

ADRC Participant Access Request

Access Request Goal

Goal - Preliminary inquiry for further discussion

Principal Investigator

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Study and Theme Details

Hypothesis

This is an exploratory study focused on understanding the informational needs of family caregivers of patients with Alzheimer's disease and related dementia's

Specific Aims

Specific Aim 1: Identify the information that FCGs of patients with moderate to severe dementia find useful in current AVS, what they find superfluous, and the gaps in their informational needs through a clinic- and community-based survey of FCGs of PWAD living in the community, grounded in the Family Involvement in Interpersonal Health Processes Model.

Specific Aim 2: Conduct one-on-one qualitative interviews using a subsample of 12-20 survey respondents from Aim 1, to elicit perspectives on: 1) attitudes and beliefs about the provision of information during dementia care clinic visits and the potential role of palliative care and 2) an outline of an informational support intervention aimed at supporting FCG informational needs.

Study related to Deep South Disparities

We hope to understand if there are disparities in informational needs among Deep South family caregivers

Funding and IRB Details

Funding source - Not yet funded

IRB Contact - Not yet discussed project with IRB

Subject Sample Size and Profile

Sample size by cognitive ability

Moderate to Severe	150
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Total N	150
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Additional inclusion/exclusion details

I am hoping to discuss whether that is a reasonable sample size with the ADRC

Racial minorities and other stratification

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

Requested Resources

Existing data

Demographics	Required
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Medical History	Required
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Human subject involvement

Study procedures

To fill out a short (<10 min) survey on their informational needs

Study duration

Not sure, hoping to discuss

Compensation

20

Statistical support

Statistician has already been consulted - Reed WR
Bratches, PhD