The Price Women Pay for Dementia

An Update to Projected Prevalence and Cost of Dementia

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Key Results

The Milken Institute's 2016 report, "The Price Women Pay for Dementia," highlighted the disproportionate economic and health burden of dementia on women in the United States.[1] Furthermore, the report provided statistical estimates of the prevalence of dementia and the economic burden associated with the disease by gender from 2012 to 2040. In this technical supplement, we update the previously reported future projections with more recent data and briefly discuss substantive changes.

Our updated numbers come from a forecast combination of estimates drawn from recently published studies. We use the same methodology as in the previous report to derive the adjusted projected economic burden of dementia. The key adjustments are as follows:

Figure 1. Projected Prevalence of Dementia by Gender (from 2016 report)

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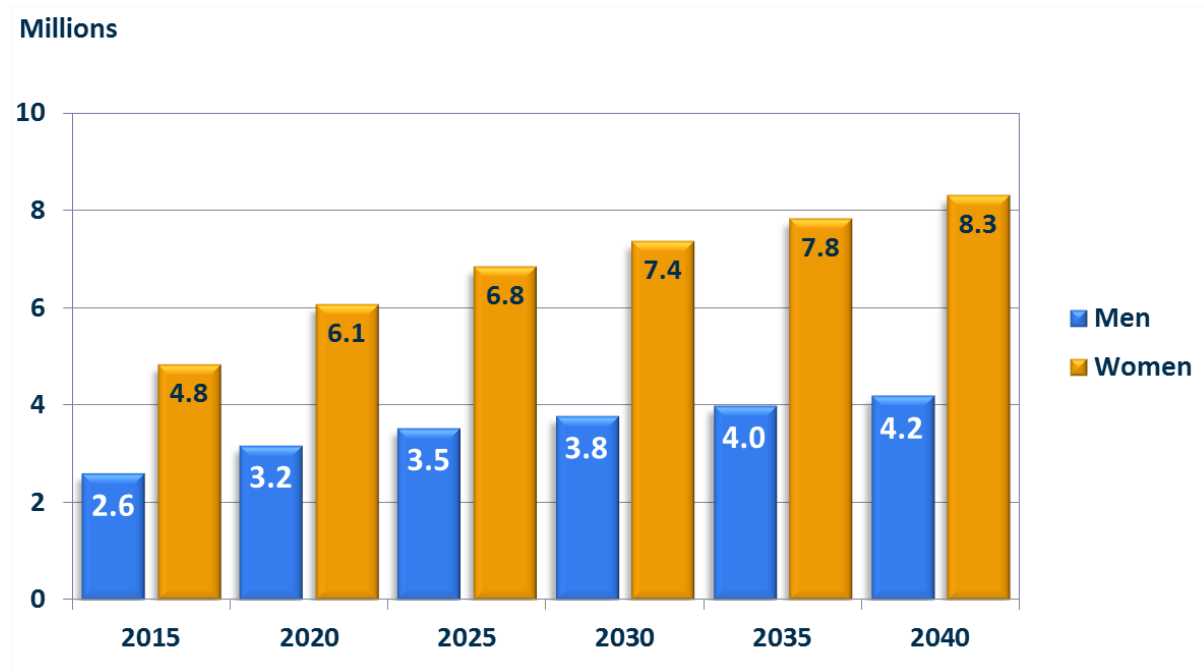
1. Sindhu Kubendran, Ross DeVol, and Anusuya Chatterjee, "The Price Women Pay for Dementia: Strategies to Ease Gender Disparity and Economic Costs," Milken Institute (2016), https://www.milkeninstitute.org/reports/price-women-pay-dementia-strategies-ease-gender-disparity-and-economic-costs.

Figure 2. Projected Prevalence of Dementia by Gender from updated data in 2019.

Millions
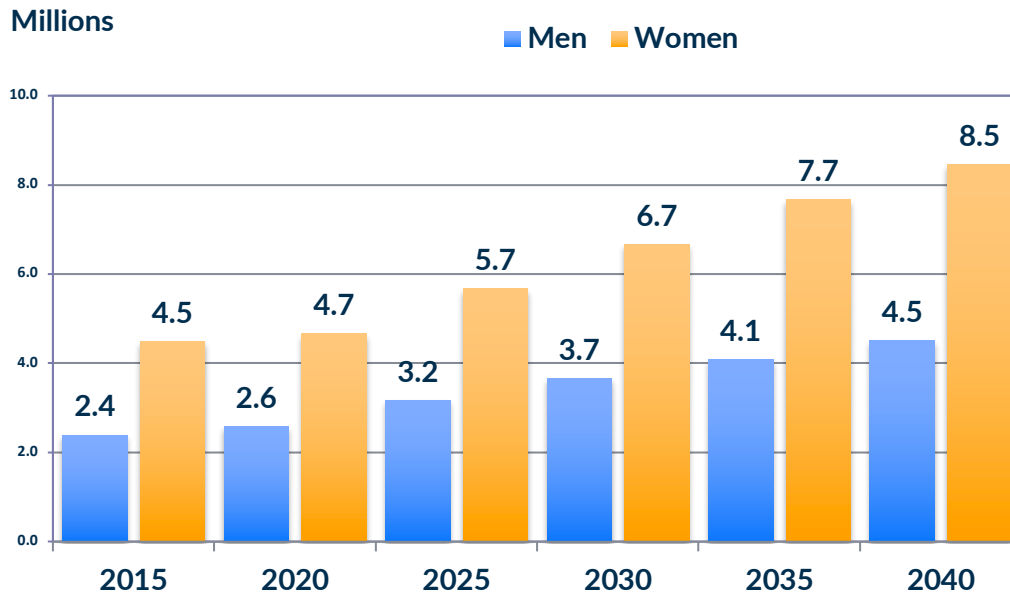
Source: Milken Institute, 2019.

We use the same direct costs per case as in the previous report and adjust the prevalence numbers to derive the following economic burden tables. (Throughout this report, numbers may not add up to totals due to the rounding to the nearest tenth.)

Table 1. Projected Population Reporting a Condition for Dementia (in thousands) from 2016 Report

	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	1,677.8	2,436.5	1,430.7	5,966.2	7,396.9
Adult Day Care	23.9	35.2	59.1	45.0	70.0	115.0
Nursing Home	216.8	454.3	671.1	408.8	902.9	1,311.6
Sources: Medical Expenditure Panel Survey, National Health Interview Survey, Milken Institute.						

Table 2. Projected Population Reporting a Condition for Dementia (in thousands) from 2019 Update

	2012			2040		
	Men	Women	Total	Men	Women	Total
Prevalence	2,211.4	4,177.1	6,388.5	4,509.3	8,458.1	12,967.3
Treated Prevalence	758.7	1,101.7	1,860.4	1,547.1	2,230.8	3,777.9
Adult Day Care	23.9	35.2	59.1	48.7	71.3	120.0
Nursing Home	216.8	454.3	671.1	442.0	920.0	1,362.0

Source: Author's calculations, Milken Institute, 2019.

Table 3. Dementia's Projected Impact on Caregivers ($ thousands) from 2016 Report

	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 Left Jobs	56.4	88.9	145.3	110.1	173.5	283.6

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

Table 4. Dementia's Projected Impact on Caregivers ($ thousands) from 2019 Update

	2012			2040		
	Men	Women	Total	Men	Women	Total
Caregivers	3,833.3	5,749.9	9,583.2	7,780.7	11,671.1	19,451.8
Employed caregivers	2,530.0	3,162.5	5,692.4	5,135.3	6,419.1	11,554.4
Caregivers who left jobs	56.4	88.9	145.3	114.5	180.4	294.9

Source: Author's calculations, Milken Institute, 2019.

Table 5. Economic Burden of Dementia ($ billions) from 2016 Report

	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	24.7	24.7	130.7	119.8	33.5	190.5	144.5
Cumulative	141.4	920.4	439.9	386.4	1,963.9	2,135.9	527.7	2,884.3	2,575.8
Net Present Value	92.3	601.4	288.7	251.5	1,278.6	1,404.5	343.8	1,880.0	1,693.2

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

Table 6. Economic Burden of Dementia ($ billions) from 2019 Update

	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	9.5	64.6	25.4	25.2	133.2	122.5	34.7	197.8	147.9
Cumulative	151.2	989.4	435.9	368.3	1,879.0	2,087.7	519.5	2,868.4	2,523.7

Source: Author's calcuations, Milken Institute, 2019.

Combined Forecast Approach

This technical supplement uses the concept of optimal forecast combination to identify a more robust series of forecast values for the prevalence of dementia by gender in the United States. All forecasts are model-based and, subsequently, are subject to model misspecification and probabilistic uncertainty. There is overwhelming evidence in the statistical literature that a combined forecast is more accurate than any of its single components. The seminal paper by Bates and Granger (1969)[2] and an earlier commentary about the superiority of averaging forecasts by Zarnowitz (1984)[3] have laid the theoretical foundation for what forecasters have known all along: Combining evidence substantially reduces the risk of model misspecification and selection. The updates in this supplement are based on 2019 Centers for Disease Control and Prevention (CDC) forecasts, 2018 forecasts from researchers at the University of California, Los Angeles, and 2013 projections from Rush Institute.[4] These studies provide projections within the

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2. I. Bates, J. M. & C. W. J. Granger, "The Combination of Forecasts," *Operational Research Quarterly*, 20 (1969): 451-468.
3. V. D. Zarnowitz, "The Accuracy of Individual and Group Forecasts from Business Outlook Surveys," *Journal of Forecasting*, 3 (1984):11-26.
4. R. Brookmeyer, N. Abdalla, C. H. Kawas, and M. M. Corrada, "Forecasting the Prevalence of Preclinical and Clinical Alzheimer's Disease in the United States," *Alzheimer's & Dementia*, 14 (2018): 121-129; L. E. Hebert, J. Weuve, P. A. Scherr, and D. A. Evans, "Alzheimer Disease in the United States (2010-2050)

same sample period, 2015-2040, used in [the Milken Institute's report](#). Although the projections were on the prevalence of Alzheimer's disease, we used a conservative estimate, which is widely accepted in the field, that Alzheimer's disease makes up 80 percent of all dementia prevalence.

In this technical update, we use the median of forecasts as our final adjusted projections. Armstrong (2001)[5] highlights the superiority of median over arithmetic mean for forecast combination by reviewing the forecast combination literature. The way we compute the median is given as follows. We first arrange forecast values in an array and then look for the middle value or the arithmetic mean of the two middle values. That is,

$$\tilde{X} = \begin{cases} X_{(n+1)/2} & \text{if } n \text{ is odd} \\ \dfrac{X_{(n/2)} + X_{(n/2)+1}}{2} & \text{if } n \text{ is even} \end{cases}$$

The reported forecasts in the literature are given in five-year intervals. We carry out a simple linear extrapolation between two periods to obtain annual forecasts and then combine them using the aforementioned approach.

Once we have derived medians, we plug these estimates back into the original Markov model described in detail in the [Milken Institute report published in 2016](#) to derive cost projections. Essentially, this update does two things. First, it combines recent forecasts in the literature with the original Milken Institute projections to get more stable predictions. Second, it feeds the updated numbers back into the original model to update projections of economic costs associated with dementia without altering any of the original Markov transition probabilities and other parameters. Table 7 shows the computed median forecast as well as individual forecasts of the prevalence of dementia.

Table 7. Projected Prevalence of Dementia: Combined Forecast (in Millions)

Period	Rush Institute		UCLA		CDC		Milken Institute		Median (Shrinkage) Estimator		
	Men	Women	Men	Women	Men	Women	Men	Women	Men	Women	Total
2015	2.22	4.15					2.58	4.83	2.40	4.49	6.89
2020	2.49	4.76	1.67	3.20	2.70	4.56	3.16	6.06	2.59	4.66	7.26
2025	3.02	5.86	1.78	3.47	3.33	5.48	3.52	6.84	3.17	5.67	8.84
2030	3.55	6.95	2.11	4.14	3.96	6.39	3.76	7.36	3.66	6.67	10.33
2035	4.21	8.29	2.53	4.97	4.60	7.50	3.98	7.83	4.10	7.67	11.76
2040	4.85	9.65	2.93	5.82	5.25	8.62	4.17	8.30	4.51	8.46	12.97

Estimated Using the 2010 Census," *Neurology* (2013); Kevin A. Matthews, Wei Xu, Anne H. Gaglioti, James B. Holt, Janet B. Croft, Dominic Mack, and Lisa C. McGuire, "Racial and Ethnic Estimates of Alzheimer's Disease and Related Dementias in the United States (2015–2060) in Adults Aged ≥65 Years," *Alzheimer's & Dementia*, Volume 15, Issue 1 (2019):17-24.

5. J. Scott Armstrong, ed., *Principles of Forecasting: A Handbook for Researchers and Practitioners*, (Norwell, MA: Kluwer Academic Publishers, 2001).

The Original Methodology[6]

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 foregone 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 US Census demographic data,[7] using the Aging, Demographics, and Memory Study supplement of the Health and Retirement Study.[8] 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.[9] 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.[10]

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

6. Kubendran S., DeVol R., and Chatterjee A., "The Price Women Pay for Dementia," 2016.

7. "Alzheimer's Disease: Estimates of Prevalence in the United States," United States General Accounting Office (1998), https://www.govinfo.gov/content/pkg/GAOREPORTS-HEHS-98-16/html/GAOREPORTS-HEHS-98-16.htm.

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

9. Alzheimer's Association, "2014 Alzheimer's Disease Facts and Figures," *Alzheimer's & Dementia* 10, no. 2 (2014): e47-e92.

10. 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): E51-55.

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, 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, 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 the number of employed people with dementia in 2007 from the National Health Interview Survey. We assumed this employment rate would remain constant and applied this proportion to the 2010-2012 treated prevalence to obtain a 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;"[11] this was used to quantify presenteeism in terms of number of days lost from work. Nominal GDP and employment rate for the US 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 of male to female caregivers were obtained from the "Caregiving in the U.S." study,[12] 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 provided care to someone with dementia and assumed this probability was the same for both women and men due to a lack of more granular survey data. Employed caregivers were based on employment rate by gender taken from the literature.[13] 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 average doing so in the middle of the year per examined literature.[14]

11. Ron Z. Goetzal 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): 398-412.
12. "Caregiving in the US," AARP Public Policy Institute and National Alliance for Caregiing (2015), https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf.
13. MetLife Mature Market Institute, "Caregiving Costs to Working Caregivers," MetLife (2011).
14. Ibid.

Historical Living Arrangements

The number of people using nursing-home care and the average number of days using adult day services center care was taken from the 2013 CDC/National Center for Health Statistics 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. The 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 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 a literature review primarily surrounding Alzheimer's disease.[15, 16, 17, 18] 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.

15. 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): 213-231.
16. Sudha Sheshadri et al., "The Lifetime Risk of Stroke Estimates From the Framingham Study," *Stroke* 37, no. 2 (2006): 345-350.
17. Ron Brookmeyer et al., "National Estimates of the Prevalence of Alzheimer's Disease in the United States," *Alzheimer's & Dementia* 7, no. 1 (2011): 61-73.
18. Lewin Group, "Changing the Trajectory of Alzheimer's Disease: How a Treatment by 2025 Saves Lives and Dollars," *Alzheimer's & Dementia* (2015), https://www.alz.org/media/documents/changing-the-trajectory-r.pdf, accessed July 2015.

Table 8. 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 femaleby 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

About the Author

KEN SAGYNBEKOV is a health economist at the Milken Institute. His research focuses primarily on applied microeconomic analysis of health and crime, with an emphasis on quantitative methods. Sagynbekov's work has been published in peer-reviewed academic journals and government reports. Before joining the Institute, he was an assistant professor of economics at the University of Regina in Canada, where he taught econometrics and the economics of health and served as lead investigator in several large government-funded research projects. In addition to academia, Sagynbekov worked as an economic consultant in Central Asia with USAID's fiscal reform initiative. He received a BSc in finance from Clemson University and earned his MA and PhD degrees in economics from the University of Mississippi. He works at the Institute's Santa Monica office.