

Dementia severity and the longitudinal costs of informal care in the Cache County population

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Abstract

Background: Dementia costs are critical for influencing healthcare policy, but limited longitudinal information exists. We examined longitudinal informal care costs of dementia in a population-based sample.

Methods: Data from the Cache County Study included dementia onset, duration, and severity assessed by the Mini-Mental State Examination (MMSE), Clinical Dementia Rating Scale (CDR), and Neuropsychiatric Inventory (NPI). Informal costs of daily care (COC) was estimated based on median Utah wages. Mixed models estimated the relationship between severity and longitudinal COC in separate models for MMSE and CDR.

Results: Two hundred and eighty-seven subjects (53% female, mean (standard deviation) age was 82.3 (5.9) years) participated. Overall COC increased by 18% per year. COC was 6% lower per MMSE-point increase and compared with very mild dementia, COC increased over twofold for mild, fivefold for moderate, and sixfold for severe dementia on the CDR.

Conclusions: Greater dementia severity predicted higher costs. Disease management strategies addressing dementia progression may curb costs.

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Keywords:

Dementia longitudinal costs; Longitudinal caregiving costs; Longitudinal informal dementia; Costs; Alzheimer's disease costs

1. Introduction

Among older adults, dementia prevalence is high and quickly rising. Without significant advances in prevention and treatment options, worldwide estimates of 35.6 million today will reach 115 million by the year 2050 [1]. Alzheimer's disease (AD), the most common type of

dementia in late life, afflicts 5.2 million Americans; this number is projected to reach 13.8 million in 2050 [2].

Regardless of etiology, most conditions causing dementia are progressive, with continuous cognitive and functional decline, and often accompanied by unwanted neuropsychiatric symptoms (NPS). As a result, dementia is one of the most costly conditions for older adults, placing significant burden on patients, their family members, healthcare systems, and society. In the United States, aggregate direct healthcare costs including short- and long-term institutional stays for dementia patients are estimated by the Alzheimer's

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Association at \$203 billion in 2013 and projected to increase to \$1.2 trillion by 2050 [2]. Despite major differences between the individual cost components of dementia and cardiovascular disease (disease onset age and related factors of loss of workforce productivity, and institutionalization) for very rough comparison purposes, the estimated cost of dementia is on the order of that of cardiovascular disease in 2009 and 2010 (excluding nursing home costs of those with cardiovascular disease [3,4]).

Direct costs associated with dementia care include physician and nursing services, home care, institutional care, and informal caregiving costs. With the exception of the latter, all these costs must be purchased. Informal caregiving costs can be valued in terms of replacement costs or forgone wages and account for a substantial portion of the total costs of dementia care (e.g., [5]). The total costs of dementia care have been shown to increase as the condition progresses from mild to more severe stages [6].

Prior studies that have estimated the component costs of dementia care and their predictors have predominantly used information from administrative databases such as Medicare databases. Although a benefit of such studies is the large sample size, the sources have significant limitations such as lower sensitivity of disease ascertainment, which can lead to inaccurate estimates of individual costs [2,7]. Furthermore, many of these studies are cross-sectional in nature and do not capture individual-level longitudinal costs. Informal caregiver costs that are generally not paid by Medicare are also excluded. Two large studies have examined longitudinal costs of care relying on information from patient surveys: The Predictors Study in the United States [6,8,9] and a French study [10]. Notable strengths of The Predictors Study included follow-up time of 7 years and longitudinal estimates of unpaid caregiver costs. The French Study had a large sample size and examined the association of costs with worsening functional impairment. However, The Predictors Study drew dementia patients from academic clinical centers, whereas the French study drew dementia patients from a randomized clinical trial. Neither study's population is representative of typical community-dwelling dementia patients and their caregivers, for example, there is greater likelihood of individuals from clinic samples to be married and of higher socioeconomic status than persons drawn from the general community [11]. Recently Hurd et al. [5] estimated that the yearly cost of care attributable to dementia ranged from \$41,689 to \$56,689 (in 2010 dollars) depending on the method used to estimate informal caregiving costs. Informal care costs accounted for 31% to 49% of the total costs of dementia care. The study sample was drawn from the Health and Retirement Study (HRS), using individual, direct clinical assessment to identify a subsample with dementia and imputation to identify the final large sample with probable dementia ($N = 10,903$). As noted by the authors, the estimated total costs of dementia care were lower than those of the Alzheimer's Association [2] likely due to

differences in study populations, dementia severity, and correction for costs of care attributable to comorbid conditions. Although the Hurd sample is likely to be representative of a typical community-dwelling population with dementia, costs of dementia care or time devoted to dementia care vary with dementia severity [8,12,13] or the presence of NPS [14]. These factors were not examined in the HRS.

The Cache County Dementia Progression Study (DPS) is comprised of community-dwelling participants, where all dementia cases were clinically diagnosed [15] and followed for as many as 7 years, with rich information including caregiver hours, dementia progression, and NPS [16]. These data enable an estimation of the effect of disease severity and NPS on longitudinal informal dementia care costs in the community. With projected rising dementia prevalence and associated costs of informal dementia care, quantifying longitudinal informal care costs is critical for influencing health care policy, and resource planning. Although there are cross-sectional estimates of these costs across disease severity, there is scant longitudinal information using U.S. data. Our objective was to determine the effect of dementia severity on the longitudinal costs of informal dementia care in this population-based sample of persons with dementia.

2. Methods

This study used extant data from the prospective, population-based study of dementia, the DPS, which observed persons with dementia and their caregivers semiannually for up to 7.8 years (mean = 1.6; SD = 1.9; median = 1.3). Cases of dementia were identified from the Cache County Study on Memory in Aging in four triennial waves of dementia screening and ascertainment, described previously [15,17]. The eligible participants, permanent residents of Cache County, Utah, aged 65 years or older in 1995 (Wave 1) and found to be without dementia, were rescreened and assessed in subsequent waves: 1998 to 1999, 2002 to 2004, and 2005 to 2007. All cases of dementia were identified from a detailed clinical examination that included a physical and neurological examination, neuropsychological testing, and clinical information provided by a knowledgeable informant. Subsequently, participants with suspected dementia were asked to complete brain imaging and standard laboratory tests for dementia, and a physician examination to aid in the differential diagnosis of dementia. A panel of experts in neurology, geropsychiatry, neuropsychology, or cognitive neuroscience assigned a consensus diagnosis for each case. Persons were classified with dementia if they met *Diagnostic and Statistical Manual of Mental Disorders, Third Edition, Revised (DSM-III-R)* criteria [18]. AD was assigned following the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association criteria [19] and for vascular dementia, the National Institute

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