

Original Article

The Need for Palliative Care in Ireland: A Population-Based Estimate of Palliative Care Using Routine Mortality Data, Inclusive of Nonmalignant Conditions

Pauline M. Kane, MB BCH, BAO, LRCP&SI, MSc, Barbara A. Daveson, BMus (Mus Thy), DipHSM, PhD, Karen Ryan, MB BCH, BAO, BMedSc, FRCPI, Regina McQuillan, MB BCH, BAO, FRCPI, Irene J. Higginson, BMedSci, BMBS, PhD, FMedSci, FRCP, FFPHM, and Fliss E.M. Murtagh, FRCP, MRCGP, PhD, on behalf of BuildCARE

Department of Palliative Care, Policy & Rehabilitation (P.M.K., B.A.D., I.J.H., F.E.M.M.), King's College London, Cicely Saunders Institute, London, United Kingdom; and St. Francis Hospice and Mater Misericordiae University Hospital (K.R.), and St. Francis Hospice and Beaumont Hospital (R.M.), Dublin, Ireland

Abstract

Context. Over the history of palliative care provision in Ireland, services have predominantly provided care to those with cancer. Previous estimates of palliative care need focused primarily on specialist palliative care and included only a limited number of nonmalignant diseases.

Objectives. The primary aim of this study was to estimate the potential population with generalist and/or specialist palliative care needs in Ireland using routine mortality data inclusive of nonmalignant conditions. The secondary aim was to consider the quality of Irish data available for this population-based estimate.

Methods. Irish routine mortality data (2007–2011) were analyzed for malignant and nonmalignant conditions recognized as potentially requiring palliative care input, using specific International Statistical Classification of Diseases and Related Health Problems-10th Revision codes. The method developed by Murtagh et al. was used to give a population-based palliative care needs estimate, encompassing generalist and specialist palliative care need.

Results. During the period 2007–2011, there were 141,807 deaths. Eighty percent were from conditions recognized as having associated palliative care needs, with 41,253 (30%) deaths from cancer and 71,226 (50%) deaths from noncancer conditions. The majority of deaths, 81% (91,914), were among those ≥ 65 years. There was a 13.9% (901) increase in deaths of those ≥ 85 years. Deaths from dementia increased by 51.3%, with an increase in deaths from neurodegenerative disease (42.8%) and cancer (9.5%).

Conclusion. Future palliative care policy decisions in Ireland must consider the rapidly aging Irish population with the accompanying increase in deaths from cancer, dementia, and neurodegenerative disease and associated palliative care need. New models of palliative care may be required to address this. *J Pain Symptom Manage* 2015;49:726–733. © 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Palliative care, terminal care, end-of-life care, needs assessment, public health, chronic illness, Ireland

Introduction

In Ireland in 2011, one in 10 (11%) of the population were aged 65 years or older. This number is projected to double to 22% by 2041,¹ as the proportion

of those aged 65 years or older is increasing in Ireland at the fastest rate in the European Union.² It is internationally recognized that the prevalence of advanced chronic conditions increases with older age. Consistent

Address correspondence to: Pauline M. Kane, MB BCH, BAO, LRCP&SI, MSc, Department of Palliative Care, Policy and Rehabilitation, Kings College London, Cicely Saunders

Institute, Bessemer Road, London SE5 9PJ, UK. E-mail: pauline.m.kane@kcl.ac.uk

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with these international findings, health care service use in Ireland has been shown to increase with age, particularly for those aged 70–80 years.^{3,4} The needs of the aging Irish population may be further complicated as it has been projected that by 2021, 30% of those ≥ 65 years will be living alone.⁵ As a lack of community support is an indicator for hospital death,⁶ these projections may signal an early alert for planning and commissioning consideration for hospital services in the future. Already, in 2006, 48% of deaths in Ireland occurred in hospitals.⁷

Specialist palliative care has been shown to decrease hospital admissions in the last year of life⁸ and increase the odds of home death,⁹ and its effectiveness in improving symptoms and quality of life has been demonstrated.^{10,11} The potential role of palliative care in improving quality of life and symptom control for individuals with diagnoses other than cancer is internationally recognized.^{12–14} Similar to the U.K., palliative care in Ireland is provided to eligible patients in addition to any ongoing medical care at no cost to the patient. However, there is a paucity of Irish data available to determine palliative care needs in the population. This limits health care commissioning future planning and delivery for this important population.^{15,16} This lack of data is evident despite the availability of clear operational definitions between generalist and specialist palliative care in Ireland, which should facilitate the quantification of these palliative care needs. Within the Irish context, generalist palliative care is defined as care provided by health care professionals who apply the principles of palliative care.¹⁷ Specialist palliative care is defined as interdisciplinary care provided under the direction of a consultant physician in palliative medicine.¹⁷ The National Advisory Committee on Palliative Care, in its 2001 report, described the minimum service requirements for specialist palliative care provision,¹⁸ but these are yet to be delivered on. Similar to the U.K., the funding for palliative care in Ireland comes from particularly diverse sources, with major charitable sector funding and variable statutory funding; this range of funding sources makes it challenging to systematically understand and quantify gaps in resourcing.¹⁹ Annually, there is an approximate €70 million deficit in the budget for specialist palliative care, amounting to a 49% shortfall compared with recommended levels.²⁰

For national and regional service planning and development, it is essential to know the numbers in a population who need palliative care, with need here being defined as “the ability to benefit from palliative care.”^{21,22} The benefits of a population-based approach have been internationally recognized, with different approaches using routine mortality statistics to estimate population-based palliative care needs developed in Australia, Spain, and the U.K.^{23–26}

Higginson²⁵ undertook one of the first population-based palliative care needs assessments in the 1990s, where deaths from cancer and six nonmalignant disease groups were multiplied by symptom prevalence.²⁴ However, nonmalignant conditions such as dementia or stroke, more lately recognized as having palliative care needs, were not included.²⁴ In 2005, Rosenwax et al. identified 10 conditions (cancer and noncancer) known to have palliative care needs, using the International Statistical Classification of Diseases and Related Health Problems-10th Revision (ICD-10), and suggested three estimates of potential palliative care need. The minimal estimate was derived from the 10 identified conditions, including Alzheimer’s disease but excluding stroke. The midrange estimate incorporated hospital admissions for any of these 10 conditions (including Alzheimer’s disease and stroke) in the year before death and the maximal estimate included all but sudden deaths, that is, apart from those attributed to injury, poisoning, maternal, perinatal, and neonatal deaths.^{23,27} In 2012, Gomez-Batiste et al.^{26,28} turned the focus to patients with chronic progressive diseases and a limited life prognosis, estimating that these accounted for 75% of all deaths. Of late, Murtagh et al. compared and further developed approaches to needs assessment²³ to both broaden and refine the ICD-10 codes identified to more comprehensively encompass those diagnoses, particularly nonmalignant conditions, that are recognized as commonly having palliative care needs.²⁴ The *Global Atlas of Palliative Care* based its needs assessment on the original approach by Higginson, thus including noncancer conditions, and references the approach by Murtagh et al. as a useful method to identify potential palliative care need.²⁹

Death certification data are available in Ireland. Therefore, we aimed to apply the most recent method to estimate need (developed by Murtagh et al.) to determine a population-based estimate of palliative care need in Ireland. The second aim was to consider the quality of the Irish data available for population-based estimates of palliative care need. Such information will aid future commissioning, planning, and palliative care service development.

Methods

Design

This was a secondary analysis of death registration data. Four estimates may be calculated using the method developed by Murtagh et al.:²⁴ a minimal estimate based on the number of deaths from the conditions identified as having palliative care needs (Table 1); a lower intermediate estimate that includes all deaths in the minimal estimate together with deaths where Alzheimer’s disease, dementia, or

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