

# **Aging & Mental Health**



ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/camh20

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**To cite this article:** L. Carter, S. O'Neill, Peter C. Austin, F. Keogh, M. Pierce & E. O'Shea (2021) Admission to long-stay residential care and mortality among people with and without dementia living at home but on the boundary of residential care: a competing risks survival analysis, Aging & Mental Health, 25:10, 1869-1876, DOI: 10.1080/13607863.2020.1857698

To link to this article: <a href="https://doi.org/10.1080/13607863.2020.1857698">https://doi.org/10.1080/13607863.2020.1857698</a>

|           | Published online: 15 Dec 2020.                           |
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# Admission to long-stay residential care and mortality among people with and without dementia living at home but on the boundary of residential care: a competing risks survival analysis

L. Carter<sup>a</sup> , S. O'Neill<sup>b\*</sup>, Peter C. Austin<sup>c</sup>, F. Keogh<sup>a</sup> , M. Pierce<sup>d</sup> and E. O'Shea<sup>a</sup>

<sup>a</sup>Centre for Economic and Social Research on Dementia, Institute for Lifecourse and Society, National University of Ireland, Galway, Ireland; <sup>b</sup>J.E. Cairnes School of Business and Economics, Upper Newcastle, National University of Ireland, Galway, Ireland; <sup>c</sup>Institute for Clinical Evaluative Sciences, Toronto, Ontario, Canada. Institute of Health Management, Policy and Evaluation, University of Toronto, Toronto, Canada; <sup>d</sup>Faculty of Science and Health, Dublin City University, Dublin, Ireland

#### **ABSTRACT**

**Background:** Health policy in many countries is underpinned by a commitment to support dependent older people to remain in their own home for as long as possible and practicable. This study explores factors affecting both admission to long-stay residential care (LSRC) and mortality among people with and without dementia who are currently living at home with intensive formal care support.

**Methods:** This is a cross-sectional study based on administrative data collected on 429 dependent older people in Ireland, 269 of whom were people with dementia. A cause-specific hazard model was used to investigate the hazard of admission to LSRC, while accounting for mortality as a competing risk and vice versa.

**Results:** Admission to LSRC was higher for people with dementia relative to people without and for those receiving lower amounts of informal care. The hazard of mortality was significantly higher for older people aged 85+, whereas it was lower for individuals with a medium level of dependency relative to those with high levels of dependency. The hazard of mortality was also influenced by the amount of informal care provision.

**Conclusion:** People with dementia are more likely to be admitted to LSRC than people without. Care for people with dementia needs to be more specialised and personal, and intensity of provision should not be equated to the number of care hours on offer. Informal care provision may help to prevent admission to LSRC. Advanced age, physical dependency and informal care provision affect mortality, raising interesting issues in relation to resource allocation.

#### **ARTICLE HISTORY**

Received 12 August 2020 Accepted 24 November 2020

#### **KEYWORDS**

Ageing; dementia; physical dependency; informal care; survival analysis

# Introduction

Health policy for dependent older people in many countries continues to be underpinned by a commitment to support them to remain living in their own homes for as long as possible and practicable (Donnelly, 2016; Gage et al., 2015; NHS, 2016; Verbeek et al., 2012). Keeping older dependent people living at home is motivated by a number of considerations, especially cost and cost-effectiveness (Tucker, 2008), as preventing or postponing admission to hospital or long-stay residential care (LSRC) may reduce the potential cost of care to the government (O'Shea & Monaghan, 2016; Wübker, 2015). There is also the underlying belief that staying at home is the preferred care option for the vast majority of older people, including those with complex cognitive care needs such as dementia (Tucker, 2008). As the population in Ireland ages, the predicted increase in the number of older people with dementia will have significant budgetary implications for the health and social care system (Wren et al., 2017). Therefore, from an economic perspective, there is considerable incentive to find the most appropriate and cost-effective ways to care for those with significant care requirements. Of particular interest is the cohort of people with dementia who are on

the boundary of admission to LSRC. Keeping these people out of residential care, or even postponing admission, may yield significant cost savings for governments.

The Health Service Executive (HSE) in Ireland is responsible for the provision of community-based formal care which is delivered directly through the HSE, or by private and voluntary agencies in receipt of HSE funding (Health Service Executive, 2018a; O'Shea & Monaghan, 2016). Home help provision has traditionally been the most important communitybased, formal home support service in Ireland, providing domestic assistance with cleaning, cooking and other light household tasks. In recent years, however, home helps have also provided assistance with personal care services, such as bathing, dressing, mobility assistance, toileting etc. (Carter, O'Neill, Keogh, Pierce, & O'Shea, 2019; Kiersey & Coleman, 2017). In 2014, as part of a process of further enhancement of home care, particularly for people with dementia, the HSE introduced an intensive home care package (IHCP) initiative to augment usual care for highly dependent older people at risk of admission to residential care (Keogh, 2018). In practice, those receiving IHCPs receive more visits and significantly more hours of care from public health nurses and home help workers than those not in the scheme, including more

personalised provision that reflects individual circumstances, family care networks and housing conditions. The initiative was closely aligned with a priority action of the National Dementia Strategy Implementation Programme (NDSIP) relating to the further development of integrated services for people with dementia to enable them to continue to live at home rather than be admitted to LSRC (Carter et al., 2019; Department of Health, 2018; Health Service Executive, 2018b; Keogh, 2018).

Balance of care (BoC) is often used to describe a systematic framework for exploring the potential costs and consequences of changing the mix of community and institutional services in a defined geographical area (Challis et al., 2014). This approach focuses on identifying the types of dependent older people whose care needs can potentially be met through the provision of enhanced supports in the community setting instead of being admitted to LSRC, if resources for the former were of sufficient scale and quality (Challis et al., 2014; O'Shea & Monaghan, 2017; Tucker, 2016). A large BoC study carried out in the UK found that up to half of new residential care home entrants could be cared for in alternative settings, if adequate resources were made available (Challis et al., 2014). People with dementia may be at a higher risk of admission to LSRC, particularly in later stages of the disease or when significant behavioral problems occur (Alzheimer Association, 2010; Gage et al., 2015; Verbeek et al., 2012). In Ireland, Aspell et al. (2019) report that higher levels of cognitive dysfunction are a predictor of admission into long-stay care, alongside being in receipt of high levels of formal community care hours. However, time to admission, rates of institutionalization and mortality along the continuum of care vary considerably among different countries (Brodaty, 2009; Feldman et al., 2009; Ribbe et al., 1997). It is also ambiguous whether delaying admission to a long-term care setting is the best approach for all individuals with significant dependency, as evidence to support the optimal timing of placement decision-making is lacking, including the relationship to mortality (Verbeek et al., 2012).

This paper is based on administrative data generated in response to a policy decision by the Irish government to introduce a limited number of IHCPs for people with dementia to allow them to remain in their own homes rather than be admitted to residential care, even when faced with significant physical and cognitive challenges. The data allows us explore the factors that impact on subsequent admission to LSRC and mortality over a three-year period, taking account of both contingencies. We are able to compare the experiences of people with and without dementia in relation to admission to residential care and mortality, in the presence of additional community-based provision. Whether and how dementia affects placement and mortality is particularly important in a country like Ireland, where there is a three-fold increase expected in the number of people with the dementia in the next twenty-five years (Pierse, O' Shea, & Carney, 2019). The data also allows consideration of the role that family carers play in influencing admission to LSRC and mortality.

# **Materials & methods**

#### Data

The IHCP scheme was a national initiative, originally focused on the appropriate discharge of dependent older

people from acute hospitals, but evolving to cover the prevention of admission in the first place, including keeping older people out of residential care for as long as possible and practicable. Once an older person was identified by care staff as potentially benefiting from an IHCP, a formal assessment was made of their care needs and social circumstances, followed by an application to the relevant Clinical Lead and the Local Manager for Older person's Services for monetary support to fund an appropriate package. In this study, we used anonymised routine data collected administratively by the Health Service Executive on all dependent older people who received an IHCP in Ireland between November 2014 and December 2017. This study covers 429 recipients of these packages, on which complete information was available; 160 (37.30%) of recipients were individuals with significant physical dependency (non-dementia-IHCPs) and 269 (62.70%) were individuals with dementia (dementia-IHCPs). The latter had either a confirmed formal diagnosis of dementia (i.e. from their own GP or another clinician), or symptoms of moderate to severe cognitive impairment based on an assessment by nursing staff or allied therapists. Ethical approval for the study was granted by the Royal College of Physicians of Ireland Research Ethics Committee in September 2016.

Two outcomes were of interest in this study: the first was admission to long-term care and the second was mortality. Ignoring one of these events may lead to misleading conclusions regarding the likelihood of the other event, so we use a competing risks approach to overcome this problem. For each recipient, information was recorded on the date of IHCP commencement and the date and cause for IHCP cessation. Time to each event was measured in days. If an individual had not experienced an event of interest over the study period, the observation was censored at the date of last follow-up/study end. Whether the individual was a non-dementia-IHCP recipient or a dementia-IHCP recipient was expressed as a binary variable.

Data were collected on additional independent variables such as gender, age, marital status, living arrangement (alone versus not alone) and the referral source for the IHCP (community or hospital) of each recipient. Information was also collected on the relationship between the IHCP recipient and their main informal carer, in addition to the amount (level) of care provided by the main informal caregiver per day measured in three time blocks: 0-8 h; 8-12 h; and 12 + hours. Physical dependency was measured using the Barthel Index (Mahoney & Barthel, 1965), which is used to measure performance in terms of activities of daily living (Hopman-Rock, van Hirtum, de Vreede, & Freiberger, 2019). The Barthel Index is scored from 0 to 20, with lower scores indicating increased disability or dependency. Finally, the number of care hours provided per week as part of the IHCP was also recorded.

# Methods

In survival analysis, outcomes may be censored, a situation which arises when, at the end of the study period (or at end of follow-up), the outcome has not been observed to occur for a given subject. Censoring may occur for various reasons, such as loss to follow-up, withdrawal from the study, or reaching the end of the study period (Feakins, McFadden, Farmer, & Stevens, 2018; Noordzij et al., 2013).

Commonly used standard survival analysis methods are the non-parametric Kaplan-Meier model which estimates survival functions, and the semi-parametric Cox proportional hazards model, which is used to estimate the effect of predictors on the hazard function (Austin, Lee, & Fine, 2016; Despa, 2010). Both approaches make the assumption that censoring is independent of the time to the outcome, i.e. non-informative. This implies that subjects who are censored at a certain time point are representative of those still under observation at that point in time (Feakins et al., 2018; Noordzij et al., 2013). In some circumstances and settings, however, individuals are at risk of experiencing more than one type of outcome (Feakins et al., 2018).

A competing risk is an event whose occurrence either prevents the observation of the primary event of interest or modifies the chance of the event occurring (Noordzij et al., 2013; Pintilie, 2007). Therefore, at any time before experiencing the first event, individuals should be at risk of both events (Noordzij et al., 2013). In this scenario, a competing risk considers censoring to be informative. When examining admission into LSRC as the outcome of interest for participants in this study, mortality is a competing risk since, if an individual dies while in the community, they are no longer at risk of entering residential care. Alternatively, when examining mortality in the community as the outcome of interest, admission into LSRC is a competing event, because admission into residential care precludes the occurrence of mortality in the community. In the presence of competing risks, the cause-specific hazard model can be used to analyze time to event outcomes. This model estimates the effect of covariates on the causespecific hazard function, which is defined as:

$$\begin{array}{l} \textit{h}_{\textit{k}}(t) = \\ \textit{lim} \quad \underbrace{ \frac{\mathsf{Prob}(\mathsf{t} \leq \mathsf{T} < \mathsf{t} \ + \Delta \mathsf{t}, \ \mathsf{failure \ from \ cause \ k \ T \geq \mathsf{t})}{\Delta \mathsf{t}}}_{} \end{array}$$

The cause-specific hazard  $h_k(t)$  is the instantaneous rate of failure from a specified cause k in those subjects who are currently event-free at time t, (Austin & Fine, 2017; Cleves, 2010), where T is equal to the time to first failure from any cause (Austin & Fine, 2017; Cleves, 2010; Hinchliffe & Lambert, 2013). A central assumption of this model is that hazards are proportional, which implies that variables have a constant effect on the hazard function over time (Bradburn, Clark, Love, & Altman, 2003).

For the purpose of our analysis, we first used a causespecific hazard model in order to examine time to admission to LSRC, when mortality is treated as a competing risk. This allows us to examine the hazard of admission to longterm care for those recipients who are currently event-free (i.e. alive and not in residential care). Next, we used a cause-specific hazard model to investigate time to mortality, while treating admission into residential care as a competing event. This allows us to consider the hazard of mortality in those recipients who are currently event-free (i.e. who are alive and not in residential care). We regressed the hazard of admission to LSRC and mortality on the set of independent variables described above (Culliford, Maskell, Judge, & Arden, 2013; Feakins et al., 2018; Ferraz & Moreira-Filho, 2017). In each of our models, we tested for violations of the proportional hazards (PH) assumption and corrected for non-proportionality by interacting the

covariate which violated the PH assumption with the natural log of time (Bradburn et al., 2003, Cleves, 2010). We assessed the sensitivity of results to the inclusion of irrelevant variables using backwards variable selection based on the Bayesian Information Criteria (BIC). Results are very similar to those using the full set of variables and hence are not reported (results available on request). The analyses were performed using STATA 16 (StataCorp, 2016).

#### Results

Table 1 presents a comparison of summary statistics on the characteristics of both non-dementia and dementia-IHCP recipients, using medians and interguartile range for continuous variables and percentages (%) for categorical variables. With respect to socio-demographic variables, the median age of non-dementia-IHCP recipients was 78 (interquartile range: 69-84) years and 81 (interquartile range: 75-87) years for dementia-IHCPs. Over half of the participants were female (59.21%). The two groups (non-dementia-IHCP recipients and dementia-IHCP recipients) were similar with regard to the proportion of individuals living alone and the proportion of those being cared for by their spouse/partner. The median level of dependency, as measured by the Barthel Index (which ranges from 0 to 20), was 5 (interquartile range: 2.5-7) for non-dementia-IHCP recipients and 6 (interguartile range: 3-10) for dementia-IHCP recipients. The median number of home support hours provided to nondementia-IHCPs was 42 (interquartile range: 35-50) hours per week, while dementia-IHCPs received 38.5 (interguartile range: 28-48) home support hours per week. IHCP provision is approximately six to seven times greater than usual weekly care support hours for older people in Ireland (Houses of the Oireachtas, 2019). Of the 429 individuals who commenced an IHCP at some point between November 2014 and December 2017, 19% (n = 80) were admitted to long-term care and 33% (n = 142) died while living in the community; 46% (n = 197) of recipients were still receiving an IHCP at the end of the study period (active).

We first used a univariate cause-specific model to regress the hazard of admission to LSRC on whether the individual was a non-dementia-IHCP recipient or a dementia-IHCP recipient, while accounting for mortality as a competing risk. The time-dependent covariate test (Cox, 1972) showed that the proportional hazards assumption was met (p = 0.08). The estimated unadjusted cause-specific hazard ratio (CSHR) was 2.52 (Table 2), suggesting that the hazard of admission to long-term care was significantly higher for dementia-IHCP recipients than for non-dementia-IHCP recipients (95% CI 1.51 to 4.19; p < 0.01). Dementia-IHCP recipients still had a significantly higher hazard of admission to long-term care compared to non-dementia-IHCP recipients after the model was modified to include a range of covariates to control for observable differences between the groups (CSHR 2.45, 95% CI 1.39 to 4.33; p < 0.01).

With regard to the level of care provided by the main informal family caregiver, the results show that the hazard of admission to LSRC was higher for dependent older people receiving between 0-8h (CSHR 3.21, 95% CI 1.56 to 6.61; p < 0.01) and 8-12 h (CSHR 2.67, 95% CI 1.21 to 5.87; p < 0.05) of informal care per day, compared to those

Table 1. Descriptive analysis for non-dementia-IHCP and dementia-IHCP recipients.

| Variable  | Non-Dementia-IHCP recipients ( $n = 160$ ) | Dementia-IHCP recipients ( $n = 269$ ) |  |
|---|--|--|--|
| Status, n (%)   |  |  |  |
| Active (receiving an IHCP at the end of the study period) | 63 (39.38)                                 | 134 (49.81)                            |  |
| Ceased (admission/readmission to hospital/respite)        | 1 (0.63)                                   | 0 (0.00)                               |  |
| Ceased (admission to acute care)                          | 3 (1.88)                                   | 5 (1.86)                               |  |
| Ceased (admission to LSRC)                                | 21 (13.13)                                 | 59 (21.93)                             |  |
| Ceased (RIP)  | 72 (45.00)                                 | 70 (26.02)                             |  |
| Ceased (HSE provided alternative service)                 | 0 (0.00)                                   | 1 (0.37)                               |  |
| Gender, n (%)   |  |  |  |
| Male  | 70 (43.75)                                 | 105 (39.03)                            |  |
| Female  | 90 (56.25)                                 | 164 (60.97)                            |  |
| Age at approval, median (interquartile range)             | 78 (69, 84)                                | 81 (75, 87)                            |  |
| Age groups, n (%)   |  |  |  |
| 65 years or under   | 29 (18.12)                                 | 18 (6.69)                              |  |
| 66-74 years   | 36 (22.50)                                 | 48 (17.84)                             |  |
| 75-84 years   | 56 (35.00)                                 | 105 (39.03)                            |  |
| 85+ years   | 39 (24.38)                                 | 98 (36.43)                             |  |
| Married, n (%)  |  |  |  |
| Yes   | 82 (51.25)                                 | 148 (55.02)                            |  |
| No  | 78 (48.75)                                 | 121 (44.98)                            |  |
| Living alone, n (%)                                       |  |  |  |
| Yes   | 45 (28.13)                                 | 73 (27.14)                             |  |
| No  | 115 (71.88)                                | 196 (72.86)                            |  |
| Barthel score, median (interquartile range)               | 5 (2.5, 7)                                 | 6 (3, 10)                              |  |
| Dependency level (BI), n (%)                              |  |  |  |
| High and Maximum dependency                               | 144 (90.00)                                | 214 (79.55)                            |  |
| Medium dependency   | 8 (5.00)                                   | 46 (17.10)                             |  |
| Low dependency and Independent                            | 8 (5.00)                                   | 9 (3.35)                               |  |
| Main informal caregiver, n (%)                            |  |  |  |
| None  | 4 (2.50)                                   | 7 (2.60)                               |  |
| Other   | 85 (53.13)                                 | 146 (54.28)                            |  |
| Spouse/Partner  | 71 (44.38)                                 | 116 (43.12)                            |  |
| Level of care by carer, n (%)                             |  |  |  |
| >12 h of care daily                                       | 39 (24.38)                                 | 95 (35.32)                             |  |
| 8 – 12 h of care daily                                    | 31 (19.38)                                 | 60 (22.30)                             |  |
| < 8 h of care daily                                       | 90 (56.25)                                 | 114 (42.38)                            |  |
| IHCP hours per week, median (interquartile range)         | 42 (35, 50)                                | 38.5 (28, 48)                          |  |

Table 2. Cause-specific hazard model regression coefficients (and 95% confidence intervals) for admission to long-term care, accounting for competing risk of mortality.

|   | Long-term care |                    |         | Long-term care, adjusted |                            |         |
|---|----------------|--------------------|---------|--------------------------|----------------------------|---------|
| Variable                                  | Coefficient    | CSHR (95% CIs)     | P-value | Coefficient              | CSHR (95% CIs)             | P-value |
| Dementia-IHCP                             | 0.925          | 2.52 (1.51 – 4.19) | 0.00*** | 0.898                    | 2.45 (1.39 – 4.33)         | 0.00*** |
| Male                                      |                |                    |         | 0.061                    | 1.06 (0.65 — 1.73)         | 0.80    |
| Age at approval                           |                |                    |         |                          |                            |         |
| 66-74 years                               |                |                    |         | -0.102                   | $0.90 \; (0.32 - 2.48)$    | 0.84    |
| 75-84 years                               |                |                    |         | 0.522                    | 1.68 (0.66 — 4.25)         | 0.26    |
| 85+ years                                 |                |                    |         | 0.255                    | 1.29 (0.47 – 3.48)         | 0.61    |
| Married                                   |                |                    |         | 0.259                    | 1.29 (0.57 — 2.92)         | 0.53    |
| Community                                 |                |                    |         | 0.027                    | 1.02 (0.56 — 1.87)         | 0.92    |
| Living alone                              |                |                    |         | 0.150                    | 1.16 (0.57 — 2.35)         | 0.67    |
| Barthel Index                             |                |                    |         |                          |                            |         |
| Medium dependency                         |                |                    |         | -1.327                   | 0.26 (0.01 - 4.32)         | 0.35    |
| Medium dependency x In(time)              |                |                    |         | 0.311                    | 1.36 (0.80 – 2.31)         | 0.24    |
| Low dependency and Independent            |                |                    |         | -8.198                   | $0.00 \ (< 0.0001 - 4.69)$ | 0.09*   |
| Low dependency and Independent x In(time) |                |                    |         | 1.576                    | 4.83 (0.92 - 25.33)        | 0.06*   |
| Main informal caregiver                   |                |                    |         |                          |                            |         |
| Other                                     |                |                    |         | 0.806                    | 2.23 (0.51 — 9.72)         | 0.28    |
| Spouse/Partner                            |                |                    |         | 0.712                    | 2.03 (0.43 – 9.56)         | 0.36    |
| Level of care by carer                    |                |                    |         |                          |                            |         |
| 8-12 h per day                            |                |                    |         | 0.984                    | 2.67 (1.21 – 5.87)         | 0.02**  |
| 0-8 h per day                             |                |                    |         | 1.167                    | 3.21 (1.56 — 6.61)         | 0.00*** |
| IHCP hours per week                       |                |                    |         | -0.008                   | 0.99 (0.97 — 1.00)         | 0.30    |

<sup>\*</sup> p<.1; \*\* p<.05; \*\*\*p<.01.

receiving more than 12h of informal care per day. None of the other covariates were statistically significant.

In our second model, we regressed the cause-specific hazard of mortality on the main independent variable of interest, indicating whether an individual was a nondementia-IHCP or a dementia-IHCP recipient, while accounting for admission to LSRC as a competing risk (Table 3). Initially, the calculation of the CSHRs (Exp (β<sub>1</sub>  $+\beta_2*In(t)$ ) showed that the hazard of mortality increased

over time for dementia-IHCP recipients compared to standard-IHCP recipients, and this difference was statistically significant (p < 0.05). After adjusting for covariates, the proportional hazards PH assumption did not hold for the dementia-IHCP variable. We modified the multivariable model to include a time-dependent covariate, by interacting the relevant covariate with the natural log of time, therefore allowing the effect of the relevant covariate to change over time (Bradburn et al., 2003). While the



Table 3. Cause-specific hazard model regression coefficients (and 95% confidence intervals) for mortality, accounting for competing risk of admission to long-term care.

|                                | Mortality   |                    |         | Mortality, adjusted |                         |         |
|--------------------------------|-------------|--------------------|---------|---------------------|-------------------------|---------|
| Variable                       | Coefficient | CSHR (95% Cls)     | P-value | Coefficient         | CSHR (95% CIs)          | P-value |
| Dementia-IHCP                  | -1.461      | 0.23 (0.06 – 0.77) | 0.02**  | -1.14               | 0.31 (0.09 - 1.09)      | 0.07*   |
| Dementia-IHCP x In(time)       | 0.261       | 1.29 (1.01 — 1.65) | 0.03**  | 0.21                | 1.24 (0.97 — 1.58)      | 0.08*   |
| Male                           |             |                    |         | 0.06                | 1.07 (0.75 — 1.52)      | 0.70    |
| Age at approval                |             |                    |         |                     |                         |         |
| 66-74 years                    |             |                    |         | 0.63                | 1.89 (0.95 — 3.73)      | 0.06*   |
| 75-84 years                    |             |                    |         | 0.21                | 1.24 (0.64 – 2.40)      | 0.51    |
| 85+ years                      |             |                    |         | 0.70                | 2.01 (1.03 - 3.93)      | 0.04**  |
| Married                        |             |                    |         | 0.26                | 1.30 (0.73 – 2.31)      | 0.37    |
| Community                      |             |                    |         | -0.20               | $0.81 \ (0.50 - 1.32)$  | 0.40    |
| Living alone                   |             |                    |         | 0.02                | 1.02 (0.62 — 1.68)      | 0.93    |
| Barthel Index                  |             |                    |         |                     |                         |         |
| Medium dependency              |             |                    |         | -1.25               | 0.28 (0.12 - 0.66)      | 0.00*** |
| Low dependency and Independent |             |                    |         | -1.12               | 0.32 (0.09 - 1.04)      | 0.06*   |
| Main informal caregiver        |             |                    |         |                     |                         |         |
| Other                          |             |                    |         | -0.19               | 0.82 (0.28 - 2.38)      | 0.71    |
| Spouse/Partner                 |             |                    |         | -0.59               | 0.55 (0.18 - 1.62)      | 0.28    |
| Level of care by carer         |             |                    |         |                     |                         |         |
| 8-12 h per day                 |             |                    |         | -0.70               | $0.49 \; (0.28 - 0.85)$ | 0.02**  |
| 0-8 h per day                  |             |                    |         | -0.15               | 0.85 (0.57 — 1.26)      | 0.43    |
| IHCP hours per week            |             |                    |         | 0.00                | 1.00 (0.99 — 1.01)      | 0.09*   |

<sup>\*</sup> p<.1; \*\* p<.05; \*\*\*p<.01.

subsequent calculation of the CSHRs again suggested that the hazard of mortality increased over time for dementia-IHCP recipients compared to non-dementia-IHCPs (year one: 1.13; year two: 1.32; year three: 1.44), the difference was no longer statistically significant at the 5% level.

Based on the CSHRs presented in Table 3, the hazard of mortality was found to be significantly higher for individuals aged 85 years and over compared to those aged 65 years and under, with a CSHR of 2.01 (95% CI 1.03 to 3.93; p < 0.05). The cause-specific hazard of mortality was lower for individuals with a medium level of dependency (CSHR 0.28, 95% CI 0.12 to 0.66; p < 0.01) on the Barthel Index compared to those with a high/maximum level of dependency. Finally, mortality was also lower for those receiving 8-12 h (CSHR 0.49, 95% CI 0.28 to 0.85; p < 0.05) of informal care per day, compared to those receiving more than 12 h of informal care per day. None of the other covariates were found to have a statistically significant effect at the 5% level.

Given the importance of the effect of covariates on the probability of events occurring over time (Austin & Fine, 2017), we also estimated the effect of covariates on the cumulative incidence function through the use of the Fine-Gray sub-distribution hazard model (results available on request). The results from the sub-distribution hazard model support our general findings. In addition, the Fine-Gray model found that the cumulative incidence of mortality was also lower for individuals classified as having low dependency/ independent on the Barthel Index (SHR 0.30, 95% CI 0.10 to 0.93; p < 0.05). The cumulative incidence of mortality was also found to be higher for those receiving an additional hour of formal care provided as part of an IHCP (SHR: 1.01, 95% CI 1.00 to 1.02, p < 0.05), suggesting that higher levels of need, proxied by additional formal provision, may impact on mortality, confirming the finding of Aspell et al. (2019).

# **Discussion**

Our findings suggest that people with dementia had a significantly higher admission rate to LSRC than people without dementia during the time-frame of the study. In a systematic review and meta-analysis by Cepoiu-Martin, Tam-Tham, Patten, Maxwell, and Hogan (2016), the authors suggest that having severe dementia was a significant predictor of admission to long-term care. Irish data on placement also highlights, more broadly, the importance of cognitive impairment and dementia for admission into residential care (Aspell et al., 2019; Walsh et al., 2020). We have confirmed those findings, using more sophisticated competing risks survival modelling. Even with enhanced community care provision, delivered through IHCPs, people with dementia remain more disposed to admission to LSRC than people without dementia. Providing people with dementia with more hours of formal care may not be enough to keep them out of long-stay residential care. Intensity is more complex than simply the provision of more care hours. The form, structure and quality of those hours are also important (Walsh et al., 2020). Meeting the needs of people with dementia may be more difficult because of the denial of personhood in their lives and the consequent absence of a person-centred approach among formal care providers (Kitwood, 1997; Trahan, Kuo, Carlson, & Gitlin, 2014; Walsh et al., 2020).

The results also indicate that dependent older people who were receiving less informal care hours had significantly higher admission to long-term care. This finding suggests that admission to residential care is affected by the availability of family care provision. While this finding is not novel, it is interesting that families still matter even when additional formal care resources, in the form of IHCPs, are provided. Substitution may eventually occur at very high levels of state provision, but this study has shown that even with mean formal support hours of up to 42 h per week (Table 1), six times that of usual care, families still matter for placement outcomes. Therefore, should informal care be absent, or reduced by choice or through demography in the future, the state may have to invest much more to support dependent older people living at home than currently envisaged by policy-makers.

Mortality was significantly higher for people aged 85 years and over relative to younger recipients aged less than 65 years of age. This raises the issue of resource allocation at end-of-life, including the question of whether chronological age should be taken into account in deciding on eligibility for IHCPs. The argument that additional resources, delivered through IHCPs, should be rationed for people aged 85+ may be attractive, on the basis that any additional investment might be better allocated to people in younger age categories who have better chances of survival, but there are other issues to consider. In particular, it is not methodologically sound to argue on the basis of one cross-sectional study that age should, or indeed should not, be used to ration scarce community-based resources. Moreover, there is a countervailing normative argument that dependent older people should have the same access to care and treatment as younger age cohorts (O'Shea, 2020), implying that resources should never be allocated on the basis of age alone.

Mortality was lower for individuals classified as having a medium dependency on the Barthel Index, relative to those with high/maximum dependency. It should also be noted that mortality was also lower for those classified as having low dependency/independent on the Barthel index, but the results did not arguably reach statistical significance (p = 0.06). These results corroborate a recently published study for Ireland, which found that high levels of physical dependency were predictors of mortality for dependent older people living in a community setting (Aspell et al., 2019). There is also evidence from other countries that reduced baseline activities of daily living (ADL) are associated with functional deterioration and mortality among older people (Na et al., 2017; Stineman et al., 2012). People with higher levels of physical dependency and limitation appear to have a higher risk of death when capacity becomes severely compromised (Kurichi, 2017). In general, therefore, a high level of physical dependency is a risk factor for mortality, highlighting the importance of movement, mobility and exercise programmes for older people living in the community. Unfortunately, formal movement and exercise programmes are scarce in Ireland, reflecting a disablement approach to ageing that impacts negatively on dependent older people living in all care settings (Kelly, O'Brien, Smuts, O'Sullivan, & Warters, 2017).

Older people receiving between 8 and 12 h of informal care per day had significantly lower mortality than those receiving more than 12h of informal care per day. This is not surprising as our a priori expectation would be that higher informal care provision, incorporating night-time care, implies a higher level of dependency and poorer health on the part of the recipient. We would have also expected a significantly lower hazard rate of mortality for individuals receiving between 0 and 8h of informal care per day, presuming, in general, that those receiving minimum amounts of informal care would be in better health. Our model suggests that this is not necessarily the case, signalling a potential influence on mortality from too little or too much informal care. It may be that people receiving low levels of informal care are more vulnerable, simply because they have less informal care available to them. The relative absence of family in the care relationship may precipitate mortality, or, at least, not reduce the risk of mortality, through complex psychological and emotional pathways (Aneshensel, 2000; Santini et al., 2015). Unfortunately, we do not have the data to explore this question any further in this paper. However, it is reasonable to speculate that there may be an optimal mix of family and formal care that is sensitive to the psychological and emotional need of care recipients for family engagement in the care process.

There are limitations to the present study. The number of study participants who switched from home care to LSRC or died over the study period was relatively small, therefore the results should be viewed tentatively. Information was not available on important variables of interest such as: prior resource utilization of usual formal care in the community setting (therefore, we had no baseline provision), caregiver work status, private care provision and important outcome measures such as quality of life and caregiver burden. While data were gathered on the level of care provided by the caregiver, there was no differentiation with regard to the type of care provided (i.e. supervision vs. providing assistance with IADL's for example). Data was not formally collected on the socioeconomic status (SES) of IHCP recipients in this study. However, SES is likely to have been incorporated indirectly into the decision-making process under social circumstances when considering need, particularly in relation to housing conditions and housing quality.

Other uncertainties surround the measurement of informal caring, as there is potential for carers to overestimate informal caring time in the way the data was collected. The use of the Barthel Index as a measure of dependency has limitations (Sainsbury, Seebass, Bansal, & Young, 2005; Yi et al., 2020). Moreover, we know very little, if anything, about how health professionals in Ireland use the Barthel Index when conducting their assessments, raising issues of reliability. Our results may also be subject to the influence of unobserved confounding. For example, predictors which may influence admission to LSRC or mortality, such as caregiver burden, income, quality of life or comorbidities were not included in the analysis, as information was not collected on these variables. Therefore, results should be viewed as descriptive rather than causal (Huang, Xu, & Dulai, 2019). Finally, it is unclear if predictors of institutionalization are country-specific, therefore further research is required across countries in order to examine the specific characteristics of people who benefit most from institutional as opposed to home-based care.

# Conclusion

This paper uses competing risks survival analysis to provide important insights into factors associated with admission into residential care and mortality for people with dementia in Ireland, with important lessons for other countries. Dementia is an important predictor of admission to residential care, even when additional formal care hours are available to keep people living at home. Therefore, increasing care hours through intensive home care packages for people with dementia living at home, while welcome, is not enough. We need to focus much more on the quality of care hours provided as much as the quantity of hours to people with dementia on the boundary of residential care. The needs of people with dementia are different and need to be recognised as such by practitioners and policy-



makers. Informal care continues to be important for placement decision-making and mortality among people with and without dementia, with our findings pointing to the importance of complementarity rather than substitutability between families and the state for keeping people out of residential care. Physical dependency matters for mortality, suggesting a role for ongoing reablement and mobility programmes for dependent older people along all stages of the continuum of care.

# **Acknowledgements**

The authors would like to express their gratitude to the HSE-Genio Dementia Programme who supported this study and the people with dementia and caregivers who participated in the study. Peter Austin was supported by a Mid-Career Investigator Award from the Heart and Stroke Foundation.

#### **Disclosure statement**

No potential conflict of interest was reported by the authors.

#### **Disclosure statement**

This work was supported by Genio.

#### **ORCID**

L. Carter (i) http://orcid.org/0000-0002-6196-0078 F. Keogh (i) http://orcid.org/0000-0003-1400-1947

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