

The Changing Face of Alzheimer's: A Survey on Burden for Caregivers from Communities of Color

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BACKGROUND

- Neurodegenerative diseases affect millions of people worldwide. More than 5.7 million Americans currently have Alzheimer's disease¹ (AD). The human toll and economic burden caused by AD can be devastating for patients, families, and caregivers; especially for certain underserved communities such as African Americans and Hispanic/Latinos, who are severely underrepresented in scientific research.² These burdens can lead to early patient institutionalization or other negative consequences for those diagnosed with AD.³
- The needs of AD caregivers are largely ignored by physicians and healthcare systems despite their important influence on patient treatment and quality of life outcomes.⁴
- UsAgainstAlzheimer's and Accelerated Cure Project (ACP), a national nonprofit focused on accelerating research in multiple sclerosis (MS), partnered on a series of caregiver burden surveys to identify common themes and priorities. Surveys focused on caregiver challenges, including the ongoing stress and burden for caregivers of color, and on their interactions with the healthcare system.

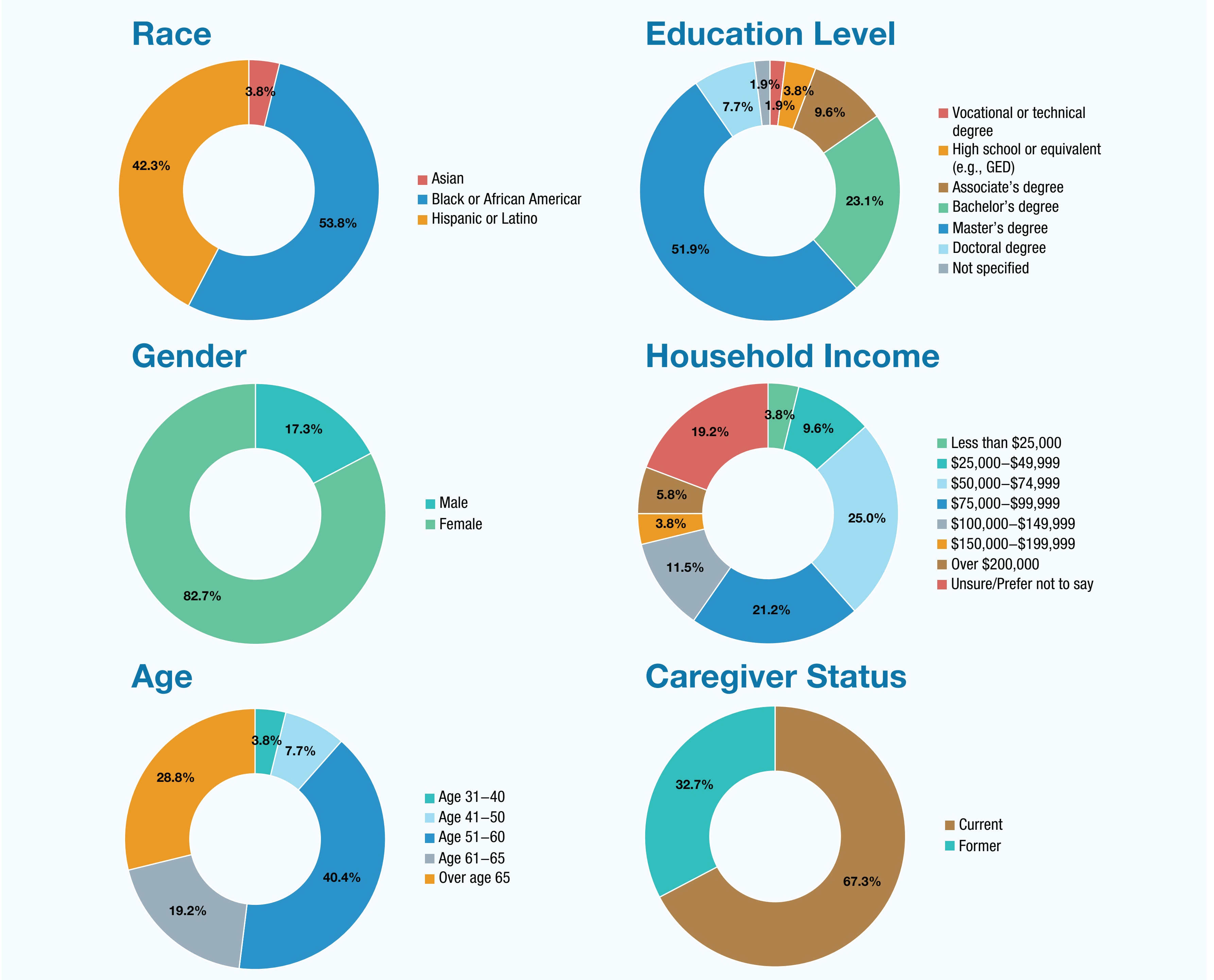
¹<https://www.alz.org/media/Documents/alzheimers-facts-and-figures-special-report.pdf>
²https://www.usagainstalzheimer.org/sites/default/files/2020-11/Urban_UsA2%20Brain%20Health%20Equity%20Report_11-15-20_FINAL.pdf
³<https://pubmed.ncbi.nlm.nih.gov/31465484/>
⁴<https://pubmed.ncbi.nlm.nih.gov/31465684/>

METHOD

This survey was developed in collaboration with two multi-stakeholder coalitions – the UsAgainstAlzheimer's Center for Brain Health Equity and ACP's MS Minority Research Engagement Partnership Network – to acknowledge and best capture the challenges faced by non-Caucasian caregivers. The survey was sent to members of UsAgainstAlzheimer's A-LIST[®] registry and ACP's iConquerMS network.

RESULTS

Respondent demographics
 Findings were analyzed from 52 non-Caucasian respondents who are/were caregivers for someone with AD or another dementia.

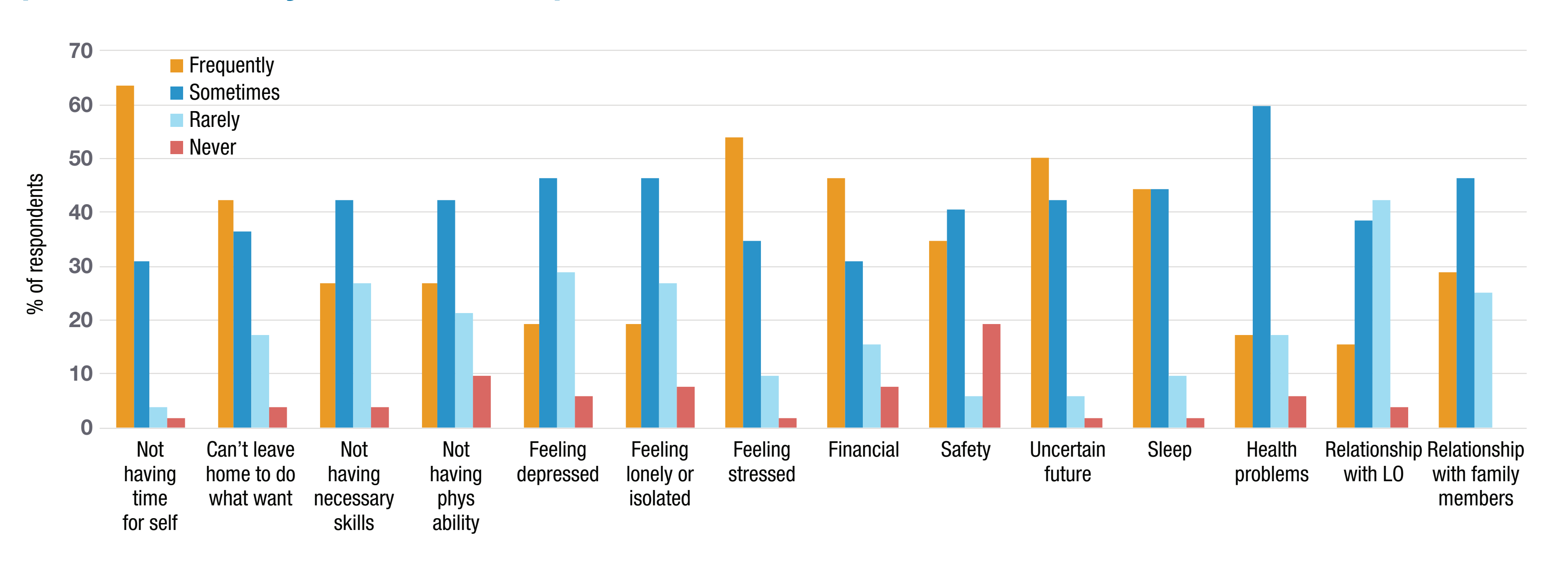


Findings

- Caregivers reported top burdens as key challenges on their journey: no time for self (63.5%), feeling stressed (53.8%), uncertain about the future (50.0%), concerns about financial status (46.1%), not getting enough sleep (44.2%), and unable to leave home (42.3%).

Figure 7. Caregiver Burden

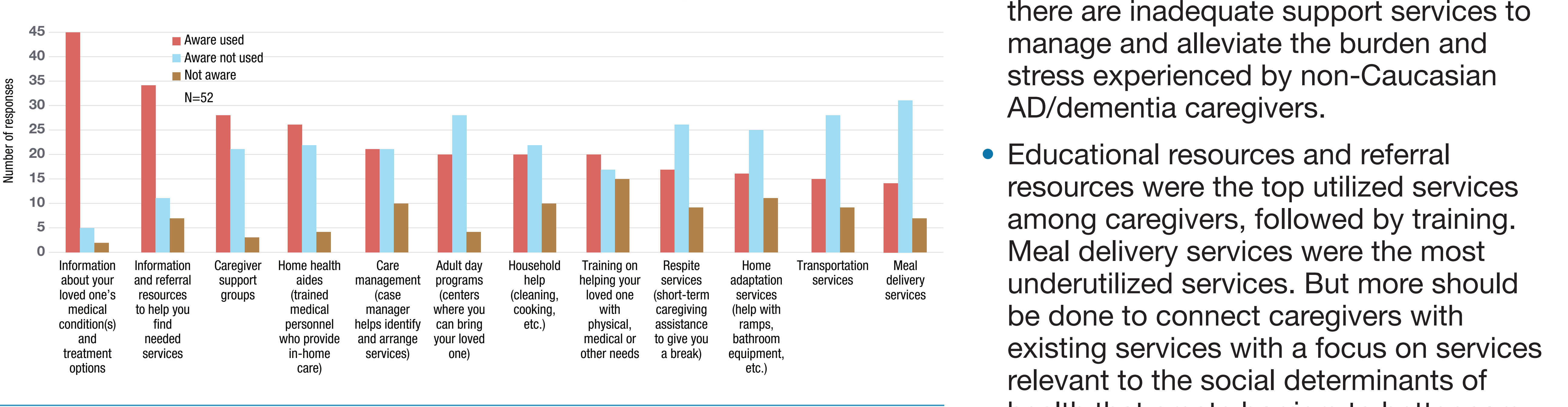
"Which burdens or challenges caused/are currently causing the most problems for you? Check up to 5 answers."



- Caregivers lack/lacked awareness or do/did not use needed support.

Figure 8. Caregiver Services

"There are a variety of services available for caregivers that you may or may not already know about. We'd like to know if you're aware of these services or have used them in the past."



- Caregivers provided feedback on services used and a variety a tips for others to alleviate key burdens and stressors.

"Have you found helpful ways of managing any of these issues that you would like to share with other caregivers? Please describe below."

Tips from Caregivers for Caregivers

- "Don't be afraid to ask for help"
- "Leverage technology to stay organized"
- "My church family helped a lot"
- "I see a therapist, go to Alzheimer's care giver support mtgs, have spouse in day care 3 days a week, have a financial planner, read, knit, and drink a fair amount of alcohol."
- "In home care assistance"
- "I carve out time on the weekends to work out and partake in activities that I love. I carve out time to spend time with my husband, who also caregives for my mom"
- "Music and singing"
- "Utilize advocacy organizations, online information, and hotlines"
- "Caregivers automatically assume patient is challenged intellectually 'all the time' and treat pt like a child or mentally disabled. Displaying annoyance over routine issue is misconstrued as aggression or agitation. Caregivers must engage pt in a creative fashion... Painting, music, stimulating conversations, interactive TV watching or book reading etc"
- "I recommend taking advantage of any respite care opportunities available"

CONCLUSION

- Caregivers reported stress was a key challenge on their journeys. They are concerned about their futures and a portion experience financial hardship. But there are inadequate support services to manage and alleviate the burden and stress experienced by non-Caucasian AD/dementia caregivers.
- Educational resources and referral resources were the top utilized services among caregivers, followed by training. Meal delivery services were the most underutilized services. But more should be done to connect caregivers with existing services with a focus on services relevant to the social determinants of health that create barriers to better care and supports.
- Innovative models that integrate technology to match families to tailored resources should be scaled to help meet the unmet needs of caregivers. For example, CommunityRX-Caregiver utilizes an automated community resource referral information system to connect caregivers to social services tailored to their community, socioeconomic status, and demographics. Research from the University of Chicago Medicine shows CommunityRX-Caregiver can help patients gain confidence in finding health resources in their community.

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