

Boston University ADC Brain Donation Protocol for African Americans

Angela Jefferson
BU ADC Education Core

ADC Directors' Meeting
October 9, 2009



Participant Registry Overview

Brain Donation Status	Whites n=357	African Americans n=97
Yes	71	41
<i>Will Consider</i>	18	31
No	11	28



Focus Groups Methodology & Results



Focus Groups - Overview

The goal of the focus groups was to increase our understanding of the motives and barriers for Black elders' participation in our brain donation program

Using this information, we wanted to:

1. Improve brain donation program procedures to make them more culturally/racially relevant
2. Create culturally competent brain donation materials
3. Analyze focus group themes for publication



Community "Action" Council (CAC)

CAC membership:

- African American/Black community leaders
- Meet quarterly to advise BU ADC on outreach, recruitment, & retention strategies
- Provided input on focus group development and guidance for querying for program participation barriers – including race of facilitator



Mr. Alfred Davis (CAC Founding Member)
& Dr. Neil Kowall (ADC Director)



Focus Groups - Participants

- 2 groups in June 2008, 3rd group in August 2008 for material verification
- Female biracial facilitator
- 15 African American registry participants, 58-88 years old, 66% women
- 60% "frequent flyers"
- Focus group brain donation status:
 - 46.6% yes
 - 46.6% undecided, "will consider"
 - 13.3% no



Participants of 3rd Focus Group



Focus Group Themes

Racial Mistrust

- Culturally inappropriate care from White doctors and healthcare providers



Excerpts – Culturally Inappropriate Care

JH (refusal): [In] the medical community...we're not getting the same type of service that...other ethnic groups [are] receiving.

SP (refusal): What you need is to not just say that the study staff is available for questions, but you need to specify that there are ethnic people on the staff that they can talk to because...some people are not comfortable talking to Caucasians about something this personal. They want to talk to whatever their group is, whether [it] is Hispanic, Black, you know, Asian, whatever...because that person knows more about their culture and is more readily sensitive.



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- Personal accounts (e.g., poor healthcare) and historical accounts (e.g., Tuskegee) of discrimination



Excerpt – Historical Discrimination

SP (refusal): African Americans traditionally do not participate in research studies...and there are a lot of reasons for that, two of which are the Tuskegee institute...with the syphilis, and the women's sterilization program...and that has impacted so many people for so long that it's very difficult to get Black Americans to participate in research.



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Excerpts – Fear of Being “Taken Early

CY (will consider): I want the community to know what AD is about...but...any time Eric asks me...I am just like, whoa...it scares me to death...My uncle was a funeral director...and he told me not to give any of my organs because they will take you early...you might be in a car accident or something...unfortunately, that stays in my mind.

LP (yes): I don't like injections...and it's like, oh my God, they're gonna take some blood...are they going to kill me now?...and then I go home, and I said, it's really weird...how your brain thinks. I wonder if that needle was clean, and maybe they just put something in me to kill me and get this brain...and then I say, get a shake of yourself [L].



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Education

- Insufficient knowledge about *general benefits* of research as well as *specific benefits* to black community



Excerpt – Increase Education

CY (will consider): Instead of having...those games [neuropsychological tests] maybe having one session where we talk about the benefits of having donation of your brain, and what it would do for the African American...I do need that education. What are you going to do with it and how long is it going to take for the study to come to some kind of results?



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- Lack of involvement of family members regarding donation decision



Excerpts – Family Involvement

JC (yes): My study partner was appalled when I said, “Sure you can have it...I don’t need it anymore”...If it’s going to do someone else good, fine, take it, and she was really like some of the rest of you. I mean, she could not believe that I was agreeing to this.

CD (yes): My wife would have nothing to do with this. I really don’t know why...but she won’t have anything to do with [any part of] the brain donation.

SP (refusal): It’s...a cultural thing in my family. Nobody has ever donated organs...it’s just an invasion of sorts.

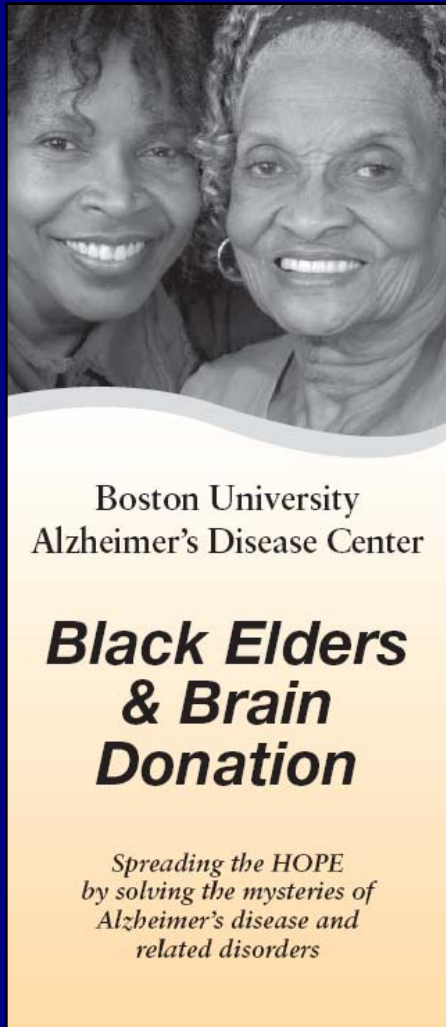
RR (yes): I told [my younger daughter] make sure if something happens to me, call the people up....I’ve sent her the card and told her to call the people.



Culturally Relevant Materials



African American Brain Donation Brochure



Brain donation program brochure was revised to be more culturally competent

Participants in third focus group provided input on:

- brochure color
- photographs, including different colored black faces and images of multi-generational families
- content and wording



Focus Group Suggestions for BU ADC



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1. Increase Black/African American representation among Clinical Core team (from staff to neurologists)
 - In past 16 months, we have hired 5 staff members from underrepresented ethnic/minority groups, including 4 African American women
 - All Black participants are seen by African American staff (Elana Cook, registry psychometrician)



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3. Make follow-up phone calls about brain donation (Elana Cook)
4. Facilitate educational discussions among registry participants about brain donation benefits to African American community
 - Converting "will considers" to "yes"



Next Steps

1. Analyze focus group themes for publication (in progress)
2. ADC ARRA Supplement Award (9/04/09-6/30/11)
 - 3 new employees: [Natalie Massenburg](#) (MPH candidate), [Susan Lambe, EdM](#) (PhD candidate), and [Fareesa Islam](#) (MPH candidate)
 - purpose is to advance brain donation program participation among African American registry participants
 - family education focus groups to be held between November-January
 - focus group content will shape development of new family-based protocol to be delivered over following 12 months



Acknowledgements

Funding Source

P30-AG013846 *Boston University Alzheimer's Disease Core Center (PI: Neil Kowall) & Education Core ARRA Supplement*

BU ADC Education Core Team

Nicole Cantwell
Kathy Horvath, PhD
Susan Lambe, EdM
Natalie Massenburg
Laura Byerly*
Vanessa Holley, MPH*
Monique Pimontel, MA*

BU ADC Clinical Core Staff

Eric Steinberg, MSN, RN, CS, CANP
Elana Cook
Angela Dwyer
Erin Whalen*

BU ADC Data Core Team

Chris Chaisson, MPH
Joseph Palmisano, MPH
Diane Dixon

Community Action Council Members

Focus Group Participants

*Contributor no longer with the Boston University ADC



Thank You

