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PERSPECTIVE

Breaking the silence: understanding the unique burden on informal Black male dementia caregivers

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Abstract

As the rates of Alzheimer's disease (AD) and AD and related dementias (ADRD) in the United States steadily rise, so too does the demand for informal caregiving. Research on AD/ADRD caregiving highlights the associated risk of adverse health outcomes and lower quality of life; however, there is a lack of discussion about Black male dementia caregivers, who already face unique health challenges. Through an intersectionality lens, this perspective will raise awareness of the multifaceted burden of Black male informal AD/ADRD caregiving, along with strategies to better support this underserved community.

KEYWORDS
black men, caregiver burden, dementia, informal caregiving, intersectionality, social determinants of health

Highlights

- The non-Hispanic Black population in the United States is disproportionately affected by Alzheimer's disease (AD) and AD and related dementias (ADRD), which will increase the demand for caregiving.
- Most dementia informal caregiving research focuses on non-Hispanic White females, with little emphasis on Black men, who represent an at-risk population.
- By adopting an intersectional approach, clinicians, researchers, and policymakers can better understand and improve the health of informal Black male AD/ADRD caregivers.
- The increasing prevalence of AD and ADRD in the US Black community can create an added strain on Black male informal caregivers.
- Examining the unique AD/ADRD caregiving needs of Black men can inform future research to improve the health of similar at-risk communities.

1 | INTRODUCTION

In the United States, Alzheimer's disease (AD) and AD and related dementias (ADRD) annually affect over six million people, with a projected increase to nearly 14 million cases by the year 2060.[1] In addition to the United States' aging population, the increased nationwide prevalence of comorbidities such as hypertension, high cholesterol, and diabetes are also related to this increase in prevalence.[2] Although AD/ADRD can affect anyone, non-Hispanic Black, hereafter referred to as Black individuals, have higher rates of these disorders than non-Hispanic White individuals in the United States.[3–5] It is believed that Black individuals are at a higher risk of AD/ADRD due to a combination of factors, such as genetic predisposition, increased prevalence of preventive vascular disorders, and social and environmental factors.[6] Given the expected increase in the prevalence of AD/ADRD and their disproportionate disease burden on Black individuals, it can be expected that the need for dementia-related caregiving will also grow disproportionately in this population.[7]

Survey data show that 30% to 40% of informal caregivers are older husbands who care for a spouse with dementia; however, this estimate may be inaccurate due to an underrepresentation of Black men who may not formally identify as caregivers.[8] Research has also shown that Black men often feel unprepared for caregiving, are reluctant to discuss their role, and tend to rely on informal support networks due to hesitancy or lack of awareness.[9] Aside from an increased risk of developing AD/ADRD, the negative health consequences of AD/ADRD informal caregiving may further compound the health disparities of Black men, who have the highest death rate of any major demographic group in the United States.[10] This perspective aims to raise awareness of the informal dementia caregiving burden for Black men and why it is essential to focus research efforts on this at-risk population.

2 | WHO ARE AD/ADRD CAREGIVERS?

Caregivers for individuals with AD/ADRD include formal (paid) and informal (unpaid) providers.[1] According to the Alzheimer's Association, over 11 million Americans serve as unpaid informal caregivers for individuals with AD/ADRD.[1]

The level of care informal caregivers provide varies widely, ranging from occasional support for loved ones living independently to round-the-clock assistance. Additionally, the burden of caregiving is not evenly distributed across the population. Research indicates that women constitute about two-thirds of all AD/ADRD caregivers, with the majority being White.[11–13] This gender imbalance has led to a greater understanding of caregiver burdens faced by women compared to men[13,14] but fails to address the dearth of research on Black male informal AD/ADRD caregivers who already represent a highly vulnerable population. The minimal literature on Black male AD/ADRD informal caregiver burden shows that, aside from an increased risk of health disparities, this population may be more susceptible to adverse socioeconomic outcomes compared to other groups.[15]

3 | WHAT IS THE INFORMAL AD/ADRD CAREGIVING BURDEN?

Informal caregivers of individuals with AD/ADRD are at high risk of adverse psychological, physical, and financial outcomes.[16] These caregivers often experience significantly higher stress levels than other caregivers, negatively impacting many areas of their daily lives.[1] Studies show that informal caregivers are more likely to experience mental health issues such as anxiety and depression, which may also be linked to poor sleep duration and quality.[17,18] Over time, the demands of AD/ADRD caregiving can have neurological consequences, leading to cognitive impairment as a result of prolonged stress.[19]

The demands of caring for someone with AD/ADRD can also harm caregivers' physical health, increasing their risk of future illness or disability by a third.[20] Roepke et al.[21] found that chronic stress from AD/ADRD caregiving is also associated with a higher risk of developing cardiovascular disease. Additionally, caregivers report declines in physical health due to the increased demands of caring for a loved one with AD/ADRD, which can lead to the development of other health issues.[1,15–19,21]

Aside from the physical and psychological impacts, caring for a loved one with AD/ADRD can create a significant financial burden.[22] Informal AD/ADRD caregivers often incur a much larger financial obligation than individuals with access to formal caregiving options, such as nursing homes and assisted living facilities. Although the total cost of care for individuals with AD/ADRD is comparable between formal and informal caregiving, informal caregivers absorb roughly 64% of these expenses, while caregivers who utilize nursing homes cover 43% of expenses.[23] Informal caregivers absorb expenses associated with out-of-pocket fees not covered by insurance (e.g., medications, durable medical equipment) and navigate lost wages or a reduction in income due to missed work days.[1] As a result, informal caregiving places a significantly higher financial strain on individuals and families.

4 | WHY THE FOCUS ON BLACK MALE CAREGIVERS?

Black men in the United States not only face a higher risk of developing AD/ADRD but also have worse health outcomes compared to other major demographic groups.[24–27] Social determinants such as poverty, lack of quality education, and poor access to healthcare are known contributors to health disparities that disproportionately affect Black men.[26] Within the Black community, there is also a well-known legacy of medical mistrust that stems from historical medical mistreatment, experimentation, and exploitation. The infamous Tuskegee syphilis study is one of many examples of unethical practices that paved the way to medical mistrust in this population.[28,29] Despite the awareness of these historical atrocities, Black men in the United States continue to experience widespread discrimination in nearly every sector of society, including education, employment, and even the criminal justice system.[30–32]

Research also shows that Black men are more likely to encounter discrimination by healthcare providers, discouraging health-seeking behavior such as routine physical exams and adherence to medical recommendations.[33,34] This healthcare barrier also affects Black males who have access to healthcare yet are 50% less likely to have seen a healthcare provider within the past year, despite having health insurance, compared to White males.[26] Given this lack of trust in the healthcare system, Black male informal AD/ADRD caregivers may be less likely to seek professional healthcare for their loved ones.

As previously noted, caring for someone with AD/ADRD can require significant financial resources, especially if this care is informal. This financial burden can have a compounding effect on Black male informal AD/ADRD caregivers, who are three times more likely to experience financial hardship compared to White female caregivers.[15] The literature shows that White individuals with AD/ADRD are more likely to be admitted to special care units compared to Black individuals due to differences in health conditions, including comorbidities, socioeconomic status, and the selection of an add-on state-sponsored Medicaid policy.[35,36] Given this knowledge, Black male AD/ADRD informal caregivers are at an increased risk of adverse health and financial outcomes compared to other populations. The combination of medical mistrust and added financial burden could cause Black male informal AD/ADRD caregivers to have reservations about placing their loved ones in a full-time care facility.

Compared to White individuals, Black individuals report closer familial connectivity, making Black males more likely to independently provide informal AD/ADRD care for a family member or loved one.[37] In addition, traditional views of masculinity within the Black male community may compound the caregiving burden as a result of striving to fulfill hegemonic masculine norms such as being a self-reliant financial provider and protector within a discriminatory society.[38] This commonly accepted stereotype of masculinity often creates misconceptions of caregiving as a "feminine" role, along with harmful and unrealistic expectations of caregiving responsibilities.[39] This may explain why Black male caregivers often provide more hours of direct care, are less likely to ask for help, and are at higher risk of social isolation and poor health outcomes compared to their White counterparts.[40]

5 | WHAT ARE THE SOLUTIONS?

Given the scarcity of knowledge regarding the unique caregiving burden experienced by Black males, there is a need to better understand the specific stressors that affect Black male AD/ADRD caregivers. Such knowledge will allow their multifaceted issues to be better addressed by researchers and clinicians. It is imperative to highlight the numerous challenges that affect Black men at the intersection of social characteristics (e.g., gender, race) and social determinants of health (e.g., economic stability, community, safety, social context, healthcare system). Adopting an intersectional approach to the Black male informal AD/ADRD caregiver burden can provide a deeper understanding of the multiple overlapping social and behavioral characteristics that influence how persons from racially and ethnically minoritized communities experience the environment in which they live.[26,41,42]

Intersectionality is a framework that focuses on understanding how social, environmental, and behavioral characteristics and experiences shape an individual's identity.[43] A common struggle for Black men in the United States relates to their need to continuously navigate societal pressures that are often encountered at the intersection of gender, race, and cultural expectations.[44] An intersectionality approach may help researchers better understand the unique circumstances that affect Black male AD/ADRD informal caregivers, which can better guide future research efforts. Specifically, adopting a lens of intersectionality can provide an opportunity to explore the lived experiences, unique needs, and specific challenges of Black male caregivers at the confluence of social characteristics, social determinants of health, and AD/ADRD. Furthermore, findings from these studies may be helpful to researchers by enhancing the effectiveness of community-based participatory research, which underscores the importance of developing community-designed interventions.[45,46]

In addition, the findings from these research efforts can potentially be leveraged to develop interventions that will offer culturally appropriate resources to enhance the education of clinicians who provide health care to Black male AD/ADRD informal caregivers. The lived experiences of Black men are not monolithic, nor are the lived experiences of Black men who are standing in the gap to provide informal care for a loved one with AD/ADRD. Increasing awareness of the informal caregiving burden experienced by Black men may spark the discussion about the need to direct policy and funding toward allocating resources to address the needs of this underserved population.[39] Awareness of the diverse challenges faced by Black male AD/ADRD caregivers is the first step to addressing this disparity. By acknowledging and acting on this information, clinicians, researchers, and policymakers can collaboratively ensure the voices of this underrepresented community are heard.

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CONFLICT OF INTEREST STATEMENT

The authors deny any conflicts of interest related to the publication of this work. All opinions were formed based on the perspectives based on the information synthesized by the authors. Author disclosures are available in the Supporting Information.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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