

# 26th Annual Alzheimer Day

## Attitudes About Brain Donation Among African American Research Participants

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**INTRODUCTION:** Alzheimer's and related dementias (ARD) disproportionately affect the African American community. Increased participation of African Americans in research is thus essential in the understanding of underlying factors of risk and resilience to ARD. Brain donation, a crucial part of translational research, is less common among African American research participants compared to White research participants at Alzheimer's Disease Research Centers (ADRCs) internationally and across the US.

**GOALS/HYPOTHESES:** Existing literature suggests three categories of factors contribute to decisions about brain donation among African American subcommunities: experience, knowledge, and concerns about participating in research and brain donation; religious practice, beliefs, and funeral arrangements; and family participation in decision making and support for brain donation. However, existing knowledge about potential interventions is limited and perspectives of African American participants within the Mesulam Center ADRC are unknown.

**METHODS:** We conducted seven focus groups, aimed to capture the perspectives and attitudes of African American research participants currently enrolled in research through the Mesulam Center ADRC. 34 research participants and/or study partners participated, 22 of whom had agreed to brain donation previously, 10 of whom had indicated they would consider brain donation, and 2 of whom had declined brain donation. Each focus group ranged in participants from 2-8 participants, plus 2-4 study personnel. Focus groups were stratified by both brain donation intent and cognitive status. Participants included 15 research participants with normal cognitive status and 6 family members, 5 research participants with mild cognitive impairment or mild dementia (CDR score of 0.5 or 1) and 5 family members, and 3 family members of research participants with moderate or advanced dementia (CDR score of greater than 1). Focus groups were co-facilitated by Northwestern social workers, a Northwestern neuroscience PhD student, and a social work intern at the regional senior center. The focus group discussions were audio recorded, subsequently deidentified, transcribed and coded for emerging themes.

**RESULTS:** 34 people participated in seven separate focus groups. Qualitative content analysis reveal themes that contribute to participant brain donation intent: personal connection to memory loss or dementia; altruism; spirituality/religion; historical and current racism in health care and research;

trauma and objectification; trust; representation of African Americans and women; understanding the purpose and process of brain donation; and fluidity in decision-making process.

CONCLUSION: Our findings are generally consistent with previous literature on the subject of brain donation among African Americans however novel insights were noted. Increased representation is necessary and integral to increased participation among diverse communities. Additional efforts to improve the relationship between ADRCs and the African American community is integral to increased participation among African American research participants. Future research will explore trauma-informed and culturally responsive interventions in research and community settings.

*This research was presented as part of the 26th Annual Alzheimer Day hosted by the Northwestern University Mesulam Center for Cognitive Neurology and Alzheimer Disease on September 24, 2020.*

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