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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

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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

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