

SPECIFIC AIMS

The unprecedented aging of the United States (U.S.) population has brought an extraordinary increase in the prevalence of Alzheimer's Disease and Related Dementias (ADRD). More than 6 million individuals in the U.S. live with ADRD and this number is projected to increase to over 15 million by 2060.¹ ADRD is a costly condition, with annual direct medical costs estimated at \$14,508 per older adult with ADRD versus \$10,096 per older adult without ADRD.² These estimates do not account for the indirect costs of ADRD including those associated with receiving informal, unpaid care. More than 16 million "family caregivers" provide 18.4 billion hours of unpaid care annually, valued at more than \$232 billion.³ ADRD caregivers are at risk for poor health outcomes such as chronic stress, sleep deprivation, anxiety, depression, physical health conditions, and potential early mortality.³⁻¹³

Assuming equal access to healthcare, approximately 32% of Latinos, 35% of Native Americans, and 30% of Whites over the age of 65 are predicted to be diagnosed with ADRD over the next 25 years.^{14,15} There is emerging evidence that ADRD caregivers from diverse backgrounds underuse formal support services¹⁶ and have different experiences with ADRD compared with their cultural majority counterparts¹⁷ including finding meaning and mutual benefit from caregiving.^{18,19} However, diverse ADRD caregivers also demonstrate knowledge gaps regarding ADRD conditions and available resources.²⁰ Rural-residing ADRD caregivers also experience unique challenges regarding access and use of support services.^{21,22} At present, little is known about the intersection of ADRD caregivers who co-identify as racially and ethnically diverse and residing in rural areas, regarding their unique needs, assets, resources, and health outcomes.

The **long-term goal** of this study is to develop culture-based, multi-system programs for underserved (Hispanic/Latino, Native American, rural) ADRD family caregivers that recognize the unique needs and assets of these populations. Guided by the Socio Ecological Model (SEM),²³ the **goal of this proposed administrative supplement** is to develop a multi-level understanding of these issues by conducting a mixed-methods study with underserved ADRD caregivers living in northern Arizona, one of the catchment areas of the parent U54 RCMI: The Southwest Health Equity Research Collaborative (SHERC) 1U54MD012388. The Specific Aims are to:

Aim 1: Characterize the population-specific needs, assets, resources, and outcomes of diverse ADRD caregivers in northern Arizona. To accomplish this aim we will engage SHERC's community partners to develop and distribute a self-report survey for underserved ADRD caregivers (N=240). The survey will include items about individual- (demographics, healthcare knowledge and practices, psychological characteristics), interpersonal- (living situation, family and social support), community- and cultural- (neighborhood safety, customs, traditions, beliefs), and systems- (availability of services and resources) level factors, as well as health outcomes (chronic stress, sleep deprivation, depression, physical health conditions). We will conduct subgroup analyses to examine needs, assets, and outcomes by race/ethnic/cultural group.

Aim 2: Determine caregiver, provider, and policy influencers' perceptions of the unique needs, assets, and resources of diverse ADRD caregivers in northern Arizona. Also informed by the SEM, we will a) conduct up to eight semi-structured focus groups with N=48 diverse ADRD caregivers; (b) Conduct up to 24 in-depth interviews with ADRD providers (i.e., primary care, behavioral health, and homecare workers) and ADRD policy influencers (N=12); (c) Based on data from Aims 2a and 2b, we will use an interpretive descriptive approach to describe and compare the multi-level needs, assets, and resources of each subpopulation in order to identify implications for future practice, policy, and research initiatives.

Aim 3: Develop GIS maps of existing and potential sites of resources to assist community members, researchers, and policy influencers to identify and address community-level health inequities among ADRD caregivers. We will accomplish this aim using point and tract-level data from the U.S. Census, in combination with geographic information systems (GIS) data from publically-available health and social services databases (e.g., InfoGroup Religious Congregations database; Arizona Department of Health Services) and our community partners, using *ArcGIS OpenStreet Map* software. The maps will be distributed to community members, providers, researchers and policy influencers engaged in ADRD efforts in northern Arizona to inform future research, policy, and practice.

Northern Arizona consists of vast, sparsely populated areas, peopled with a variety of cultural groups steeped in unique perspectives and caregiving traditions. The unique geographical and cultural setting of the SHERC, combined with the experience and expertise of this interdisciplinary team of investigators, well-positions the proposed study for success. Achieving the study Aims will stimulate additional activity and progress in the area of ADRD research by providing preliminary data on the needs, assets, resources, and outcomes of diverse ADRD caregivers, which will guide our future SHERC supported and NIA or NIMHD R21 intervention studies addressing cultural relevance and the development of resources for policy and practice.