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Dementia and out-of-pocket spending on health care services

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Abstract

Background: High levels of out-of-pocket (OOP) spending for health care may lead patients to forego needed services and medications as well as hamper their ability to pay for other essential goods. Because it leads to disability and the loss of independence, dementia may put patients and their families at risk for high OOP spending, especially for long-term care services.

Methods: We used data from the Aging, Demographics, and Memory Study, a nationally representative subsample (n = 743) of the Health and Retirement Study, to determine whether individuals with dementia had higher self-reported OOP spending compared with those with cognitive impairment without dementia and those with normal cognitive function. We also examined the relationship between dementia and utilization of dental care and prescription medications—two types of health care that are frequently paid for OOP. Multivariate and logistic regression models were used to adjust for the influence of potential confounders.

Results: After controlling for demographics and comorbidities, those with dementia had more than three times the yearly OOP spending compared with those with normal cognition ($8216 for those with dementia vs. $2570 for those with normal cognition, $P < .01$). Higher OOP spending for those with dementia was mainly driven by greater expenditures on nursing home care ($P < .01$). Dementia was not associated with the likelihood of visiting the dentist ($P = .76$) or foregoing prescription medications owing to cost ($P = .34$).

Conclusions: Dementia is associated with high levels of OOP spending but not with the use of dental care or foregoing prescription medications, suggesting that excess OOP spending among those with dementia does not "crowd out" spending on these other health care services.

Keywords: Dementia; CIND; Out-of-pocket spending; Nursing home care; Population-based study

1. Introduction

The Medicare health insurance program offers nearly universal coverage for Americans aged 65 years and older, but paying for deductibles, copayments, and uncovered services may, nonetheless, represent a substantial financial burden. High levels of out-of-pocket (OOP) spending for health care are potentially problematic because they may lead patients to forego needed services and medications as well as hamper their ability to pay for other essential goods, such as food and housing, leading to sharp reductions in quality of life [1–4]. High OOP spending among those with illness and injury has also been cited as a common cause for personal bankruptcy [5] The significance of this issue is underscored by recent trends toward increasing OOP health care spending; 1 in 10 Medicare recipients spend at least 60% of their income on health care costs, up from 48% in 1997 [6]. Concerns about OOP spending have risen to prominence in the national policy discussion. Medicare Part D was enacted in 2006 mainly to protect seniors from high OOP spending on prescription drugs [7]. There are also calls to extend Medicare coverage to long-term care, another current source of high OOP expenditures [8].

Dementia is a chronic condition of aging characterized by cognitive decline that leads to a loss of independence. Owing

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to population aging, our calculations based on age-specific rates of dementia and population projections suggest that by 2040 the number of dementia cases will nearly triple (from approximately 3.4 million to 9.5 million cases). Because dementia limits the ability to function independently, demented individuals are much more likely to use long-term care facilities, such as nursing homes [9–11]. Medicare and private insurance coverage for these services are limited, and therefore, spending on long-term care represents the largest share of OOP expenditures for Medicare recipients [12]. Medicaid, the federal-state insurance program, does provide coverage for long-term care, but patients typically must meet income and asset tests to be eligible for Medicaid (eligibility rules vary across states). Consequently, patients suffering from dementia are at high risk of incurring very large OOP expenditures until they have "spent down" their assets below the Medicaid eligibility threshold [13–15].

Although there are reasons to suspect that dementia leads to higher levels of spending and health care utilization, the evidence remains mixed. Some studies find higher levels of cost and utilization among demented individuals [16–19], whereas others find reductions [20,21]. A key limitation of this line of research is the lack of data with reliable information on both costs and dementia diagnoses. Studies [17] using claims records have high-quality data on costs incurred by the payer, but they severely understate the prevalence of dementia and have limited information on spending on uncovered services (such as long-term care) [11,22–24]. Other studies use self-reported levels of OOP spending available in nationally representative data such as the Health and Retirement Study (HRS), but until recently, these data had no information on actual diagnoses of dementia [19,21]. In addition, owing to the sampling frame of the HRS, the samples used in earlier analyses likely undersampled individuals residing in nursing homes, who are precisely those at the greatest risk for very large OOP expenses [19]. Finally, no studies we are aware of have directly examined whether dementia reduces spending on types of medical care that are not directly related to dementia and that are typically paid for OOP. Were that to be the case, a possible explanation would be that high spending for dementia reduces economic resources for other types of health care spending, which could have additional health impacts.

This article addresses these limitations using newly available data from the Aging, Demographics, and Memory Study (ADAMS), a substudy of the HRS. The ADAMS includes clinical diagnoses of dementia status for a sample of individuals drawn from the HRS. We estimate the relationship between dementia and OOP spending for health care as well as between dementia and two types of health care that are typically paid for OOP and are not associated with dementia. Specifically, we use these data to test the following three hypotheses:

1. Dementia is associated with higher average OOP spending.
2. The increase in average OOP spending is driven by the incidence of large OOP expenditures on long-term care services, which are heavily used by individuals with dementia but are not typically covered by insurance.
3. Dementia reduces utilization of two types of health care (dental care and prescription drugs) that are not directly associated with care for dementia and that are typically paid for OOP.

This study is the first of its kind to use nationally representative data that combine information on (1) clinical diagnoses of dementia, (2) information on health care utilization and expenditures, and (3) detailed information on demographic characteristics and comorbidities that may confound the relationship between dementia and OOP spending. It is also the first study that we are aware of that uses nationally representative data to explicitly address whether dementia reduces utilization of two types of health care that are usually paid for OOP.

2. Data

2.1. HRS and ADAMS

This study examines the relationship between OOP spending reported in the HRS and diagnoses of dementia status made among individuals in the ADAMS. The HRS is a nationally representative longitudinal survey of individuals aged 51 years and older that began in 1992. Since 1996, the HRS core interviews have been conducted every 2 years. All individuals who enter the HRS are recruited from the community, but the HRS follows subjects even if they enter facilities such as nursing homes. The core interviews collect information on a wide variety of topics, including health status, health care utilization and spending, wealth and income, and employment histories [25]. All spouses of HRS respondents are interviewed, regardless of year of birth. Proxy interviews are used for study subjects who are unable to complete the survey interview without assistance.

HRS respondents aged 70 years and older formed the basis for the ADAMS sampling frame, the first nationally representative study of dementia in the United States. Subjects in ADAMS were drawn from either the 2000 or 2002 HRS. Sampling was stratified based on age, gender, and cognitive functioning, as measured by the cognitive assessment administered to HRS respondents. The final ADAMS sample consists of 856 respondents of 1770 who were recruited, which gives a response rate of 56%, net of mortality [26]. We further limit the sample to the 743 individuals who completed the HRS interview after the ADAMS assessment because, as explained later, this was when information on health care expenditures made during the period of the ADAMS assessment was collected.