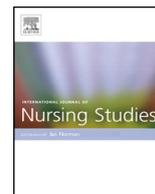




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Direct and indirect costs and resource use in dementia care: A cross-sectional study in patients living at home



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ABSTRACT

Background: Due to the high prevalence of dementia, health care needs are increasing beyond existing formal resources. In Spain, it is the family that takes care of this disease. **Aims:** To analyze the direct (health and non-health) and indirect economic costs related to care of people with dementia living with their informal caregiver in the home care/community environment, from the perspective of illness severity, associated comorbidity and social impact.

Design: Multicentric, descriptive study.

Setting: Three primary care public health centers associated with Hospital Clínic, Barcelona (Spain).

Participants: Patients over 65 years old with a diagnosis of dementia, and included in a home care program.

Inclusion criteria: People with a diagnosis of dementia made by a specialist neurologist; aged 65 years or older; a score ≤ 24 on the Mini-Mental State Examination, and identification of an informal caregiver.

Exclusion criteria: Patients unable to identify an informal caregiver, and those with primary psychiatric pathology or Korsakoff's syndrome.

Measurements: Use of Resources in Dementia to assess costs; Mini-Mental State Examination to evaluate cognitive capacity; Katz-Index to measure functional capacity; Neuropsychiatric Index for neuropsychiatric symptoms, and the Charlson-Index for comorbidity. Data collection took place between November, 2010 and April, 2012.

Results: The average estimated monthly care costs for people with dementia in the home setting are 1956.2€ (SD 1463.9). Informal care was the major contributor to this with a mean estimated cost of 1214.86 (SD 902.68)€/month. Greater illness severity, dependency in activities of daily living, comorbidity and behavioral disturbance are associated with higher costs. Behavioral disturbance appeared as the only factor independently associated

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with cost in dementia care. The group of people with dementia with severe behavioral disturbance requires the most care resources with an average cost of 2545.2 (SD 1753.2)€/month.

Conclusions: There is a direct association between dementia severity and increased costs. In addition, informal caregivers looking after people with dementia in Spain represent an important social cost. The independent factor associated with an increase in the total costs of patient care was neuropsychiatric symptoms.

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What is already known about the topic?

- Dementia illness is one of the major concerns in socio-health planning and one of the most important public health issues.
- In Spain, 87% of the total cost of caring for people with dementia is managed by the family and only the remaining 13% comes from the public purse to pay direct costs.
- In Spain, there is a tendency to keep people with dementia living at home, owing to cultural factors and organizational aspects in the health system.

What this paper adds

- This paper is the only Spanish study to analyze the costs related to the principal factors that have an impact on the cost of dementia care.
- The independent factor associated with an increase in the total costs of patient care was neuropsychiatric symptoms.
- Understanding the factors that contribute to increases in these costs can help to establish supportive socio-health policies based on determinant factors.

1. Introduction

Dementia forms part of a group of chronic, disabling illnesses requiring increases in care needs which exceed the capacity of existing formal resources (Oliva et al., 2007). These care needs are frequently covered by informal caregivers who are mainly family members of the care recipient. Taking changes in family composition and population aging into account, it can be expected that, in the near future, informal caregivers will no longer be able to respond to the care needs of people with dementia (Hurd et al., 2013).

In Spain, prevalence rates for those over 65 are found to be between 5.2 and 16.3% (López-Pousa and Garre-Olmo, 2010), reaching up to 30% for those over 85 (Antón Jiménez, 2010) and resulting in a total of some 400,000–500,000 sufferers (Coduras et al., 2010). These rates, and the natural course of the illness, make dementia one of the major concerns in socio-health planning and one of the most important public health issues (Turró-Garriga et al., 2010; Waldemar et al., 2007).

Care needs arising from dementia are associated with high health care and social costs (Hurd et al., 2013). In

Europe, these reach 160 billion €, according to estimates in a study carried out by Wimo et al. (2011) on the total costs of dementia. In Spain, the few economic studies on dementia care that exist show estimates of over 9000€ per patient/year for direct health care expenses alone (medication, diagnostic studies, etc.). When indirect costs are added, the figure rises to 19,000€ per patient/year for mild and moderate cases (Lema, 2005) and 37,000–52,000€ per patient/year for more advanced cases (Coduras et al., 2010; Jonsson and Wimo, 2009; Lopez-Bastida et al., 2006; Zhu and Sano, 2006).

In the early stages of the illness, patients are looked after at home and mainly receive informal care focused on help with activities of daily living. However, due to the progression of the illness and worsening physical and cognitive functioning, demand for community-based socio-health services increases, eventually leading to a need for formal care, which involves more nursing time, with its associated higher direct costs (Darbà et al., 2014; Jönsson et al., 2006). Although there is a general tendency to keep people with dementia living at home (Tucker et al., 2008; Verbeek et al., 2012), European studies show that, in Spain, this tendency is more marked owing to cultural factors and organizational aspects of the health system. In contrast to countries in the north of Europe, where informal care and indirect costs represent a third to two-fifths of the total (Gustavsson et al., 2010; Jonsson and Wimo, 2009), these costs account for three-quarters of the total in Spain due to patients being admitted later to long-term care institutions. As such, informal care covers a substantial portion of total dementia care costs (Jonsson and Wimo, 2009; Quentin et al., 2010), and an assessment of the value of the unpaid care services provided requires economic analysis from a social perspective (Drummond, 2005; Wimo et al., 2003).

In Spain, 87% of the total costs of caring for people with dementia is managed by the family and only 13% comes from the public purse to pay direct costs. These are principally health care costs and, in accordance with other studies, rise in line with the progress of the illness (Coduras et al., 2010; Georges et al., 2008; Jönsson et al., 2006; Jorgensen et al., 2008; López-Pousa et al., 2004; Turró-Garriga et al., 2010; Wimo et al., 2013). According to the literature, the main predictors of increased costs are loss of cognitive and functional capacity, neuropsychiatric symptoms and comorbidity (Jönsson et al., 2006; Wimo et al., 2013; Zhu and Sano, 2006). There are very few dementia studies carried out in Spain which show the association of

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