

Improving Dementia Diagnosis in Older Adults of Color

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The Elements in The Diagnosis

“There is no single test to diagnose Alzheimer’s disease. Rather, a formal diagnosis requires gathering information from a variety of sources, including obtaining medical and family history, reports from family or close friends about changes in thinking skills and behavior, blood tests and brain imaging such as MRI and PET scans, and cognitive tests conducted by a trained specialist such as a neuropsychologist, to carefully assess changes in memory and thinking skills.”

Testimony of Jennifer Manly, PhD

Taking Aim at Alzheimer’s: Frontline Perspectives and Caregiver Challenges United States Senate Special Committee on Aging

Manly 20, 2021

Conceptualizing The Issues

Informed by Critical Constructionist Views and Intersectionality Framework

- Critical constructionism seeks to understand how humans interpret or construct knowledge in social, linguistic and historical contexts.
- Intersectionality provides insight into how multiple identities of individuals/families (e.g., race , ethnicity, age, gender, religion, socioeconomic status, nationality, family norms and beliefs) help co-construct “reality” and interpret that reality in context.
- Giving meaning to dementia when co-constructed in racial, cultural and ethnic context helps interpret and evaluate actions and behaviors of those with dementia or changing memory.
- The co-constructed meaning of dementia or changing memory provides information to act or not and what actions need to be taken.
- Both non-action or taking action in seeking a diagnosis may be considered on time.
- Importantly, both critical constructionist views and the intersectionality framework inform and shape the notion of timeliness of diagnosis.
- Timeliness of diagnosis of dementia in diverse populations may not necessarily be in line with a clinical decision of timeliness of diagnosis.

The Role of Culture in Co-constructing Dementia and Seeking a Diagnosis

Culture Matters

“Cultural factors are crucial to diagnosis, treatment, and care. They shape health-related beliefs, behaviors, and values.”

Kleiman & Benson, 2006

The Importance of Culture and Intersectionality

- **Culture is a set of shared symbols, beliefs, and customs that shape individual and group behavior, and can change over time.**
- **Culture:**
 - cultural processes can differ within the same ethnic group due to differences in age cohort, gender, political association, social class, religion, and personality.
 - provides a living and dynamic "blueprint" to follow throughout life,
 - provides guidelines for speaking, doing, interpreting and evaluating actions,
 - develops through experiences, interactions, and thoughts of the perception of others

The Importance of Culture and Intersectionality

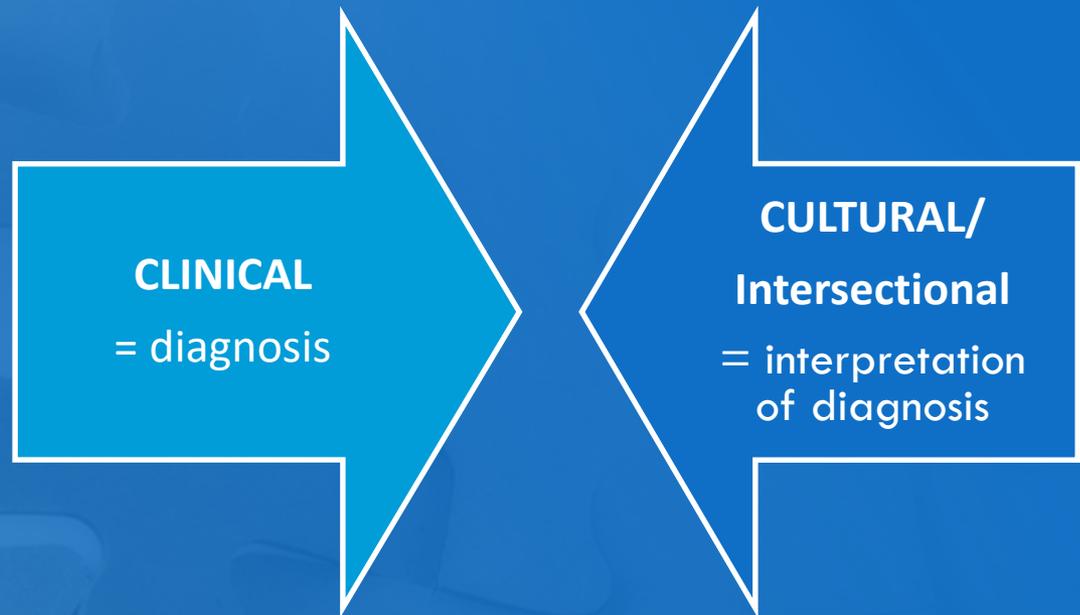
- Minority caregivers with less formal educational backgrounds have been found to incorporate **“folk beliefs”** into their understanding and knowledge of dementia
- Cultural beliefs social class intersect to help shape health perceptions (**what people see and give meaning to**)
- Cultural beliefs social class intersect (education, income, occupation) to help shape the range of what is considered **“normal”** cognitive behavior outside of clinical testing
- Cultural beliefs intersect with sense of power and knowledge about (**trust factor**) Alzheimer’s Disease
- Cultural beliefs may contribute to disparities in the detection and treatment of high-risk populations (**The case of African Americans & Native People**)

Diagnosing and Interpreting Dementia in Cultural/Intersectional Contexts

Clinical vs. Cultural/Intersectional Interpretation

Neuropsychology needs to continue to move away from a universalistic approach to cognition and testing, even within seemingly homogenous ethnic groups.

(Mindt et al, 2010)



Summary Comments

- Improving Diagnosis of Dementia Among Older Adults of Color Includes:
 - Understating that perceiving and giving meaning to dementia is constructed in cultural context
 - Knowing that the intersection of social status, history, etc. and the “lived experiences” of people do not reflect a biomedical model to understanding and giving meaning to dementia among people of color.
 - Understanding that diagnosis of dementia needs to be understood within cultural context and how this context is informed by the intersection of the “lived experiences” of racial ethnic groups.
 - Knowing that the cultural interpretation of cognition relates to the interpretation of the diagnosis and not the clinical interpretation of cognition relates to diagnosis
 - Providing diverse communities with more culturally relevant education on dementia symptoms and diagnosis.
 - Providing clinicians with more training on how best to integrate cultural factors in the diagnosis of dementia (e.g., use of ELECTIC Framework).

References

- Charmaz, K. (2020). “With constructivist grounded theory you can’t hide”: Social justice research and critical inquiry in the public sphere. *Qualitative Inquiry*, 26(2), 165-176.
- Daryl E. M. Fujii (2018). Developing a cultural context for conducting a neuropsychological evaluation with a culturally diverse client: the ECLECTIC framework, *The Clinical Neuropsychologist*, 32:8,1356-1392.
- Dilworth-Anderson, P. & Gibson, B.E. (2002). The Cultural Influence of Values, Norms, Meanings, and Perceptions in Understanding Dementia in Ethnic Minorities, *Alzheimer Disease and Associated Disorders*, 16(S2), S56-S63.
- Fujii, DE.M. (2018) Developing a cultural context for conducting a neuropsychological evaluation with a culturally diverse client: the ECLECTIC framework, *The Clinical Neuropsychologist*, 32:8, 1356-1392
- Gallagher-Thompson, D., Leary, M.C., Ossinalde, C., Romero, J.J., Wald, M.J., & Fernandez-Gamarra, E. (1997). Hispanic Caregivers of Older Adults with Dementia: Cultural Issues in Outreach and Intervention, *Group* 21, no. 2: 211-232.
- Goodenough, W. H. (1981). *Culture, language, and society*. Menlo Park, CA: Benjamin/Cummings.
- Goodenough, W. H. (1999). Outline of a framework for a theory of cultural evolution. *Cross-Cultural Research*, 33, 84-107.
- Hinton, L., Franz, C., Yeo, G., & Levkoff, S. (2005). Conceptions of dementia in a multiethnic sample of family caregivers. *Journal of the American Geriatrics Society*, 53(8), 1405-1410.
- Kleinman A, Benson P (2006). Anthropology in the Clinic: The Problem of Cultural Competency and How to Fix It. *PLoS Med* 3(10), e294. <https://doi.org/10.1371/journal.pmed.0030294>.

References

- Kokorelias, Kristina M., et al. (2021). A Qualitative Exploration of how Gender and Relationship Shape Family Caregivers' Experiences Across the Alzheimer's Disease Trajectory." *Dementia* 20.8, 2851-2866.
- Lee, S.E., Lee, H.Y., & Diwan, S. (2010). What Do Korean American Immigrants Know about Alzheimer's Disease (AD)?, *International Journal of Geriatric Psychiatry*, 25, 66-73.
- Lui, D., Hinton, L., Tran, C., Hinton, D., & Baker, J.C. (2008). Reexamining the Relationships Among Dementia, Stigma, and Aging in Immigrant Chinese and Vietnamese family caregivers.
- Manly, J. (2021). Taking Aim at Alzheimer's: Frontline Perspectives and Caregiver Challenges United States Senate Special Committee on Aging. A Report
- Roberts, S., Connell, c., Cisewski, D., Hipps, Y., Demissie, S., & Green, R. (2003). Differences between African Americans and Whites in Their Perceptions of Alzheimer's Disease, *Alzheimer Disease and Associated Disorders*, 17(1), 19-26.
- Mindt, M.R., Byrd, D., Saez, P., & Manly, J. (2010). Increasing culturally competent neuropsychological services for ethnic minority populations: a call to action. *Clinical Neuropsychology*. 24(3), 429–453.
- Rovner, B., Casten, R.J., & Harris, L.F. (2013) Cultural Diversity and Views on Alzheimer's Disease in Older African Americans. *Alzheimer Disease Associated Disorders*, 27(2), 133–137.
- Teng, E. (2002). Cultural and Educational Factors in the Diagnosis of Dementia, *Alzheimer Disease and Associated Disorders*, 16 (2), S77-S79.
- Yeo, G., Gerdner, L. A. & Gallagher-Thompson, D. (2018). *Ethnicity and the Dementias* (3rd edition). Routledge, Taylor & Francis Group: New York.
- Vila-Castelar, C., Fox-Fuller, J.T., Guzmán-Vélez, E., Schoemaker, D., & Quiroz, Y.T., (2022). A Cultural Approach to Dementia — Insights from US Latino and Other Minoritized Groups, *Nature Review, Neurology*, 18: 308-314