Rural Outreach at the Knight ARDC

October 10, 2014

Andrea Denny, JD, MSSW

Outreach, Recruitment and Education Core Leader

Rural Outreach Core Leader

KnightADRC Alzheimer's Disease Research Center | WASHINGTON UNIVERSITY ST. LOUIS

A Brief History of Our Rural Outreach

- Program 1st funded in 1990 as the Iowa-Missouri Consortium, a partnership between the ADRC and the University of Iowa.
- Goal: improve diagnosis and treatment of Alzheimer patients by educational outreach to rural physicians and healthcare professionals.
- Consortium ended in 2000, but the program continued as the Knight ADRC Rural Outreach Satellite, now focused on Missouri but expanded to included lay education.

Defining "Rural"

- US Census definition: "open country and settlements with fewer than 2,500 residents."
- Urban areas: "larger places and densely settled areas around them."
- Most counties in the United States, including metropolitan and non-metropolitan, contain a combination of urban and rural areas.
- Researchers commonly use the term "rural" to refer to traditionally non-metropolitan areas perhaps as a proxy for underserved populations.

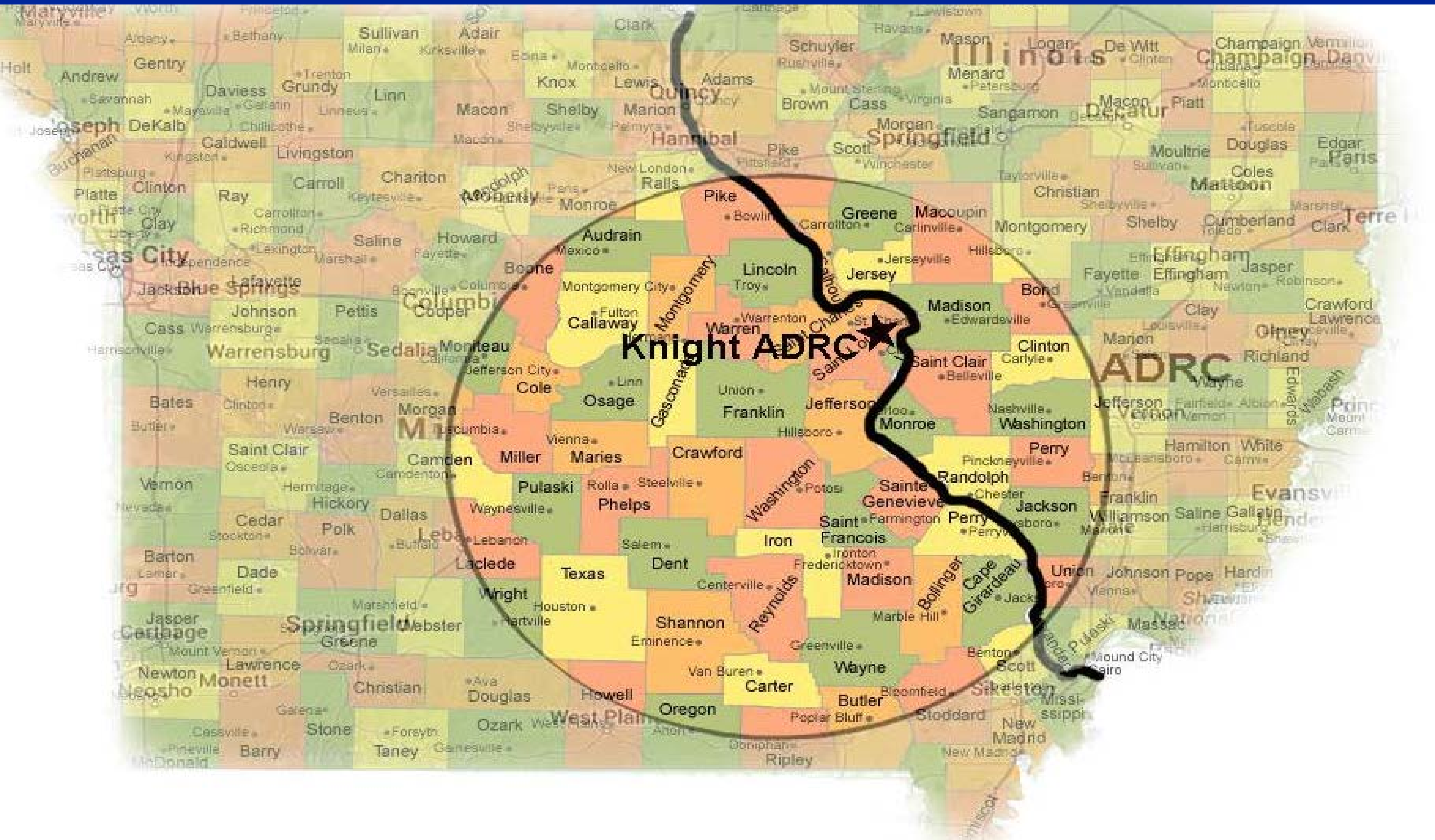
United States Census 2010

Rural Outreach Core Aims

- Aim 1: Raise awareness of AD and dementia in the underserved rural counties of Missouri and Illinois within a radius of approximately 2-hour drive from St. Louis.

- Aim 2: Recruit rural participants for Knight ADRC research.

Knight ADRC Catchment Area



Why Serve These Counties?

- **Justice:** served when all groups have access to resources, many of which are located in urban areas.
- **Lack of services:**
  - 18% of MO Primary Care Physicians (PCPs) work in rural MO, whereas 37% of the population resides there
  - Few specialists practice in rural areas
  - Rural medical centers lack cutting edge techniques and access to technology
- **Necessity**: rural death rates from Alzheimer disease (AD) are increasing faster than urban. Since 2007 rural AD death rates increased 28.6% while urban AD death rates slightly declined.

Missouri Department of Health & Senior Services, 2007

Community Engagement

- To share knowledge and opportunities in rural areas, the Knight ADRC must demonstrate why our information is important to the communities.
- Barriers of mistrust have to be overcome.
- We must earn the buy-in of rural communities.
- Combating metro-centrism
  - As metro dwellers from elite academic institutions, we often assume that what we know/do/practice is the cultural norm outside the city.
  - Our challenge is to reconcile that with issues of equal access to services, knowledge, and training.

Initiatives

1) Host the Clinician Partner Program (CPP)

2) Create an online Clinician Partner resource library and hub

3) Provide AD lectures in rural communities

4) Provide statewide AD8 training

5) Provide statewide driving education

Clinician Partners Program

- 2.5 day “mini-residency” to educate rural health professionals about:
  - AD and related dementias
  - Research opportunities at the Knight ADRC
  - Practical tools to better manage and diagnose dementia in a clinical setting.

- Inaugurated in 2000, 166 clinicians (MD, DO, PA, NP, GNP) have completed the program, plus an additional 63 observers in related disciplines.

Clinician Partners Program

- Nominations come from word of mouth from CPP alumni or the Alzheimer's Association, St. Louis Chapter
- Program offers ~20 hours CME (free of charge to the Partners), paid travel and accommodations, and training from leaders in AD research and care.
- The monetary stipend was discontinued in 2013 and determined unnecessary to recruit participants.
- Program now offered annually.

What Have We Learned?

- Clinicians are interested in learning more about AD, dementia and AD research.
- New measurements used in 2012 and 2013 indicated positive outcomes with highlights including increased comfort with:
  - Evaluating driving & counseling on driving retirement
  - Assessing, treating and diagnosing dementia
  - Disclosing a dementia diagnosis to patients/families
  - Using dementia screening tools in clinical practice
- Need for further reinforcement. Some changes plateau or even backslide at the 1-year post test.

Response to Outcomes

- As knowledge and practice changes start to fade over time, ROC is implementing strategies to maintain gains from the CPP.

- Some Clinician Partners may come for free CME and an expense-paid trip. ROC minimizes this during participant screening and selection, and by dropping the stipend.

- ROC is maximizing dollars invested in the CPP by developing a continued partnership with program alumni.

CPP Alumni Development

- Information translation: cultivating CPP alumni to speak in their communities about AD and research studies at the Knight ADRC
- Championing: connecting Knight ADRC faculty with opportunities in their rural communities
- Resources: developing a portion of the Knight ADRC website or a separate website for rural clinician support.
- Collaboration: potential to have CPP alumni as research partners in future. Example: study of emergency departments and dementia screening.

Driving and Dementia

- Clinician Partners and other rural clinicians continue to identify the need for education about dementia, driving assessment and driving retirement.
- In next grant cycle, continued collaborations:
  - David Carr, MD (Washington University)
  - Tom Meuser, PhD (University of Missouri St. Louis, former ROC leader)
  - Marla Berg-Weger, PhD (Saint Louis University)
- Collaborators propose 3-4 educational conferences in rural regions of Missouri and the creation of a webinar.

AD and Dementia Education

- Since ROC programming began, the percentage of rural participants has ↑ from 8% to 18% of the Knight ADRC cohort. 258 participants are from rural zip codes.
- In the current grant cycle, 1,407 people were educated at rural community talks by Knight ADRC faculty or staff
- Highlight: *Project Learn More*
  - 2-year grant from the Missouri Administration on Aging
  - Partnered the Alzheimer's Association, statewide Area Agencies on Aging and the Veteran's Administration
  - Goal = administer the AD8 to identify individuals with cognitive impairment and guide them to seek medical diagnosis and supportive services

The AD8 Dementia Screening Interview

Remember, "Yes, a change" indicates that you think there has been a change in the last several years cause by cognitive (thinking and memory) problems	**YES**, A change	**NO**, No change	**N/A**, Don't know
Problems with judgment (e.g. problems making decisions, bad financial decisions, problems with thinking)			
Less interest in hobbies/activities			
Repeats the same things over and over (questions, stories, or statements)			
Trouble learning how to use a tool, appliance or gadget (e.g. VCR, computer, microwave, remote control)			
Forgets correct month or year			
Difficulty handling complicated financial affairs (e.g. balancing checkbook, income taxes, paying bills)			
Trouble remembering appointments			
Daily problems with thinking and/or memory			
TOTAL AD8 SCORE			

Adapted from Galvin JE et al, The AD8, a brief informant interview to detect dementia, Neurology 2005:65:559-564

Project Learn More

- Co-developer of the AD8, James Galvin, MD, PhD, (Knight ADRC, now NYU) was the lead consultant and trained the screeners.

- Results of Project Learn More:
  - Decreased depression & increased knowledge in people with dementia
  - Improved overall confidence and knowledge of caregivers
  - Increased likelihood that person with dementia would seek formal Dx and treatment.

MO State Plan Task Force

- The Missouri Alzheimer's State Plan Task Force was created in 2009 by the Missouri General Assembly. ADRC Director, Dr. John C. Morris, was a Task Force member.
- After 2 years of community engagement and evaluation, the Task Force submitted six formal recommendations to the governor and general assembly.
- In part due to *Project Learn More*, one of the recommendations was to increase use of the AD8 as an early screening tool.
- The ROC is working with the Alzheimer's Association, St. Louis Chapter, to pilot statewide AD8 trainings for clinicians and social support staff.

Road Map

- Healthy Brain Initiative, the Public Health Road Map for State and National Partnerships, 2013-2018 was published by the CDC and Alzheimer's Association.

- Two action items relevant to ROC:

1. Education to improve healthcare providers' ability to recognize early signs of dementia.

2. Education about validated cognitive assessment tools for use in physicians' offices, clinics, emergency rooms, and acute care hospitals' admission offices.

Next Steps

- ROC is partnering with the Alzheimer's Association to provide content & speakers for statewide events and a webinar. Content includes:
  - Dementia overview
  - Tools for early detection / training on the AD8
  - Next steps after screening tools flag someone as potentially demented.
- Content will be shared statewide with LPHA (local public health agencies-113 across the state, many in rural areas) and VA.
- CPP alumni are connecting us with forums in their towns for lay and professional education.

Overcoming Challenges

- Education, collaboration, persistence and community engagement have been strong tools, but barriers remain.
- Geography, transportation, lack of local supports, and more all provide challenges.
- How do other centers engage rural populations? How can we build and share successful models for outreach?

Acknowledgements

- Thank you to the faculty, staff, and participants of the Knight ADRC.
- Special Thanks to:
  - Jennifer Phillips, MPA, Education Core Coordinator
  - Myrtis Spencer, BA, Community Outreach Coordinator
  - John C. Morris, MD, Principal Investigator Knight ADRC
  - Krista Moulder, PhD, Associate Executive Director, Knight ADRC
  - Virginia Buckles, PhD, Executive Director, Knight ADRC
  - David Carr, MD, African American Outreach Core Leader
  - Tom Meuser, PhD, University of Missouri, Saint Louis
  - James Galvin, MD, PhD, New York University
  - Carroll Rodriguez and Stephanie Rohlfs-Young, Alzheimer's Association, St. Louis Chapter

Funding Source: P50AG005681.