Lessons from a Research Collaboration with the Oneida Nation of Wisconsin

Carrie Trojanczyk, BA1,2, Megan Zueldorff, PhD1,2, Marlene Summers3,4,5, Lois Strong4,6, Patricia Lassila3,4, Wesley Martin4,5, Hector Salazar, BSN1,2, Nickolas H. Lambrou, PhD7, Donald W Skenandore Jr., MD8, Fabu P Carter1,2, Nathaniel A. Chin, MD1,2, Mary F. Wyman, PhD7, Tierra Smith, BS1,2, Brieanna L Harris, BA1,2, Alice Spalitta, BS1,2, Carola A Ferrer Simo, MPH2, Dorothy Farrar Edwards, PhD2, Sanjay Asthana, MD1,2,7 and Carey E. Gleason, PhD7

1Wisconsin Alzheimer’s Disease Research Center, Madison, WI, USA, 2University of Wisconsin-Madison, Madison, WI, USA, 3Oneida Nation Commission on Aging, Oneida, WI, USA, 4Oneida Community Advisory Board, Oneida, WI, USA, 5Great Lakes Native American Elder Association, Oneida, WI, USA, 6Oneida Elder Services, Oneida, WI, USA, 7VA Geriatric Research, Education and Clinical Center (GRECC), William S. Middleton Memorial Veterans Hospital, Madison, WI, USA, 8University of Wisconsin Psychiatry Residency Program, Madison, WI, USA.

Background: As Alzheimer’s disease and related dementias prevalence (ADRD) increases it will disproportionately burden racial and ethnic minority communities. Recent population-based evidence suggests that American Indians and Alaska Natives (AI/AN) are at increased risk for dementia relative to non-Hispanic Whites and Asians. Despite evidence that 1 of every 3 AI/AN elders will develop dementia, they remain substantially underrepresented in ADRD research. As of March 2019, only 248 of the 40,000+ individuals enrolled at Alzheimer’s Disease Centers (ADC) were AI/AN. Subsequently, little is known about dementia etiology, progression, and care in AI/AN communities. We describe an ongoing partnership between the Oneida Nation of Wisconsin and the Wisconsin Alzheimer’s Disease Research Center (ADRC) that seeks to address this knowledge gap and respond to the ADRD-related concerns in Wisconsin’s Indian Country.

Methods: We implemented an NIA-funded, community-based, culturally-relevant approach to address barriers to participation in ADRD research and access to services for persons with dementia. This approach is comprised of four aims: (1) Establish a Community Advisory Board (CAB) to guide culturally-tailored outreach programs to increase research enrollment and retention of AI/AN participants, (2) Improve access to culturally appropriate dementia diagnostic services, (3) Survey of Oneida caregivers of persons with dementia to understand caregiving experiences, and (4) Initiate liaisons with ten other Wisconsin tribes.

Results: Project leaders and Oneida CAB members meet monthly on Oneida lands, and ADRC staff attend quarterly meetings with an Inter-Tribal Elders Association. In 2018, project leaders held an inaugural National Conference on Dementia in Native American Communities. Preliminary results for Aim 1 are promising. Following establishment of the partnership, the number of AI/AN participants enrolled in the ADRC has increased tremendously (see Figure 1), and rises at a rate of two new participants per month. 77% of AI/AN participants also participate in an imaging sub-study.

Conclusions: The Wisconsin ADRC has enrolled nearly a quarter of all AI/AN participants included in the combined ADC dataset. Actively prioritizing a collaborative partnership and investing in community-based relationships was essential to our inclusion efforts with AI/AN communities. These elements are fundamental for establishing research and clinical efforts that effectively respond to the needs of AI/AN populations.
Figure 1. American Indian Recruitment Over Time

Dashed line represents beginning of ADRC-Oneida partnership. In just over four years, AI/AN participant enrollment has increased by nearly 200%.