 2008 in specialist LTC) is relatively short. A longer study period is needed to reveal the possible changes over time in the frequency of burdensome transitions.

Conclusions

Our findings point out potential problems in the end-of-life care of persons suffering from dementia and indicate that further research is needed into the organization and practices regarding dementia care. In Finland, as in several other countries, care of older people is changing, and home care and housing services are being emphasized over institutional care. Simultaneously, the number of care providers is increasing, the role of private companies and NGOs is expanding, and the financial responsibility of the users themselves will be increased. Our research suggests that sheltered housing with 24-hour assistance may be less prepared for end-of-life care than traditional

nursing homes. Further research should focus on both organizational and financial aspects of this care transformation. During their final stages of life, people suffering from dementia constitute one of the most vulnerable groups of people in care. Adequate care practices, including the avoidance of unnecessary transitions, are necessary to guarantee the best possible well-being at the end of life for this rapidly increasing group of older people.

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