

Simulation shows the high cost of dementia, especially for families

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Eric Jutkowitz is the assistant professor in the Brown University School of Public Health. Credit: Brown University

A new simulation of how the costs and the course of the dementia epidemic affect U.S. families finds that neurodegenerative conditions



can more than double the health care expenditures of aging and that the vast majority of that financial burden remains with families rather than government insurance programs.

The total average cost to care for a person with dementia was more than \$321,000 over about five years, compared to an average cost of \$137,280 to care for the same person without dementia, the simulation showed. Typically, 70 percent of the total cost burden fell on the patients and their families to cover with their own labor and out-of-pocket spending, with the balance split evenly by Medicare and Medicaid. In each year, costs of care, which ranged from the informal time and services of family members to acute care hospitalizations, reached as high as \$89,000.

The findings generally agree with prior peer-reviewed estimates of dementia care costs. But lead author Eric Jutkowitz, an assistant professor in the Brown University School of Public Health, said that because the novel simulation is explicitly based on data about the clinical progression of dementia symptoms, it provides a unique tool for public health officials and other policymakers to ask and answer detailed questions about the impact of different interventions. Also unlike other estimates, Jutkowitz said, the simulation shows how the costs of dementia shift year by year as people typically transition from informal care at home to institutional care in nursing homes.

With about 5 million Americans living with Alzheimer's disease and other dementias and more than 61 million baby boomers reaching the age of 65 or older by 2029, understanding what dementia costs families and public insurance programs is critical for planning both for households and governments alike, Jutkowitz said. But there is no comprehensive data set that documents these total costs directly. Instead, the data must be gathered together to generate estimates, including through simulation.



"The modeling structure I used was able to synthesize data from different sources and put them together to form this long-term picture, over the course of the disease, that currently doesn't exist in any one place," said Jutkowitz, whose paper appears in the *Journal of the American Geriatrics Society*. "Each of the data points are part of the broader picture. By themselves, they can't tell us anything about how costs unfold over the course of the disease, but they all come together to develop this picture."

Aging with and without dementia

By bringing together reams of data from the National Alzheimer's Coordinating Center Uniform Data Set; the Aging Demographics and Memory Study; and federal Medicare records, Jutkowitz and his coauthors at the University of Minnesota were able to model the medical course of a nationally representative, albeit computer-generated, cohort of seniors. In proportions derived from the data, the seniors varied by gender, race, education, income, Medicaid eligibility, number of children (e.g. potential caregivers) and geographic region. Based on realworld likelihoods evident in research, the simulation assigned them one or more medical problems such as diabetes, stroke or congestive heart failure.

In all, the team ran 16,000 such hypothetical seniors through the simulation. In one run of the simulation, they had dementia with progressively worsening cognition, behavior and psychological symptoms, and losses in function or independence in basic daily tasks. On average they were diagnosed with dementia at age 83.

As symptoms mounted, their care needs increased. As data suggest, family members often provided "informal" care, valued in the model at \$19.71 an hour, or professional caregivers provided care at \$22 an hour. At some point, patients in the model would typically move to more



institutional care settings such as a nursing home. Along the way they'd sometimes have doctor visits or hospitalizations, for instance because of their other medical problems. These might be covered by Medicare, albeit with varying out-of-pocket costs. As money ran low, some seniors became eligible for Medicaid. The typical senior with dementia lived for about five years after diagnosis before succumbing either to that disease or another medical problem.

In another run of the simulation, the exact same computer-generated senior would age all over again, just as healthy or sick as before, but this time without dementia. That "counterfactual" run allowed Jutkowitz to document the substantial cost difference that dementia makes.

While most aging people eventually encounter serious and complex medical problems, dementia's prolonged erosion of seniors' ability to take care of themselves creates a need for years of informal but intensive caregiving by loved ones, hired staff, or a combination of the two, Jutkowitz said.

"The predominant cost drivers are the loss of independence and the challenging behavioral symptoms such as aggression," he said.

Modeling interventions

The simulation allowed Jutkowitz to vary any parameter to understand the difference doing so can make down the line. He ran various best- and worst-case scenarios and looked at how costs varied for people diagnosed earlier or later, or who lived longer or shorter times. He was also able to see the added <u>costs</u> of dementia for seniors compared to varying alternate lives with different degrees of non-dementia impairment.

But what really makes the simulation a potentially powerful policy tool,



he said, is that it can project the impact of various interventions that could mitigate the severity of dementia symptoms. In the study, for example, he found that an intervention that reduced the rate of functional decline by 10 percent for a year would save \$3,880 per senior, while another that reduced the number of behavioral and psychological symptoms by that much would save \$680.

Jutkowitz said he hopes policymakers will also use the tool to consider the enormous informal burden on families.

"A lot of people, I think, believe that Medicare will pay for their longterm care," he said. "That's not the case. Private long-term care insurance may help, but benefits can be exhausted and few families have policies. For a disease like dementia, the burden and cost falls on the individual and the family."

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