Testimony of Jennifer Manly, PhD

Taking Aim at Alzheimer's: Frontline Perspectives and Caregiver Challenges

United States Senate Special Committee on Aging

May 20, 2021

Chairman Casey, Ranking Member Scott, and Distinguished Members of the Committee, thank you for the opportunity to share information on the challenges we face in meeting the needs of people with Alzheimer's disease and their caregivers.

Introduction:

My name is Jennifer Manly. I am a Professor of Neuropsychology in Neurology at the Gertrude H. Sergievsky Center and the Taub Institute for Research in Aging and Alzheimer's Disease at Columbia University. I have been the Principal investigator or a Co-Investigator on over 45 successful grant applications and authored more than 185 peer-reviewed articles that have contributed insights into disparities in dementia across racial and ethnic groups. My research has explored how early life inequalities, including school policies and educational opportunities influence risk and resilience for cognitive decline and biomarkers of brain health, as well as measurement of cognitive function among Black or African American and Latinx or Hispanic older adults. I am one of the lead investigators for several large longitudinal studies that include adults from diverse racial, ethnic, linguistic, and socioeconomic backgrounds, including the Washington Heights-Inwood Columbia Aging Project (WHICAP), Offspring Study of Mechanisms for Racial Disparities in Alzheimer's Disease (Offspring), and the Reasons for Geographic and Racial Differences in Stroke Study (REGARDS). I also lead the School Quality in Project Talent Aging Study and was the PI of the multi-site African American Alzheimer's Disease Genetics Study.

Overview:

Over the last decade we have seen a tremendous increase in the federal investment for research on Alzheimer's disease. While this investment has accelerated our understanding of the heterogeneity of the disease and has allowed us to engage a more diverse group of Americans in Alzheimer's research, little progress has been made in decreasing racial/ethnic disparities in the development of Alzheimer's disease (AD), or equitable care for those living with AD.[1] Today, my goal is to shed some light on ways we can narrow disparities in Alzheimer's disease risk, diagnosis, and access to care and long term services.

Alzheimer's Disease 101:

Before discussing dementia inequalities, I would like to provide a brief overview of the disease.

Dementia vs AD

Dementia is an umbrella term for cognitive difficulties that have their onset in adulthood that affect a person's ability to independently perform everyday activities. Cognitive abilities that can be affected by dementia include memory, language, attention, spatial abilities, problem-solving, and other thinking skills. As result, as the disease progresses, individuals with dementia need help making decisions and increased supervision, and ultimately, they may require full-time, long-term care.

There are several different types of dementia, and each type is associated with a unique set of clinical characteristics and cognitive profile. Alzheimer's disease is the most common cause of dementia; it accounts for approximately 60%-80% of all dementia cases.[2] As people get older, they are at higher risk for developing Alzheimer's disease. People with a family history of Alzheimer's are also at higher risk.

Symptom Onset & Course of Alzheimer's Disease

Alzheimer's disease is a clinical syndrome that is caused by loss of brain function. It has a gradual onset, and is a progressive disease that becomes worse with time. The neuropathology (abnormal changes in the brain) associated with AD appears in the fifth and sixth decade of life, many years before the onset of symptoms. The first symptoms usually occur in older adulthood and are typically subtle problems with memory that may be noticeable to the individual and their family and friends, but do not interfere with everyday activities. Over time memory problems worsen and other areas of cognitive function also decline. Gradually, the ability to independently complete complex daily activities, such as driving, learning new routines, remembering appointments, finances, following a recipe, doing laundry, and housecleaning, begins to decline. Eventually, cognitive impairment gets to the point where an individual is no longer able to remember names and faces of family members, and complete very basic tasks such as toileting, dressing, and/or feeding. At the severe stage of the disease, individuals are no longer able to swallow.

Diagnosis

There is no single test to diagnose Alzheimer's disease. Rather, a formal diagnosis requires gathering information from a variety of sources, including obtaining medical and family history, reports from family or close friends about changes in thinking skills and behavior, blood tests and brain imaging such as MRI and PET scans, and cognitive tests conducted by a trained specialist such as a neuropsychologist, to carefully assess changes in memory and thinking skills.

Access to cognitive testing is important because there is often a disconnect between burden of neuropathology and clinical symptoms, such that two people with the same amount of brain disease (or neuropathology) can have different severity of memory deficits. Brain autopsy of people who did not have dementia and who die in their 80's and 90's shows that many of them have neuropathological changes that look just like people who had dementia. This imperfect link between neuropathological burden and cognitive function is called cognitive reserve or cognitive resilience. This is important because while we are searching for treatments to stop the neuropathology associated with AD, there may be ways to slow progression or prevent dementia by increasing cognitive reserve or resilience.

Access to neuropsychological testing and a full diagnostic workup is also important because other subtypes of dementia, such as Vascular Dementia and Lewy body dementia can have similar symptoms to Alzheimer's Disease. Accurate diagnosis based on a comprehensive diagnostic assessment is important to determine the right treatments, and the right types of family supports and planning that may be needed.

Researchers have identified abnormal levels of proteins, such as beta-amyloid and tau, as well as vascular changes in the brain, that are associated with loss of cognitive function in people with Alzheimer's disease. However, recent trials of drugs that remove amyloid from the brain suggest that it might not be enough to remove the abnormal proteins once they are already present in the brain, to slow cognitive decline or prevent dementia.

Incidence & Prevalence of AD

Currently, an estimated 6.2 million Americans age 65 and older are living with AD.[3] That is more than 1 in 9 people age 65 and older living in the United States. By 2025 the number of those living with AD is expected to increase by 16% to 7.2 million. By 2060, that number is expected to reach 13.8 million.[2] Younger or Early Onset Alzheimer's disease, defined as onset of symptoms before the age of 65, is less common; researchers think that anywhere from 4 – 5% of all of the people with AD had symptom onset before age 65.

Disparities

Rates of AD are higher among Black or African Americans and Latinx or Hispanics than non-Hispanic White older adults.[4–9] In other words, at the same age, a higher proportion of Black and Hispanic older adults live with AD than White older adults. More women are affected by Alzheimer's disease (AD) than men because women live longer, and age is the primary risk factor for AD. Of the approximately 6.2 million Americans age 65 and older currently living with AD, about 3.8 million are women.[2] Women also represent approximately two-thirds of the dementia caregivers in the United States.[10–12] It is now well established that people who had fewer opportunities to receive education when they were children, are at higher risk for Alzheimer's disease later in life.[13,14] There is evidence that early life residence in a "Stroke Belt" state, including states that Committee members represent, such as Georgia, North Carolina, and South Carolina, leads to higher risk for AD, even if you move out of the Stroke Belt .[15,16]

Overall, Alzheimer's disease is underdiagnosed. In other words, only about half of the people who have Alzheimer's disease ever receive a formal diagnosis by a doctor. There is evidence that missed diagnoses of Alzheimer's and other dementias are more common among Black and Hispanic older adults than among older Whites.[17–19]

Dr. Manly's Research

For the past 23 years I have been an investigator for a community-based longitudinal study of aging and dementia,[7] where I have worked closely with the older residents of the Washington Heights, Hamilton Heights, and Inwood communities of Northern Manhattan in New York. These communities are primarily African American and Caribbean Hispanic. The older adults in this incredibly strong and vibrant community have taught me about their life experiences and allowed my research team to partner with their families. I have seen how structural inequalities in education, housing, jobs, and access to quality and culturally and linguistically appropriate health care influence and maintain disparities in AD risk, diagnosis, and care.

My work largely focuses on understanding why disparities in Alzheimer's disease and dementia are maintained and how to narrow or eliminate them. Our research suggests that the core explanation for disparities in dementia is structural inequalities. There are historical and contemporary policies that have created unequal access to resources and may increase exposure to stressors throughout life. These conditions get "under the skin" at a very young age and account for racial/ethnic disparities in Alzheimer's disease as people get older. For example, the United States has a long legacy of denying Black Americans equal access to high quality education, and this legacy has been shown to have an impact on health of older adults. Segregation of schools in the South and the North was accomplished through local laws and state-level resources for public schools varied widely across states. Across all U.S. States, before and after Brown v. Board of Education, racist policies and residential segregation forced Black children to attend underfunded schools that had large student/teacher ratios, shorter term length, lower teacher salaries, inadequate budgets for supplies and school buildings, and discriminatory disciplinary policies. Many older residents of Washington Heights immigrated from the Dominican Republic, where, especially in the rural areas, there was very little governmental investment in education, and fewer opportunities for children to go to school or to learn to read or write. My research team found that that later life dementia risk and cognitive decline are influenced by early-life educational policies in the places where people went to school. This work suggests that investment in schools that serve Black and Hispanic children would narrow inequalities in dementia.

We do not yet know exactly what it is about schooling that lowers risk for dementia, but one strong possibility is that more years of school, and a higher quality education, leads to the credential and skills needed to get better jobs, earn more money, live in healthier neighborhoods, and lower exposure to stress. There is some evidence that the benefits of higher education are not as strong in Black people as they are among Whites, suggesting that racism in school, at work, in housing, and in health care impedes Black people from converting educational credentials to lasting brain health later in life. This research suggests that investment in neighborhoods, housing, and health care in racial and ethnic communities that are underserved, and advancing racial equity in institutions would have a positive impact on later life brain health of our nation.

Disparities in Dementia Services, Care, & Caregiving

There are also racial/ethnic disparities in the diagnosis and care of individuals with AD, including availability of support services and time spent on caregiving.[20–23]

Dementia Services

Primary care providers who practice in communities with increased African American and Latinx populations (compared with White) have fewer community resources to refer patients to behavioral health professionals.[24] Where I work in Washington Heights and Harlem, there are very few neurologists, psychiatrists, geriatricians, and neuropsychologists who are fluent in Spanish, who can provide language-concordant diagnosis and care for Spanish speaking older adults. Those that are bilingual in Spanish and English have long waiting lists of patients and families who need an assessment. The lack of community resources is also striking for providers who practice in rural areas, regardless of neighborhood-level insurance status. Primary care physicians in urban communities with larger proportions of minoritized and uninsured populations have the greatest unmet need for local behavioral health professionals. Lack of culturally appropriate resources for dementia diagnosis and care is a key reason why African Americans and Hispanics with dementia are less likely than White people with dementia to have a formal diagnosis, and are more advanced in their disease when they are diagnosed.

In order to close this gap, we should invest in training programs that graduate qualified, culturally competent behavioral health professionals with specialty training in dementia care. Diversity and cultural competence of these trained professionals is key to responding to the needs of older adults from traditionally underserved communities who are at higher risk of developing cognitive impairment and AD. To improve patient access to behavioral health services, behavioral health professionals must practice in the neighborhoods where underserved communities live. Behavioral health professionals who provide dementia care should be incentivized to practice in communities that are traditionally underserved. In other words, narrowing inequalities in dementia services will require policy that focuses on the neighborhood or local level, increasing options for families seeking dementia serviced in the places that they live. We need to increase the number of providers who have the individual skills, cultural competencies, and capacity to provide dementia care services.

There is a need for investment in capacity and coordination of community health centers and/or older adult day centers that provide direct services within underserved communities, with specific strategies for improving access to brain health services and dementia assessments.[25] One other tool for meeting high demand for dementia diagnosis and care in underserved communities is telehealth. However, federal investment must be expanded to address culturally relevant telehealth solutions for dementia diagnostic services and ongoing care in both rural and urban settings.[25]

Family Caregiving

More than 11 million Americans provide unpaid care for people with AD or other dementias.[27] Unpaid caregivers in each of the four most populous states provided care valued at more than

$10 billion.[2] In 2020, unpaid family caregivers of people with AD provided an estimated 15.3 billion hours of unpaid help.[2] Many of these family caregivers are employed, working full-and part-time jobs while caregiving.[28] Approximately one-quarter of dementia family caregivers are "sandwich generation", caring not only for an aging parent, but also for a child.[28] There is uneven access to paid family leave, because Black and Hispanic individuals are less likely to hold a job that provides paid family leave.[29,30]

People from minoritized backgrounds are more likely to rely on informal and unpaid family care for people with dementia than to employ formal direct care workers. Our healthcare system has not earned the trust of many Americans from minoritized backgrounds [31–33] and, as a result, even if they can afford it, many choose to keep caregiving responsibilities among family members. Racial and ethnic differences in family caregiving is also related to the high cost of paid care inside and outside of the home. On average, Medicare beneficiaries age 65 and older with Alzheimer's or other dementias paid $11,571 out of pocket annually for health care and long-term care services not covered by other sources.[2] Medicare covers home health services, such as part-time skilled nursing care, home health aide (personal hands-on) care, therapies and medical social services in the home, but does not include homemaker or personal care services. Although Medicare covers care in a long-term care hospital, skilled nursing care in a skilled nursing home, and hospice care, long-term care in a nursing home is not covered by Medicare.[34] While Medicaid may cover some services that Medicare does not, these benefits vary state-to-state, as do the criteria to receive home-based care.[35]

Gaps in the Dementia Care Workforce

Direct Care Workers

Direct care workers play an important role in home-based care. This workforce largely consists of women of color, many of whom have less than a high school education and were born outside of the US.[36] Direct care workers earn low wages and experience high turnover.[37] About 25% of direct care workers have an income below 138% of the federal poverty line and 42% rely on public assistance. Studies have shown that compensation for direct care workers plays a key role in turnover rates.[38]

Direct care jobs are often viewed as "dead-end jobs" because they are offered little career advancement. It is time to elevate the value of the direct care workforce to be consistent with the essential role that these carers play in the wellbeing of our society. Facilitating career advancement opportunities within direct care will help strengthen recruitment and retention, and this stability and training produces better quality of life among people with dementia and their families. Workers who are offered opportunities for advancement can mentor, support, and supervise other workers entering the field, which will increase the retention of direct care workers overall.[38,39]

Language is often cited as a barrier to receiving dementia-related care.[40] One of the biggest challenges for families in Washington Heights is that most of the doctors who provide specialized dementia care do not speak Spanish. Using an interpreter for any medical visit has limitations, but this is even more of a barrier to quality care when the patient has cognitive deficits. In communities like Washington Heights, bilingual home health care workers are a necessity, and highly sought after. In the dementia care workforce, bilingual staff are a valuable, under-recognized and underpaid resource.

Recommendations

1) Several studies show that Black and Hispanic older adults are at higher risk of Alzheimer's Disease than non-Hispanic Whites, and that these disparities are linked to structural inequalities that begin early in life. My research suggests that investment in schools that serve Black and Hispanic children, in neighborhoods, housing, and health care among racial and ethnic communities that are underserved, and advancing racial equity in institutions would narrow inequalities in dementia.
2) Early and accurate diagnosis of dementia is at the core of provision of dementia services, yet there are fewer resources to refer patients to dementia care professionals in underserved communities. Limited number of clinicians who can provide language concordant dementia assessment creates long waiting lists and delays diagnosis in many underserved communities. Investing in training programs that increase the number of culturally competent dementia care providers, innovating and broadening dementia care options in neighborhoods with a higher impact of dementia among minoritized people, and incentivizing clinicians to practice in these communities would help to narrow the gap in dementia care and services.
3) Investment in the direct care workforce will improve quality of life among people with dementia and their families and narrow disparities in care. Investment in the direct care workforce must take an equity-focused approach that is geared toward restoring access and allocating resources to communities that are currently underserved by most dementia care services. This may include, for example, targeted recruitment and training of community members interested in health care careers, and increased reimbursement for skills such as bilingualism, that help narrow gaps in access to high quality, culturally and linguistically appropriate services.
4) Expansion of paid family leave is an equity issue for dementia care and services, because while people from minoritized backgrounds are more likely to rely on family caregiving, they are also less likely to hold a job that provides paid family leave.

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