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 4.2% (RR 1.042) more transitions than people without dementia (Table 2).

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% of those without dementia moved more.

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.

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

<table>
<thead>
<tr>
<th></th>
<th>Dementia</th>
<th>No dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Proportion (%) who had contacts</td>
<td>Median number of transitions (quartiles)</td>
</tr>
<tr>
<td>All (n = 70,363)</td>
<td>79.1</td>
<td>6 (3,11)</td>
</tr>
<tr>
<td>Men</td>
<td>87.0</td>
<td>7 (4,13)</td>
</tr>
<tr>
<td>Women</td>
<td>75.6</td>
<td>6 (3,10)</td>
</tr>
<tr>
<td>At home at baseline (n = 51,667)</td>
<td>99.0</td>
<td>8 (4,13)</td>
</tr>
<tr>
<td>Men</td>
<td>99.1</td>
<td>9 (5.15)</td>
</tr>
<tr>
<td>Women</td>
<td>98.9</td>
<td>7 (4.12)</td>
</tr>
<tr>
<td>In residential care facility at baseline (n = 12,096)</td>
<td>70.4</td>
<td>4 (2.7)</td>
</tr>
<tr>
<td>Men</td>
<td>75.3</td>
<td>4 (2.8)</td>
</tr>
<tr>
<td>Women</td>
<td>68.9</td>
<td>4 (2.7)</td>
</tr>
</tbody>
</table>

*In those who underwent care transitions.

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

<table>
<thead>
<tr>
<th>Number of transitions</th>
<th>All (n = 70,366)</th>
<th>At home at baseline (n = 51,677)</th>
<th>In residential care facility at baseline</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>RR</td>
<td>95%</td>
<td>RR</td>
</tr>
<tr>
<td>Dementia (reference = no dementia)</td>
<td>1.042</td>
<td>1.019–1.065</td>
<td>1.319</td>
</tr>
<tr>
<td>Age</td>
<td>0.992</td>
<td>0.991–0.993</td>
<td>1.003</td>
</tr>
<tr>
<td>Gender (reference = male)</td>
<td>0.923</td>
<td>0.907–0.940</td>
<td>1.007</td>
</tr>
</tbody>
</table>

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.
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 medial 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.

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**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.

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**Conflicts of interest**

None declared.

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coauthors had full access to all data in the study, and have the final responsibility for the decision to submit this manuscript for publication.

References


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