TRANSFORMING ALZHEIMER'S DISEASE DIAGNOSIS & CARE THROUGH POLICY

A Call for Action and Empowerment

Society for
Women's Health Research

BACKGROUND

As the most common cause of dementia, Alzheimer's disease is a progressive neurodegenerative condition that impairs memory, thinking, and the ability to perform daily tasks. Research has identified several risk factors for Alzheimer's disease, including genetics, medical history, and environmental influences, though its exact causes remain unknown. Research also supports the increasing importance of maintaining brain and cognitive health throughout the lifespan. What we do know, however, is that earlier detection, improved diagnosis, and reducing the stigma around cognitive decline can empower individuals to seek care and support sooner, ultimately improving outcomes for those at greatest risk.

One factor that warrants greater attention in Alzheimer's disease is the influence of sex and gender and their role in the disease's onset, progression, and overall impact. Women are disproportionately affected by Alzheimer's disease and other forms of dementia, making up nearly two-thirds of the Alzheimer's disease population in the United States, and it is the fifth leading cause of death among women.[1, 2]

Researchers are increasingly investigating why women are more susceptible. One reason is longevity; age is a major risk factor for Alzheimer's disease and other forms of dementia, and women tend to have longer lifespans than men.[3] Emerging research also suggests that sex-specific differences in gene networks and brain tissue may be contributors, and variations in brain immunometabolism may play a role in heightened risk and severity of Alzheimer's disease in women.[4] Lastly, cognitive changes are found in various life stages unique to females and women such as pregnancy, postpartum, perimenopause, and menopause.

The observed sex disparities in Alzheimer's disease are further exacerbated by other socioeconomic factors like race and geography. For example, Black patients with Alzheimer's disease often have to present with more advanced clinical presentations to warrant a dementia diagnosis from physicians than white patients.[5] The complex interplay of structural sexism and race can also compound disparities, with memory loss and cognitive decline being more pronounced in Black women than in their white counterparts.[6] Inequities are likewise observed in other minoritized populations. Despite being up to 1.5 times more likely to have Alzheimer's disease and other dementias, Hispanics populations are only 18% more likely to be diagnosed.[7]

Communities in rural or underserved areas, particularly where health care resources are in short supply, may encounter difficulties in obtaining access to advanced diagnostic tools and specialized care.[8] Research examining regional differences in dementia care highlight significant gaps, showing that rural residents with dementia experience higher death rates, fewer doctor visits, more hospitalizations, and less access to home care compared to those in urban areas.[9]

Financial strain is equally important to consider in evaluating impacts of Alzheimer's disease. Economic hardship, especially for women from low-income backgrounds, create further obstacles in obtaining care, often resulting in delayed diagnoses and limited support. For uninsured and underinsured populations, out-of-pocket costs related to dementia care remains a major challenge, making it difficult for patients to access the early diagnostic care and treatment they need. Studies show evidenced connections between low socioeconomic status and increased "risk of dementia and cognitive dysfunction."[10]

The impact of Alzheimer's disease extends to caregivers, the majority of whom are women. Over 60% of unpaid Alzheimer's disease and dementia caregivers are women, with many balancing caregiving responsibilities with other personal and professional obligations. These competing priorities can impact a caregiver's physical, psychological, financial, and spiritual health. In fact, compared to non-caregivers, caregivers are at higher risk of not having health insurance and foregoing health care due to cost.[11]

CALL TO ACTION

Addressing the Alzheimer's disease burden for women has never been more urgent. Without groundbreaking medical discoveries or interventions, the number of people with Alzheimer's disease is projected to double from 6.9 million to nearly 14 million by the year 2060, creating a sense of urgency for prioritizing earlier and more accurate diagnosis, which can significantly improve the course of treatment and care.[12]

Now is the time to meaningfully invest in improved diagnosis, treatment, care, and support systems for those affected and to ensure that policymakers go beyond short-term and patchwork solutions and instead prioritize long-term, comprehensive policies that address the full scope of Alzheimer's disease care.

The Society for Women's Health Research emphasizes the following priority areas to support cognitive health across the lifespan, address gaps, reduce stigma, and improve Alzheimer's disease diagnosis, treatment, and care for women and their caregivers:

Expand Brain Health Investment and Integration into Women's Health

The growing prevalence of Alzheimer's disease underscores the urgent need for greater investments in brain health across the lifespan and recognition of brain health as a lifelong priority, especially for women. Integrating brain health into women's health research and care – including research into hormone and age-related factors that disproportionately affect women – and fostering early and open conversations between patients and health providers can help tailor more effective care strategies. Furthermore, advocating for brain health education focused on earlier detection and diagnosis of cognitive conditions and with a sex differences lens in medical curricula can equip both patients and clinicians with the knowledge to better recognize, treat, and prevent brain health issues from an early age.

Champion the Use of Innovative Technology and Digital Health Solutions in Clinical Care

Supporting the development and adoption of innovative diagnostic and treatment tools is crucial for streamlining disease diagnoses and improving care. Policies should promote investment in technologies like telehealth, especially for individuals living in rural areas or without transportation to in-person care settings. It also is essential to ensure these solutions are user-friendly, particularly for individuals with memory loss or limited technology experience. Furthermore, expanding access to cutting-edge tools, such as blood biomarkers, advanced imaging, and genetic tests is crucial for early, more accurate detection and diagnosis of Alzheimer's disease and other neurodegenerative conditions.

Enhance Care Coordination by Addressing Workforce Challenges

Comprehensive, multidisciplinary care teams are essential for providing the full range of services required for Alzheimer's disease patients, especially those with comorbidities. These teams, including doctors, nurses, social workers, and other care specialists, are crucial for integrated, patient-centered care. However, workforce challenges — such as lack of care coordination and physician shortages — pose significant barriers. Policies should address shortages in for dementia care support workers, such as certified nursing assistants (CNAs), dementia care navigators, and paid caregivers, and incentivize recruitment, retention, and training of these vital roles. Policies can also create financial incentives to support the creation of multidisciplinary care teams, enabling coordinated care from diagnosis through treatment and long-term support.

Improve Support for Caregivers

Workforce challenges highlight the need for a "both/and" approach to support both professional and family caregiving. Meaningful compensation, workplace protections like paid leave, and respite care can preserve caregiver well-being and mitigate undue strain. Recognizing caregivers as integral partners in medical care teams for Alzheimer's disease is crucial because they often possess the most intimate knowledge of the patient's daily functioning, preferences, and evolving needs. This firsthand insight can greatly inform clinical decisions, improve care planning, and enhance patient outcomes. To make this a reality, policymakers should consider incorporating caregiver input into electronic health record (EHR) systems by ensuring that caregivers are identified as key members of the care team. This could involve creating sections within EHRs specifically for caregiver documentation, such as tracking their involvement, concerns, and feedback. Additionally, increasing access to training, culturally appropriate resources, and a simple entry point for support services can ease caregiving challenges, while technology training could help older caregivers navigate available resources.

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