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Factors influencing transition to care homes for people with dementia in Northern Ireland

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Abstract

Introduction: The increasing number of people with dementia (PwD) is a significant health and financial challenge for countries. PwD often transition to a care home. This study explored factors predicting transition to care homes for PwD and the place and causes of death.

Methods: Data about dementia medication, care home transitions, demographic characteristics, deaths, and hospital admissions were extracted from national databases from 2010 to 2016.

Results: PwD (n = 25,418) were identified through prescriptions of dementia medication, from which 11,930 transitioned to care homes. A logistic regression showed that increased age, female sex, living in less deprived and urban areas, and hospital admissions predicted this transition. PwD who transition to care homes are more likely to die there. The most common cause of death was dementia.

Discussion: Certain demographic characteristics are significant predictors for care home transitions and they should be considered in the development of early community-based care services to delay transitions. In the last decades, dementia has been reported more frequently in death certificates.

Keywords:
care homes, death, dementia, nursing homes, transition

1 | BACKGROUND

The increasing number of people with dementia (PwD) is a major health and financial challenge for the UK. Approximately 850,000 people live with dementia in the UK and this number is expected to rise to 1 million by 2025 and 2 million by 2051. It is estimated that dementia care costs £26 billion per year in the UK and this is likely to increase due to the increasing number of PwD. The vast majority (70%) of people living in care homes in the UK have dementia or severe memory impairment. In Northern Ireland, the number of PwD was approximately 20,000 in 2015, a number which could potentially increase to 60,000 by 2051 because of the rapidly aging population. Almost half of these people live in care homes. The estimated cost for supported accommodation, such as care homes, for PwD in Northern Ireland in 2011 was £192 million with the overall estimated cost for dementia care being £476 million. A better understanding of the risk factors for transitioning to a care home in dementia may contribute to the improvement of early community-based services to delay institutionalization and decrease the financial costs for countries and family members by improving the independence of PwD and supporting caregivers. This is in line with policies aiming to maintain PwD in the community, delay the time of transitioning to a care home, and consider caregivers’ needs.
Past research has shown that after a hospital admission, PwD are more likely to transition to a care home instead of returning home.8 Other studies have explored factors that predict whether PwD will transition to a care home after their diagnosis.4,6,9–17 Older age4,6,9–15 and female sex9,10,13,14,16,17 predicted transitioning to a care home in some studies but not in others. Married PwD with spousal caregivers have been shown to be less likely to transition to a care home compared people who are single, divorced, or widowed.11–13,15 However, other evidence suggests that people who are widowed are less likely to transition to a care home6 or that PwD with spousal caregivers are just as likely to transition to a care home.6 This is in line with the finding that the relationship between the person with dementia and their caregiver does not predict transition to a care home.6 Caregivers with higher family income and socioeconomic status are more likely to place their care receiver in a care home.9,11 From previous studies, the duration of providing care to a person with dementia and the severity of cognitive and functional impairment did not affect the time to transitioning to a care home for PwD.10,15 However, little is known about the duration of living with dementia and the likelihood of transitioning to a care home. Other factors, such as depression, self-reported health, comorbidities, home-care services, and day-care services are not predictors for transition to care homes in most studies.18

In the UK, the majority of deaths in PwD occur in nursing homes or in hospitals.19,20 A Marie Curie and Alzheimer’s Society report published in 2015 showed 60% of deaths for PwD in Northern Ireland in 2013 occurred in care homes, 29% in hospitals, and 10% in the person’s own home.2 The most common primary and secondary causes of death were pneumonia, vascular diseases, and Alzheimer’s disease (AD) or dementia.20

The present study explored factors that may predict the rates and nature of transitioning to a long-term care setting for PwD in Northern Ireland, including their demographic characteristics, hospital admissions, and the duration of living with dementia. Long-term care settings, referred to as care homes in this article, included residential care and nursing homes; nursing care is provided in nursing homes while healthcare assistants provide care in residential homes. Clients in residential homes are less dependent than those in nursing homes. Another aim was to explore sex differences in the time taken to transition to a care home following a dementia diagnosis. Finally, this study investigated the causes and place of death for PwD who transitioned to care homes.

2 | METHODS

2.1 | Population and methods

All data from January 2010 to December 2016 were linked through the Honest Broker Service in the Business Services Organisation (BSO). Ethical approval was gained from the Honest Broker Service's committee prior to data access.

The Enhanced Prescribing Database (EPD) contains 80% to 90% of medication data that are prescribed by general practitioners and dispensed by a pharmacist in Northern Ireland.21 Within the EPD, each medication is categorized according to the section of the British National Formulary (BNF) to which it belongs. All dementia medication is grouped in Section 4.11 of the BNF. Using data extracted from the EPD, the first date that a dementia medication was prescribed was used as a proxy for the dementia diagnosis. The time from the dementia diagnosis to a transition to a care home was calculated by the time of the first dispense of dementia medication to the time of the first transition. For PwD who did not transition to a care home, this variable was calculated by the first medication dispense to the time of death or the end of the database (December 2016).

Demographic data, including people’s age, sex, marital status, and hospital admissions, were linked from the patient administration system, which holds data from hospitalizations, to the Honest Broker service. People’s age was provided at the beginning of the database (January 1, 2010). Data for hospital admissions were provided for all...
TABLE 1  Demographics and predictors for transition to care homes

| Demographics and predictors                  | All PwD (N = 25,418) | People in own homes (N = 13,488) | People in care homes (N = 11,930) | Odds ratio for transition to care homes | 95% confidence limits | P      |
|---------------------------------------------|-----------------------|----------------------------------|----------------------------------|----------------------------------------|-----------------------|--------|
| Age (mean [SD])                             | 77.31 (8.33)          | 75.02 (8.23)                     | 79.90 (7.67)                     | 1.09                                   | 1.08–1.09             | <0.001 |
| Sex                                         |                       |                                  |                                  |                                        |                       |        |
| Males                                       | 8881                  | 5201                             | 3680                             |                                        |                       |        |
| Females                                     | 16,537                | 8287                             | 8250                             | 1.17                                   | 1.11–1.24             | <.001  |
| Number of hospitalizations (mean [SD])      | 4.63 (14.79)          | 4.87 (18.31)                     | 4.35 (9.33)                      | 0.996                                  | 0.99–1.00             | .029   |
| Maximum days in hospital (mean [SD])        | 18.05 (26.01)         | 15.21 (23.57)                    | 21.26 (28.18)                    | 1.01                                   | 1.01–1.01             | <.001  |
| Time to transition (days; mean [SD])        | 945.67 (742.65)       | 839.06 (712.62)                  | 1,088.71 (757.99)                | 1.00                                   | 1.00–1.01             | <.001  |
| Deprivation                                 | 5.68 (2.93)           | 5.51 (2.91)                      | 5.87 (2.95)                      | 1.04                                   | 1.03–1.05             | <.001  |
| Living area                                 |                       |                                  |                                  |                                        |                       |        |
| Urban area                                  | 17,560                | 8717                             | 8843                             |                                        |                       |        |
| Rural area                                  | 7131                  | 4379                             | 2752                             | 0.64                                   | 0.60-0.68             | <.001  |
| Unknown                                     | 727                   | 392                              | 335                              |                                        |                       |        |
| Marital status                              |                       |                                  |                                  |                                        |                       |        |
| Married                                     | 8256                  | 4367                             | 3889                             |                                        |                       |        |
| Single                                      | 1633                  | 882                              | 751                              | 0.97                                   | 0.86–1.09             | .611   |
| Divorced/separated                          | 504                   | 255                              | 249                              | 1.08                                   | 0.89–1.32             | .440   |
| Widowed                                     | 6052                  | 3267                             | 2785                             | 0.94                                   | 0.87–1.01             | .074   |
| Unknown                                     | 8973                  | 4717                             | 4256                             |                                        |                       |        |

*Time to transition refers to the time PwD were on dementia medication before transitioning to a care home. For PwD who did not transition to a care home, this variable was calculated from the first dementia medication to the time of death or the end of the dataset.

Abbreviations: PwD, people with dementia; SD, standard deviation.

7 years in the dataset and included the date of each admission and the number of days (if any) each person stayed in the hospital.

The area of living (urban or rural) was provided for January 2010 and was extracted from the Statistical Classification and Delineation of Settlements of the Northern Ireland Statistics and Research Agency. Data for deprivation were provided for January 2010 and extracted from the Northern Ireland Multiple Deprivation Measure, with values closer to 10 meaning less deprived areas, and values closer to 1 representing more deprived areas.

Whether a person transitioned to a care home or not was extracted from BSO data. General practitioners report visits to people in care homes quarterly to BSO to claim their payment. Therefore, data about transitions in care homes were provided in quarters of the years in the dataset. Transitions to care homes were also identified from death certificates from the General Register Office for people who were deceased. Other data extracted from death certificates included the date and place of death, and the primary and secondary causes of death recorded with codes from the International Classification of Diseases and Related Health Problems (Version 10). The place of death was grouped in three categories: hospital; hospice or nursing/care home; and all other places, which mostly included people’s home address (93%). The demographic characteristics of the identified PwD (n = 25,418) are presented in Table 1.

2.2  | Statistical analysis

Descriptive statistics were conducted to calculate means, standard deviations, and sums of raw numbers for demographic characteristics and hospital admissions. A binomial logistic regression was conducted to identify which demographic factors predicted whether PwD would transition to a care home at least once. Independent samples t-tests were conducted to explore: (1) transitions to care homes from hospitals, (2) sex differences on the time taken from the dementia diagnosis to the time of transitioning to care home, and (3) differences in the age of death for people who transitioned to care homes compared to PwD who had never been to a care home. Chi-square tests were conducted to investigate associations between transition to care homes, and the most common primary and secondary causes of death and the place of death. A significance level of <0.05 was assumed for all statistical analyses.

3  | RESULTS

In total, there were 25,418 PwD in the final dataset. The majority were females (n = 16,537), married (n = 8256), and living in urban areas (n = 17,560; Table 1).
On logistic regression analysis people were more likely to transition to a care home if they were female (odds ratio [OR] 1.17, 95% confidence interval [CI] = 1.11–1.24, P < .001), older (OR 1.10, 95% CI = 1.08–1.10, P < .001), had fewer hospital admissions (OR 0.996, 95% CI = 0.99–1.00, P = .029), with longer hospital stay (in days; OR 1.01, 95% CI = 1.01–1.01, P < .001), if they lived in less deprived areas (OR 1.04, 95% CI = 1.03–1.05, P < .001), and lived in urban areas instead of rural areas (OR 0.64, 95% CI = 0.60–0.68, P < .001; Table 1).

PwD were equally likely to transition to a care home regardless of the time they received dementia medication and were diagnosed with dementia (OR 1.00, 95% CI = 1.00–1.01, P < .001).

The majority of people transitioned to care homes once (n = 1,162,572, 97.44%) while transitioning to a care home twice (n = 294, 2.46%) or three times was less frequent (n = 11, 0.09%). From all 22,079 PwD who were admitted to a hospital, 20,368 people (92.25%) returned home, and 1,711 people (7.75%) transitioned to a care home after leaving the hospital. From all 11,930 PwD in care homes, 1,711 (14.34%) were transferred to the care home from the hospital and 10,219 (85.66%) were transferred to a care home from their own home. An independent samples t-test showed that people who transitioned to a care home after the hospital stayed in the hospital for significantly more days (mean = 29.46 days, standard deviation [SD] = 30.84) than people who returned home (mean = 17.23 days, SD = 25.43; t[25,416] = -18.919, P < .001).

Following a dementia diagnosis, males (n = 3,680) who transitioned to a care home had stayed longer in their own residency (mean = 1.48 years, SD = 2.28) before this transition compared to females (n = 8,250; mean = 1.26 years, SD = 1.21; t[11,928] = 4.860, P < .001).

From all PwD, 12,129 deaths were recorded by the end of 2016 with the majority (n = 7,873) corresponding to people who had transitioned to a care home at least once compared to people who lived in their own home (n = 4,256). The mean age of death for all PwD was 84.66 years (SD = 7.34); however, people who transitioned to a care home lived longer (85.38 years, SD = 7.12) compared to people who always lived in their own home (82.67 years, SD = 7.42; t[12118] = -19.698, P < .001).

The most common primary and secondary causes of death were similar for people living in their own home and people in care homes, with dementia being the most commonly recorded primary cause of death for people who had transitioned to a care home at least once (21.10%) and for people who had never transitioned to a care home (21.62%). Pneumonia was the most commonly recorded secondary cause of death (31.74% and 30.03%, respectively, Table 2).

Chi-square tests revealed that people who transitioned to care homes were significantly less likely to die from acute myocardial infarction, stroke, and Parkinson’s disease as primary causes of death, and from congestive heart failure and chronic ischemic heart disease as secondary causes (Table 2).

A significant association was also found between transitioning to a care home and place of death (χ²[2] = 6,674.965, P < .001). The most common place of death for people who transitioned to a care home was the care home (n = 5,717) rather than a hospital (n = 2,039) or their own home (n = 77). People who never transitioned to a care home were more likely to die in the hospital (n = 2,493) than in their own home (n = 1,709).

### 4 DISCUSSION

This study aimed to explore, for the first time, factors that predict whether a person with dementia will transition to a care home in Northern Ireland following a dementia diagnosis. The results of the present study show that certain characteristics, including increasing age, female sex, living in less deprived areas, residence in an urban area, fewer hospital admissions, and longer hospital stays, significantly increase the likelihood of transitioning to a care home for PwD. Living in an urban area is a significant predictor for transitioning to a care home. Rural living is associated with fewer admissions to a care home, which could be because of different home care services in urban and rural areas. The finding that living in less deprived areas is associated with an increased risk of transitioning to a care home is supported by past research showing that higher family income and socioeconomic status...
result in this transition sooner.9,11 Family caregivers with greater financial sources appear to have more long-term options, including private nursing homes.9 These findings suggest that caregivers’ characteristics, including their socioeconomic status, are more important in the decision to transition PwD to a care home instead of the characteristics of the care receivers, such as the duration of being diagnosed with dementia or the severity of cognitive and physical impairment.10,15

In this study females were more likely to transition to a care home compared to males; this may be due to their poorer health or their increased life expectancy22 and is supported by the fact those in care homes were also significantly older than those living at home. Moreover, females transitioned to care homes earlier than males following a dementia diagnosis. A previous study showed that transition to care homes for females is associated with less health impairment and disabilities than for males; however, the decision of caregivers for this transition differs for females and males.23 For example, females are more likely to receive care from their children, while males are more likely to receive care from their spouse. Furthermore, males are more likely to transition to a care home if they live alone compared to males who live with a caregiver.16

Inconclusive results in past research about the effect of age on transitioning to a care home can be due to differences in the age of participants. Past studies included PwD who were 75 years old or older,13 or people with higher mean age.12 Moreover, a European study about placement in long-term care showed that the factors predicting transition to a care home for PwD vary across different countries.7 For example, increasing age can predict transition to a care home for PwD in the United States,5,9,11 but not in the UK.12,13 Another international study showed that PwD in Australia are more likely to transition to a care home compared to PwD in the UK and the United States possibly because of the different health-care systems.24

In a similar vein, cultural differences may also explain the contradictory results for the effect of sex and marital status on care home transitions.

Another aim of the present study was to explore the nature of transitioning to a care home for PwD. The results showed that PwD in Northern Ireland are more likely to transition from their own home to a care home. Past research in the United States suggests that the majority of care-home transitions for PwD were transfers from hospitals; however, PwD in this study had increased rates of comorbidities such as cancer.8

This was a surprising finding for the authors who, based on anecdotal clinical experience, expected more people to transition to a care home after a hospital admission. Staying in the hospital for more days was expected for people who transitioned to a care home due to poorer health or inadequate care-home beds available and pressures on social services. PwD waiting on care-home beds are often fit for discharge many days before a bed becomes available in a care home.

In line with past research, dementia and pneumonia were the most common causes of death for PwD.20 Dementia is reported on death certificates more often in the past decades because the underlying causes of death include conditions contributing to death since 1984.24 However, dementia is currently reported not only as an underlying cause of death, but also as a primary cause of death in Northern Ireland. The results about the place of death for PwD are supported by past research,19,20 with the majority of PwD dying in care homes or hospitals. This finding shows that frequent hospital admissions for people living in their own home may result in dying at a least preferred place, such as the hospital.

In this study PwD in care homes lived longer than those living at home. Without being able to stage the severity of dementia it is difficult to explain this result. A previous German study25 showed people at home lived significantly longer than those in residential care but numbers were small. There is very little in the literature reporting on survival according to place of residence. From clinical experience the authors postulate PwD in care homes may live longer as they are receiving regular nursing care, regular nutrition, and medications are delivered on time and at the appropriate dose, compared to PwD at home who may miss regular meals and medication.

In Northern Ireland “Living Matters Dying Matters: A Palliative and End of Life Care Strategy for Adults in Northern Ireland”26 was published in 2010 and implemented over the past number of years. As many PwD have been enabled to die in care homes in this study we can only assume that this strategy has been successfully implemented in Northern Ireland over the past several years.

This study has limitations that are worthy of consideration. Marital status was recorded through data from the first hospital admission per person and it was not updated thereafter. Therefore, these data are missing for people who were not admitted to a hospital between 2010 and 2016 (65%), making it difficult to determine the effects that marital status had on transitioning to a care home after diagnosis. Another limitation concerns the identification of PwD. Dementia cases were identified from the EPD using the first date that a dementia medication was prescribed as proxy for the date of diagnosis. Thus, the majority of people in the datasets are expected to have dementia with AD, mixed dementia, or Lewy body dementia, while people with other types of dementia are not included in this sample. Some PwD may have had their dementia medication withdrawn due to a lack of efficacy or an intolerance of the side effects. In addition, the EPD does not hold data for medication bought over the counter or prescribed in a hospital. Finally, data for transitioning to a care home were recorded on a quarterly basis and thus, we do not know the specific date each PwD transitioned to a care home.

The present study explored the factors predicting transitions to care homes for PwD in Northern Ireland. Increasing age, female sex, living in less deprived areas and urban areas, fewer hospital admissions, and longer hospital stays are significant predictors for this transition. A better understanding of these predictors can raise awareness of the care needs for PwD and improve services not only in care homes, but also in community-based services that aim to delay transitions to care homes by improving the independence of PwD and reducing caregivers’ burden. Some risk factors, such as living in less deprived and urban areas, can be considered by policy makers when developing community care services for PwD and caregivers, while the risk factor of female sex could indicate the need for providing training to males for caregiving for their female spouse with dementia. Future research could explore whether caregivers’ characteristics, such as their health status and
demographic characteristics, affect transitioning to care homes for care receivers.

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CONFLICTS OF INTEREST
The authors have no conflicts of interest to declare.

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