

The Changing Face of Alzheimer's: A Survey on Relationships of Caregivers of Color with Health Care Providers

Theresa L. Frangiosa¹, Virginia Biggar¹, Jason Resendez¹, Stephanie Monroe¹, Hollie Schmidt², Sara Loud²
¹UsAgainstAlzheimer's, ²Accelerated Cure Project

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
- 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.³
- UsAgainstAlzheimer's, a national nonprofit advocating for AD prevention and treatments, 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. This survey focused on AD caregiver challenges, specifically interactions with healthcare providers (HCP) for caregivers of color.

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/31465684/>

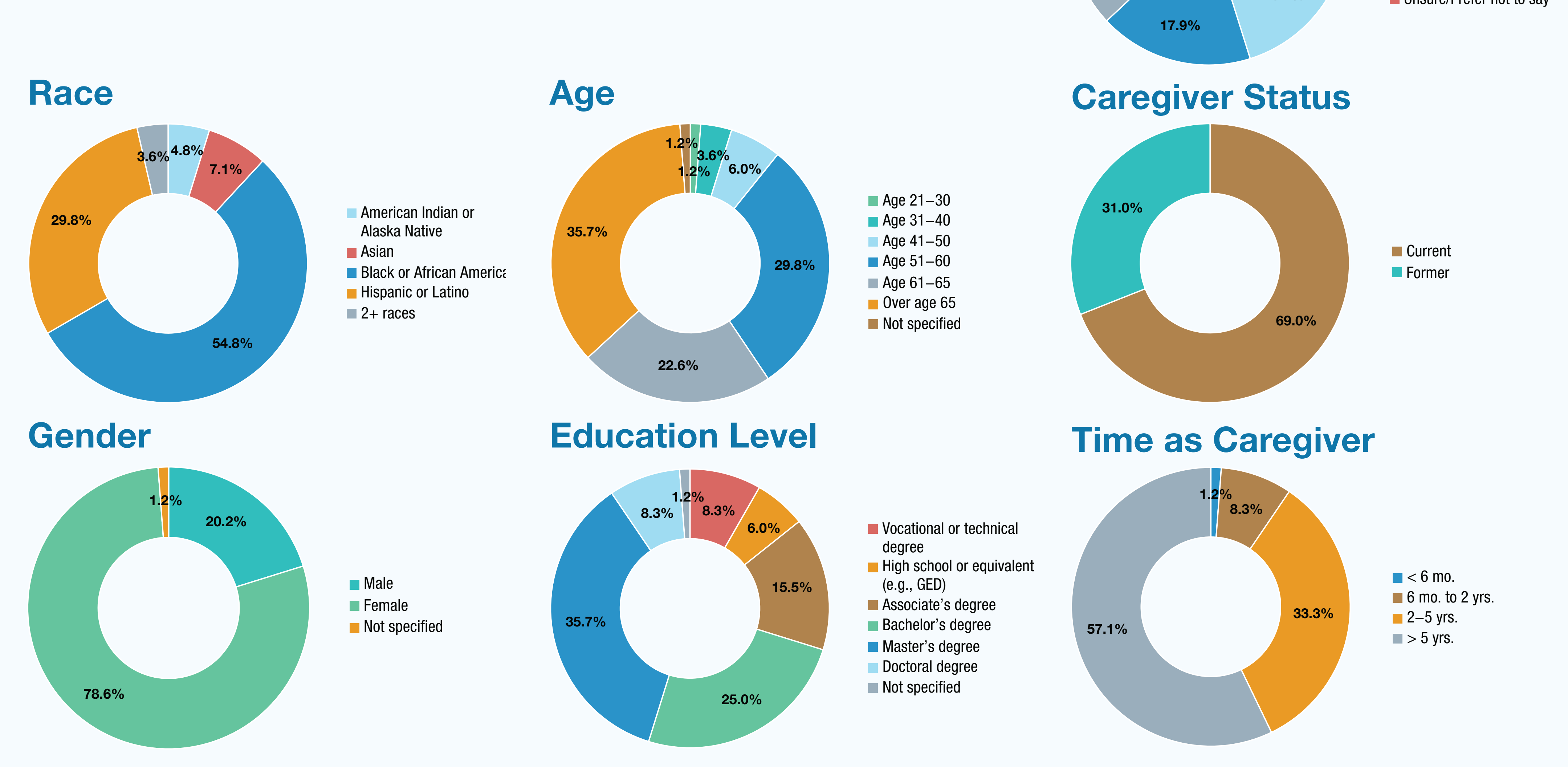
METHOD

- 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

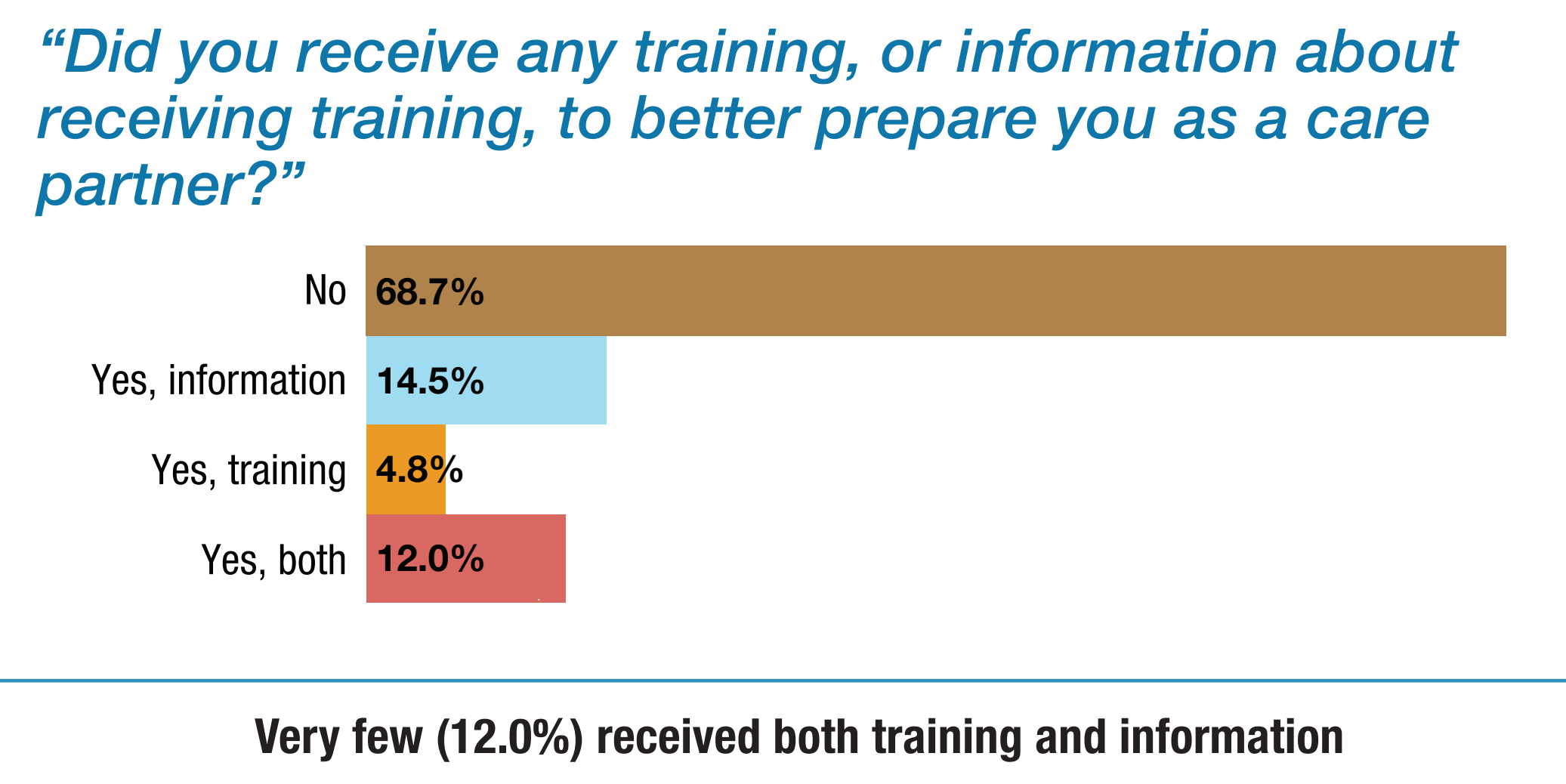
Findings were analyzed from 84 non-Caucasian respondents who are/were caregivers for someone with AD or another dementia.



Findings

- Caregivers reported how few received training and information related to caregiving, and on the quality of that training.

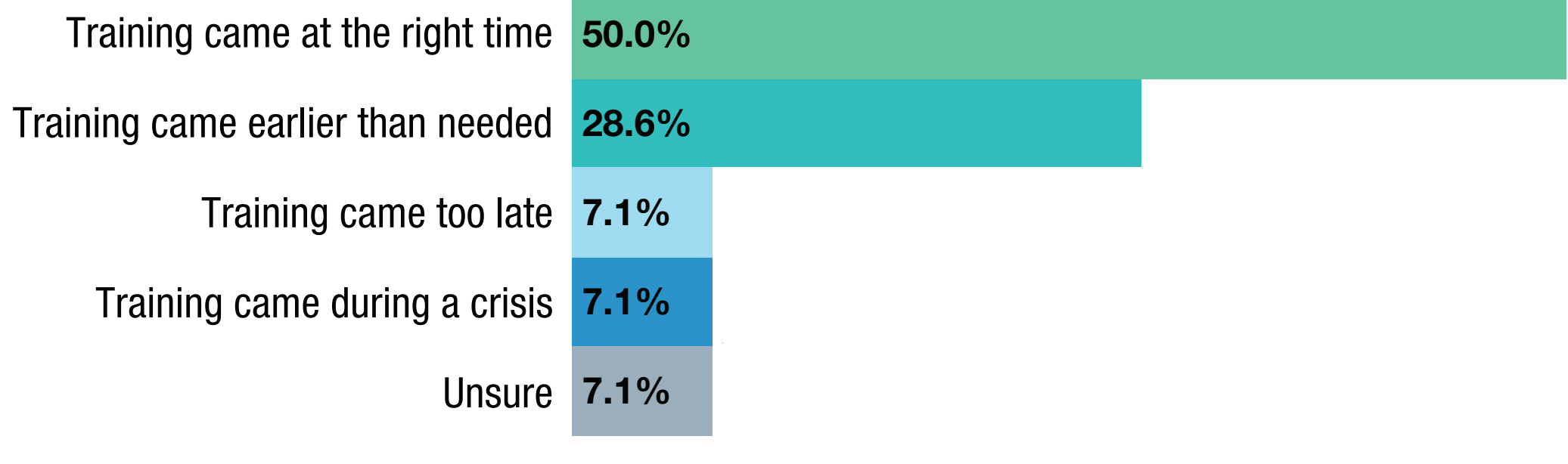
Figure 8. Answer



- There is a mismatch between the timing of the training and when caregivers need it.

Figure 9. Circumstance

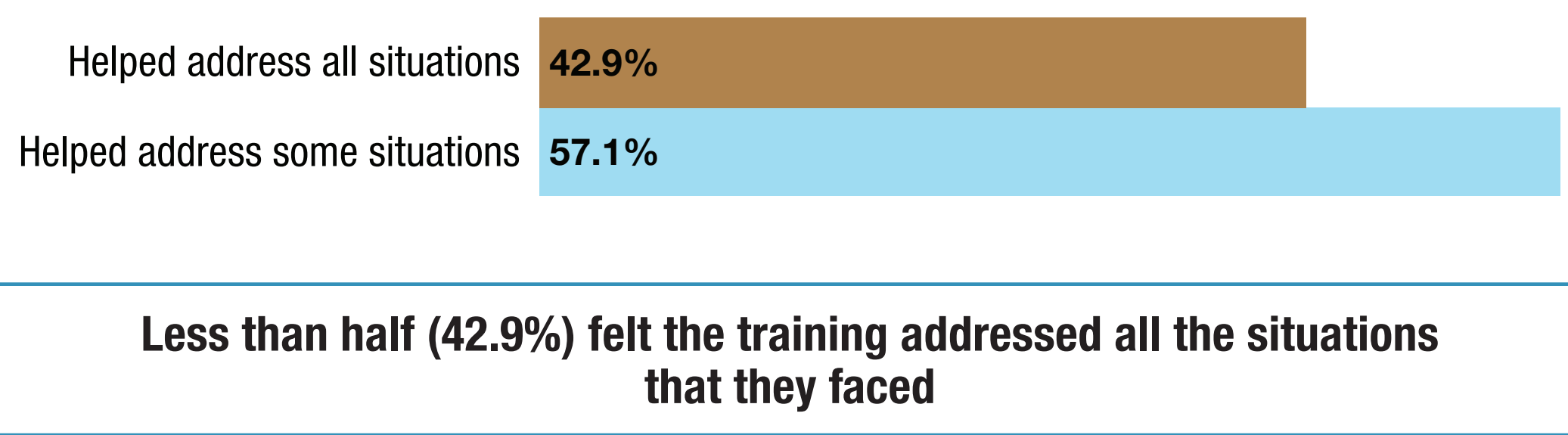
"Which best describes the circumstances in which you received training to prepare you to be a care partner?"



- Only a limited number of caregivers felt all their needs were met.

Figure 10. Effectiveness

"How well did the training that you received help you to prepare for situations that you faced? (select the answer that MOST applies)"



RESULTS

"What topics are/were most important to receive training in (as a care partner)? Please consider training that you received, and training you wished you had."

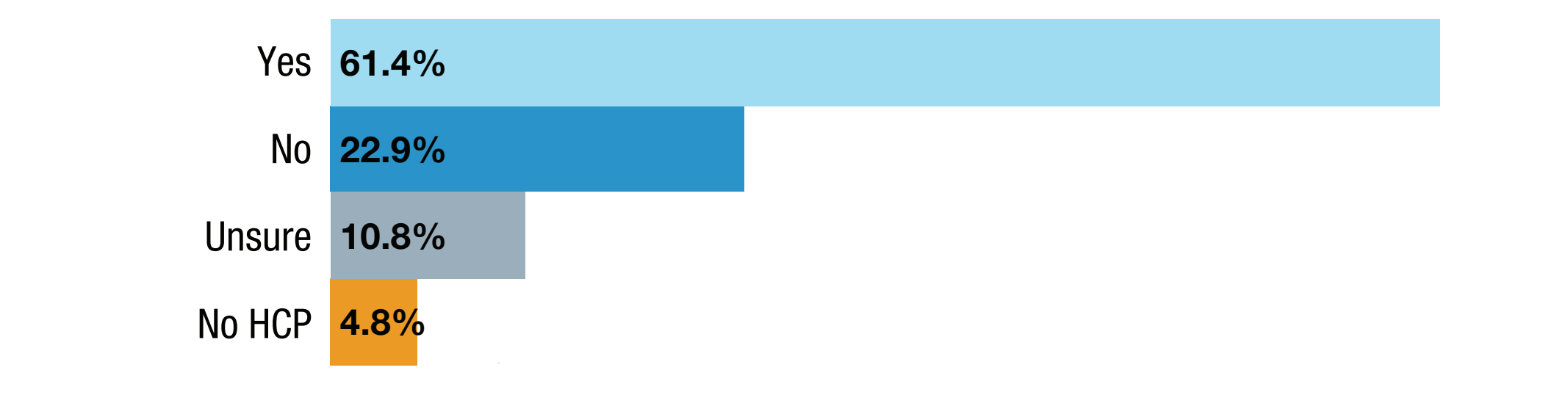
- "How to be compassionate to individuals with dementia and how not to take their behavior personally."
- "Anger Management"
- "I wish I had training in basic nursing care"
- "What benefits they were entitled to and what support is for the caregiver"
- "There is very little information or resources or support groups for those with loved ones suffering the mid-late to the late stages of ALZ"
- "Legal decision-making"
- "Dealing with hallucinations, outbursts and aggression"

Findings: The caregiver/physician relationship

- 61% of respondents believed that their HCP is/was aware of their caregiver status.

Figure 11. HCP Awareness

"Do you think YOUR OWN healthcare provider is/was aware that you are/were a care partner?"



- But only 25.3% with their own HCP have received help or advice from them about caregiving.

Figure 12. MD Advice

"Has YOUR OWN healthcare provider ever given you help or advice about being a care partner, or suggested where you might get help?"



- Caregivers want the diagnosed person's HCP to ask how the caregiver is coping, but this happens just 40.5% of the time.

Figure 13. Select Caregiver Requests at Appointments

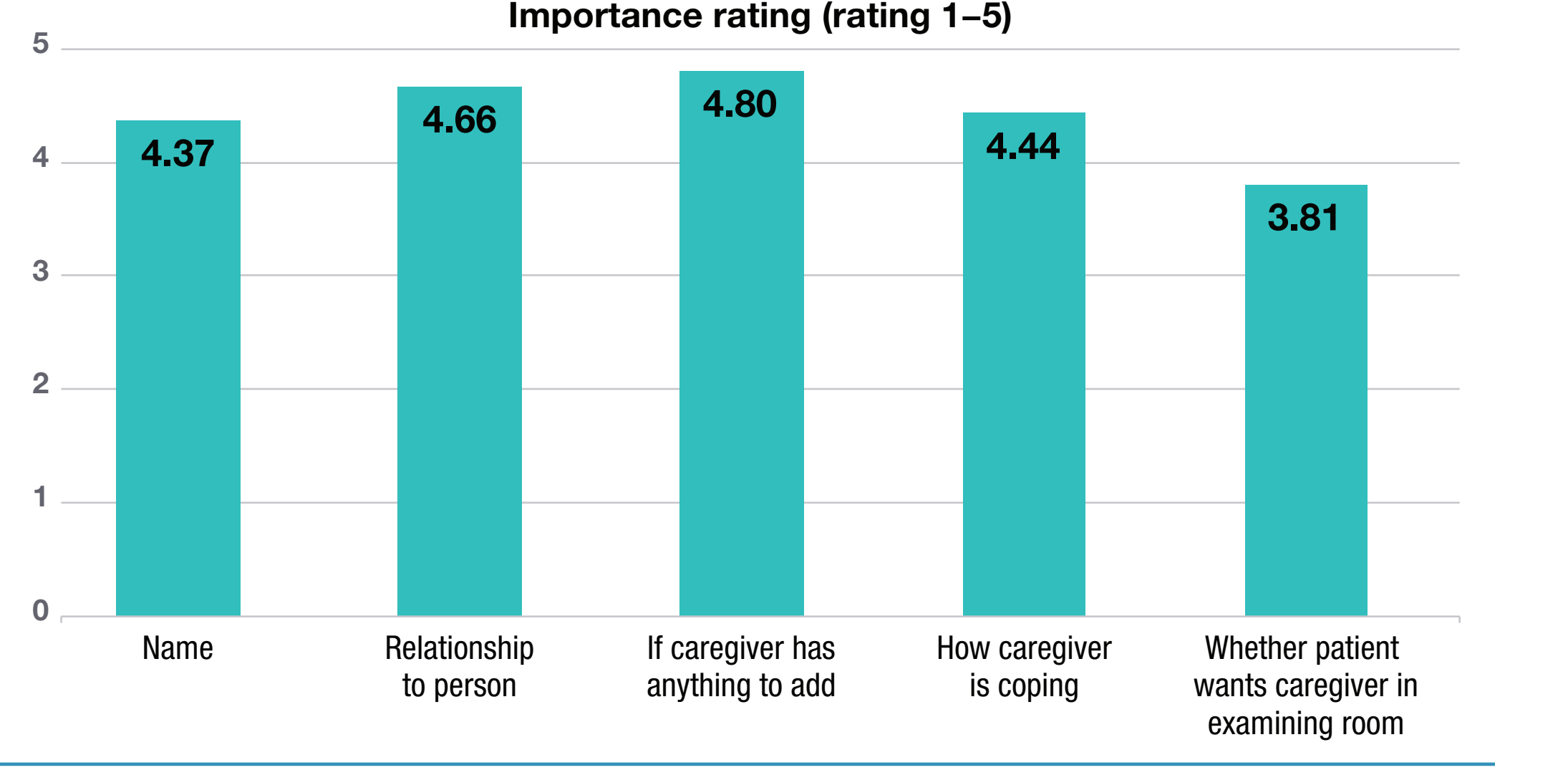
"During at least one appointment with the main healthcare provider (of the person you care(d) for), did they ask any of the following? (check all that apply) Response for option 'MD asks about coping'"



- Caregivers reported on a variety of behaviors where HCPs for the diagnosed person could improve their support of caregivers.

Figure 14. Importance of Provider Questions

"How important is it to you that the main healthcare provider (of the person you care(d) for) asks you the following questions? (Please rate each question on a scale from 1 to 5: where 1 = completely unimportant; 3 = neither unimportant nor important; and 5 = completely important)"



CONCLUSION

- Non-Caucasian AD/dementia caregivers are not receiving the training and supports they need from their own and their loved ones' healthcare providers, and the training that is accessed is often inadequate.
- The majority of caregivers say their own HCP knows they are caregivers but few receive any training at all from providers. And for those who do, more than half say it wasn't at the right time so did not help when they needed it most. Those that did receive training did not feel it adequately prepared them for all situations.
- Provider education and training are needed related to dementia caregiving, including information on the range of available services, including psycho-social support (i.e. dealing with anger, being more compassionate), managing AD symptoms and relevant legal issues. This could support the well being of caregivers and improve access to higher quality care for those living with Alzheimer's and related dementias.

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Contact Information
Terry Frangiosa: tfrangiosa@usagainstalzheimer.org