

ADRC Participant Access Request

Access Request Goal

Goal - Preliminary inquiry for further discussion

Principal Investigator

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|-------------|--------------------------------------|
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No Co-PI listed in survey

Study and Theme Details

Hypothesis

This is an exploratory study to identify the informational needs of family caregivers of patients with serious dementia

Specific Aims

Specific Aim 1: Identify the information that FCGs of patients with dementia receiving palliative care 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 PwD living in the community.

Specific Aim 2: Using a subsample of 12-20 survey respondents from Aim 1, conduct one-on-one qualitative interviews 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

Our exploratory aim is to identify potential disparities in informational needs or behaviors by race/ethnicity

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 ~290

Additional inclusion/exclusion details

Our target population is family caregivers of patients with moderate to severe dementia. Family caregivers will be those who self-identify as being “A relative, friend, or partner who has a close relationship with and provides medical assistance to a person with advanced dementia, and who may or may not live in the same residence.” No other formal screening criteria will be used.

Racial minorities and other stratification

This study does NOT test hypothesis on racial disparities

Requested Resources

Human subject involvement

Study procedures

They will be asked to complete a short survey about their experiences providing care for a person with dementia. While the survey has not been pilot-tested yet, we anticipate the survey will take about 10 minutes.

We will also ask them to identify whether they are comfortable participating in a semi-structured qualitative interview about their informational needs as a caregiver

Study duration

Unclear, depends on the survey response rate

Compensation

\$10

Statistical support

Statistician has already been consulted - I have advanced statistical training and am comfortable with sample size and power calculations