

Educational intervention to improve brain donation assent rates among African American participants

Angela Jefferson
BU ADC Education Core

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Presentation Overview

1. Background leading to project development
2. Review of discussion intervention goals & protocol
3. Proposed intervention outcomes
4. Project status, preliminary outcomes, & next steps



Background



Focus Groups - Overview

2 focus groups held in June 2008 to increase our understanding of the motives/barriers for Black elders' participation in Center's brain donation program

3rd group held in August 2008 for learner verification of brain donation materials

n=15 ADC registry participants

Focus groups transcripts analyzed using Consensual Qualitative Research methods with 8 themes emerging



Participants of 3rd Focus Group

Lambe, Cantwell, Islam Horvath & Jefferson, 2010, The Gerontologist



2008 Focus Groups – Key Results

Nondonors or undecided participants commented that donation is too intrusive and expressed misconceptions about donation procedures

Racial mistrust related to African American human rights violations is a barrier to clinical research participation and brain donation

Disbelief that research will be used to benefit Black communities

Family perceptions of donation and family involvement in decision were cited as key, including possible resistance to decision

Participants suggested peer discussion groups would be helpful

Lambe, Cantwell, Islam Horvath & Jefferson, 2010, The Gerontologist



Education Intervention Protocol



Intervention – Goals

1. Increase participant knowledge about brain donation and improve attitudes about research participation
2. Improve research participation and brain donation assent rates among African American participants
3. Secondarily, enhance Center's presence in the African American community



Intervention Development

Initial protocol conceptualization included:

- Small group discussion format (4-8) with family members attending
- Content would address key themes from 2008 focus groups and emphasize benefits of research participation and brain donation

2 groups (n=10) held winter 2009 to assess guide content; discussion revised according to participant feedback:

- Additional information fundamentals (prevention, family hx) of AD added
- Family focus not feasible because many participants had no family in Boston area (protocol revised to include family/close friends whenever possible); Shaped into a peer discussion

Implementation launched in January 2010



Intervention - Discussion Guide Content

1. Past: Historical issues & medical research advances

- Acknowledge historical human right's violations to African American community and related ethical guideline reform
- General medical research advances (e.g., antibiotics for infectious diseases)



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2. Present: Current health concerns in African American community

- Discuss how research can lead to treatment advances for diseases that disproportionately affect the African American community (i.e., hypertension)



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- Discuss how research can lead to treatment advances for diseases that disproportionately affect the African American community (i.e., hypertension)

3. Future: Making a difference

- Discuss AD fundamentals (symptoms, risk factors, prevention, & treatment)
- Review why participants joined the registry & how that participation contributes to research
- Review ongoing BU ADC studies and ways to get involved
- Review rationale for donation program and personal/societal benefits for assenting to donation



Proposed Outcomes



Intervention – Proposed Outcomes

Short term

Pre-Discussion

*Group enrollment:
survey mailing*

- Brain Donation Knowledge
- Research Attitudes Questionnaire
- Trust in Medical Researchers
- Barriers to Participation in Medical Research

Post-Discussion

*2 weeks:
telephone call*

- Query for process elements of discussion
- Assess early change behaviors (e.g., speaking to family about donation)
- Interest in additional study participation
- Donation status change
- Referrals (family/friends) to Center's registry

Post-Discussion

*2 months:
survey mailing*

- Repeat Brain Donation Knowledge
- Repeat Research Attitudes Questionnaire
- Repeat Trust in Medical Researchers
- Repeat Barriers to Participation in Medical Research

Long term

Post-Discussion

*Annual visit &
Clinical Core
follow-up*

- Documentation of any donation status change at annual registry visit
- Over time, increase African American autopsy rate



Project Status & Preliminary Outcomes

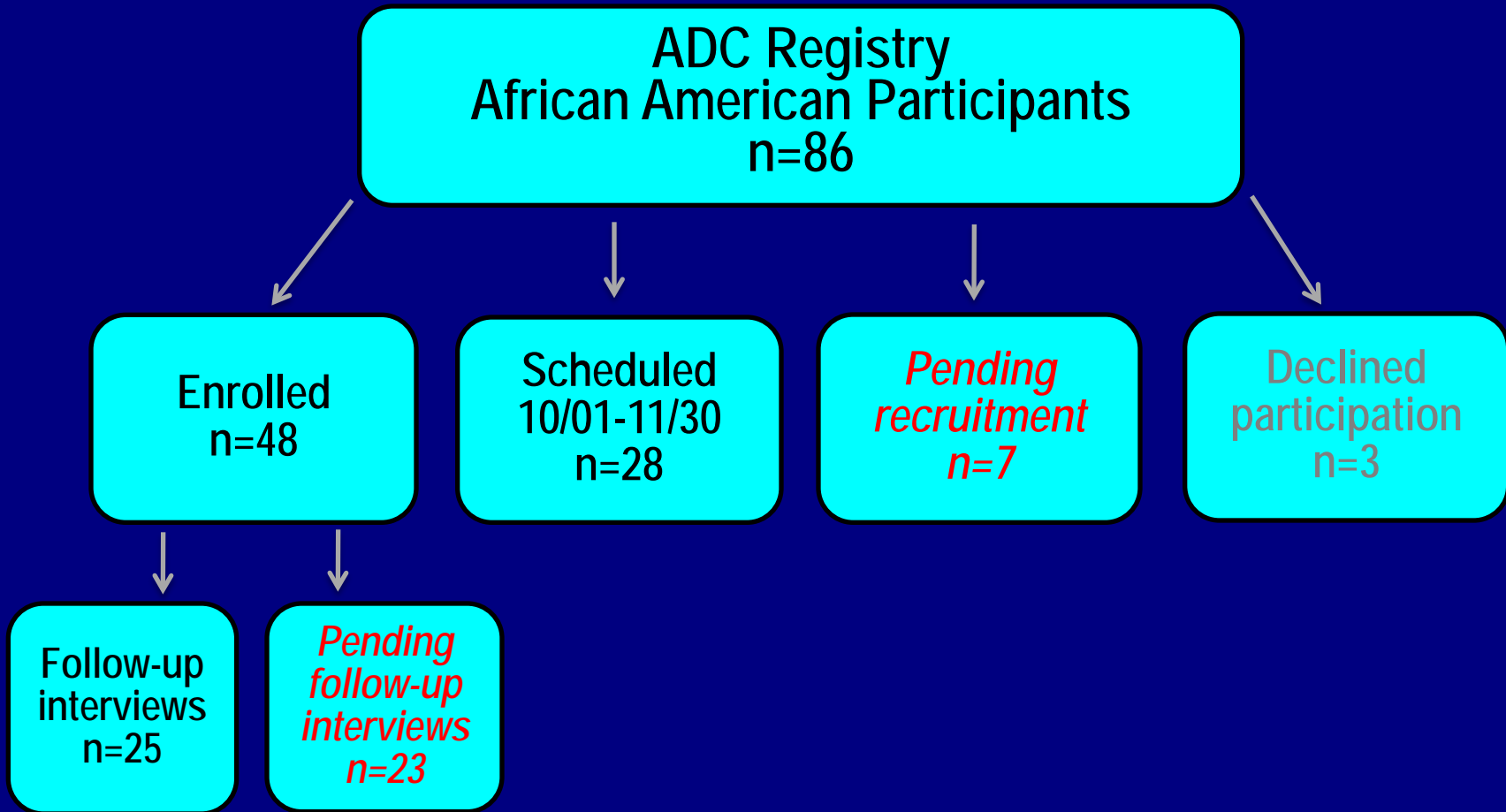


Active African American Registry Ptps

		n=86
Age, years		74±8
Sex, % female		78
Education, years		14±3
Registry participation, years		5±2
Diagnosis, % with dementia		15
Brain Donation Status	<i>Yes</i>	48
	<i>Will Consider</i>	32
	<i>No</i>	20



Project Status (as of 9/01/10)



Intervention - Preliminary Outcomes (Registry Participants)

Date**	Registry Attendees	Brain Donation Status Prior to Group			Interest in Donation Change	Referrals to Sponsored Studies	Presentation Requests
		Yes	WC	No			
1/28/10	6	4	2	0			
3/25/10	3	3	0	0			
4/08/10	6	2	2	2			
4/20/10	4	3	1	0			
5/13/10	3	2	1	0			
6/14/10	6	5	0	1			
Total	28	19	6	3			

***4 additional groups held between 7/01/10 and 8/31/10 with n=20 registry participant attendees; outcomes pending*



Intervention - Preliminary Outcomes (Registry Participants)

Date**	Registry Attendees	Brain Donation Status Prior to Group			Interest in Donation Change	Referrals to Sponsored Studies	Presentation Requests
		Yes	WC	No			
1/28/10	6	4	2	0	2 (100%)		
3/25/10	3	3	0	0	0		
4/08/10	6	2	2	2	1 (25%)		
4/20/10	4	3	1	0	0		
5/13/10	3	2	1	0	0		
6/14/10	6	5	0	1	0		
Total	28	19	6	3	3 (33%)		

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Intervention - Preliminary Outcomes (Registry Participants)

Date**	Registry Attendees	Brain Donation Status Prior to Group			Interest in Donation Change	Referrals to Sponsored Studies	Presentation Requests
		Yes	WC	No			
1/28/10	6	4	2	0	2 (100%)	2	
3/25/10	3	3	0	0	0	4	
4/08/10	6	2	2	2	1 (25%)	3	
4/20/10	4	3	1	0	0	1	
5/13/10	3	2	1	0	0	1	
6/14/10	6	5	0	1	0	0	
Total	28	19	6	3	3 (33%)	11 (39%)	

***4 additional groups held between 7/01/10 and 8/31/10 with n=20 registry participant attendees; outcomes pending*



Intervention - Preliminary Outcomes (Registry Participants)

Date**	Registry Attendees	Brain Donation Status Prior to Group			Interest in Donation Change	Referrals to Sponsored Studies	Presentation Requests
		Yes	WC	No			
1/28/10	6	4	2	0	2 (100%)	2	0
3/25/10	3	3	0	0	0	4	0
4/08/10	6	2	2	2	1 (25%)	3	1
4/20/10	4	3	1	0	0	1	2
5/13/10	3	2	1	0	0	1	0
6/14/10	6	5	0	1	0	0	1
Total	28	19	6	3	3 (33%)	11 (39%)	4 (14%)

***4 additional groups held between 7/01/10 and 8/31/10 with n=20 registry participant attendees; outcomes pending*



Intervention - Preliminary Outcomes (Family/Friend Attendees)

Date**	Family/Friend Attendees	Referral to ADC Registry
1/28/10	1	1
3/25/10	1	0
4/08/10	0	0
4/20/10	1	1
5/13/10	1	0
6/14/10	1	0
<i>Total</i>	5	2

***4 additional groups held between 7/01/10 and 8/31/10 with n=5 additional family or friend attendees; outcomes pending*



Next Steps

1. Complete recruitment and enrollment of n=35 remaining active participants (October-December)
2. Complete short-term outcome data collection, including pending follow-up calls & post-discussion survey collection
3. In conjunction with Clinical Core, follow participants to document long-term outcomes
4. Prepare manuscript summarizing short-term outcomes



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Thank you

