Families Bear Most of the Costs Related to Dementia Care

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A new study on the lifetime cost of dementia indicates that families of people living with the disease incur the largest financial burden. The findings, which are published in the Journal of the American Geriatrics Society, indicate that policy and services should be implemented to support family members of individuals with Alzheimer's disease and related dementias.

As the population ages and as dementia becomes more prevalent, gaining a better understanding of how the disease impacts families, the health care systems, and the economy will be essential to us all as we age. To estimate the lifetime cost of dementia and caring for someone with the disease compared with more routine care costs, Eric Jutkowitz, PhD of Brown University School of Public Health and his colleagues developed a mathematical model—based on data from the National Alzheimer's Coordinating Center Uniform Data Set; the Aging Demographics and Memory Study; and federal Medicare records—to simulate disease progression for newly diagnosed individuals with dementia.

The team’s model estimates that individuals with dementia in the United States receive $321,780 in care over an average of five years living with the disease. This is compared with $137,280 in care costs for the same person without dementia.

Health care costs, including the value of informal care, for a person with dementia over a lifetime were estimated to be $184,500 greater than for someone without dementia, with 86 percent of costs incurred by families. Family costs came from informal care and out-of-pocket payments for medical and long-term care.

Reducing functional decline or behavioral and psychological symptoms by 10 percent resulted in $3,880 and $680 lower lifetime costs, respectively, compared with letting the disease progress naturally.

“Families can use the data from our study to understand the potential financial burden associated with caring for a family member with dementia,” said Dr. Jutkowitz. “Data on the lifetime cost of dementia can also be used by policy makers for planning at the local, state, and national levels, and they can use the dementia simulation model to ask questions about the impact of different interventions on cost of care.”

Additional Information


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