New Surveys Expose Disparities in Barriers to Dementia Care

Black, Hispanic, Native American, and Asian adults expect and experience more barriers when accessing dementia care, according to two new national surveys released this week as part of the Alzheimer’s Association 2021 Alzheimer’s Disease Facts and Figures.

This year’s special report — Race, Ethnicity and Alzheimer’s — examines perspectives and experiences of Asian, Black, Hispanic, Native and White Americans with regard to Alzheimer’s and dementia care. Findings include:

- Two-thirds of Blacks (66%) believe it is harder for them to get excellent care for Alzheimer’s or other dementias. Likewise, 2 in 5 Native Americans (40%) and Hispanics (39%) believe their own race or ethnicity makes it harder to get care, as do one-third of Asian Americans (34%).
- Nearly two-thirds of Blacks (62%) believe that medical research is biased against people of color — a view shared by 45% of Asian Americans, 40% of Native Americans, and 36% of Hispanics.
- Fewer than half of Blacks (48%) and Native Americans (47%) feel confident they have access to providers who understand their ethnic or racial background and experiences. And only 63% of Asian Americans and 59% of Hispanics feel similarly confident.

The special report also finds that half or more of Black, Hispanic, Native American, and Asian American caregivers say they have experienced discrimination when navigating health care settings for their care recipient. Read the full report at alz.org/facts.

The Healthy Brain Initiative’s Road Map series includes promotion of health equity as a guiding principle to accelerate progress against dementia across all communities. This includes addressing disparities such as those mentioned above, rebuilding trust among populations that have experienced structural and systemic injustices (including among Blacks, Hispanics, Native Americans, and Asian Americans), and embracing the unique strengths of communities to advance health and well-being.

Impact of COVID-19

2021 Alzheimer’s Disease Facts and Figures also examines the impact COVID-19 is having on people living with Alzheimer’s. According to the report, there were at least 42,000 more deaths from Alzheimer’s and other dementias in 2020 compared with the previous five-year average — a 16% increase.

Preliminary and anecdotal evidence indicates that the COVID-19 pandemic is having adverse effects on family caregivers. Many are facing pandemic-related caregiving challenges, including the shutdown of adult day centers and the inability of families to visit or communicate with relatives in long-term care communities. Tips, data, and resources are available for public health agencies to address the unique needs of people living with Alzheimer’s in their COVID-19 response. Learn more at alz.org/publichealth-covid19.
Latest Alzheimer’s Facts and Figures
In addition to the special report on race and ethnicity as well as COVID-19 data, 2021 Alzheimer’s Disease Facts and Figures provides the latest national and state-specific statistics on Alzheimer’s prevalence, incidence, mortality, cost of care, and caregiving. Nationally, 2021 Alzheimer’s Disease Facts and Figures reports:

Prevalence and Mortality

- An estimated 6.2 million Americans aged 65 and older are living with Alzheimer’s dementia in 2021.
- Two-thirds of Americans over age 65 with Alzheimer’s dementia (3.8 million) are women.
- Deaths due to Alzheimer’s between 2000 and 2019, has more than doubled, increasing 145%.

Caregiving

- In 2020, more than 11 million caregivers of people with Alzheimer’s or other dementias provided an estimated 15.3 billion hours of unpaid care, a contribution to the nation valued at $257 billion.
- Nearly half of all caregivers (48%) who provide help to older adults do so for someone with Alzheimer’s or another dementia.
- Approximately two-thirds of caregivers are women, and one-third of dementia caregivers are daughters.
- Forty-one percent of caregivers have a household income of $50,000 or less.

Cost of Care

- Total health and long-term care costs for all individuals with Alzheimer’s or other dementias are estimated at $355 billion (not including unpaid caregiving). Medicare and Medicaid are expected to cover $239 billion or 67% of the total costs. Out-of-pocket spending is expected to be $76 billion.
- Total payments for health care, long-term care and hospice care for people with Alzheimer’s and other dementias are projected to increase to more than $1.1 trillion in 2050.
- The total lifetime cost of care for someone with dementia is estimated at $373,527.

Updated state-specific fact sheets are available for each state and the District of Columbia. Each provides a comprehensive picture of Alzheimer’s in the state and includes estimates of Alzheimer’s prevalence and incidence, the burden of dementia caregiving in the state (including total hours of unpaid care provided and value of that care), the total cost of Alzheimer’s to the state Medicaid program, and more.

Download the full report, find infographics, and other quick facts at alz.org/facts
Career Opportunity: Interdisciplinary Summer Research Institute 2021

The Alzheimer’s Association® Interdisciplinary Summer Research Institute (AA-ISRI) is an immersive, no-cost opportunity for early-career researchers in public health and psychosocial care to become engaged in dementia science and accelerate breakthroughs in the field. Twelve individuals in each field will be selected to participate in the Institute, which will be held in Chicago (COVID-19 circumstances permitting), August 9-13, 2021. Public health researchers will hear from experts with diverse perspectives on the public health aspects of dementia. Participants will also receive individual mentoring in the development of their research proposals.

Applications are due April 8, 2021. Individuals from diverse backgrounds are encouraged to apply. To learn more and submit an application, visit alz.org/summerinstitute.

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