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Gender Differences: A Lifetime Analysis of the Economic Burden of Alzheimer's Disease

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A B S T R A C T

Background: Gender is one of the best-established differences in risk for Alzheimer's disease (AD) and other forms of dementia, with women being at greater risk. However, the financial implications are unknown. This study aims at understanding the economic burden of AD by gender.
Method: This study takes a life-time perspective to investigate the burden of AD over the course of the disease. Nationally representative Medicare Current Beneficiary Survey data were used to estimate the course of illness of AD from age 65 to death and the incremental costs of AD on Medicare and Medicaid. Published data on the use and costs of assisted living facilities, home health care, and informal care were imputed into the course of illness to calculate the lifetime costs of these services.
Results: Females and males have distinctively different patterns of course of illness of AD. Women face higher risks of having AD (15.5% vs. 13.1%) and of serving as informal caregivers for AD patients (6.8% vs. 4.0%) before death. Medicare and Medicaid account for major payers of AD care for both genders, but the greatest economic challenge of AD to women is the cost of the informal care they deliver, resulting in women bearing six times the cost of men.
Conclusion: Public policy interventions that aim at curing or slowing the progress of AD will greatly benefit the welfare and economic status of women.

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Alzheimer's disease (AD) and other dementias pose a major health and economic challenge to U.S. society. At least one in eight Baby Boomers will develop AD before death (Plassman et al., 2007) and the average annual monetary cost of care for each AD patient is estimated to be between $41,689 and $56,290 (Hurd, Martorell, Delavande, Mellen, & Langa, 2013). However, a gap exists in literature investigating the differences in the health and economic burden of AD by demographic and socioeconomic features to guide more "targeted" interventions for the prevention, treatment, and care of AD patients.

One of the most established differences in AD risk across demographic categories is gender based, although the financial implications are unknown. Women face greater risks of either being diagnosed with AD or serving as informal caregivers for their family members with AD. Using nationally representative data, Hurd et al. (2013) found that surviving elderly women at age 65 or older have 38% higher (12.1% vs. 8.8%) risk to develop AD than surviving men. The National Alliance for Caregiving reported that approximately 60% to 70% of the informal care givers for AD patients are females, and females often take the most physically and mentally challenging roles in caregiving, including bathing, feeding, toileting, and so on, whereas men usually take the less stressful roles of reading, transportation, and spiritual support (National Alliance for Caregiving, 2009). Therefore, this study aimed to quantify the health and economic burdens of AD by gender.

Methods

Unlike the majority of existing literature that investigates the economic cost of AD at annual levels, this study takes an innovative lifetime perspective to investigate the burden of AD by

gender, over the course of the disease. Because AD is an extremely challenging and complicated chronic disease that could last more than a decade and requires a large variety of clinical and nursing care, the net cost of AD per capita throughout the lifetime is more informative for policy discussions than the annual cost. The lifetime cost is determined by three factors: 1) the probability to develop the disease before death, 2) the duration of the disease, and 3) the component and intensity of the formal or informal care that patients received over the course of illness. This study captures the gender differences in the lifetime cost of AD, to compare the costs of both formal and informal care reimbursed by a third party, paid out of pocket, or that are uncompensated, throughout the lifetime. These costs include Medicare cost for formal clinical and nursing care, Medicaid cost for clinical and long-term care (LTC), out-of-pocket cost for assisted living (ASL) facility care, out-of-pocket cost for home health (HH) care, and informal care provided by family members. This study used secondary data without identifying information that could link to the human subject. The data were analyzed on an authorized and protected computer on the Emory University campus. The Institutional Review Board of Emory University waived the review of human subject protection.

The data used in this study is from the Cost and Use Files of the Medicare Current Beneficiary Survey (MCBS) from 2000 to 2010. The MCBS is collected by Centers for Medicare & Medicaid Services (CMS) as a nationally representative sample of Medicare beneficiaries. It merges the survey information of the respondents' demographic, socioeconomic, and general health with their Medicare and Medicaid claims data. The details of MCBS are introduced by Centers for Medicare & Medicaid Services (2014) Respondents were identified as having AD based on any one of these three criteria: 1) a yes response for a survey question regarding whether the respondent has been diagnosed with Alzheimer's disease or dementia; 2) ICD-9 codes of inpatient and outpatient claims that indicate dementia (ICD-9-CM 290 or 331.0), and 3) outpatient prescription drugs claims showing utilization of drugs prescribed for dementia, including donepezil (Aricept), revastigmine (Exelon), galantamine (Reminyl or Razadyne), and memantine (Namenda; Taylor, Østbye, Langa, Weir, & Plassman, 2009; Taylor, Schenkman, Zhou, & Sloan, 2001; Yang, Zhang, Lin, Clevenger, & Atherly, 2012) We used these three criteria to include all possible AD cases, to avoid underestimates of the prevalence; 93% of the AD sample were identified by survey and/or the claims data, and the remaining 7% were identified by prescription drug utilization.

To focus on the gender differences, this study conducts a multistage analysis from the lifetime perspective among men and women separately. Such method is an expansion of the lifetime estimation method introduced in earlier publications (Lin, Yang, Howard, Cohen, & Neumann, 2014; Yang et al., 2012) First, we used regression analysis to estimate the risk of experiencing AD before death, the probability of death conditional on AD status, and the annual costs conditional on AD status and time to death. Then, a cohort-based, counterfactual simulation was conducted to estimate the duration of the disease after onset, the duration of time that AD patients will spend in the community versus in LTC facilities, and the lifetime incremental costs of AD on Medicare and Medicaid. The cohort-based demographic features were incorporated in the simulation, and all the costs were inflated to 2013 dollar value, based on Consumer Price Index of Medical Goods published by Bureau of Labor Statistics (U.S. Department of Labor, 2013), and all the cost estimates from the simulation are discounted to current 2013

dollar value for the current cohort at age 65. The details of the model can be found in the previous publication of Yang et al. (2012), and results of the regression models by gender will be provided by the authors upon request.

We calculated four types of cost related to AD: 1) Medicare cost for the reimbursement of clinical care, 2) Medicaid cost for the reimbursement of LTC, 3) out-of-pocket cost for ASL and HH care, and 4) the cost of uncompensated, informal care. The first two types of costs are borne by publicly financed entitlement programs, and the last two types of cost are usually borne by the family of AD patients and their caregivers.

The costs of Medicare and Medicaid are obtained from MCBS directly, because the claims data of MCBS provide the amount of reimbursement from Medicare or Medicaid to clinical or LTC services. The lifetime incremental Medicare and Medicaid costs of AD are then calculated by counterfactual simulation. For other types of cost, we imputed cost data from other sources into the simulated course of illness to obtain the lifetime estimates.

For ASL and HH cost, to simplify the estimation, we assume spouses are the primary caregivers for each other. The cohort covered by the MCBS survey and used in the simulation were born in the 1920s and 1930s, and entered into marriage age in 1940s and 1950s; according to the data from the National Vital Statistics System, the marriage rate among this cohort was close to 83% among both men and women in the 1940s and 1950s, and we used this marriage rate data in our analysis (Levine, 2014; Perrin et al., 1973; U.S. Census Bureau, 2000). We are aware that the marriage rate of this cohort after age 65 is likely lower because part of the population could have been widowed or divorced. However, that level of technical details is beyond the scope of this particular study because identification of marriage and divorce rates by age, gender, cohort, and AD status is quite challenging, and accounting these factors will not change the conclusions significantly. Therefore, we use the 83% marriage rate for the analysis, but acknowledge it as a limitation of this particular study.

Although ASL facilities provide nursing care, we count the AD patients in ASL as living in the community instead of LTC facilities, because MCBS data only specified nursing homes as LTC facilities. According to the National Association of Professional Geriatric Care Managers, currently there are around 735,000 residents in ASL nationwide, according to data provided by managers of ASL facilities, and 40% of those patients have AD (National Association of Professional Geriatric Care Managers, 2013). This accounts for about 5% of the 5.8 million AD/dementia patients. Therefore, we assume that there is a 5% probability that AD patients who stay in community will use ASL services, and we use this probability to calculate the out-of-pocket cost of ASL care for AD patients by gender in this study.

Besides the cost of ASL, this study assumes that the rest of community-dwelling AD patients use some form of HH care. We calculate the cost of HH care for AD patients in the community to be based on the probability that they will require HH care (1 minus 5% to use ASL at 95%) and impute the average annual cost of HH care as estimated by Hurd et al. (2013) at $5,678 per year.

Finally, the majority — 70% — of informal caregivers for AD/dementia patients are women. In this study, the informal care cost per AD calculation is based on the duration of time the AD patient spends living in the community, the average marriage rate of 83%, the probability of being a caregiver by gender, and the average annual cost of informal care based on replacement costs of $27,789 as estimated by Hurd et al. (2013). We are aware that no "gold standard" exists for estimating the cost of informal care, and we choose to use the replacement cost from Hurd et al.
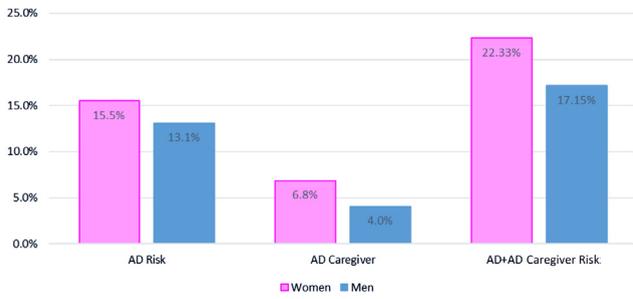
Figure 1. Lifetime risk of Alzheimer's disease by gender.

(2013) for two reasons. First, this is the most recent publication using nationally representative data. Second, we believe this particular estimate is conservative, to match with the economic theory of opportunity cost—low-income women are more likely to be caregivers themselves instead of hiring caregivers because of the lower opportunity cost of lost income.

Results

Risk of Developing AD or Serving as a Caregiver

Figure 1 depicts the lifetime per capita risk of developing AD or serving as a caregiver for a spouse with AD. Women have a greater risk of developing AD before death than men (15.5% vs. 13.1%). Such estimates of the lifetime AD risk are higher than the cross-sectional annual-based estimates among survivors by Hurd et al. (2013; 12.1% for women, and 8.8% for men), but are lower than the most recent study by James et al. (2014), which reported an estimated 15% per-capita risk of developing dementia across gender before death, using death certificate data.

Considering the lifetime risk of AD by gender, the marriage rate of 83%, and the 70% versus 30% gender distribution of probability to serve as a caregiver, women, on average, also have a higher risk of being affected by AD as a caregiver (6.8% vs. 4.0%).

Duration and Course of Illness of AD

Female AD patients live for about 6 months longer with the disease after diagnosis than men (5.3 vs. 4.7 years), and they are much more likely to live in LTC facilities than male AD patients (Figure 2). On average, female AD patients spend the vast majority (94%) of their years with AD in LTC facility after a confirmed diagnosis (5 out of 5.3 years), whereas men spend only 60% of that time (2.8 out of 4.7 years) in nursing home facilities. Therefore, on average, men spend about 2 years and women spend 0.3 year living in their home community after
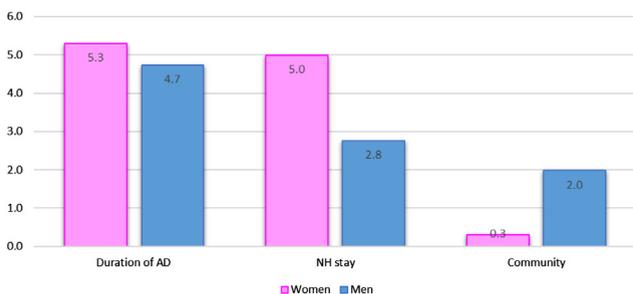

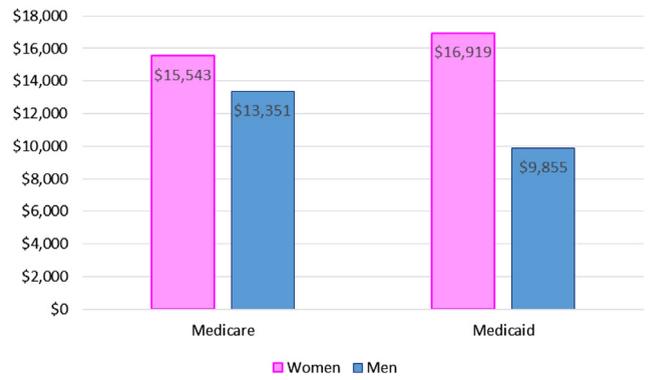**Figure 2.** Duration and course of illness of Alzheimer's disease by gender.

Figure 3. Lifetime incremental costs of care of Alzheimer's disease by third-party payer.

being diagnosed with AD. The estimates of the duration of AD on average and by gender are close to findings in the publication of Jing, Carol and Fiona (2008), which reported that the average survival time of AD after diagnoses is 4.5 years across both genders. However, we are aware that AD, especially among women, could last for as long as 8 or 10 years depending on disease stage at diagnosis, if onset of first symptoms or mild cognitive impairment is considered (Dementia Care Central, 2010) or the disease remained undiagnosed and the symptoms were attributed to "aging" (Dubois et al., 2007).

Incremental Costs of AD

Results indicate that, when taking a lifetime perspective, female AD patients cost the publicly financed health care system, namely, Medicare and Medicaid, more than male AD patients per capita (Figure 3). Female AD patients have a 16% higher incremental Medicare cost ($15,531 vs. $13,351) and a 70% higher incremental Medicaid cost ($16,919 vs. $9,855) than male patients over their lifetime. The major reason for the greater incremental Medicaid costs from AD among females is that women are more likely to be widowed and living in poverty, and therefore eligible for Medicaid.

As caregivers or family members of AD patients, women face higher risks of financial drain from caring for their spouses than men, by placing the AD patient in ASL or paying out-of-pocket for HH care (Figure 4). On average, each male AD/dementia case will
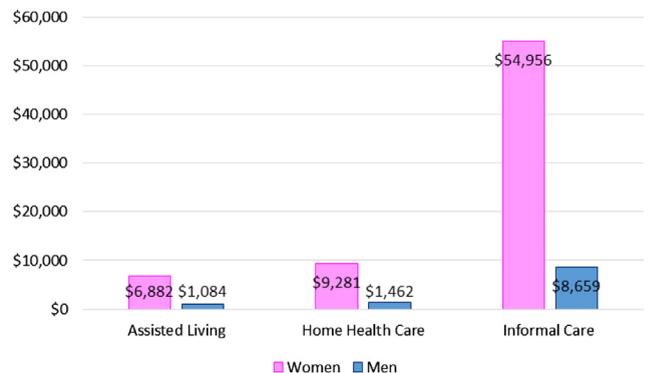

Figure 4. Lifetime incremental out-of-pocket and informal care costs absorbed by caregivers.

bring a financial loss of $6,888 to the female spouse from ASL costs, whereas each female AD/dementia case will bring a financial loss of $1,084 to her male spouse. For HH care costs, the financial loss for women with a male spouse suffering from AD/dementia is $9,212 per case, compared with a financial loss of $1,462 for men.

The most dramatic gender difference in cost of AD care is in uncompensated informal care. Throughout the lifetime, a female family member of a male AD patient will likely bear a burden of informal care six times greater than will a male family member of a female AD patient ($54,956 vs. $8,659).

Aggregate Costs among the Baby Boom Generation

Combining the estimates of risk of AD before death, the estimated lifetime incremental costs per AD case, and the gender distribution of 76 million Baby Boomers (52% women and 48% men, 2010 census), we calculated the total economic burden of AD at aggregate levels by gender (Table 1). Similar to the per AD case estimates, at the aggregate level, the cost of female AD patients, the financial drain from AD to female family members, and the replacement cost of LTC provided by female members are significantly greater than those among males. The most obvious difference is again in uncompensated informal care costs, with women providing 20 times greater costs than men across the entire Baby Boom generation. The least difference is in Medicare costs, with women AD patients costing Medicare 1.5 times more than do men.

Discussion

This study provides strong evidence that women and men have distinctively different patterns of course of illness and incremental costs of care for AD throughout the lifetime. Although the clinical and nursing care covered by Medicare and Medicaid represents much of the economic burdens from AD in both genders, female AD patients cost these two programs more than male patients. The greater dependence on Medicaid among women is owing to the overall lower economic status of women in older age, because the majority are widowed and face a greater risk of poverty. In addition, unpaid informal care provided by women to AD family members accounts for another major economic challenge of AD to women. Women face higher risks of being affected by AD as either patients or informal caregivers.

Implications for Policy and/or Practice

First, considering our findings that women have a higher risk of developing AD before death than men, female AD patients cost Medicare and Medicare more than males, and females face a higher burden of informal caregiving than males for family

Table 1
Aggregate Costs of Alzheimer's Disease Among 76 Million Baby Boomers

Payer	Women ($ Billion)	Men ($ Billion)	Women to Men Ratio
Medicare	95.12	63.84	1.5
Medicaid	103.54	47.13	2.2
Assisted Living	35.65	6.13	5.8
Home Health Care	48.06	8.24	5.8
Informal Care	235.22	12.11	19.4
Total	517.59	137.46	3.8

members with AD, curing or preventing AD would be certainly the most effective solution to alleviate the health and financial burden of this disease on women. Greater investment in scientific and clinical research from government, industry, and other funding sources to find solutions to cure or prevent AD could increase the well-being of the entire population and significantly improve quality of life for women—in particular, middle-age and elderly women.

Investment in research that leads to reduced risk or postponing the onset of AD could bring long-term financial savings to government entitlement programs. For example, previous studies found that small improvements in delaying the onset of AD, from better education or lowering the obesity rate or from scientific breakthroughs that slow the deterioration of cognitive functions and/or compress the duration of AD, will bring tremendous economic benefit to society with billions of savings to entitlement program benefits to women at the aggregate level (Langa et al., 2008; Lin et al., 2014; Yang et al., 2012).

Owing to the distinctively different patterns of course of illness of AD among women and men, as well as the sharp difference in Medicare and Medicaid costs of AD by gender, we urge that Medicare and Medicaid payment reforms are needed to meet the individual need of AD patients, in particular females, because female patients are more likely to be older, widowed, and living in poverty. The current Medicare fee-for-service payment model is out of date and ill suited to keeping up with the chronic and complicated demands for medical and nursing care for AD patients. Medicare reforms might reimburse innovative, integrated, and coordinated care delivery models, tailored to the needs of local AD patients in the field. As for nursing care, to date, there is no consensus on federal LTC reform, and to make matters worse, the current Medicaid LTC financing policy is also out of date. It leaves AD patients and their families, in particular, female patients and caregivers, with difficult choices: either to take care of their loved ones at home at their own cost or to spend down the patient's savings and assets and place them in a LTC facility that is reimbursed by Medicaid. There is no middle ground to achieve greater efficiency and provide women and families with better options. Hence, this study suggests an urgent need for LTC policy reform to enhance flexibilities in third-party reimbursement systems and LTC subsidies to promote cooperation between informal caregivers, the community, and the federal and state governments to keep patients at home, thereby saving costs and improving their quality of life (Edvardsson, Winblad, & Sandman, 2008).

Third, this study made a strong assumption that a spouse (most often a woman) will often service as the primary informal caregiver, and our estimate of the average duration of AD is on the conservative side at around 5 years. In fact, AD could last for up to 8 or 10 years, including earlier stages of mild cognitive impairment and undiagnosed cases (Dementia Care Central, 2010; Dubois et al., 2007). Many working women who are the daughters and granddaughters of an AD patient are the primary informal caregivers. Younger female caregivers are more likely to be well-educated with higher incomes. Older women tend to work longer, retire later, and have higher incomes. For this reason, our estimates of the informal care cost are also very conservative. We, therefore, call for more in-depth research to assess the burden of informal caregiving among working women to more fully understand the problem and provide sensible public policy solutions.

Last, owing to the complexity of the course of illness of AD, a better solution to this challenge in an aging society must be not

only multifaceted, but also individualized. Starting with addressing the cost and caregiving issues among women is a first step toward a more mature system to treat and care AD patients of all demographic and/or socioeconomic backgrounds.

Acknowledgments

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