



Discussion Guide: Achieving Health Equity in Dementia Care

Objective

To explore strategies that promote equity in diagnosis, treatment, care, and research for individuals affected by Alzheimer's and other dementias, particularly among historically underserved and disproportionately affected populations.

1. Framing the Issue

Opening Prompt:

What does "health equity" mean in the context of Alzheimer's and dementia?

Key Discussion Points:

- Disparities in diagnosis and treatment among racial and ethnic minorities.
- The impact of social determinants of health.
- Stigma and cultural beliefs about cognitive decline.
- Barriers to early detection and care.

Suggested References:

- Alzheimer's Association. (2021). *Race, Ethnicity and Alzheimer's in America*. <https://www.alz.org>
 - Sterling MR, Shaw AL, Kearns D, & Pollack HA. (2020). Culturally tailored dementia care: A scoping review of available interventions for racially and ethnically diverse populations. *Innovation in Aging*, 4(6), igaa049. <https://doi.org/10.1093/geroni/igaa049>
 - Hinton L, Tran D, Peak K, Meyer OL, Quiñones AR. Mapping racial and ethnic healthcare disparities for persons living with dementia: A scoping review. *Alzheimers Dement*. 2024;20(4):3000-3020. doi:10.1002/alz.13612
 - Aranda MP, Kremer IN, Hinton L, et al. Impact of dementia: Health disparities, population trends, care interventions, and economic costs. *J Am Geriatr Soc*. 2021;69(7):1774-1783. doi:10.1111/jgs.17345
 - Coe NB, Lee C. Racial and Ethnic Disparities in Dementia Care: Next Steps. *JAMA Netw Open*. 2022;5(6):e2216267. Published 2022 Jun 1. doi:10.1001/jamanetworkopen.2022.16267
 - Findley CA, Cox MF, Lipson AB, et al. Health disparities in aging: Improving dementia care for Black women. *Front Aging Neurosci*. 2023;15:1107372. Published 2023 Feb 9. doi:10.3389/fnagi.2023.1107372
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2. Building Equitable Public Health Infrastructure

Discussion Questions:

- How can we better support community-based organizations to address dementia disparities?
- What role can public health campaigns play in raising awareness?
- What kinds of resources (e.g. interpreters, community liaisons, culturally adapted tools) are currently available in your practice? What additional resources would you like to see?

Ideas to Explore:

- Investing in local health departments and aging services.
- Community-driven messaging in multiple languages.

Suggested References:

- CDC. (2022). *Road Map for Indian Country and the Healthy Brain Initiative*. <https://www.cdc.gov/aging/healthybrain>
- Centers for Disease Control and Prevention (CDC). (2022). *The Healthy Brain Initiative: State and Local Public Health Partnerships to Address Dementia, The 2023–2027 Road Map*. <https://www.cdc.gov/aging/healthybrain/roadmap.htm>
- U.S. Department of Health and Human Services. (2022). *Healthy People 2030: Dementias Including Alzheimer's Disease*. <https://health.gov/healthypeople/objectives-and-data/browse-objectives/dementias-including-alzheimers-disease>

3. Expanding Access to Diagnosis and Care

Discussion Questions:

- What are the current barriers to timely diagnosis?
- How can telemedicine help bridge geographic gaps in care?
- Studies have found that utilization of hospice among minority groups with AD/D and are less likely to have advanced care planning. How can we ensure equitable access to and utilization of advanced care planning and hospice?
- Have you had patients or families whose care was impacted by cultural, linguistic, or economic barriers? How did you or your team respond?

Strategies:

- Mobile memory clinics.
- Cognitive screening in primary care settings.
- Training for non-specialist providers.

Suggested References:

- Lin PJ, et al. (2020). *Racial and Ethnic Disparities in the Diagnosis of Dementia in Medicare Beneficiaries*. JAMA Neurology, 77(5), 594-602.
- Lin PJ, Zhu Y, Olchanski N, et al. Racial and ethnic differences in hospice use and hospitalizations at end-of-life among Medicare beneficiaries with dementia. *JAMA Netw Open*. 2022;5(6):e2216260. doi:[10.1001/jamanetworkopen.2022.16260](https://doi.org/10.1001/jamanetworkopen.2022.16260)
- Babulal GM, et al. (2019). *Perspectives on ethnic and racial disparities in Alzheimer's disease and related dementias: Update and areas of immediate need*. Alzheimer's & Dementia: Translational Research & Clinical Interventions, 5, 365–383.

4. Ensuring Cultural Competence and Trust

Discussion Questions:

- How do cultural values influence attitudes toward dementia care?
- What builds trust between families and health providers?

Key Concepts:

- Culturally adapted care models.
- Workforce diversity and language access.
- Community health workers.

Suggested References:

- Gilmore-Bykovskyi AL, Jin Y, Gleason, C., Barnes LL, Zuelsdorff M, & Edwards DF. (2022). *Addressing systemic racism in Alzheimer's disease research and care*. Alzheimer's & Dementia, 18(10), 1987–1995. <https://doi.org/10.1002/alz.12500>
- Mendez-Luck CA, Gillian E, Kim M, & Mora A. (2023). *Latino family caregivers navigating dementia care: Trust, respect, and cultural attunement in the health care system*. The Gerontologist, 63(2), 312–322. <https://doi.org/10.1093/geront/gnac16>
- Parker LJ, Wood ER, & Jones L. (2021). *Racial and ethnic disparities in Alzheimer's disease: The role of trust and health literacy*. Journal of Aging & Health, 33(7–8), 543–552. <https://doi.org/10.1177/0898264321998379>
- Sterling MR, Shaw AL, Kearns D, & Pollack HA. (2020). *Culturally tailored dementia care: A scoping review of available interventions for racially and ethnically diverse populations*. Innovation in Aging, 4(6), igaa049. <https://doi.org/10.1093/geroni/igaa049>

5. Investing in Diverse Research and Data Collection

Discussion Questions:

- How can clinical trials be more inclusive and accessible for Alzheimer's disease and dementia patients?
- Why is it important to include diverse populations in dementia research?

- How do we address mistrust in research participation?

Strategies:

- Incentivizing inclusive recruitment practices.
- Partnering with trusted community institutions.
- Transparent communication about study outcomes.

Suggested References:

- National Institute on Aging. (2023). *Inclusion Across the Lifespan II: Diversity in Clinical Trials*. <https://www.nia.nih.gov/research/resources/inclusion-across-lifespan-ii-workshop-report>
- Barnes LL, & Bennett DA. (2014). *Alzheimer's disease in African Americans: Risk factors and challenges for the future*. *Health Affairs*, 33(4), 580-586.

6. Policy and Advocacy for Equity

Discussion Questions:

- What policies can reduce inequities in dementia care?
- How can communities advocate for equitable funding and support?

Topics to Address:

- Medicaid expansion and long-term care coverage.
- Paid family leave and caregiver support.
- Federal funding for minority-serving institutions.

Suggested References:

- National Institute on Aging. (2021). *NIA Health Disparities Research Framework*. <https://www.nia.nih.gov>
- U.S. Department of Health and Human Services. (2021). *National Plan to Address Alzheimer's Disease: 2021 Update*. <https://aspe.hhs.gov/reports/national-plan-address-alzheimers-disease-2021-update>
- AARP Public Policy Institute. (2020). *Valuing the Invaluable: 2020 Update—Charting a Path Forward*. <https://www.aarp.org/ppi/info-2020/valuing-the-invaluable-2020.html>
- Milken Institute. (2021). *Reducing the Economic Burden of Alzheimer's Disease*. <https://milkeninstitute.org/report/economic-burden-alzheimers>

7. Caregiver Support and Community-Based Services

Discussion Questions:

- How can we support family caregivers in diverse communities?
- What are models of successful community-based dementia programs?

Ideas to Explore:

- Respite services, education programs, support groups.
- Partnerships with faith-based and cultural organizations.

Suggested References:

- Rosalynn Carter Institute for Caregivers. (2020). *Caregiver Interventions and Equity*. <https://rosalynncarter.org>
- National Alliance for Caregiving & AARP. (2020). *Caregiving in the U.S.* <https://www.caregiving.org/caregiving-in-the-us-2020/>

Closing Reflection

Prompt:

- Reflect on concrete actions participants can take in their practice or institution.
 - Identify areas where further education, policy change, or advocacy is needed.
 - What are potential collaborative efforts?
 - What is one action—personal, institutional, or policy-level—you can take to advance equity in dementia care?
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