

ADRC Participant Access Request

Access Request Goal

Goal - Formal request for ADRC data

Principal Investigator

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No Co-PI listed in survey

Study and Theme Details

Hypothesis

There are differences in determinants of Family Quality of Life in dementia for Black/African American families and Non-Hispanic White families.

Specific Aims

1. To collect Family Quality of Life in Dementia (FQOL-D) questionnaire responses from 30 dementia caregivers who identify as white (non-Hispanic white) for comparison to identical existing data from family caregivers of Black/African American persons with dementia.

Study related to Deep South Disparities

We will explore differences in dementia caregiving experience between Black/African American and Non-Hispanic white families in Alabama

Funding and IRB Details

Funding source - Already funded

Entity - Intramurally funded

Details - Default funding to Warren Endowment and spendable gifts

IRB Contact - Yes, we have IRB approval

IRB Protocol # - IRB Project Number (IPN): IRB-141003003

Subject Sample Size and Profile

Sample size by cognitive ability

Mild Dementia 0-30

Moderate to Severe 0-30

Additional inclusion/exclusion details

Family caregivers of persons with ADRC Consensus diagnosis of Dementia; self-identified race/ethnicity as non-Hispanic White; total enrollment ~30

Racial minorities and other stratification

This study tests hypothesis on B/AA disparities or other race issues

Additional stratification details

NHW caregiver cohort matched to gender, relationship, and education to existing B/AA cohort's data

Requested Resources

Human subject involvement

Study procedures

Caregivers will participate in a one-time 30-45 minute telephone survey; consent will be oral and over the phone during the same call.

Study duration

12

Compensation

Caregivers will receive a \$25 gift card after completing the survey.

Statistical support

Would like to discuss statistics with the ADRC