

Underrepresented Communities and Dementia: Disproportionate Prevalence, Stigma, and Barriers to Care

In 2023, the WHO reported that “more than 55 million people worldwide have dementia, with over 60% who live in low-and middle income countries. Indeed, dementia disproportionately affects underrepresented communities, exacerbating existing health disparities. These communities face unique challenges, including a higher prevalence of dementia, pervasive stigma, and significant barriers to accessing care, which contribute to poorer outcomes and a lower quality of life for those affected.

Disproportionate Prevalence

Research consistently shows that dementia prevalence is higher in underrepresented communities. Factors such as socioeconomic status, education level, access to healthcare, and lifestyle differences contribute to this disparity. For instance, African Americans and Hispanic/Latino populations in the United States have higher rates of Alzheimer’s disease and related dementias compared to non-Hispanic Whites. These disparities can be attributed to a complex interplay of genetic, environmental, and social factors that increase the risk of developing dementia. In addition, dementia is often underdiagnosed in non-Hispanic Blacks and Hispanics, further complicating the issue and delaying access to care. These disparities have also translated into lower proportional numbers from these groups in research studies.

Stigma

Stigma surrounding dementia is a significant issue in many underrepresented communities. Cultural beliefs and misconceptions about dementia can lead to shame, denial, and social isolation for individuals and their families. In some cultures, dementia may be perceived as a normal part of aging or as a punishment for past behaviors, deterring individuals from seeking help. This stigma not only affects the individual’s willingness to seek a diagnosis and treatment but also influences how they are treated by their community and healthcare providers.

Barriers to Care

Accessing quality dementia care is fraught with challenges for underrepresented communities. Key barriers include:

- **Healthcare Access:** Limited access to healthcare facilities and specialists in rural and underserved urban areas makes it difficult for individuals to receive timely and accurate diagnoses. Even when care is available, transportation issues and financial constraints can hinder access.
- **Cultural and Linguistic Differences:** A lack of culturally competent healthcare providers can lead to miscommunication and mistrust. Language barriers further complicate the delivery of appropriate care and the ability of patients to understand their diagnosis and treatment options.
- **Economic Constraints:** The high cost of dementia care, including medical treatments, long-term care, and caregiving expenses, can be prohibitive for many families in underrepresented communities. Limited financial resources often mean that individuals must rely on unpaid family caregivers, who may themselves face economic and emotional burdens.
- **Education and Awareness:** Lower levels of education and health literacy can impede understanding of dementia and the importance of early diagnosis and intervention. Community outreach and education programs are often insufficient in reaching these populations effectively.

Addressing the Disparities

To address these disparities, a multifaceted approach is required:

- **Community Engagement:** Engaging with community leaders and organizations can help build trust and raise awareness about dementia. Culturally tailored education programs can dispel myths and encourage early diagnosis and treatment.
- **Culturally Competent Care:** Training healthcare providers in cultural competence can improve communication and trust between patients and providers. Employing bilingual staff and offering translation services can also enhance care delivery.

- Policy Interventions: Policies aimed at reducing economic barriers, such as increased funding for dementia care programs and support for unpaid caregivers, can alleviate some of the financial burdens faced by these communities.
- Research and Data Collection: More research is needed to understand the specific needs and challenges of underrepresented communities. Collecting and analyzing data on dementia prevalence and outcomes in these populations can inform targeted interventions and resource allocation.

Conclusion

The disproportionate prevalence of dementia, compounded by stigma and barriers to care, presents significant challenges for underrepresented communities. Addressing these issues requires a concerted effort from policymakers, healthcare providers, researchers, and community organizations to ensure that all individuals have access to the care and support they need. By tackling these disparities, we can move towards a more equitable healthcare system that recognizes and addresses the unique needs of every community.

Resources:

- <https://www.who.int/news-room/fact-sheets/detail/dementia>
- Lennon, et al. Black and white individuals differ in dementia prevalence, risk factors, and symptomatic presentation. *Alzheimer's and Dementia*. 2021; <https://doi.org/10.1002/alz.12509>
- Lin PJ, Daly AT, Olchanski N, Cohen JT, Neumann PJ, Faul JD, Fillit HM, Freund KM. Dementia Diagnosis Disparities by Race and Ethnicity. *Med Care*. 2021 Aug 1;59(8):679-686. doi: 10.1097/MLR.0000000000001577. PMID: 34091580; PMCID: PMC8263486.