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Long-Term Care Around the Globe

International Variation in Place of Death of Older People Who Died From Dementia in 14 European and non-European Countries

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A B S T R A C T

Objectives: The objective of this study was to examine variation in place of death of older people dying from dementia in countries across 4 continents.
Design: Study of death certificate data.
Methods: We included deaths of older (65 + years) people whose underlying cause of death was a dementia-related disease (ICD-10: F01, F02, F03, G30) in Belgium, the Netherlands, England, Wales, France, Italy, Spain, Czech Republic, Hungary, New Zealand, United States, Canada, Mexico and South Korea. We examined associations between place of death and sociodemographic factors, social support, and residential and health care system factors.
Results: Overall, 4.8% of all deaths were from a dementia-related disease, ranging from 0.4% in Mexico to 6.9% in Canada. Of those deaths, the proportion occurring in hospital varied from 1.6% in the Netherlands to 73.6% in South Korea. When controlling for potential confounders, hospital death was more likely for men, those younger than 80, and those married or living in a region with a higher availability of long-term care beds, although this could not be concluded for each country. Hospital death was least likely in the Netherlands compared with other countries.
Conclusions: Place of death of older people who died from a dementia-related disease differs substantially between countries, which might point to organizational differences in end-of-life care provision.

JC and DH contributed equally as last author.
The authors declare no conflicts of interest.

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Increasing the availability of long-term care beds might be important to reduce the number of hospital deaths, while focusing specialized end-of-life care services on married people or those aged 65 to 79 might be crucial for achieving home death. However, proper end-of-life care needs to be ensured in hospitals, should this be the most appropriate end-of-life care setting.

Dementia has become a major public health issue, particularly due to its rapidly increasing global prevalence.[1,2] It has been estimated that 35.6 million people worldwide were living with dementia in 2010 and this has been projected to double every 20 years, with 7.7 million new cases per year.[1] Evidently, such an increase poses challenges to providing adequate care, including end-of-life care,[2,3] for these patients, and countries tend to differ in how these challenges are approached. An international study on the place of death of older people dying from a dementia-related disease could provide important insights into such diversity.

Older people with dementia often experience medical problems at the end of life (eg, pneumonia or hip fractures),[3–8] that may result in hospital admission.[9,10] Although hospitalization might be considered justified in some circumstances,[9] it also has been suggested that the acute hospital setting is not an adequate place for end-of-life care and death for chronic terminally ill patients and this might be particularly so for patients with advanced dementia.[11–13] In this setting, they may be more likely to experience delirium,[14] falls, or other adverse events,[6,14–16] and often experience burdensome interventions or procedures that might be of little benefit, such as tube feeding.[7,8,16–18] Moreover, relatives or family carers generally seem to be dissatisfied with hospital care,[19,20] whereas acute care staff often experience difficulties in caring for older people with dementia.[12,13,21,22]

Although there have been several national studies exploring the location of death for older people with dementia and associated factors,[23,24] only one study has examined cross-national variations in 5 European countries, showing that the proportion of hospital deaths of older people who died from a dementia-related disease differed substantially among countries.[25] More recent, larger cross-national studies, including non-European countries, on place of death focusing on dementia, are lacking.

The aim of this study was to examine variations in place of death of older people who died from a dementia-related disease and their association with sociodemographic factors, social support, residential, and health care system factors in European and non-European countries, across 4 continents, and the cross-national variations in place of death when controlling for these confounders. Studying variation in place of death across different countries could elicit important differences in where patients with dementia die and might be helpful in identifying policy priorities to monitor and safeguard the quality of end-of-life care for these patients.

Methods

Study Design and Data

This study is part of the International Place of Death study, a collection of death certificate data on all deaths of 1 year in multiple countries. Following an open call from the principal researchers and preliminary negotiations, it was decided that 2008 would be used as the reference year, given that this was the most recent year available in all targeted countries at the time of data collection (2011–2013). Fourteen countries were able to obtain permission to use the data from 2008 or the most recent available year in an international study: Belgium, Canada (Quebec excluded), Czech Republic, England, France, Hungary, Italy, Mexico, the Netherlands, New Zealand, Spain (Andalusia; 2010), South Korea, United States (2007), and Wales. Datasets were integrated into one international database, coordinated by the principal researchers to ensure uniform coding.

Population

We included deaths of people whose underlying cause of death was dementia-related (henceforth also labeled as "patients with dementia"): vascular dementia (ICD-10:F01), dementia in other diseases (ICD-10:F02), unspecified dementia (ICD-10:F03), and Alzheimer disease (ICD-10:G30). Given the low prevalence of dementia-related diseases in those younger than 65, we selected only those aged 65 and older.

Data and Measurements

The dependent variable in the analysis was the place of death as recorded on the death certificate, recoded into 5 categories: home, long-term care (LTC) setting (including nursing homes and care homes), palliative care institution (eg, hospice), hospital, and other (eg, public space). Exceptions were Hungary (only "hospital" or "other" were available as categories) and Mexico (only "home," "hospital," "other"). Furthermore, "palliative care institution" was recorded only in England, New Zealand, Wales, and United States.

The independent variables included factors known to affect place of death: sociodemographic factors, social support, residential factors, health care system factors, and country of residence.[24,26] Sociodemographic factors included gender, age (65–79, 80–89, 90 + years of age) and educational attainment (no formal or elementary, lower secondary, higher secondary, higher). Social support was measured by marital status (unmarried, married, widowed, divorced/separated); a residential factor was the degree of urbanization in the municipality or region of residence; and health care system factors included the average number of hospital beds per 10,000 inhabitants, general practitioners (GPs) per 100,000 inhabitants, and LTC beds per 1000 inhabitants aged 65 + available in the health care region of the deceased. For Hungary, Czech Republic, and South Korea, health care system factors were provided for the country as a whole, as privacy regulations did not allow detailed information on the health care region of residence of the deceased. For Wales only, LTC beds per 1000 inhabitants aged 65+ were used, in the absence of available regional data.

Analysis

Study population characteristics and the distribution of place of death were described for each country using crude proportions. To examine the factors associated with dying in hospital versus other places within each country, a binomial multivariable logistic regression analysis was performed for each country using a forward stepwise likelihood selection procedure of variables. To examine the association between place of death and country of residence, taking into account potential confounders, multinomial logistic regression models (first with hospital as reference category, and second with home as reference category) were performed with the dependent variable recoded into 3 categories (home, hospital, and LTC setting). Each multinomial logistic regression model was built up in 3 consecutive steps: we estimated the unadjusted association between