Advancing Care for Women with Alzheimer's Disease

A Call to Action from the Society for Women's Health Research

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Background

Alzheimer's disease is a progressive neurological disorder that affects cognitive functions, such as memory, language, and thought. According to the Alzheimer's Association, 6.7 million adults ages 65 and above are estimated to live with Alzheimer's disease in the United States, and this number is expected to increase to 13.8 million by 2060 [1]. Alzheimer's is the most common form of dementia, disproportionately impacting women. Approximately two-thirds of Americans living with Alzheimer's are women, and after age 45, the chance of developing Alzheimer's is 1 in 5 in women compared to 1 in 10 in men [2,3]. Moreover, in the U.S., Alzheimer's disease is the fifth leading cause of death for women and the seventh leading cause of death for men [4,5].

Studies have shown that sex differences in brain physiology and function contribute to an increased vulnerability to Alzheimer's disease risk and pathology in females, as well as faster and more severe cognitive deficits and decline [6]. Disparities also exist among people of color – some studies indicate that in the U.S., older Black adults are twice as likely, and Hispanic adults are 1.5 times as likely to develop Alzheimer's disease and related dementias (ADRD) than older non-Hispanic white adults. Additionally, women from these racial groups are more likely to have a missed or delayed clinical dementia diagnosis than their white counterparts [7]. However, non-Hispanic white women have the highest mortality rate for Alzheimer's disease, with 285.1 deaths per 100,000 compared to 234.7 for non-Hispanic Black women and 218.8 for Hispanic women [8].

In addition to increased risk, prevalence, and mortality, Alzheimer's disease has significant impacts on the mental health and professional lives of women, largely due to their disproportionate role as caregivers. It is estimated that over 60% of ADRD caregivers are women, and more than one-third of dementia caregivers are daughters [2].

The Alzheimer's Association reports that 74% of caregivers for people with Alzheimer's or other dementias are concerned about maintaining their own health since becoming a caregiver [9]. Over 1 in 3 dementia caregivers say their health has worsened due to their care responsibilities, and 60% rated the emotional stress of caregiving as “high” or “very high” [10]. More than a quarter of dementia caregivers delay or don't pursue interventions or practices to maintain good health. Furthermore, research has indicated that the cost of informal caregiving is the most significant economic challenge of Alzheimer's disease for women. Throughout their lifetime, a woman is likely to incur six times greater cost than a man to provide care for their loved one with Alzheimer’s [11].
Notable Gaps in Alzheimer's and Women's Health

Despite the broad investment in Alzheimer’s disease research and care, there remain significant gaps in our understanding and approach to addressing disease disparities for women.

**Diagnostic Delays**

Diagnosing Alzheimer’s involves a combination of neurological exams, brain imaging, and genetic and cognitive testing. Women have been shown to perform better on certain verbal memory tests and are more likely to sustain cognitive function longer [12]. As a result, women tend to be diagnosed later, with more severe disease burden, and experience a faster cognitive decline than compared to men [13].

**Inclusion in Clinical Trials**

Women are underrepresented compared to national disease prevalence estimates in clinical trials for Alzheimer’s disease. The prevalence of female participants across all trials was estimated to be 56%, less than the estimated female disease prevalence [14]. Also, studies often fail to analyze data by sex and gender, making it challenging to understand how Alzheimer’s disease manifests and should be treated differently in women.

**Caregiving Burden**

More than 60% of individuals providing care for an individual with ADRD are women [2]. Studies report that female caregivers experience higher levels of depression, a greater toll on their health and well-being, financial burden, and workplace disruptions [15]. This is likely because women provide more intensive care and for longer periods of time compared to their male counterparts.

**Limited Policy Solutions**

Despite a more than 7-fold increase in federal research funding for ADRD since 2011, Alzheimer's research specific to women remains severely underfunded. Advocacy organizations have defined various goals to address the public health disparities associated with Alzheimer’s; however, few policies are geared specifically toward the research and health care of women as patients and caregivers in the Alzheimer’s space.
Inform the public about the differences between cognitive changes due to normal aging versus dementia. Stigma and misconceptions about Alzheimer’s disease continue to persist due to a combination of lack of knowledge, cultural and social beliefs, and historical attitudes among various communities of people. These trends tend to misconstrue dementia-related cognitive decline with characteristics of normal aging, resulting in delays seeking care only in advanced stages of disease.

Public awareness campaigns and community outreach efforts should address these misconceptions and gaps in knowledge concerning the signs and symptoms of Alzheimer’s disease and related dementias. Education should also address risk factors, practices for prevention and early diagnosis, and lifestyle interventions to promote brain health and slow disease progression.

Educate women, especially women of color, about the risk factors for Alzheimer’s disease and the benefits of early detection. An estimated 4.1 million women aged 65 and above have Alzheimer’s, compared to 2.6 million men [7]. The strongest genetic risk factor for Alzheimer’s disease is the apolipoprotein E (APOE) gene, which has been shown to have a stronger association and more deleterious effects on brain pathology and memory in women than men [16]. Increased frequency of this and other genetic markers have been observed among different racial and ethnic groups.

Women also display faster cognitive decline and brain atrophy with mild cognitive impairment (MCI) diagnoses and have 30% increased risk of mortality due to Alzheimer’s [17]. Hence, it is crucial that women understand the importance of disease prevention and early diagnosis to maintain brain health and quality of life as they age.

Train health care providers in practices for early diagnosis, advancements in treatment options, and patient-centered care for Alzheimer’s disease. Because women tend to perform better than men in verbal memory tests, those with MCI (a precursor to Alzheimer’s disease), may still pass diagnostic tests despite having an underlying brain pathology for dementia. The scales for these tests are not stratified by sex, often resulting in false negatives and delayed diagnoses for MCI or Alzheimer’s [12]. Such delays can lead to more severe symptoms, irreversible damage, and reduced responsiveness to treatment for many women.

Patient-provider communication and educational materials must be linguistically and culturally inclusive and appropriate to reach diverse target populations. For instance, compared to African American, Hispanic, and white caregivers, Asian American caregivers report being more likely to need help locating educational resources in languages other than English, understanding and completing paperwork, and using technology to provide care.

Promote public awareness and education about Alzheimer's disease knowledge gaps and disparities.

Calls To Action
Prioritize sex and gender analyses and adequate representation of women in clinical trials for Alzheimer's disease research.

- Earmark sex and gender-focused studies in Alzheimer's research through targeted funding allocation and requests for proposals. Despite the significant increase in investments in Alzheimer's disease research over the past decade, there are significant knowledge gaps that could enhance our understanding of the disease's risk factors and improve patient outcomes for women, who are the majority of Alzheimer’s patients.

The sex differences and disparities in brain health and disease are well-known, yet poorly understood. Current research does not prioritize investigating the sex and gender-specific underpinnings of MCI or advanced Alzheimer's disease. The genetic basis for Alzheimer's, namely, the correlation between the APOE alleles and disease susceptibility, must continue to be studied through a sex and gender lens to better understand causality, clinical impact, and treatment outcomes in different populations of women as well as men.

- Encourage longitudinal studies and research that investigate disease pathology, treatment interventions, caregiving burden, and mental health in women. Alzheimer’s disease not only manifests differently in women due to biology, but it also impacts women differently as a result of social and cultural factors. Evidence is limited, especially concerning longitudinal studies across clinical and behavioral topics. Understanding the sex and gender influences of Alzheimer's disease can lead to advances in preventive care, precision medicine, and economic and social interventions that are much needed for women, both as patients and caregivers.

- Hold funding organizations and individual researchers accountable for inclusion and diversity in clinical trials. Sex and gender differences and disparities in brain structure, function, and Alzheimer's disease are known. Therefore, it is unacceptable not to include and retain diverse populations in clinical trials, including underrepresented, rural, and marginalized groups. Clinical trials for new therapies must plan for adequate sample sizes that can assess potential differences in therapeutic effects between men and women, and then report this data accordingly.
• Design customized care plans for family caregivers of Alzheimer’s patients, using dementia-specific needs assessments. Individuals with dementia have complex cognitive, functional, and behavioral challenges that can place significant demands and stress on their caregivers, which are often female (more than 60%) [2]. These caregivers often lack the support and resources needed to provide the best care for their loved ones.

To reduce this burden on caregivers, tailored treatment and support plans for dementia patients should be developed, considering the patient’s living situation, insurance coverage, and disease stage, as well as the capacity and available resources of their caregiver(s).

• Expand opportunities and access to financial support for unpaid caregivers through federal insurance coverage, paid family leave, and employment benefits. Although a caregiver of someone with severe dementia is more likely to report more emotional and physical burdens than financial burden, the latter is not without significant impact.

Caregivers who live with their recipient tend to have lower annual household incomes (less than $75,000) and higher financial impacts due to caregiving responsibilities. Few employers have formal policies that support caregivers – while flexible work hours or paid sick days are more common (up to 53%), paid family leave and employee assistance programs are offered by less than one-third of companies, and even fewer allow telecommuting [18].

Such accommodations would likely reduce the prevalence of female caregivers cutting working hours and leaving the workforce, reportedly submitting to gender role expectations. Moreover, their increased loss in wages, social security, and pension benefits compared to their male counterparts puts them at higher risk of financial strain and poverty.

• Increase awareness and implementation of respite care policies and support to promote self-care for caregivers. More than 60% of ADRD caregivers are women, often sandwich caregivers – daughters caring for a parent while managing a family of her own [2]. One study found that 73% of caregivers who spend more than 40 hours per week providing care were women.

Caregivers often report that they had no choice in becoming a caregiver. The responsibilities can quickly become overwhelming, warranting a need for personal counseling or respite care to address the emotional demands. Emotional burden is reported 1.5 times more in females than males and is most common among white females [19]. Moreover, the majority of dementia caregivers who express a need for individual counseling (85%) or respite care (84%) are also women [20].
Implement policy solutions that support comprehensive coverage, care, and education for whole-person health.

- Expand awareness and education for beneficiaries and caregivers about the relevant services covered by Medicare. According to a 2018 study of middle-income Boomers, 56% mistakenly believed that Medicare covered the cost of ongoing long term care [21,22]. Knowing what is fully or partially covered by Medicare is essential to providing quality care for individuals with Alzheimer's and reducing the caregiving burden.

It is important, for example, to understand the differences between memory care, assisted living, and skilled nursing home care to ensure that the Alzheimer's patient is maximizing the resources available to receive the most appropriate care and support. As the disease progresses beyond a family caregiver’s capacity, it is even more imperative that they are aware of additional resources that are available to them and their care recipient.

- Develop policies that address the holistic needs of Alzheimer's patients and caregivers – from treating comorbid conditions to navigating the health care landscape. Alzheimer's is a disease associated with older age, when women are usually postmenopausal. During this stage of life, many women face an increased risk of chronic diseases and comorbid health conditions, such as osteoporosis, cardiovascular disease, and mood disorders. Treatments for Alzheimer's disease cannot be siloed from these other health considerations.

Caregivers who also reside in this midlife and senior stage of living should not have to compromise their own physical and mental health [23]. Policies and interventions for Alzheimer's patients should be accessible and easily understandable, so that caregivers can effectively help their loved ones and themselves. Training and support, such as dedicated patient navigators and layman resource aides, should help to simplify complex health care documents and policies.
About the Society for Women's Health Research

The Society for Women’s Health Research (SWHR) is a national nonprofit and thought leader dedicated to promoting research on biological sex differences in disease and improving women’s health through science, policy, and education. Founded in 1990 by a group of physicians, medical researchers, and health advocates, SWHR is making women’s health mainstream by addressing unmet needs and research gaps in women’s health. Thanks to SWHR’s efforts, women are now routinely included in most major medical research studies and more scientists are considering sex as a biological variable in their research.

SWHR Science Programs identify research gaps and address unmet needs in diseases and conditions that exclusively affect women or that disproportionately or differently affect women. The Alzheimer's Disease Program was launched in 2011 to investigate the role of biological sex hormones in the brain and Alzheimer’s disease etiology, prognosis, and treatment. The Program engages researchers, health care providers, patients, advocates, and health care policy decision-makers to explore strategies to address knowledge gaps and create recommendations for future research and policies related to women’s health and Alzheimer’s disease.

SWHR Women's Health Dashboard

The SWHR Women’s Health Dashboard offers a platform to explore the latest national and state data on diseases and health conditions that have significant impacts on women’s health across the lifespan.

SWHR works to bring attention to these issues, highlight current opportunities to address these disparities in women’s health, and track progress regarding science, education, and health care policy outcomes.

The five key areas that featured on the Dashboard are:
- Alzheimer’s disease
- Breast cancer
- Chronic obstructive pulmonary disease
- Depressive disorders
- Ischemic heart disease

Through the Dashboard, SWHR aims to track progress regarding science, education, and health care policy outcomes for these high impact women’s health issues.

Explore the SWHR Women’s Health Dashboard: swhr.org/womenshealthdashboard
References


