

The Price Women Pay for Dementia

Strategies to Ease Gender Disparity and Economic Costs

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MILKEN INSTITUTE

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Acknowledgments

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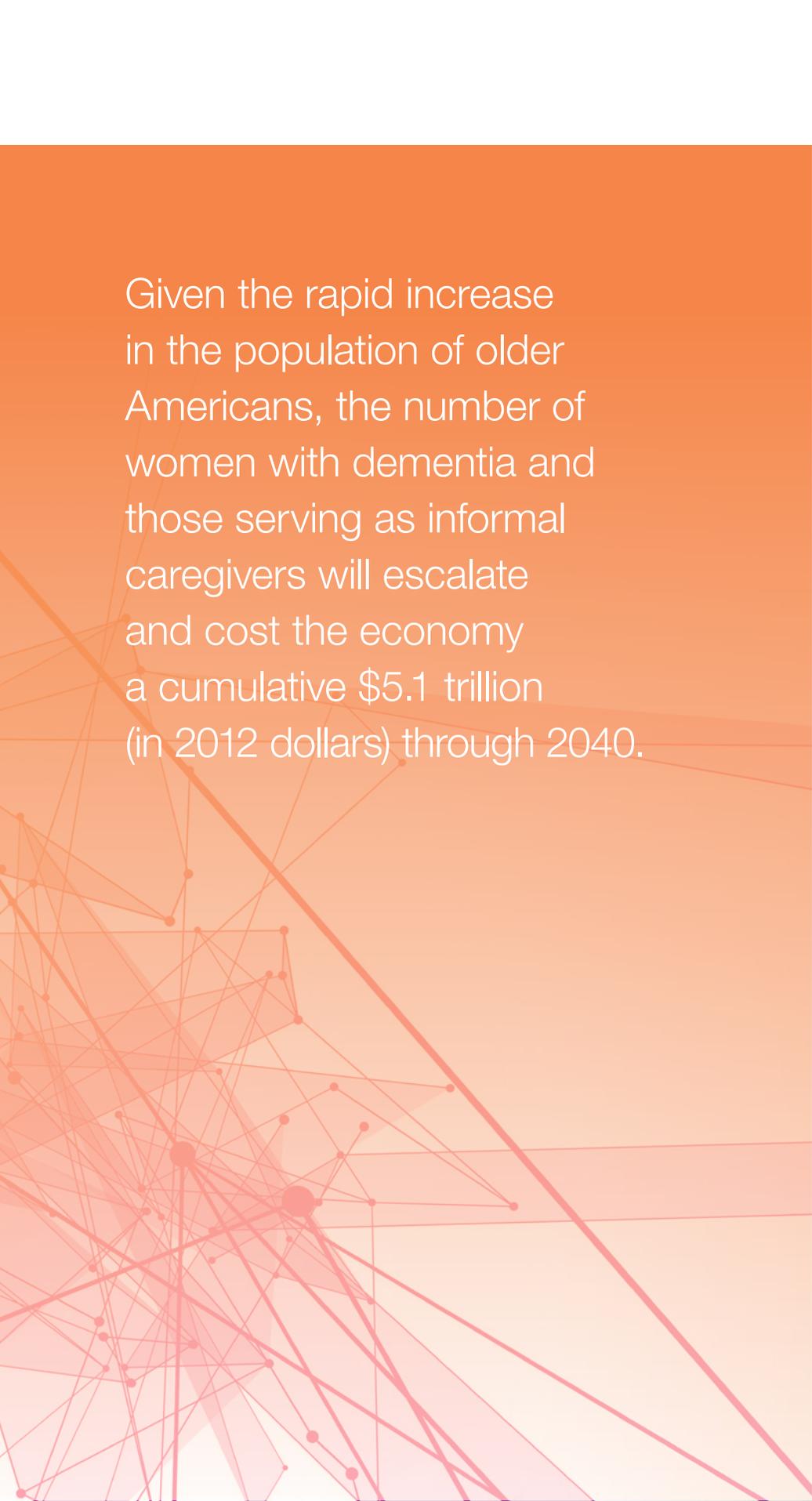
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Given the rapid increase in the population of older Americans, the number of women with dementia and those serving as informal caregivers will escalate and cost the economy a cumulative \$5.1 trillion (in 2012 dollars) through 2040.

Executive Summary

Dementia presents a pernicious gender-based health disparity in the United States, inflicting a disproportionate burden on women as both patients and caregivers. Of the 6.4 million Americans with dementia, women account for 4.2 million of them—or two-thirds of the patient population. This has been attributed to the fact that women live longer than men and have higher incidences of chronic diseases that increase the risk of developing dementia; however, recent research suggests there may be biological pathways that lead to greater cognitive impairment in females.¹ Women also make up the majority of informal caregivers, often as family members of dementia patients who need around-the-clock assistance with the most basic needs. Given the rapid increase in the population of older Americans, the number of women with dementia and those serving as informal caregivers will escalate and cost the economy a cumulative \$5.1 trillion (in 2012 dollars) through 2040.²

Clearly, if we don't change the current trajectory by delaying the average age of dementia onset, slowing its progression and severity, and ultimately, finding a cure, the human and economic toll on women, their families, and society will be immense. In addition to the financial incentive for narrowing gender disparities, there is a moral obligation to do so. Such a gender-related health disparity works to aggravate other economic disparities for women and impairs quality of life for all. And as it stands, preexisting societal norms often result in women becoming the default caregivers who grapple with insufficient support and the extraordinarily difficult demands of dementia care.

The severe effects of this malicious disease make the caregiver's role an exceptionally challenging one. Dementia gradually diminishes a person's memory, cognition, and ability to perform basic activities of daily life (ADLs)—these include bathing, grooming, dressing, and using the restroom independently—as well as instrumental activities such as cooking and getting around.³ Dementia can cause a person's brain cells to deteriorate so severely that it leads to an inability to swallow and eventually death.

Historical Effects: Social and Economic

Using federal survey data, we cataloged the number of cases and costs of treating dementia, and also developed non-treatment cost estimates.⁴ The overall economic burden of dementia on women in 2012 was \$91.1 billion, or a staggering 76 percent of the total economic burden in the U.S. (see Table 1). This figure is conservative as it excludes the incremental costs that

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1. Alzheimer's Association International Conference, "Women With Mild Cognitive Impairment Decline Twice as Fast as Men With the Condition," https://www.alz.org/aaic/_downloads/tues-8am-women-risk.pdf (accessed January 31, 2016).
 2. All projected numbers reported in the executive summary are in 2012 U.S. dollars, unless otherwise noted.
 3. Alzheimer's Association, "Alzheimer's Disease Facts and Figures," *Alzheimer's & Dementia* 11, no. 3 (2015), pp. 332+.
 4. Analysis based on data through 2012 from the Medical Expenditure Panel Survey provided by the Agency for Healthcare Research and Quality.

dementia adds to other chronic diseases such as heart disease, the detrimental impact on caregiver health and resulting increase in caregiver health-care costs, and the potential underreporting of self-reported dementia treatment costs.

Data on the number of cases from the Medical Expenditure Panel Survey is based on the treated prevalence. Because many individuals with dementia are undiagnosed, this causes underreporting. For example, the actual number of women with dementia is four times higher than the treated prevalence of 1.1 million. Dementia treatments are very expensive: Direct costs for women are \$6,800 per case, more than \$3,000 higher than for men. This yielded an estimate of \$7.5 billion in dementia treatment expenditures for women in 2012.

Table 1. Historical Economic Burden of Dementia (average, 2010-2012, US\$ billions)

	Treatment expenditures	Living arrangements	Indirect impact	Total
Men	2.8	19.2	7.2	29.2
Women	7.5	39.9	43.7	91.1
Total	10.3	59.1	50.9	120.3

Source: Medical Expenditure Panel Survey, National Health Interview Survey, Milken Institute.

In 2012, only 628,800 females with dementia were estimated to be in the workforce. In fact, the majority of patients are over 65 and not employed, resulting in a modest effect on the labor force. On the other hand, the missed workdays (absenteeism) and/or diminished productivity (presenteeism) of the informal female caregivers is many times greater. Of the total 5.8 million women caregivers in 2012, 60 percent were employed. Using average GDP per employed person, the combined indirect effect of absenteeism and presenteeism of female caregivers and patients was \$43.7 billion that year.

Further, because many caregivers need to work for financial reasons or choose to do so as a means of purposefulness, they often make use of adult day-care services. These services are tailored for younger, higher-functioning dementia patients. Increased access to these services could reduce the number of women leaving their jobs to be caregivers. However, nursing homes are the most expensive form of long-term care, costing \$80,000 per dementia patient on an annual basis. With over 450,000 female dementia patients using nursing homes, the total cost for women with dementia alone was \$39 billion in 2012.

Projections: Treatment and Cost Burden

Because the risk of developing dementia increases rapidly with age, the “silver tsunami” expected in the United States over the next few decades will accelerate the prevalence of the disease. For example, the probability of developing dementia in the 71-74 age cohort is 2.8 percent, but jumps to 20.3 percent for individuals in the 85-89 cohort.⁵ The U.S. Census Bureau projects that the share of Americans aged 65 and over will jump to 20 percent in 2040 from just 13 percent today.⁶ Without some breakthrough treatment for dementia, the prospect for the future is grim.

The dementia prevalence projection is based on a modeling approach⁷ developed by incorporating statistical relationships from an assortment of studies on dementia and Alzheimer’s disease. The associated treatment rates, caregiver demands, and living arrangement utilization rate projections are assumed to be proportional to the growth in the population with the disease. Treatment expenditures per person and costs of long-term care services are projected to rise commensurate with the growth rate of health-care expenditures in excess of the growth rate in nominal GDP, based on projections from the Centers for Medicare & Medicaid Services. The indirect labor market effects from lost work hours and lower productivity are based on forecasts of gains in GDP per employee.

Figure 1. Increasing Dementia Prevalence by Gender (2015-2040)



Sources: Medical Expenditure Panel Survey, Milken Institute.

5. Michael D. Hurd et al., “Monetary Costs of Dementia in the United States,” *New England Journal of Medicine* 3, no. 68 (2003), pp.1,326-34.
6. U.S. Census Bureau, 2014 National Population Projections, <http://www.census.gov/population/projections/data/national/2014.html> (accessed December 2015).
7. A Markov model was developed that examines the future population reporting a condition by incorporating disease states and probabilities of progression among them.

Table 2. Difference in Annual Economic Burden Between 2012 and 2040 (2012 US\$ billions)

	Treatment expenditures	Living arrangements	Indirect impact	Total
Men	6.0	40.5	17.2	63.8
Women	17.2	90.9	74.9	183.0
Total	23.2	131.4	92.1	246.7

Sources: Medical Expenditure Panel Survey, National Health Interview Survey, Milken Institute.

By 2040, under this current trajectory projection, the number of women afflicted with dementia would more than double, rising to 8.3 million. Women engaged as informal caregivers jump to 11.2 million. Annual dementia-related health expenditures for women reach \$24.7 billion, an increase of over 200 percent from today. Long-term care service costs for women vaults to \$130.7 billion in 2040. The indirect labor market effects from women informal caregivers will result in a GDP loss of \$118.6 billion. The combined figures for treatment, living arrangements, and indirect impacts increase the annual economic burden on women to \$274 billion in 2040, three times the burden from 2012. The total economic burden, including men, rises to \$367 billion in 2040.

Policy Prescriptions

There is no single policy that could address the multiple effects of dementia. Instead, it will take a concerted effort on various fronts to tackle the disease effectively. To that end, here are five policy prescriptions for creating an alternative future:

Policy One: Widen Access to Health Care

Improving access to primary care and home health is necessary to shift toward more reliance on inpatient and outpatient care for dementia. The current shortage of health-care professionals trained in geriatrics will only be exacerbated as dementia cases rise in the future. A wide range of medical professionals, including but not limited to doctors and nurses, must be trained. Incentivizing this process will require substantial financial resources and falls outside the traditional definition of health-care costs associated with a disease.

Policy Two: Expand Scope and Flow of Services

Until a cure is found or more efficacious treatments are available, an expansion in the scope of health care is needed to improve coordination between long-term care services and other categories of social service organizations. As dementia patients' cognitive functions deteriorate, families providing informal care will require more long-term-care services to assist with activities of daily living. Increasing insurance coverage for long-term-care services such as

nursing home and adult day-care services, as well as making long-term-care insurance more affordable, could reduce the burden on informal caregivers and minimize labor market side effects. Enhancing coordination of care between the health-care system and the community is a framework that's now being incorporated into new models of health-care delivery such as the patient-centered medical home.

Policy Three: Raise Dementia Awareness and Expand Caregiver Training

A significant percentage of people living with dementia are undiagnosed, which means they aren't receiving treatments that could slow the progression of the disease or minimize its side effects. Raising public awareness of the signs of dementia and better communicating the steps toward diagnosis could lead to earlier and more effective treatment. Earlier diagnosis could also provide opportunities for better caregiver training and reduce stress associated with informal caregiving, which could ameliorate absenteeism and presenteeism in the workplace by caregivers. In addition, greater public awareness could encourage employers to provide elder care in the workplace similar to child care, minimizing productivity loss.

Policy Four: Provide Support in the Workplace

As women's participation in the labor force has risen, the demands on women as caregivers at home have become even more stressful. Women have made progress toward gender parity in the workplace; many are the primary breadwinners of households. An increase in the demand for long-term care services and home health services will likely result from rising prevalence. A small level of financial assistance from employers or government could allow informal caregivers to remain employed, especially if the dementia case is not yet severe. Simply raising awareness and understanding in the workplace, along with providing more comprehensive services, would reduce disparities for women. If a policy change could result in a 60 percent reduction in lost workdays for women caregivers, it would boost GDP by a cumulative \$776 billion in 2012 constant dollars by 2040.

Policy Five: Increase Funding for Alzheimer's and Dementia Research

Finally, we cannot ignore that more funding for both basic and translational research is necessary. There are few clinical trials underway targeting Alzheimer's disease and dementia. Past trials suffered from very low success rates and many drug firms have diminished or eliminated programs. Better understanding of the brain's biological mechanisms would aid drug development and medical technologies. The 2016 budget bill that Congress passed contained a \$350-million increase in funding for dementia research at the NIH. This is a good down payment, but more should be done in funding basic research in the field.

The importance of investing in medical innovation for dementia is demonstrated by an economic evaluation. We examined an alternative future where the burden of the disease could be diminished by an increase in R&D that would yield a novel medical technology that reduces dementia prevalence by 20 percent, compared with its current trajectory, by 2040. We chose 2025 as a starting point because drug development studies reveal an average span of 13 years before a new therapy is approved. All other assumptions for projecting treatment costs, living arrangements, and labor-market effects were maintained at the same levels. It would result in 1.7 million fewer

female patients by 2040. This alternative projection saves a cumulative \$33 billion in treatment expenditures and \$170.4 billion in living arrangement costs while boosting GDP by \$170.7 billion for women alone (see Figure 2). That translates to a cumulative savings of \$374.1 billion in 2012 constant dollars.

Figure 2. Projected Cumulative Savings Associated With Increased Research Incentives (2012-2040, US\$ billions)



Sources: Medical Expenditure Panel Survey, Milken Institute.

Conclusion

Dementia is one of the most underappreciated health crises facing the country over the next few decades as its prevalence is likely to jump. A granular examination of the issues associated with the disease exposes an insidious impact that is often discussed in whispers: the gender disparities that women suffer as patients and caregivers, and the particularly intensive role of the dementia caregiver. Quantifying dementia's effects on the health-care system, long-term support services, and the labor market makes a case for increased awareness, funding, research, and care. To achieve an efficient solution, members of all affected groups—from government to patients, from researchers to employers—must coordinate and collaborate. Ultimately, a cure must be found, but in the interim, there are actions that we can take to lessen the suffering of patients, families, society, and the detrimental impacts on our economy.

Introduction

Dementia is a chronic, progressive health condition with no cure. Although the risk of dementia increases with age, not every older adult is afflicted with the disease. Alzheimer's disease is a common form of dementia, making up an estimated 60 percent to 80 percent of total cases.⁸ According to the National Institutes of Health (NIH), Alzheimer's affects as many as 5.3 million people in the United States.⁹ And with a growing aging population resulting in a more than commensurate rise in the proportion of Americans with chronic diseases, it is likely that the number of dementia-affected cases will grow drastically in the future. As researchers work to find a cure for Alzheimer's disease and dementia, many other issues related to dementia need to be addressed. One such issue is the gender disparity in the impact of dementia/Alzheimer's.

According to the Alzheimer's Association, two in three Alzheimer's patients are women. The prevailing literature assumes the main reason for this is the greater longevity of women compared with that of men, although there have been studies indicating increased health-related risks for women.¹⁰ For example, obesity has been cited as a potential risk factor for dementia, and as obesity is higher in women, this raises the concern that they might become even more disproportionately affected by the disease in the future.

Activities of daily living (ADL)

Basic tasks for self-care

- Getting in and out of beds and chairs
- Bathing
- Grooming
- Dressing
- Using the restroom

Instrumental activities of daily living (IADL)

More complex tasks required for independent living

- Cooking
- Shopping
- Transportation
- Managing finances

Dementia hinders a patient's ability to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs), which are many of the things that enable a person to maintain independence (see box). As the disease progresses, the patient begins to require the assistance of a caregiver, usually a family member. The typical caregiver for someone with dementia assists with 2.2 ADLs and 4.6 IADLs per week, in addition to other tasks such as medical assistance and monitoring.¹¹ Caregiving for dementia in particular is more demanding, requiring more intensive care and longer hours than typical caregiving. If informal caregiving is insufficient, patients can also use formal home health services, which are paid for either by insurance or out of pocket.

8. *FasterCures*.

9. Alzheimer's Association. "Alzheimer's Disease Facts and Figures," *Alzheimer's & Dementia* 11, no. 3 (2015), pp. 332+.

10. Katherine A. Lin et al., "Marked Gender Differences in Rate of Progression of Mild Cognitive Impairment of 8 Years," *Alzheimer's & Dementia* 1, no. 2 (2015), pp.101-103.

11. National Alliance for Caregiving and AARP, "Caregiving in the U.S." (2015).

About 70 percent of informal caregivers are women.¹² Due to the time-consuming nature of dementia care, many of them drop out of the labor market, reduce work hours, or incur lost workdays and productivity losses. All of these adversely affect the economy, reducing GDP. With women's participation in the labor force expected to rise in the future, the impact on the economy would be magnified. This projection also implies a need for more formal care services, in the form of either home health or long-term support services such as adult day care and nursing homes.

It is essential to develop a plan to allocate resources for more adult day services and home health care, especially geared toward women. Trends already reveal an increase in utilization for these types of care. Women tend to live longer, often surviving their spouses, so the need for these services for women are more prevalent. The expensive nature of long-term care creates access issues. Without adequate resources, patients must rely increasingly on informal caregivers, aggravating the aforementioned negative impact on the economy.

Considering all the factors discussed, dementia disproportionately affects women. The increasing prevalence of dementia is alarming. And its consistently disproportionate impact on women represents a disparity in health. Unless effective steps are taken in the near future, the drain on the health-care system and the economy will be tremendous. Consider, too, that disparities in health lead to economic loss and diminished quality of life—a gender-related health disparity aggravates other economic disparities for women. There is a moral and financial incentive for reducing disparities in health. While dementia differentially affects women, both genders suffer substantial consequences from the diseases. Sustainable solutions to end such disparities are important not only for women but would improve the quality of life for all.

The objective of this project is to provide fact-based evidence of the economic burden of dementia on women by aggregating the effects on the health-care system, the labor market, and living arrangements. In order to do that, we examine historical effects and estimate disparities through 2040.

This type of data evidence is imperative, we believe, and the results of this study can be used to accomplish the following:

- Raise public awareness surrounding gender-specific effects of dementia.
- Advocate for increased funding for research on dementia and related treatment development.
- Assess labor-market impacts of dementia so employers can strategically address the issue.
- Quantify the burden of dementia on caregivers and increase discussion of long-term care options.
- Encourage solutions to the problems identified by better understanding the magnitude of the potential human and economic consequences.

12. Alzheimer's Association. "Alzheimer's Disease Facts and Figures," *Alzheimer's & Dementia* 11, no. 3 (2015), p. 332+.

Reducing the Cost of Dementia and Closing the Gender Gap

Background

To assess the costly nature of dementia, it is important to look at historical experience. The U.S. spends billions of dollars per year on dementia care, making it one of the costliest diseases. The prevalence of dementia is rapidly rising as well, compared with other diseases.¹³ This not only magnifies overall health-care costs, but affects the need for different sites of services within the health-care system. For example, a higher prevalence of dementia will increase the burden on office-based and outpatient care as physicians determine what combination of treatment works best for each patient. Specifically, women have different health concerns and lifestyles from men. As dementia treatment and care is not contained just within the health-care system but rather is relevant to many aspects of daily life, health professionals must tailor care according to gender.

Populations Affected

Patients

We identified the number of people reporting dementia, or the treated prevalence, and the expenditures associated with the disease using the Medical Expenditure Panel Survey (MEPS). MEPS is a nationally representative survey of the U.S. civilian, non-institutionalized population. We aggregated data using the following sites of services: office-based, outpatient, inpatient, emergency room, home health, and prescription.¹⁴

This report specifically examines the difference in dementia's effect on women compared with men. Being a woman has been associated with increased risk of having the disease, though the consensus in the literature is that this difference stems largely from women's longer life expectancy. Studies that adjust for age often eliminate the significance of gender as a risk factor for incident disease.¹⁵

However, dementia is not well understood. What's clear so far is that it is associated with a variety of risk factors, including genetics, cardiovascular and metabolic diseases, and lifestyle. In concert, they help explain women's vulnerability to dementia. Among people older than 75, for example, women are more likely to have chronic diseases such as hypertension and diabetes compared with men.¹⁶ Women also tend to have a more aggravated cerebral response to cardiovascular conditions such as hypertension and stroke.¹⁷ Having certain dementia-related

13. Walter A. Rocca et al., "Trends in the Incidence and Prevalence of Alzheimer's Disease, Dementia, and Cognitive Impairment in the United States," *Alzheimer's & Dementia* 7, no. 1 (2011), pp. 80-93.

14. As home health is often covered by insurance such as Medicare, it was considered an expense of the health-care system.

15. Alzheimer's Association, "2010 Alzheimer's Disease Facts and Figures," *Alzheimer's & Dementia*, no. 6 (2010).

16. Nahid A. Azad et al., "Gender Differences in Dementia Risk Factors," *Gender Medicine* 4, no. 2 (2007) pp. 120-9.

17. Ibid.

genes can impose a more detrimental effect on cognition for women compared with men.¹⁸ As women age, often outliving their spouses and other peers, they may lose the social networks that help shield against dementia.¹⁹ Further research may reveal a more complex interplay among genetics, co-morbidities, and lifestyle. New studies are revealing further links between female gender and incident disease.²⁰ This could provide further insight into cures and treatment methods. Regardless of a causal connection, the number of women suffering from dementia is larger than that for men, and it has significant implications for the patient's interactions with her family, support systems, and community.

Data from MEPS shows that there are more women reporting dementia than men: 1.1 million compared with 758,700 men (see Table 3). This estimate is not equal to the disease prevalence because MEPS relies on self-reported data. The reported value is known as treated prevalence or population reporting a condition (PRC). People with dementia may not report having the disease because they are undiagnosed, uninformed by their providers, or unaware of the nature of their medical care. Studies in the community indicate that over half of people with dementia may be unaware of their disease status.²¹ The dementia sample size in MEPS is small. To improve accuracy, three-year averages between 2010 and 2012 are calculated and reported for all historical figures.

Table 3. Population Reporting Dementia (average 2010-2012, thousands)

	Treated prevalence	Prevalence	Difference
Men	758.7	2,211.4	1,452.7
Women	1,101.7	4,177.1	3,075.4
Total	1,860.4	6,388.5	4,528.1

Sources: Medical Expenditure Panel Survey, Alzheimer's Association, Milken Institute.

The Alzheimer's Association reports the prevalence of Alzheimer's disease in people over 65 to be 5.2 million in 2012, affecting 3.4 million women and 1.8 million men. Total prevalence is reported at 5.4 million, with only 200,000 people under 65. According to the association, Alzheimer's disease accounts for 60 percent to 80 percent of dementia cases. A conservative estimate of total dementia prevalence would then be 6.4 million (average 2010-2012), with 4.2 million women and 2.2 million men (see Table 3). Women with dementia outnumber men almost 2:1.

The treated prevalence estimate derived from MEPS accounts for 4.5 million fewer people, signifying millions of patients or family members not reporting incidence, potentially because they are unaware of the disease or not receiving treatment (see Table 3). There is a significant gender

18. Ibid.

19. Alzheimer's Association, "Alzheimer's Disease Facts and Figures," *Alzheimer's & Dementia* 11, no. 3 (2015), pp. 332+.

20. Ibid.

21. Ibid.

disparity in the figures for difference in treated prevalence and prevalence, with underreporting of dementia occurring more frequently for women. Specifically, 3 million women with dementia are not reporting disease or not receiving treatment, compared with 1.5 million men. There are many reasons for underreporting, and so it is difficult to quantify the extent of the correlation between underreporting and undertreatment, but the discrepancy could indicate a harmful disparity in health for women, and should be further investigated.

Caregivers

The effects of dementia are far-reaching, extending past the patient and the health-care system and into the community. Dementia entails a chronic decline; as the disease worsens, patients are able to perform fewer of the activities of daily living. They enlist loved ones to assist them. Fortunately, the majority of dementia patients have people in their lives willing and able to serve as informal, unpaid caregivers, allowing them to “age in place”—that is, in the comfort and safety of their own homes and communities. These informal caregivers represent a crucial component of the dementia-care complex, providing as much as 80 percent of the long-term support services.²²

Informal caregiving is common in the United States, with 39.8 million adults giving care to another adult, and 22 percent of these caregivers providing support for a patient with dementia.²³ Six in 10 caregivers are female, and most are adult children of the care recipients.²⁴ Informal caregiving primarily involves assisting incapable individuals with ADLs, ranging from helping with housework to dealing with incontinence or diapers. They often advocate for the patient, monitor care, and communicate and coordinate with multiple medical providers. Increasingly, informal caregivers are performing medical tasks such as tube feedings, catheter care, and injections.²⁵

This often involves heavy burdens on the caregivers, who on average spend 24.4 hours a week caring for their loved ones.²⁶ Half of informal caregivers feel they had no choice but to take on their caregiving responsibilities.²⁷ For patients with severe illness, the need to provide care can influence caregivers to miss work or quit, and female caregivers are 40 percent more likely to quit their jobs than male caregivers.²⁸ Additionally, as the burden increases the stress in one’s life, caregiving is associated with worsened health outcomes and an increase in health-care costs by \$4,766 per year per caregiver.²⁹

Treatment Expenditures

Dementia is an expensive disease to treat. Dementia-related expenditures per person for women are \$6,769 per year. This is over \$3,000 more than dementia-related expenditures for men (see Table 4). There is no significant difference in per-person treatment expenditures

22. Regina A. Shih et al., “Improving Dementia Long-Term Care: A Policy Blueprint,” RAND Corp. (2014).

23. National Alliance for Caregiving and AARP, “Caregiving in the U.S.” (2015).

24. *Ibid.*

25. *Ibid.*

26. *Ibid.*

27. *Ibid.*

28. MetLife Mature Market Institute, “Caregiving Costs to Working Caregivers,” MetLife (2011).

29. *Ibid.*

for men and women if home health is removed. This further emphasizes the dramatic effect of Alzheimer's disease and dementia on the home and family life of a patient, and the crucial role of informal caregiving as a treatment mechanism.

Table 4. Expenditures Per Person Affected (average 2010-2012 US dollars)

	Patients with dementia		Patients without dementia
	Dementia-related expenditures/PRC*	Total expenditures/PRC*	
Men	3,696	14,207	3,818
Women	6,769	19,795	4,424
Total	5,516	17,615	4,127

* PRC is population reporting a condition.
Source: Medical Expenditure Panel Survey.

Dementia can also increase an individual's overall health-care costs. Because of the diminished ability to perform ADLs and IADLs, patients may be less able to manage their disease, thereby increasing treatment expenditures associated with other diseases. Dementia is associated with risk factors for or incidence of chronic disease such as heart disease. In fact, one of the standards of care for dementia patients is to control and maintain their cardiovascular health.³⁰

Total treatment expenditures were examined comparing patients with dementia to patients without dementia. Expenditures were much higher for patients with dementia, and in fact the difference in expenditures per PRC for patients with dementia compared to those without (\$13,488) was larger than the average annual dementia-associated expenditures per PRC (\$5,516) (see Table 4). It must be noted that these comparisons are not adjusted for age.

Table 5. Treatment Expenditures Associated With Dementia and Dementia Patients (average 2010-2012 US\$ billions)

	Dementia	
	Expenditures associated with dementia	Total expenditures for dementia patients
Men	2.8	12.7
Women	7.5	28.0
Total	10.3	40.7

Source: Medical Expenditure Panel Survey.

30. Alzheimer's Association. "Alzheimer's Disease Facts and Figures," *Alzheimer's & Dementia* 11, no. 3 (2015), pp. 332+.

For the 1.1 million women represented by MEPS, dementia-related health-care expenditures are \$7.5 billion per year, representing over one-fourth of their total health-care expenditures (see Table 5). As discussed, as many as 3 million more women may have dementia but are not receiving care or not reporting the disease. The \$7.5 billion estimate may be conservative.

However, with better diagnostic methods and education, underreporting and underdiagnoses could be reduced. More women would know that they have disease and more women would receive and report treatment, which could mean as much as \$20.8 billion in additional reported dementia-related health-care costs (see Figure 3). The equivalent for men would total \$5.3 billion. A proportion of these estimates would not be new costs introduced to the health-care system but rather existing costs newly identified as being associated with dementia. It is likely that the undiagnosed dementia population has a larger proportion of mild disease, and therefore expenditures per patient for this group would be lower than for the currently diagnosed population.

If everyone with dementia received the same treatment as those identified in MEPS, health-care expenditures related to dementia alone would be \$36.5 billion, \$26.2 billion more than our initial \$10.3 billion estimate (see Figure 3). Still, increased costs associated with more robust screening and treatments should not represent a disincentive. There is not only an ethical incentive to improve dementia care, but also early and improved treatment for all patients may reduce downstream treatment expenditures as well as living arrangement costs and indirect impact.

Figure 3. Expenditures Linked to Dementia (average 2010-2012)



Sources: Medical Expenditure Panel Survey, Milken Institute.

Current diagnostics and treatment for dementia are limited relative to other clinical conditions. Treatment includes managing both symptoms and risk factors (such as diabetes, heart disease, and hypertension). There are several FDA-approved medications for dementia, but these treatments target the symptoms instead of the cause of the disease.³¹ Prescriptions related to dementia make up a significant chunk of the treatment expenditures.³² There is still a huge need for innovation in drugs and technology to effectively identify and slow the progression of dementia.³³ This is all the more difficult because there are different types of dementia (Alzheimer's disease, vascular dementia, mixed dementia, etc.).

With the current standard of care, managing dementia becomes much more about helping patients maintain their ways of life as their cognitive abilities decline. Representative of this is the fact that home health accounts for the largest portion of treatment expenditures. To truly understand the economic burden of the disease, we cannot examine only the costs to the health-care system. It is clear that much of this burden falls on the caregiver instead of the patient. Even if a cure is on the way, caregivers face a predicament in the present.

Broader Economic Effects

In addition to the effects on the health-care system, dementia indirectly affects the labor market by decreasing the productivity of dementia patients and caregivers. We examined three facets of productivity loss due to dementia or related caregiving:

- Absenteeism: lost workdays
- Presenteeism: underperformance at work
- Job departure effects: productivity loss associated with employees leaving their jobs

Patients and Employment

The majority of patients with dementia are over the traditional retirement age of 65, but that does not preclude them from working. In the initial stages of dementia, the cognitive decline may be mild enough that the person can continue to work. Based on treated prevalence calculations from MEPS, the National Health Interview Survey (NHIS) and Bureau of Labor Statistics (BLS), over 200,000 people with dementia were employed to some extent (average 2010-2012). Accounting for the undiagnosed population and underreporting bias expands this number to 825,600.

Though many patients will leave work or retire as the disease progresses, employed patients might miss workdays (absenteeism) and/or perform less productively (presenteeism). (We did not calculate job departure effects associated with dementia because a large majority of the dementia patient population is over the retirement age.) Combining this data with average GDP output per employed person, the indirect impact of dementia associated with patients was calculated to be \$14.9 billion for women and men combined.

31. *FasterCures* Philanthropy Advisory Service, "Alzheimer's Disease Report," *FasterCures* (2015).

32. Medical Expenditure Panel Survey.

33. *FasterCures* Philanthropy Advisory Service, "Alzheimer's Disease Report," *FasterCures* (2015).

According to NHIS data, women with dementia were more likely to be employed than men, and therefore the large majority of foregone GDP is associated with female patients. However, these differences were not statistically significant, likely due to the small sample size associated with the 2007 NHIS survey. The treated prevalence population represents \$3.9 billion of the total foregone GDP.

Table 6. Workplace Outcomes for Dementia Patients (average 2010-2012)

Patients	EPRC* (thousands)	Absenteeism (\$ millions)	Presenteeism (\$ millions)	Total Foregone GDP (\$ millions)
Men	196.8	14.5	106.5	120.9
Women	628.8	1,769.9	13,031.6	14,801.4
Total	825.6	1,784.3	13,138.0	14,922.4

* EPRC is employed population reporting a condition.

Sources: Medical Expenditure Panel Survey, National Health Interview Survey, Milken Institute.

Caregivers in the Workforce

There are many more dementia caregivers in the workforce than there are dementia patients. The time and stress associated with caregiving can result in the same effects: absenteeism, presenteeism, and job departure. The number of caregivers was calculated from the “Caregiving in the U.S. 2015” report by the National Alliance for Caregiving and AARP, based on data collected in late 2014. This should not be compared to prior reports in 2004 and 2009 as a new survey methodology was used, resulting in some variation in reported outcomes across versions. Because the number of caregivers varied, we assume the number from the 2015 report was the most accurate.

The number of caregivers for dementia patients is 9.6 million, which is in fact more than the number of patients with dementia (see Table 7). Many patients require more than one caregiver to assist with the range of their needs.

Incorporating caregiver effects into calculating the economic burden of dementia is crucial because caregiving is a stressful and time-consuming activity that can depress finances and job performance, ultimately affecting an individual’s capacity to contribute to GDP. Almost 60 percent of dementia caregivers are employed, the majority of whom are full-time. Dementia tends to be a particularly burdensome condition to care for. People who provide informal care more hours per week are less frequently employed, which could be due in part to caregivers leaving their jobs because of their caregiving responsibilities.

Table 7. Dementia Caregiver Workplace Outcomes (average 2010-2012, thousands)

	Dementia caregivers	Employed caregivers	Caregivers who left jobs
Men	3,833	2,530	56
Women	5,750	3,162	89
Total	9,583	5,692	145

Sources: Medical Expenditure Panel Survey, Metlife Market Institute, Milken Institute.

Of the 9.6 million employed dementia caregivers who are women, 145,000 left their jobs on average in one year (see Table 7). Compared to male caregivers, 60 percent more female caregivers left their jobs. Foregone GDP due to job departure totals \$8.3 billion annually, with 61 percent of that involving women. Unfortunately, this represents only 20 percent of the indirect impact from dementia caregiving (see Table 8). The remaining 80 percent of foregone GDP, totaling a staggering \$27.6 billion annually, is associated with absenteeism and presenteeism in the workplace. As women are more likely to be intensive caregivers, it follows that 86 percent of absenteeism and presenteeism is associated with them.

Table 8. Indirect Impact of Dementia Caregiving (average 2010-2012, US\$ millions)

	Foregone GDP for employed	Foregone GDP due to job departure	Total
Men	3,850	3,239	7,090
Women	23,822	5,102	28,925
Total	27,673	8,342	36,014

Sources: Medical Expenditure Panel Survey, Metlife Market Institute, Milken Institute.

Living Arrangements

Dementia patients often require a large amount of daily care, and dementia caregivers are more likely than other caregivers to have difficulty assisting with ADLs, experience high stress, and suffer negative health effects.³⁴ The burden of responsibility can be too much to handle. Some informal caregivers must maintain their employment and require assistance for when they are at work. Some may be physically incapable of performing all the necessary tasks to maintain the dementia patient's health.³⁵ Further, at a certain level of disease severity, a patient needs acute medical care. Services that provide assistance include adult day-services centers,

34. National Alliance for Caregiving and AARP, "Caregiving in the U.S." (2015).

35. Alzheimer's Association. "Alzheimer's Disease Facts and Figures," *Alzheimer's & Dementia* 11, no. 3 (2015), pp. 332+.

home health agencies, hospices, nursing homes, and residential care communities.³⁶ These are collectively termed long-term care or long-term support services.

Institutions such as adult day-care centers and nursing homes are often not covered by insurance. They also usually include services outside the typical purview of doctors, such as social work, occupational therapy, and hospice care.³⁷ Women are more likely to use all of these types of services than men.³⁸ The prevalence of dementia in these institutions of care is high, ranging from 31.9 percent in adult day care to 48.5 percent in nursing home care.³⁹

To understand the full impact of disease, we also calculated the costs of care due to living arrangements, aggregating expenses for nursing homes and adult day-care services. While home health care is sometimes grouped with nursing home and adult day-care services under the umbrella of “long-term care,” we included home health in the health-care costs portion of our analysis. The function of home care is different from that of nursing home or adult day care. Nursing home and adult day-care services are likely to provide respite for informal caregivers, so they may continue to work full-time. As home care is generally provided in two to four hour blocks, and is more affordable during working hours, it is less suited to enabling caregivers to maintain their careers.⁴⁰

We focused on two types of care we believe are most relevant to informal caregivers and therefore are particularly relevant to the role of women. Adult day-services care can ease the burden on caregivers, potentially enabling them to hold on to their jobs or rejoin the workforce. Nursing homes are used more widely and are more available than these other types, but use of less acute support services is increasing.⁴¹ Regional variation is substantial so the availability and accessibility of these services depends on location. These discrepancies in access may create differences in caregiver employment effects, and further research may inform long-term care policy on a more granular scale.

We calculated the yearly use and costs associated with adult day services and nursing home care. The number of users was obtained from the Centers for Disease Control and Prevention’s National Center for Health Statistics.

Adult Day Care

Adult day-care services are facilities that oversee older patients during working hours. They are geared toward younger and more able patients whose caregivers need to maintain employment. Adult day-care services, which attempt to fill the gap between informal care and nursing homes, is an increasingly available resource, with the number of centers expanding 35 percent from 2002 to 2010.⁴² Spending on adult day services totaled \$1.5 billion annually, with 59,111 users of care (average 2010-2012) (see Table 9). Sixty percent of users are women.

36. Centers for Disease Control and Prevention, “Long-Term Care Services in the United States,” U.S. Department of Health and Human Services (2013).

37. Ibid.

38. Ibid.

39. Ibid.

40. Regina A. Shih et al., “Improving Dementia Long-Term Care: A Policy Blueprint,” RAND Corp. (2014).

41. Centers for Disease Control and Prevention, “Long-Term Care Services in the United States,” U.S. Department of Health and Human Services (2013).

42. MetLife Mature Market Institute, “Caregiving Costs to Working Caregivers,” Metlife (2011).

Table 9. Use and Cost of Adult Day-Services Care (average 2010-2012)

	Number of users	Total cost per year (\$ millions)
Men	23,881	610
Women	35,230	900
Total	59,111	1,510

Sources: Metlife Market Institute, Centers for Disease Control and Prevention.

Nursing Homes

Nursing homes are primarily residential facilities with employees covering both health care and social services. They tend to have older and less able patients than adult day care centers do, as patients often start using services when informal caregivers are not able or available to manage patient needs. With increasing interest in the benefits of “aging in place,” people are looking to move away from nursing homes unless absolutely necessary, and toward the “home and community-based settings” portion of long-term support services, such as adult day care. However, nursing homes still account for a large portion of dementia-related spending.⁴³

Unfortunately, these services are expensive and often not covered by insurance. Nursing homes cost, on average, over \$80,000 per patient per year. Therefore, these services are frequently out of reach for all but the highest-income brackets. Medicare does not cover nursing-home costs, but Medicaid does. Often people have no choice but to spend down their savings on nursing-home costs until they qualify for Medicaid. In addition, some dementia patients have no access to informal caregivers and must be placed in nursing homes although their disease is not acute enough to require one, amounting to an unnecessary use of an expensive site of service.

Annual spending on nursing homes in the United States exceeded \$57 billion on average between 2010 and 2012 (see Table 10). Almost 70 percent of this utilization is by female dementia patients.

Table 10. Use and Cost of Nursing Home Care (average 2010-2012)

	Number of Users	Total cost per year (\$ millions)
Men	216,764	18,593
Women	454,331	38,970
Total	671,095	57,563

Sources: Metlife Market Institute, Centers for Disease Control and Prevention.

43. Centers for Disease Control and Prevention, “Long-Term Care Services in the United States,” U.S. Department of Health and Human Services (2013).

Projections

In the near future, the United States is expected to see a “silver tsunami”—a dramatic increase in the percentage of older adults in our communities. As age is the primary risk factor for dementia, the prevalence of the disease will increase accordingly. Projecting the affected population and care expenditures associated with dementia will reveal not only the growing magnitude of disease but also the increasingly disparate nature of its effects on women if nothing is done to change the trend.

The future population with the disease is examined through the creation of a Markov model based on statistics from literature on Alzheimer’s disease and dementia. A Markov model is a statistical model that projects prevalence by identifying disease stages and probability of transitioning between them. Dementia treatment rates, caregiver demand, and utilization of living arrangements are projected to be proportional to the population with disease. Treatment expenditures per person and cost of long-term support services are projected to increase based on growth of health-care expenditures in excess of GDP, as projected by the Centers for Medicare & Medicaid Services. The indirect impact from the labor market is projected based on estimates of GDP and employment from Oxford Economics.

In the next 20 years, the total prevalence of Alzheimer’s disease is expected to approximately double, from 6.4 million to 12.5 million, with 8.3 million women and 4.2 million men (see Table 11). We assumed a constant rate of treatment determined from MEPS of 34 percent of men and 26 percent of women.

Table 11. Projected Population Reporting a Condition for Dementia (thousands)

	2012			2040		
	Men	Women	Total	Men	Women	Total
Prevalence	2,211.4	4,177.1	6,388.5	4,170.1	8,301.1	12,471.2
Treated prevalence	758.7	1,101.7	1,860.4	1,430.7	2,189.4	3,620.1
Users of adult day services	23.9	35.2	59.1	45.0	70.0	115.0
Users of nursing homes	216.8	454.3	671.1	408.8	902.9	1,311.6

Sources: Medical Expenditure Panel Survey, National Health Interview Survey, Milken Institute.

As more people develop dementia over the next 20 years, the number of informal caregivers will also rise, from 9.6 million to 18.7 million (see Table 12). In 2040, we project 11.1 million of these caregivers will be employed and almost 300,000 will leave their jobs due to the strain of caregiving.

Table 12. Dementia's Projected Impact on Caregivers (thousands)

	2012			2040		
	Men	Women	Total	Men	Women	Total
Caregivers	3,833.3	5,749.9	9,583.2	7,483.0	11,224.6	18,707.6
Employed caregivers	2,530.0	3,162.5	5,692.4	4,938.8	6,173.5	11,112.3
Caregivers who left jobs	56.4	88.9	145.3	110.1	173.5	283.6

Sources: Medical Expenditure Panel Survey, National Health Interview Survey, Milken Institute.

If this were to continue, dementia-related health care costs would reach \$33.5 billion by 2040 (see Table 13). This is a cumulative \$593 billion over a 28-year period. Over 70 percent would be used to treat women, despite the fact that women are less likely to be treated for the disease than men. With most patients and caregivers being women, the loss to the economy associated with women alone will total \$2.4 trillion, representing over 80 percent of the cumulative burden from 2012 to 2040.

Table 13. Economic Burden of Dementia (2012 US\$ billions)

	Men			Women			Total		
	Treatment	Living arrangements	Indirect impact	Treatment	Living arrangements	Indirect impact	Treatment	Living arrangements	Indirect impact
2012	2.8	19.2	7.2	7.5	39.9	43.7	10.3	59.1	50.9
2040	8.8	59.7	24.4	24.7	130.7	118.6	33.5	190.5	143.0
Cumulative	158.6	1,037.0	493.9	434.7	2,218.9	2,397.9	593.3	3,255.9	2,891.9

Sources: Medical Expenditure Panel Survey, National Health Interview Survey, Metlife Market Institute, Milken Institute.

As the prevalence of disease rises, caregivers will turn to long-term care services such as nursing homes and adult day-care centers to bear the burden of disease. Adult day-care use is projected to increase from 59,100 users in 2012 to 115,000 users in 2040 (see Table 11). Nursing home use for dementia patients will increase from 671,100 in 2012 to 1.3 million by 2040. These increases represent an additional \$131 billion per year spent on long-term care for dementia patients in the U.S. alone (see Table 13). Cumulatively, spending will reach \$3.3 trillion for women and men.

Our projection method assumed the proportion of patients using long-term care services would remain constant, providing a conservative estimate of the related costs. However, recent trends

reveal an increase in utilization rates of both adult day care and nursing home care over time, a pattern likely to persist into the future.⁴⁴ Aggregate costs of long-term care services would then increase accordingly.

Implications

It is clear from the historical data that the physical and financial burdens of Alzheimer's disease and dementia are undeniable, and that women suffer the brunt of the problem. Over the next quarter of a century, the prevalence of dementia will grow even larger and the consequences of the disease for patients and the economy will become more severe. It is an issue concerning not only physicians and insurance companies, but one with the potential to affect virtually every individual in the United States. Many researchers and policy professionals have examined what needs to be done to alleviate this impending crisis, and numerous policy solutions have been offered. However, implementation of such policies is not happening quickly enough, and allocation of resources is neither substantial nor commensurate to the burden of disease.⁴⁵

Dementia has a wide range of effects, and no single policy can combat them all. It requires a multifaceted approach involving multiple policies. Understanding the scope of each policy—in terms of target population, wellness benefits, and economic consequences—can enable decision-makers to hone in on the most efficient and cost-effective interventions.

Policy Solutions

In the following analyses, we examine the scope and effects of potential dementia policy solutions. This list is by no means exhaustive, but lays out avenues for change that could lead to a substantial impact.

Increase Access to Health Care

Health-care costs related to dementia are calculated by summing expenditures associated with visits at differing sites of service. With increasing prevalence, there will be more utilization of care, but this will vary among the sites of service. For example, inpatient and outpatient care associated with dementia alone is relatively low. However, office-based care, prescriptions, and home health care are significantly higher. Limited access to primary care and home health care have already been identified in the literature. With an increasing population of older adults, these access problems are likely to be exacerbated.

Further, the health-care workforce at these sites must be bolstered and trained to serve the needs of the dementia patient population. Adequately staffing services would require strengthening the range of medical professionals, including physicians, physician assistants, nurse practitioners, registered nurses, medical assistants, home health aides, social workers,

44. Centers for Disease Control and Prevention, "Long-Term Care Services in the United States," U.S. Department of Health and Human Services (2013).

45. *FasterCures* Philanthropy Advisory Service, "Alzheimer's Disease Report," *FasterCures* (2015).

occupational therapists, physical therapists, community health workers, and more. Training and incentivizing this process may be expensive, requiring an investment that would not be included in the typical definition of health-care cost associated with disease. The effects of disease-related costs are difficult to determine, as such effects are dependent on factors such as disease type and prevalence, professional training costs, insurance reimbursement, and geography.

Expand the Scope and Flow of Services

The scope of health care will also have to expand to coordinate effectively with long-term care services and other types of social service organizations. While typically not thought of as part of the health-care system, dementia patients' need for assistance with personal activities of daily living makes use of long-term care necessary for many families. As prevalence of dementia increases, use of this type of care service will increase as well. And while most of the focus is on treatment, living arrangements and indirect impact represent the majority of the economic burden of the disease.

It is important that better medical treatments for Alzheimer's and dementia be found, which would subsequently reduce the need for long-term care services. In the meantime, access to these services needs to be improved as do funding sources. As it stands, dementia care is resulting in patients and their families spending their way to poverty, while access to long-term care services varies from region to region.

Location is only one component of the access equation. For many patients, the cost of obtaining services can be prohibitive. Increasing insurance coverage for long-term care services such as nursing-home and adult day-care services and making long-term care insurance more affordable could reduce the burden on informal caregivers and minimize effects on the labor market.

Most older adults regularly seek care from a clinician in a health-care practice; this is likely where they receive a diagnosis of dementia. While many practices have a protocol to refer patients to medical specialists, the same referral procedure is often not standardized for other community services such as adult day care centers. As informal caregivers rarely receive training on their new responsibilities, they may not know where to turn if the burden of caregiving becomes too much to handle. This may lead to increased stress on the caregiver, depressed labor market outcomes, and worsened medical outcomes for the patient.

An improved referral process would not be a one-way street, but rather a line of communication between two providers of care. Staff at long-term-care centers can inform clinicians of changes in symptoms and side effects in a more informed manner than informal caregivers. Increased coordination of care between the health-care system and the community is a framework that health-care leaders are already calling for, and it is incorporated into the new models of health-care delivery such as the patient-centered medical home.

Improving coordination of care generally requires an increase in administrative spending on the part of a medical practice. Investments in electronic health records, patient tracking registries, and staff to oversee care coordination can have a significant effect on a clinic's bottom line, and not every practice can afford such investments. However, as improvements in technology make coordination easier and as value and quality of care are increasingly monitored, these shifts are happening and will continue to do so. The lifetime effects of these structural changes

on spending are difficult to measure. Some say they increase health-care spending due to growing administrative investments on the part of the clinic. However, others see a slowing of growth in health-care costs in recent years and attribute at least part of this moderation to structural changes in the health-care system.⁴⁶

Raise Dementia Awareness and Caregiver Training

There is very little public awareness about the risks and consequences of dementia. A large proportion of people living with dementia are estimated to be undiagnosed. These people are likely not receiving the treatment that they need, treatment that could potentially slow progression of disease or minimize side effects. Raising public awareness of the signs of dementia and the steps to take when one suspects a loved one might have the disease would increase diagnoses and proper treatment. Awareness of incident disease can enable people without disease or with early cognitive impairment to manage risk factors and delay onset or slow progression of the disease.

Increased awareness of disease could also lead to more opportunities for caregiver training. Knowledge about caregiving tasks and opportunities for support can reduce stress related to informal caregiving, reducing absenteeism and presenteeism. It may improve patient outcomes. Perhaps this reduction in stress would result in longer periods of dementia patients living in the community, in the preferred situation of “aging in place.”

Disease education would also improve community knowledge of local services and long-term support services. Particularly, use of adult day-care services, which provide respite to caregivers but allow the dementia patient to maintain residence in the community, will likely increase. Awareness on the part of employers may increase access to respite services such as elder care provided in a similar manner to child care, which could also minimize productivity loss at work.

Provide Support in the Workplace

Gender roles historically assigned to women drive the increased probability for women to be caregivers for dementia patients. These stereotypes influence a variety of decisions that ultimately create this difference in probability. For example, women may be regarded by society as more nurturing, and for this reason may be more likely to assume the role of the caregiver. At the same time, more women are taking on full-time careers, and as life expectancies lengthen, careers do as well.

With employment becoming more crucial to maintaining quality of life, people taking care of dementia patients at home will find it more difficult to leave their jobs. Women have made strides toward gender parity, and are increasingly the household breadwinners. But because women still represent the majority of caregivers, dementia patients and caregivers will likely seek out community resources to assist in managing the disease. This would result in increased use of long-term care services. It may also increase use of home health services. While home health services are generally provided in two-to-four-hour timeslots, a small level of assistance could allow informal caregivers to remain employed, especially if dementia is not yet severe.

46. David M. Cutler and Nikhil R. Sahni, “If Slow Rate of Health Care Spending Growth Persists, Projections May Be Off by \$770 Billion,” *Health Affairs* 32, no. 5 (2013), pp. 841-850.

Awareness, education, and more comprehensive services can reduce disparities for women. Caregivers are more likely to be women and female caregivers are more likely to drop out of the workforce. If policy changes can reduce the burden on caregivers, the effect will benefit the women who are disproportionately affected by this additional responsibility. Reducing female caregivers' lost workdays by 60 percent would yield a situation in which workdays lost for women were still double that for men. However, that would save \$776 billion to the GDP (2012 dollars) by 2040, providing a significant incentive to create policies for cost-effective solutions.

Increase Funding for Alzheimer's and Dementia Research

Relative to the magnitude of the problem, few clinical trials targeting Alzheimer's disease and dementia are being undertaken.⁴⁷ The existing trials have low success rates; for the 2002-2012 period, Alzheimer's disease drug development had a success rate of 0.4 percent.⁴⁸ Some companies are re-evaluating their programs, as Pfizer and Johnson & Johnson did in July 2013.⁴⁹ More resources need to be allocated toward development of treatments and cures for dementia, in terms of clinical and pre-clinical research. It is something that decision-makers are beginning to realize, with the 2016 federal budget allocating an additional \$2 billion in total funding for the NIH.⁵⁰ Specifically, the budget assigns \$85 million for the BRAIN initiative, which is expected to provide insight into brain activity and potential treatment mechanisms for diseases such as Alzheimer's and dementia.⁵¹

It is imperative to fund both basic and translational research. The brain is not well understood, and improved knowledge of its biological mechanisms can facilitate better drug development. Some say that less is known about dementia biology as compared with cancer, and this may be related to the differences in drug development success rate for the two conditions. A better understanding of disease diagnostics and progression would help in detection and treatment of disease, and would assist in choosing patients for clinical trials.

The difficulty of developing drugs is undisputed. Simple changes such as recruiting more researchers and training more regulators could make the process more efficient. Increasing funding could also improve outcomes.

Incentives could also come in the form of regulatory measures. The Food and Drug Administration (FDA), for example, gives special status such as Fast Track, Breakthrough Therapy, and Accelerated Approvals, to some drugs targeting populations at risk, encouraging pharmaceutical companies to invest in developing drugs for that market on a faster timeline. Alterations to intellectual property rules such as adaptive or conditional licensing so that patents do not expire prior to completion of clinical trials may make development less risky.⁵²

47. Jeffrey L. Cummings et al. "Alzheimer's Disease Drug-Development Pipeline: Few Candidates, Frequent Failure," *Alzheimer's Research & Therapy* 6, no. 37 (2014).

48. Ibid.

49. Maria Burke, "Why Alzheimer's Drugs Keep Failing," *Scientific American* (2014), <http://www.scientificamerican.com/article/why-alzheimers-drugs-keep-failing> (accessed July 2015).

50. National Institutes of Health BRAIN Initiative website, <http://www.braininitiative.nih.gov/> (accessed Jan. 13, 2016).

51. National Institutes of Health, "NIH Wide Strategic Plan: Fiscal Years 2016-2020."

52. Maria Burke, "Why Alzheimer's Drugs Keep Failing," *Scientific American* (2014), <http://www.scientificamerican.com/article/why-alzheimers-drugs-keep-failing> (accessed July 2015).

Targeting research funding specifically for dementia can improve research outcomes. Until 2015, the increased prevalence of dementia in women was attributed to their longevity. However, new research reveals that women may indeed have increased risk factors for disease due to genetics.⁵³ The absence of this knowledge before 2015 may be due to lack of funding for Alzheimer's and dementia research.

Research funding can be increased in a variety of ways. Advocacy groups and foundations can raise funds for research. Collaborations among sectors, such as public-private partnerships, have been particularly effective. In the United Kingdom, a public-private partnership between the Medical Research Council of the UK and six bio-pharma companies has raised millions of pounds for dementia research.⁵⁴ Aspects of the research process include basic and translational research, improvements in diagnostics, and training of the dementia research workforce.⁵⁵

How can investment in research and innovation, along with improvement in medical care and technology, affect the burden of dementia? The Alzheimer's Association predicted that by 2025, research breakthroughs could delay the onset of disease by five years.⁵⁶ This would result in a decrease in prevalence of Alzheimer's by 5 million by 2040.

This is only one example of how a treatment could affect the patient population. In fact, there are several ways that medical innovation could alter the course of Alzheimer's disease and dementia by improving diagnostics and treatment mechanisms. It is difficult to predict exactly how a new innovation will affect burden of disease, but examining the effects of potential improvements can illustrate the value of investing in innovation.

Increased diagnostics generally result in a higher number of patients on record with disease, simply because more people come to know they have disease. This leads to an increase in health-care expenditures associated with disease, though some of those expenditures may have previously existed without being linked to a dementia billing code. Additionally, better diagnostics can potentially lead to increased use of treatment methods. Better treatments can improve outcomes, leading to an aggregate reduction in disease severity for the patient population as a whole. Similarly, improved treatments often keep patients alive longer, increasing the comparative size of the disease population and related health-care expenditures while reducing mortality. Changes in the proportion of disease severity will affect patients' functional limitations and associated burden on long-term care services and informal caregivers.

We examined how burden of disease would be affected if increased investment in research and development yielded a novel medical technology that reduced prevalence of dementia by 20 percent by 2040. This reduction would be half of that assumed by the aforementioned Alzheimer's Association study.⁵⁷ We assumed the percent difference would increase linearly starting in 2025 to 20 percent in 2040. We chose 2025 for a starting point as studies reveal

53. Nahid A. Azad et al., "Gender Differences in Dementia Risk Factors," *Gender Medicine* 4, no. 2 (2007), pp. 120-129.

54. Maria Burke, "Why Alzheimer's Drugs Keep Failing," *Scientific American* (2014), <http://www.scientificamerican.com/article/why-alzheimers-drugs-keep-failing> (accessed July 2015).

55. Ibid.

56. Lewin Group, "Changing the Trajectory of Alzheimer's Disease: How a Treatment by 2025 Saves Lives and Dollars," *Alzheimer's & Dementia* (2015), http://www.alz.org/documents_custom/trajectory.pdf (accessed July 2015).

57. Lewin Group, "Changing the Trajectory of Alzheimer's Disease: How a Treatment by 2025 Saves Lives and Dollars," *Alzheimer's & Dementia* (2015), http://www.alz.org/documents_custom/trajectory.pdf (accessed July 2015).

that drug development times average 13 years, which can be used as a proxy for the time it takes for biomedical research to produce a new therapy. This difference was applied uniformly to men and women, and all other assumptions for projecting health-care costs, living arrangements, and indirect impact were maintained.

Table 14. Projected Population Reporting Dementia in 2040 (thousands)

	Baseline	Research Incentive	Difference
Men	4,170.1	3,336.1	834.0
Women	8,301.1	6,640.9	1,660.2
Total	12,471.2	9,977.0	2,494.2

Sources: Medical Expenditure Panel Survey, Milken Institute.

Such a therapy would produce significant reductions in the burden of disease. It would result in 2.5 million fewer people with disease in 2040—1.7 million of whom would be women (see Table 14).

Table 15. Savings Associated With Increased Research Incentives (2012 US\$ billion)

	Men			Women			Total		
	Treatment expenditures	Living arrangements	Indirect impact	Treatment expenditures	Living arrangements	Indirect impact	Treatment expenditures	Living arrangements	Indirect impact
2012	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
2040	1.8	11.9	4.9	4.9	26.1	23.7	6.7	38.1	28.6
Cumulative	11.9	78.6	35.2	33.0	170.4	170.7	44.9	249.0	205.9

Sources: Medical Expenditure Panel Survey, National Health Interview Survey, Metlife Market Institute, Milken Institute.

This reduction would translate into savings to the health-care system and economy as well. The examined scenario saves a cumulative \$44.9 billion in dementia treatment expenditures, \$249 billion in cost of living arrangements, and \$205.9 billion to the economy. Between 2012 and 2040, this would result in a cumulative savings of \$499.8 billion. This majority of the savings would reduce burden on women; when totaling the cumulative difference in treatment expenditures, living arrangements, and indirect impact, savings to women represent 75 percent of the total.

Conclusion

If the course of dementia is not altered, the disease will cost the nation trillions of dollars over the next 25 years. While dementia may not be a high-profile disease relative to a few others, its consequences are far-reaching. The disease affects patients, caregivers, clinicians, researchers, pharmaceutical companies, long-term support service providers, and employers alike. Our analysis reveals that the situation will only worsen as the number of people suffering from dementia increases over time.

Quantifying dementia's effects on the health-care system, long-term support services, and the labor market makes a case for increased awareness, funding, research, and services. A granular examination of the issue reveals another compelling argument: The gender disparities inherent in the cases and costs of disease reinforce the societal burdens on women. As we strive for gender equity, we must develop solutions to contributing factors. To achieve an efficient solution, members of all affected groups—government and patients, researchers and employers—must coordinate and collaborate. It is a problem that needs discussion to identify policy priorities for both the short and long term. If we can achieve this agenda, perhaps we will be able to reduce the stress and suffering associated with disease while producing economic savings.



Quantifying dementia's effects on the health-care system, long-term support services, and the labor market makes a case for increased awareness, funding, research, and services.

Methodology

This report uses a cost-of-illness approach to examine dementia treatment expenditures in the period between 2010 and 2012. The term “economic burden” refers to the aggregate sum of treatment expenditures, costs of living arrangements, and indirect impact (in terms of forgone gross domestic product). Similar to an increase in treatment expenditures, an increase in the burden of indirect impact is represented as a positive increase in dollars, but actually represents a reduction in GDP for the United States.

Historical Population Reporting a Condition

Previously published estimates of Alzheimer’s disease or dementia in the United States use a variety of methods, including the application of regionally based incidence and prevalence estimates on U.S. Census demographic data,⁵⁸ using the Aging, Demographics, and Memory Study (ADAMS) supplement of the Health and Retirement Study.⁵⁹ In a self-reported survey of dementia or cognitive impairment, prevalence and incidence are likely to be underreported, due to self-reporting bias or the fact that as many as 50 percent of people with dementia may not know that they have it.⁶⁰ This study examines the treated prevalence of dementia using the Medical Expenditure Panel Survey (MEPS). Treated prevalence is the number of people with an event associated with one of the related sites of service, as determined by the condition codes in MEPS. The condition code used for dementia was 653. The examined sites of service include office-based, outpatient, inpatient, emergency room, home health, and prescription. Rates from MEPS are also underreported because they are self-reported. The reported treated prevalence is the three-year average from 2010 to 2012. Total dementia prevalence (for comparison) was reported from Loef 2013.⁶¹

Historical Treatment Expenditures

Aggregate treatment expenditures were calculated as the sum of expenditures from all unique events associated with a dementia-related condition code for the examined sites of service. Expenditures per person were calculated as the aggregate treatment expenditures divided by the treated prevalence. The cost of calculating the untreated population was determined as the prevalence of untreated dementia (the difference between total dementia and the treated dementia prevalence) multiplied by the expenditures per person from MEPS.

Historical Indirect Impact

A disease can have an economic impact in the workplace as well as the health-care system. Disease can cause patients and caregivers to miss days of work, known as absenteeism,

58. United States General Accounting Office, “Alzheimer’s Disease: Estimates of Prevalence in the United States,” 2008.

59. Brenda Plassman et al., “Prevalence of Dementia in the United States: The Aging, Demographics, and Memory Study,” *Neuroepidemiology* 29, no. 1 (2007), pp.125-132.

60. Alzheimer’s Association. “2014 Alzheimer’s Disease Facts and Figures,” *Alzheimer’s & Dementia* 10, no. 2 (2014), E47-92.

61. Martin Loef and Harald Walach, “Midlife Obesity and Dementia: Meta-Analysis and Adjusted Forecast of Dementia Prevalence in the United States and China,” *Obesity* 21 (2013), pp. E51-55.

and to be less productive while they are at work, known as presenteeism. The collective sum of these effects is known as the indirect impact of disease.

Absenteeism associated with dementia was calculated from the 2007 National Health Interview Survey (NHIS), which asked whether patients had been diagnosed with dementia and calculated missed days from work due to illness. We then obtained the ratio for dementia in 2007 to number of employed people with dementia in 2007 from the NHIS. We assumed this employment rate would remain constant and applied this proportion to the 2010-2012 treated prevalence to obtain the number of employed dementia patients by gender. The same was done for work loss days per person with dementia by gender. Absenteeism/presenteeism ratio was obtained from Goetzel, assumed to be the same for absenteeism and presenteeism for “Depression/sadness/mental illness”⁶²; this was used to quantify presenteeism in terms of number of days lost from work. Nominal GDP and employment rate for the U.S. were obtained from the Bureau of Labor Statistics. These numbers were used to quantify absenteeism and presenteeism in terms of lost output to the GDP.

Data on the number of caregivers for dementia and the breakdown by gender was obtained from the “Caregiving in the U.S.” study, which reported that 43.6 million adults provided care, 60 percent of whom were female and 40 percent male. This report also said 22 percent of caregivers provide care to someone with dementia and assumed this probability was the same for both women and men due to lack of more granular survey data. Employed caregivers was based on employment rate by gender taken from the literature.⁶³ We calculated a proportion of caregivers would leave their jobs and experience absenteeism based on data from the literature. We assumed caregivers would experience 75 percent of the presenteeism per absentee day compared with dementia patients. We assumed dementia caregivers leaving their job would do so, on average, in the middle of the year per examined literature.⁶⁴

Historical Living Arrangements

Number of people using nursing-home care and average number of days using adult day services center care were taken from 2013 CDC/NCHS report on long-term care. This report said for adult day care, 40.4 percent of patients were men, 59.6 percent were women, and 31.9 percent had dementia. For nursing home care, 32.3 percent were men, 67.7 percent were women, and 48.5 percent had dementia. We assumed that men and women in nursing homes and adult day cares were equally likely to have dementia, which underestimates the disparity associated with care. Yearly cost of adult day care and nursing home care were obtained from Metlife and the CDC.

Projections

Future prevalence of dementia is forecast based on a Markov model of the disease. Projected estimates assume constant utilization rates of health-care services, long-term support services, and informal caregiving from historical calculations. The employment effects of dementia on

62. Ron Z. Goetzel et al., “Health, Absence, Disability, and Presenteeism Cost Estimates of Certain Physical and Mental Health Conditions Affecting U.S. Employers.” *Journal of Occupational and Environmental Medicine* 46, no. 4 (2004), pp. 398-412.

63. MetLife Mature Market Institute, “Caregiving Costs to Working Caregivers,” Metlife (2011).

64. Ibid.

patients and caregivers were assumed to remain constant, affecting the same proportion of the dementia population. GDP and employment were obtained from projections by the Census Bureau. Disease stages and transition probability were informed by literature review primarily surrounding Alzheimer's disease.^{65, 66, 67, 68} True prevalence, as opposed to treated prevalence by MEPS, was examined based on unreporting percentages from Alzheimer's Association values. Costs increased based on the excess growth of health-care expenditures over the GDP. Net present values were collected based on a 3 percent discount rate and presented in 2012 dollars.

Table 16. Markov Model Inputs

Description	Value	Source
Initial proportion of population less than 60 years old	0.8033	Census Age
Initial proportion of well population 60 years and older	0.1919	Census Age
Initial proportion of population with dementia and male	0.0029	Alzheimer's Association
Initial proportion of population with dementia and female	0.0046	Alzheimer's Association
Probability of dying if less than 60 years old	0.0010	Census Death Tables
Probability of turning 60 if less than 60 years old	Aging table	Census Age
Probability of dying if 60 years or older	0.0335	Census Death Tables
Probability of well population by age group	Aging table	Census Age
Probability of being female by age group	Aging table	Census Age
Probability of developing dementia by age group, gender	Incidence table	Sloane et al., 2002; Seshadri et al., 2006; Brookemeyer et al., 2011; Lewin Group, 2015
Relative risk of dying with dementia	1.5000	Sloane et al., 2002; Seshadri et al., 2006; Brookemeyer et al., 2011; Lewin Group, 2015

Sources: Medical Expenditure Panel Survey, Milken Institute.

65. Philip D. Sloane et al. "The Public Health Impact of Alzheimer's Disease, 2000-2050: Potential Implication of Treatment Advances." *Annual Review of Public Health* 23, no. 1 (2002), pp. 213-231.

66. Sudha Seshadri et al., "The Lifetime Risk of Stroke Estimates From the Framingham Study," *Stroke* 37, no. 2 (2006), pp. 345-350.

67. Ron Brookemeyer et al., "National Estimates of the Prevalence of Alzheimer's Disease in the United States," *Alzheimer's & Dementia* 7, no. 1 (2011), pp. 61-73.

68. Lewin Group, "Changing the Trajectory of Alzheimer's Disease: How a Treatment by 2025 Saves Lives and Dollars," *Alzheimer's & Dementia* (2015), http://www.alz.org/documents_custom/trajectory.pdf (accessed July 2015).

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