African-American Research Recruitment and Brain Donation: Building a Community of Trust

Presented by:
Caitlin McGuire & Deborah Danner
University of Kentucky
Sanders-Brown Center on Aging and
Alzheimer's Disease Center

Growth of African American Normal Controls

- In 2005, only one African American had agreed to participate as a normal control through our satellite clinic.

2010	African-American Normal Controls	Number Agreeing to Brain Donation
Satellite clinic	36	17
ADC primary clinic	8	8
Total	44	25

- Two African American brain autopsies were completed in 2009.

Why was recruiting African Americans for research a problem?

- African Americans make up the largest minority group in KY at 7% of population. In Lexington African Americans are13.5% of the population.

- Few African Americans sought help through our research and diagnostic clinics.

- Local and national barriers were strong. ADC relationship based on trust and mutual respect was needed.

Why was recruiting African Americans for research a problem?

Focus groups allowed us to identify local barriers

- Cultural beliefs about AD
  - Considered memory loss a normal part of aging.
  - Strong respect for their elders and didn't want to insult them by suggesting they were suffering from a mental disease.
- African Americans were not informed about the importance of research and need for normal controls as participants.
- If they participate, they want to be active partners in studies.
  - Want to know what they are doing and why.
  - Want to feel respected for their contribution.
  - Want to be kept informed of results of research.

Churches must be included in education and outreach as they are a strong part of local culture.

What we did?

Formed a Partnership. We could not do it alone:

- In 2003, obtained funding from the Administration on Aging to begin to identify African Americans with AD and involve them with our ADC programs.
- Created a partnership with the Alzheimer's Association and the Commonwealth of Kentucky, and our ADC: **African-American Dementia Outreach Partnership (AADOP).**
- Using the resources of our partnership, began education about AD and importance of research.

Established a Satellite Clinic:

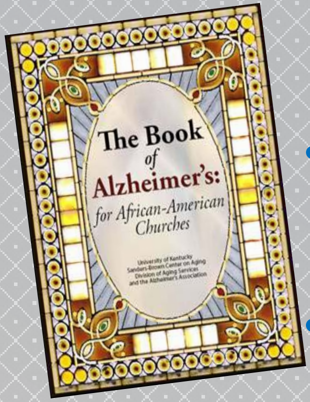
- Clinic was located in a predominately African-American community.
- Neuropsychological testing was completed in the home by an African-American nurse to keep clinic visits short and friendlier.
- Education materials were created and provided to families.
- Free memory screens were conducted with the goal of identifying African Americans early in the disease.

What we did?

Growing the partnership:

- Convened a Council of Ministers made up of six local ministers.
- Community Action Council of community leaders was formed.

Products of the partnership:



- Ministers requested a resource book for their church ministers: **The Book of Alzheimer's for African American Churches** was produced.
- A play, **Granny Pearl**, was written and performed by African-American adolescents and later filmed for distribution.
- Conferences were conducted to educate the community based on input from ministers. In 2008 the partner ministers asked for a conference on the importance of research participation and funded it!

Major outcome of partnership:

- Facilitated the development of trust.

What specific approach was used to recruit African-American normal controls?

- Replication of Gloria Bonner's University of Chicago study.
  - The tool used to recruit new normal controls consists of a face to face interview protocol completed by two study investigators that describes our Center and the individuals and the work at our Center.
- Dr. Bonner found that pairing brain autopsy requests with end of life information increased Chicago's brain donation from 2% to 32%.

*** The Bonner protocol would not have been successful without the established trust and rapport that had been established in the local community.

How were potential volunteers recruited and what was involved with the interview?

Community Registry Database:

- Used to identify African Americans age 65 and older.

Contact:

- Scripted telephone contact was made to schedule a time and place for the interview.
- Interviews were conducted in 2006 and again in 2010 with funding from ARRA.

Outcome:

- A total of 46 interviews were completed with 36 agreeing to yearly testing, 78% success rate and 17 of the 36 agreeing to brain autopsy (44%).

How were potential volunteers recruited and what was involved with the interview?

Interview consisted of three parts:

I. History of Center and information about AD

II. Familiarity with life-sustaining and end of life procedures (Mechanical Ventilation, Tube Feeding and Autopsy)

III. Attitudes about research participation

- Brain donation is not a requirement to be a normal control. Interviewer used rapport developed and responses related to autopsy to decide whether to ask for brain donation at interview. Caucasian participants in ADC clinics are all required to agree to brain donation.

What were the findings?

The following data are for the 46 who went through the interview protocol.

	Mechanical Ventilation	Tube Feeding	Autopsy
Were familiar with procedure	64.4% (n=29)	88.9% (n=40)	86.7% (n=39)

	Mechanical Ventilation	Tube Feeding	Autopsy
Agree to physicians recommendation	54.5% (n=24)	61.4% (n=27)	68.2% (n=30)

Why were participants interested in research?

	To help others	Increase scientific knowledge	Participation incentives	Other(combination of responses)
% n=46	30.8% (n=12)	7.7% (n=3)	5.1% (n=2)	56.4% (n=29)

Summary of qualitative findings and reoccurring themes:

- "Because you asked."
    - Have to find culturally sensitive ways to ask.
- "I would like to help African Americans with medical issues."
    - Understanding that research helps others, more specifically, their race
- "I'm having some trouble with my memory and I want help remembering things."
    - Want reassurance of their cognitive status as they age.

What relationships were found when data were examined?

- A significant moderate relationship was found between hypothetical consent for mechanical ventilation and consent to brain donation. (r=.40, p=.008, P=.017, Fisher's exact test)

- Moderate correlation between participant's knowledge of certain medical procedures frequently used to prolong life and willingness to donate one's brain.

What were the findings?

	Agreed to brain donation	Did not agree to brain donation	Not asked because of protocol	Wanted to discuss with family
% (n=46)	28.3% (n=13)	13.0% (n=6)	34.8% (n=16)	13.0% (n=6)

Summary of qualitative findings and reoccurring themes:

- “You can have this brain of mine, maybe you can learn something from it.”
- “My family had a bad experience with autopsy following my brother’s death.”
- “I don’t need it when I’m gone, but I need to discuss it with my son because he’s funny about things like that.”

Reasons for loss to follow-up?

	Withdrew from study	Deceased	Received non-normal diagnosis	Dropped because of exclusion criteria
% (n=46)	12.3% (n=7)	3.51% (n=2)	8.77% (n=5)	5.2% (n=3)

Trends in reasons for withdrawal:

- Health was poor at time of annual testing.
- Didn't like testing.
- Didn't want to be tested every year.

Have we met our goals?

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- 13.5% of Lexington’s population is African American, and 17% of participants in our clinics are African American. We have exceeded parity with local population.

- 56.8% of our African American normal controls have agreed to brain donation.

Retention -- How do we plan on keeping the 44?

- Planned focus group: Fall 2010 with six normal controls to find out what they would like us to do to keep them engaged.

Maintain current retention strategies

- ADC *newsletter*
- *Holiday Luncheon*
- *Birthday/sympathy cards*

Presenter Contact Info:

Deborah D. Danner
Caitlin McGuire
University of Kentucky
Sanders-Brown Center on Aging
African-American Dementia Outreach Partnership
800 South Limestone Street
Lexington, Kentucky 40536-0230
Telephone 859.257.1412 ext.230
Email dddann00@uky.edu
cmcgu2@uky.edu