



FLORIDA ATLANTIC UNIVERSITY

## Christine E. Lynn College of Nursing

# Improving Lives of Rural Residents Who Face Dementia Disparities

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Advisory Council on Alzheimer's Research, Care, and Services

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### The Glades, FL

- Nearly 38 percent of FL residents who have ADRD are undiagnosed, with rates higher in rural counties
- 40 miles west of Palm Beach, FL is a rural area of Florida known as “the Glades”:
- Racially and Ethnically Diverse:
  - 58.4% African American, Hispanic ethnicities (32.9%), and Haitian Creole (4%)
- Field/farm work is the primary means of employment
- The poverty rate is 41%
- Strong sense of community: *PATCH* (Planned Approach to Community Health) and *Healthier Glades*



### Barriers to promoting health in this disparaged region



- Demand for clean water
- No specialty providers or easy access to PCP
- Language and Health Literacy Barriers
- 48% without digital access, and 49% with no digital literacy
- Communication is done largely through the Radio
- Transportation - even if resources are available not used
- Structures are in place to host educational and recreational events, but no routine organized activities.



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### Increased risk of Alzheimer's Disease and Other Dementias; expected to bankrupt the nation by 2050



#### Risk is 2-4 times greater those living on "the Coast":

- Rural Glades residents are 92% racially/ethnically diverse

#### Over a dozen risk factors are modifiable, including:

- Vascular diseases (hypertension and diabetes)
- Air pollution from sugar cane burning
- Childhood trauma, neglect
- Lack of exercise
- Lack of socialization
- Lack of fresh fruits and vegetables (can't afford to buy)
- Traumatic Brain Injury (over 50 football players are from Glades)
- Low education
- Lack of access to health care, health information, and health services

- These risk factors affect caregivers too, not just older adults.



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Early detection and management is key to decreasing burden for caregivers:

**Cost Burden: One year at home rather than in an institution can save a minimum of \$33,000.00**

**In addition to the financial burdens, Caregivers neglect themselves:**

- chronic illnesses increase
- stress increases; inflammation increases, disease increases
- Although they gain some positive feelings from caregiving, they report increased stress and depression

**When asking caregivers in the Glades what their greatest need was, they said:**

- *Information about how to communicate with and manage difficult behaviors.*



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### Successful Engagement in the Glades:



- **Service** (monthly screenings for hypertension, weight, and diabetes, with a light meal)
- **Education** (short series of presentations among stakeholders and community leaders at their meetings)
- **Training** (of faith-based congregants as health educators and research assistants)
- **Clinical** (Nurse Practitioners followed screening with in-depth home-based assessments)

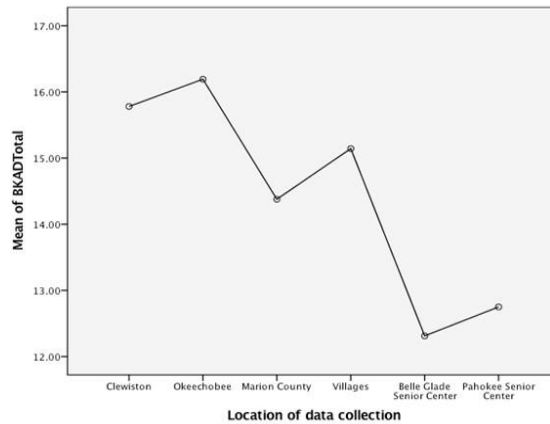


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**Research #1:**

**Investigating Knowledge of Alzheimer’s Disease and Perceptions about Cognitive Screening in Ethnically Diverse Rural Populations. (Association of Community Health Nurse Educators)**

**Gaps in Knowledge varies across Rural Regions:**



**Research #2:**

**Exploring Perceptions among Rural Stakeholders regarding Cognitive Screening (Sigma Nursing)**

**Based on stakeholder’s responses to the PRISM\* survey items:**

- 81% indicated that they would want an examination annually to determine if they developed memory problems or AD.
- All stakeholders responded that earlier cognitive testing would provide the opportunity for better treatment.
- Similarly, regardless of stigma, 86% believed that family would be able to provide better care if they knew of an AD diagnosis earlier.
- About half of the respondents indicated that if their family members knew about an AD diagnosis, it would create financial (47.6%) or emotional distress (61.9%) for the family.
- Although a third of those interviewed indicated their belief that they would be depressed (33.3%) and even more would be anxious (42.9%) if they were aware of an AD diagnosis,
- 95% stated that they “would not give up on life.”



**Research #3:**  
**Dementia Detection and Treatment Benefits through Home Health Care as Compared to Clinic Care in a Rural Florida Underserved Population**  
 (FDOH Ed/Ethel Moore Alzheimer's Disease Research Foundation)

	f	%
Lived in Rural Area ≥ ten years	113	81
Health Literacy < 3 <sup>rd</sup> grade	65	47
Saw Provider routinely	132	95
Provider checked Memory	14	10
Depression Risk	14	9.5
Dementia Risk (Mini-Cog < 3)	28	19

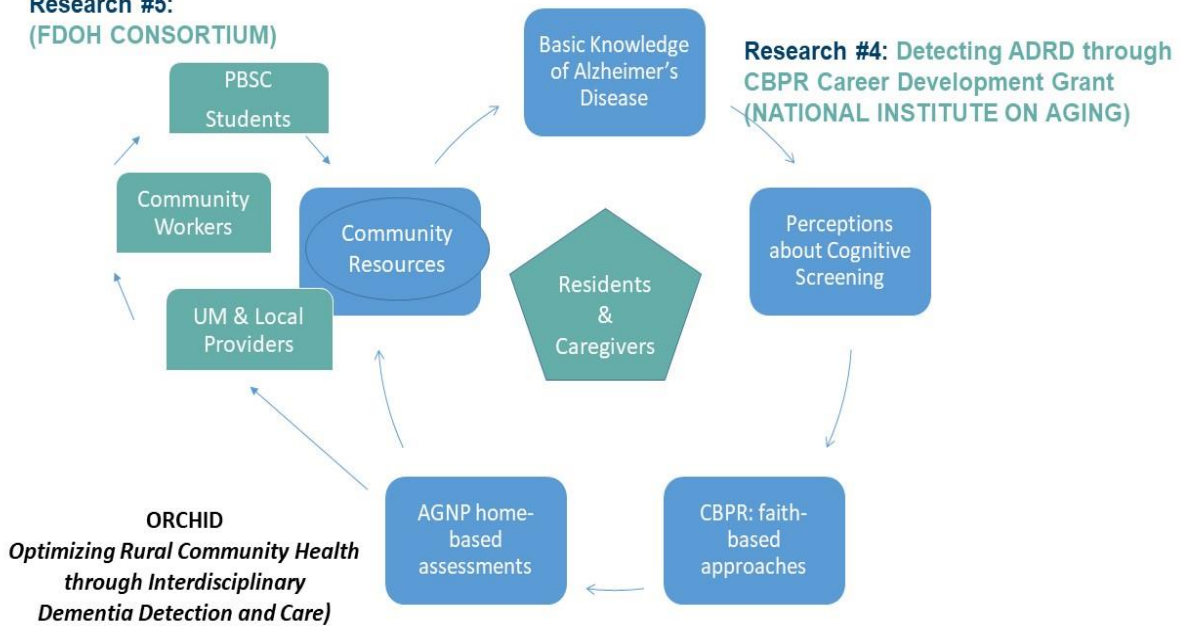
**Frequency of Dementia Risk, Detection, and Diagnosis**

(n = 139)	f	%
Risk of Dementia	28	20.1
Seen by a Provider	25	18
Dx with Dementia	15	10.8

	f	%
Spanish	34	25
African American	90	65
Afro Caribbean	21	15
Farm or Factory Work	11	85
Male	43	31

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**Research #5:**  
 (FDOH CONSORTIUM)



FDOH Ed/Ethel Moore Alzheimer's Disease Research Foundation

## The ORCHID Research Team:

- Hispanic and Afro-Caribbean AGNPs
- Local Afro-Caribbean and African American social workers
- Neurologist specializing in ADRD research, including rural and racially/ethnically diverse
- PhD RN with advanced mental health practice certification and research in culturally relevant communication with families facing ADRD
- Trained faith health educators
- Faculty from three Colleges and Universities
- University Memory and Wellness Center



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### EDUCATION of PROVIDERS by University of Miami Comprehensive Center for Brain Health:

1. Dementia epidemiology, clinical outcomes, societal and financial impact, racial disparities, risk factors
2. Current screening guidelines (American Academy of Neurology, US Preventative Services Task Force recommendations)
3. Treatment of dementia pharmacological and nonpharmacological treatments
4. Clinical diagnostic guidelines and current clinical guidelines for the diagnosis of AD and VaD
5. Differential diagnosis of dementia causes of dementia, related symptoms, disease stages, fluid and imaging biomarkers, neuropathology, brief neurological examination
6. Neuropsychological testing commonly used cognitive tests for the screening and diagnosis of ADRD
7. Interview-based evaluations, clinical interviewing, with a focus on administration and interpretation of the CDR
8. Common behavioral challenges in dementia including agitation, aggression, delusions/hallucinations, sleep, communication, mobility (driving), and nutrition
9. Patient and caregiver support Impact on patient and caregiver health with a focus on stress, burden, grief, dementia disclosure strategies, legal issues/future care planning,
10. Available local and regional resources of support



**EDUCATION of COMMUNITY:**

1. Defining Dementia
2. Why You are at Greater Risk
3. Ten Ways to Decrease Your Risk
4. Benefits of Annual Screening
5. Ten Warning Signs of AD
6. Legal, Financial, and Long-term Care Planning



**Research:** 82% of older residents who were offered brain health education across ten rural churches and senior living facilities have participated (*n* = 696).

95% have participated in screening.

86% have signed Research Registry Consents: Problem; requires online access.

**Pilot Studies:**

- “Students for Seniors” (Healthier Glades Mini-grant, Palm Healthcare Foundation)
- Testing the Feasibility of Tracking Behavior and Physiology Patterns using Wearable Technology to Detect Potential Cognitive Risk among Rural, Racially/Ethnically Diverse Older Adults (Washington State University)



**EDUCATION of CAREGIVERS:**

1. Defining Dementia
2. Why Does it Matter?
3. Caregiver Health
4. Caregiver Risk of Dementia
5. Reducing Your Risks
6. Identifying Your Needs
7. Identifying Your Supports
8. Ten Ways to Love Your Brain
9. Discussing Your Health Needs with your Provider
10. If there are only two of you
11. Social Engagement
12. Maintaining Safety
13. Legal, Financial, and Long-term Care Planning
14. Planning for the Future
15. Getting Regular Medical Care and Services
16. Connecting with Community Resources

**Measuring:**

- Caregiver Burden Inventory
- Revised Caregiver Self-efficacy Scale
- Caregiver Depression Scale
- Caregiver Self-Esteem Scale



**IN SUMMARY: SIX-POINT MODEL TO CHANGING THE NARRATIVE of DISPARITIES:**

1. **Faith-based approaches:** training congregants as health educators
2. **Home visits:** Need to allow NPs to bill for consults
3. **Support for providers/offices:** partnering with Neurology Clinics and local nursing students
4. **Attending to the “forgotten patient”:** A “buddy system” of caregivers with community health workers, faith health educators, or nursing students
5. **Simulation Training for caregivers** for coping with Difficult Behaviors
6. **Putting in the Functions to match the Structures:** Health Education, Literacy Programs, Cooking Classes, Exercise Programs, Walking Groups, Volunteer Drivers, Digital Training and Access



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