

AN INDUSTRY BRIEF FROM INSTITUTE@PRECISION

Caregiving in Alzheimers and Related Dementias

Finding Opportunities to Optimize Caregiver Support

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Alzheimer's disease (AD) is the leading cause of dementia, affecting an estimated 6.9 million Americans aged 65 and above.¹ By 2040, it is expected that nearly 12 million Americans will be living with Alzheimer's disease and related dementias (ADRD) and the majority of those individuals will likely be receiving in-home care provided by a family member or close friend.² Caregiving is essential to optimizing outcomes for individuals with ADRD and frequently involves assisting with activities of daily living and communicating and coordinating care with healthcare providers.^{1,3}

Caring for individuals with ADRD can be challenging, and the stressors and time demands of caregiving can adversely affect the physical, emotional, mental, and financial health of the caregiver. To better understand the impact of caregiving and

the opportunities to provide caregiver support, Precision AQ conducted a survey of physicians and case managers who often or very often interact with individuals providing care for a family member with ADRD.

Challenges for caregivers

Survey respondents considered emotional or mental health challenges to be most burdensome to caregivers (see Figure 1). Financial strain is a major driver of these challenges, as is social isolation. This sense of isolation may result from the time required for the responsibilities of caregiving or from friends and family distancing themselves from the caregiver or the individual with ADRD. Caregivers may even experience affiliate stigma, a phenomenon whereby they internalize negative

societal attitudes toward dementia, leading to feelings of shame and embarrassment. Research has shown that caregivers' perceptions of stigma are associated with increased burden and a higher risk for reduced quality of life.^{4,5}

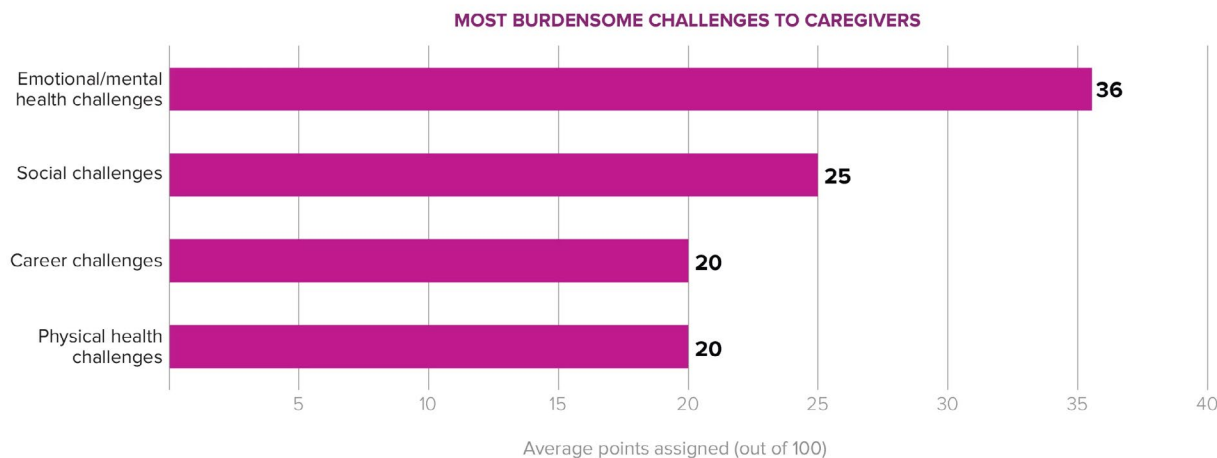
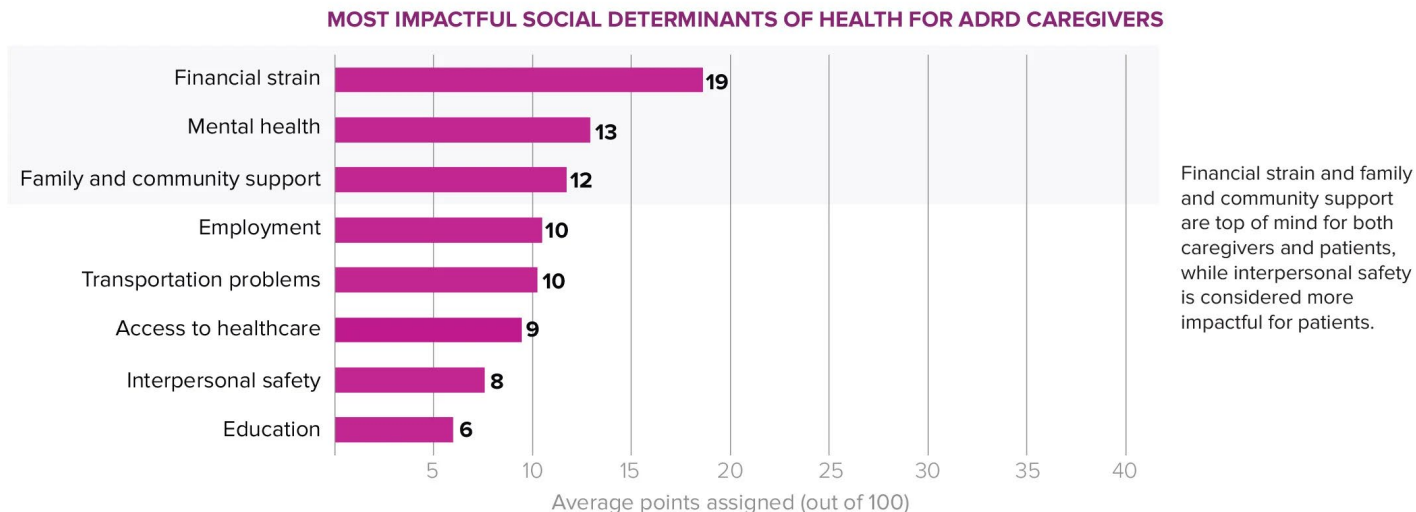


Figure 1. Most burdensome challenges to caregivers

Our survey further investigated the social determinants of health (SDOHs) among ADRD caregivers. Survey respondents determined financial strain followed by mental health to be the top SDOHs for caregivers, who face substantial out-of-pocket costs related to medical and personal care expenses for the individual with ADRD (see Figure 2). Nearly 60% of caregivers experience work-related disruptions, such as arriving late, leaving early, or missing out on promotions, which can lead to reduced income and career opportunities.¹ Further, financial strain among caregivers is linked to adverse health outcomes, including increased rates of diabetes and depression and higher body mass index.³



Financial strain and family and community support are top of mind for both caregivers and patients, while interpersonal safety is considered more impactful for patients.

N=23.
 Q: How impactful are each of the following social determinants of health on caregivers of patients with ADRD? Distribute 100 points across the top 5 options (with more points indicating a higher level of impact).
 Additional options presented to respondents but receiving a score of ≤5 include physical activity, substance use, food insecurity, disabilities, housing instability, and utility needs help.

Figure 2. Most impactful social determinants of health for caregivers

Race and ethnicity may also impact aspects of caregiving. Several studies have highlighted significant disparities in dementia care among different racial and ethnic groups. One study found it took 11% longer for Black Americans and 40% longer for Hispanic Americans to receive a diagnosis of dementia compared to non-Hispanic White Americans.[1] In our survey, more than 40% of survey respondents attested that race and ethnicity often or very often impact ADRD medication, while over one-third indicated that race and ethnicity affect diagnosis of ADRD (see Figure 3).

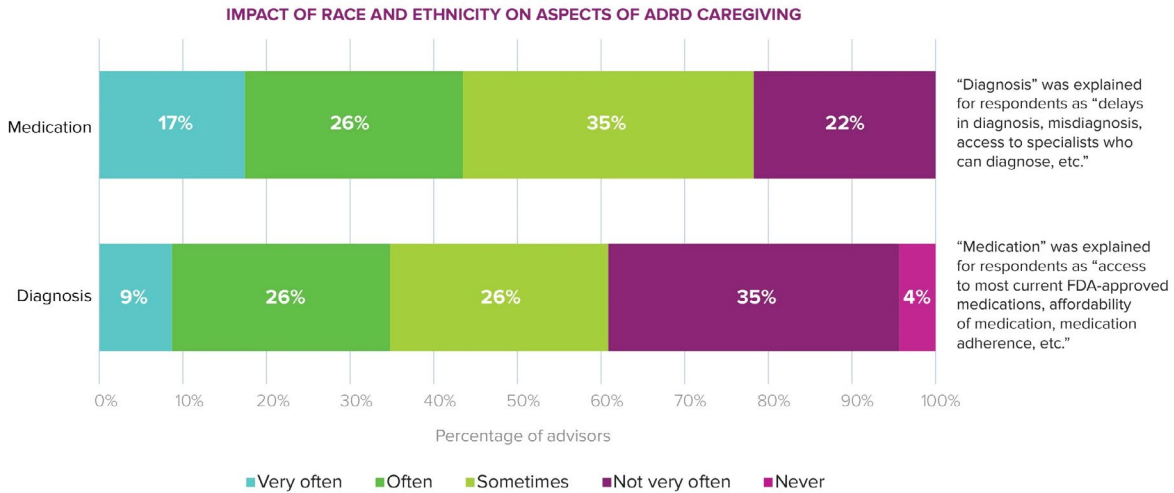


Figure 3. Impact of race and ethnicity on aspects of ADRD caregiving

Factors associated with medications included access to most current FDA-approved medications and affordability. Factors associated with diagnosis included delays in diagnosis and access to specialists.

Opportunities for pharmaceutical companies to reduce caregiver burden

By understanding the challenges that caregivers face, pharmaceutical companies can identify opportunities to help reduce caregiver burden. Our survey suggests that manufacturers are well-positioned to alleviate the strain on caregivers through financial assistance, support for medication access and adherence, and education programs (see Figure 4).

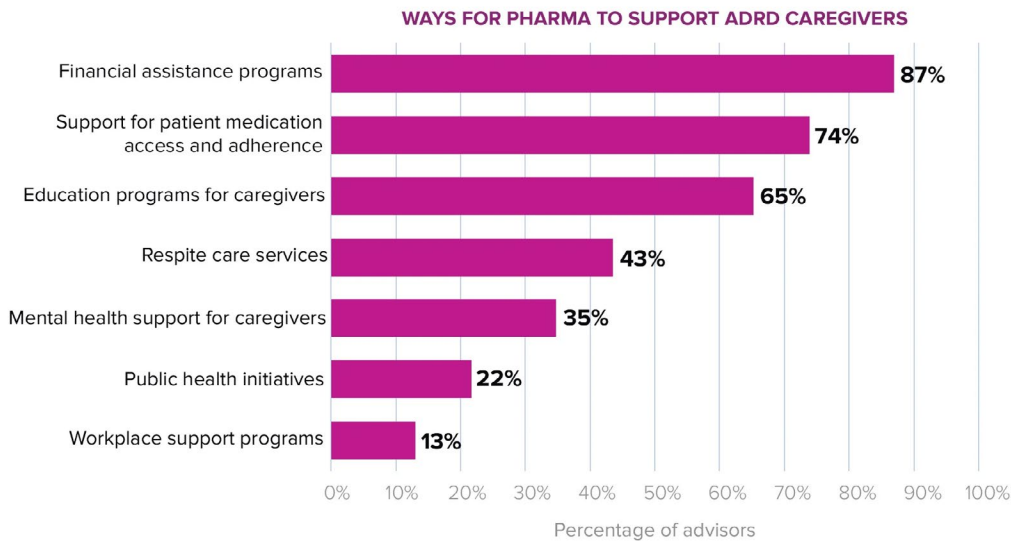


Figure 4. Opportunities for pharmaceutical manufacturers to support caregivers

Survey respondents also stressed the importance of manufacturer collaboration with patient advocacy groups and healthcare providers (see Figure 5).

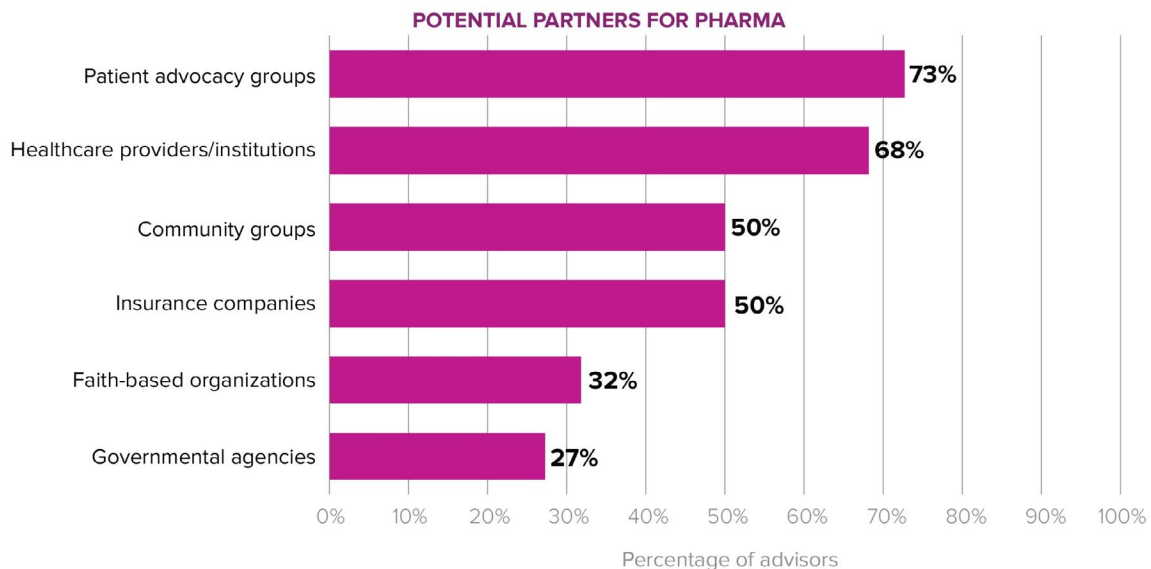


Figure 5. Potential partners for pharmaceutical manufacturers

Based on these findings, here are 5 best practices for manufacturers to optimize caregiver support and reduce caregiver burden:

1. Informing caregivers of the resources available to support timely, appropriate medication access and adherence for all persons with ADRD, including financial assistance programs, where available
2. Providing information on clinical trials and support options for caregivers of individuals participating in clinical studies, who may be responsible for decision-making and medication adherence
3. Sharing information on the health risks faced by caregivers
4. Offering education on self-care, stigma reduction, and patient advocacy and support services
5. Collaborating with patient advocacy groups, healthcare providers, and community-based organizations, with the aim of capacity-building for caregivers to provide in-home care for family members with ADRD

Conclusion

ADRD are conditions that affect not only the individual living with dementia, but also their family members and close friends. While there are positive aspects to caregiving, the responsibility of caring for a loved one with dementia can cause physical, emotional, mental, and financial strain, all of which impact the caregiver's health and their ability to continue providing in-home care. Pharmaceutical manufacturers are uniquely poised to intervene in reducing caregiver burden through education and collaboration, optimizing outcomes for both caregivers and individuals living with ADRD.

To learn more how Precision AQ can help with this and other market access challenges, [click here](#).

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