

Improving dementia outcomes in Indian Country: The Oneida Nation Alzheimer's Disease Project

F4-06 Global Initiatives to Improve Assessment, Diagnosis and Care for Cognitive Disorders in Underserved Populations, Wednesday, July 17, 2019: 4:15 PM - 5:45 PM, 515 AB

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Background:

Recent analyses suggest that American Indians/Alaskan Natives (AI/AN) are at increased risk for dementia compared to other populations.^{1, 2} The Wisconsin Alzheimer's Disease Research Center's (ADRC) Inclusion of Under-Represented Groups (IURG) Core partnered with the Oneida Nation of Wisconsin to develop a community-centered approach to address Alzheimer's Disease (AD) dementia. We describe our process of establishing the Oneida Nation Alzheimer's Disease Project, highlighting efforts to improve access to high-quality diagnostic services and culturally-competent inclusion in Alzheimer's disease (AD) research.

Methods:

After learning of the dearth of data on AI/AN's risk for dementia, the Oneida Nation Commission on Aging (ONCOA) led efforts to establish this community-based participatory research and education partnership with the Wisconsin ADRC. Efforts were stepped and started with formation of an Alzheimer's Community Advisory Board (CAB) and four Specific Aims. New

Aims were recently developed, and the CAB membership reconstituted based on revised project aims. To institute these initiatives, ONCOA and the Alzheimer's CAB proposed a tribal resolution, presenting the proposal to the Oneida Business Committee – the Oneida Nation's elected governing body.

Results:

Of the 40K+ Uniform Data Set (UDS) participants enrolled in AD research through the network of Alzheimer's Disease Centers, only 252 are AI/AN.³ Initial CAB and IURG Core efforts to address this disparity focused on education and memory screening events. Additional focus was on improving access to culturally competent diagnostic services. The approach to accomplishing this aim changed as challenges were encountered. The Alzheimer's CAB worked with the Tribal health clinic to build interest and momentum to equip primary care providers to address dementia diagnostic needs. A clinician consultant shadowed Oneida Comprehensive Health providers. Next steps are to implement a screening protocol to address patient's cognitive concerns in the primary care setting. Additionally, the Alzheimer's CAB continues to consultant on numerous research projects and to disseminate education efforts through the Great Lakes Native American Elder Association (GLNAEA).

Conclusions:

Research teams partnering with AI/AN communities must recognize tribal sovereignty and work with local government. Collaborating with local leadership, the Wisconsin ADRC's IURG Core supports efforts to improve access to diagnostic services and inclusion of AI/AN in AD research.

1. Mayeda ER, Glymour MM, Quesenberry CP, Whitmer RA. Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimers Dement* 2016;12:216-224.
2. Chen HY, Panegyres PK. The Role of Ethnicity in Alzheimer's Disease: Findings From The C-PATH Online Data Repository. *J Alzheimers Dis* 2016;51:515-523.
3. National Alzheimer's Coordinating Center NACC. June 1, 2019. <https://www.alz.washington.edu/WEB/UDSonepage.pdf>