

Perceptions, Knowledge, Incentives, and Barriers of Brain Donation Among African American Elders Enrolled in an Alzheimer's Research Program

Susan Lambe, EdM,^{1,2} Nicole Cantwell, BA,¹ Faresa Islam, BA,¹ Kathy Horvath, PhD, RN,^{1,3} and Angela L. Jefferson, PhD*¹

¹Alzheimer's Disease Center and Department of Neurology, Boston University School of Medicine, Boston, Massachusetts.

²Department of Psychology, University of Massachusetts at Boston.

³Edith Nourse Rogers Memorial Veterans Hospital, Bedford, Massachusetts.

*Address correspondence to Angela L. Jefferson, PhD, Alzheimer's Disease Center, Boston University School of Medicine, Robinson Complex, Suite 7800, 72 East Concord Street, Boston, MA 02118-2526. E-mail: angelaj@bu.edu

Received March 22, 2010; Accepted July 9, 2010
Decision Editor: Nancy Schoenberg, PhD

Purpose: To learn about African American older adults' knowledge and perceptions of brain donation, factors that relate to participating or not participating in a brain donation research program, and methods to increase African American brain donation commitment rates in the context of an Alzheimer's disease (AD) research program. **Design and Methods:** African American older adults ($n = 15$) from the Boston University Alzheimer's Disease Core Center participant research registry enrolled in 1 of 2 focus groups of 90 min about brain donation. Seven participants were selected for a third follow-up focus group. **Results:** Focus group transcripts were analyzed using consensual qualitative research methods, and 8 overarching themes emerged: (a) perceptions of and misconceptions about brain donation procedures, (b) racial minorities in medical research, (c) racial disparities and discrimination in medical settings, (d) influence of religion and spirituality, (e) family perceptions of and involvement in donation, (f) family history of disease and desire to find a cure, (g) prior exposure to medical and research settings, and (h) culturally sensitive approaches to brain donation. **Implications:** Culturally relevant educational protocols need to be created for use with African American older adults. These protocols

should include information about brain donation procedures, rates of AD among Black elders, and potential benefits of donation to Black communities; inclusion of religious figures, family, and peers in donation education and decisions; and methods to address mistrust, including cultural competence trainings for staff.

Key Words: AD, Brain donation, African American, Racial disparity

Alzheimer's disease (AD) affects African American older adults at higher rates than their White counterparts (Froehlich, Bogardus, & Inouye, 2001), and AD is an increasingly significant concern for African American communities because its frequency is expected to double among Black individuals age 65 and older by 2030 (Plassman et al., 2007). (Please note: as part of the focus groups outlined in this article, we queried participants about whether they prefer for us to use the term "African American" or "Black." Participants did not come to a consensus about which term to use, primarily because many do not identify solely as African American due to their Caribbean or African heritages [e.g., some participants identify as Black, African,

and, as a result of being in the United States for an extended period of time, African American]. Participants suggested we use the terms interchangeably to represent Black and African American elders in our program, so we use these terms interchangeably here to respect our participants' requests.) Although differential rates of AD among Black and White elders have been attributed to genetic and environmental factors (Harris, 1998; Luchsinger et al., 2001), additional research is necessary to more fully understand the disparity.

In particular, neuropathological research is critical to advancing knowledge about AD because postmortem brain autopsy is the only definitive method to establish an AD diagnosis with important scientific and personal implications. First, clinicopathological comparisons enhance our ability to understand the clinical expression of AD and improve in vivo diagnostic markers. Second, direct examination of AD neuropathology contributes to the development and advancement of important treatment targets. Finally, because dementia is associated with hereditary risk factors, an AD diagnosis provides important family health information for surviving loved ones. However, compared with their White counterparts, African Americans are underrepresented in brain donation programs (Bonner, Darkwa, & Gorelick, 2000; Jefferson et al., in press).

Although a body of literature exists on racial disparities in organ donation and clinical research participation (Corbie-Smith, Thomas, & St. George, 2002; Minniefield, Yang, & Muti, 2001; Terrell, Moseley, Terrell, & Nickerson, 2004), there is limited research on brain donation research participation in general and among African Americans in particular. In a study by Bonner and colleagues (2000) on a brain donation recruitment program for African Americans, 133 patients and family caregiver pairs were interviewed to assess reasons for donation preferences and to identify interested donors. Results suggested that brain donation barriers include familial objections, concerns about funeral delays, fears of disfigurement, mistrust about the underlying rationale for conducting the autopsy, and negative responses to procedural elements. Our own recent work suggests that African American elders may be less familiar with certain aspects of brain donation, as they are more likely than their White peers to believe that most religions do not support donation (Jefferson et al., in press).

Research examining barriers to clinical research participation and organ donation consent may

elucidate why African Americans are underrepresented in brain donation programs. Such participation barriers include general societal mistrust (Freimuth et al., 2001), mistrust in health care institutions and physicians (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003; Freimuth et al., 2001; Minniefield et al., 2001), cultural mistrust (Corbie-Smith et al., 2002; Terrell et al., 2004), need for family support (Robbins, 2001), lack of awareness about donation needs and benefits (Callendar & Miles, 2001; Glasgow & Bello, 2007; Park, 1998), and religious myths (Hall et al., 1991). To increase organ donation program participation rates, researchers and medical staff must facilitate end-of-life discussions (McNamara et al., 1999) and ensure that next of kin are aware of their loved one's donation decision (S. E. Morgan, 2004). In addition, research on clinical research participation indicates that culturally sensitive strategies should be used with African Americans (Bonner & Miles, 1997).

To better understand reasons for underrepresentation of African Americans in brain donation research programs, the present study aimed to (a) assess African American older adults' knowledge about and perceptions of brain donation, (b) explore factors related to participating or not participating in a brain donation program, and (c) determine methods to increase African American brain donation rates.

Methods

Participants

Focus groups are a unique research method that promotes interaction among participants to gather information not only about what individuals think but also to learn about past experiences that have contributed to a perception or attitude about a particular topic (D. Morgan, 1997). Focus groups are useful with cultural subgroups, such as people of color, because they enable participants to dialogue with one another about sensitive topics using their own language (Kitzinger, 1995).

Black participants from the Boston University Alzheimer's Disease Core Center (BU ADCC) research registry were recruited to participate in a focus group study. The participant registry includes approximately 420 adults age 55 and older who agree to an annual memory evaluation. Twenty percent of the registry includes African American elders ($n = 84$). As part of their registry participation, these individuals are available for recruitment

into AD-related research studies sponsored by the BU ADCC, including a brain donation program. As part of the annual visit, participants are provided with a brochure and a fact sheet that cover the purpose of and procedures for brain donation. Participants are encouraged to contact research registry staff after their visit with follow-up questions or to enroll in the program.

For the focus group study, exclusion criteria included the presence of dementia to ensure that all participants were able to dialogue with the group leader and other participants about brain donation. Purposeful sampling techniques were used to recruit participants based on their brain donation status (D. Morgan, 1998) to ensure that all focus groups contained individuals representing each of the three donor perspectives (i.e., agree, do not agree, undecided). Fifteen focus group participants enrolled in one of two initial focus groups in June 2008 (Group 1 $n = 8$, Group 2 $n = 7$). Seven individuals returned to participate in a third and final focus group in August 2008, which served two purposes. First, it was an opportunity for participants to continue their discussions from the first two groups. Second, it served to validate a brain donation brochure created from information collected during the two earlier focus group meetings. The participants' common experience in the BU ADCC registry promoted a comfortable context for group interaction, and the size of each group allowed for rich discussion.

The groups were held in a conference room on the Boston University Medical Campus. Participants were compensated with \$25 gift cards and provided dinner and parking validation. Transportation was provided as needed ($n = 9$).

Procedures

The study was approved by the local Institutional Review Board. After reviewing the purpose of the study and obtaining consent, the group facilitator (Susan Lambe) positioned herself as a multiracial Asian American woman with research and clinical focuses on experiences of racism among racial/ethnic minorities. The focus group guide, which was strictly followed for Group 1 and Group 2, included open-ended questions related to participants' knowledge about brain donation procedures, perceptions of brain donation research, and factors functioning as barriers or incentives to their participation. Participants were queried about ways in which the Center could

increase African American participation in brain donation research and information that should be included in brain donation materials for African American participants. Prior to Group 3, the group facilitator and project director (Angela L. Jefferson) reviewed the audio recordings to extract aesthetic and content suggestions for a brain donation brochure for African Americans, which was validated in the final focus group using a modified version of the learner verification process (Doak, Doak, & Root, 1996). This modified process included querying about the clarity of content (i.e., comprehension), whether the information was relevant and influential (i.e., persuasion), selection of colors and pictures (i.e., attraction), and the cultural competence of the language used (i.e., cultural acceptability). During the final focus group, participants were also asked an open-ended question about whether they had any thoughts or reactions to brain donation after Group 1 and Group 2, which provided the opportunity to continue conversations from initial discussions.

Data Analysis

Following the focus group meetings, the recordings were transcribed verbatim, and the focus group facilitator reviewed the transcripts for accuracy. Although the purpose of the third focus group was to verify a brain donation print material, this focus group was included in the data analysis because participants provided additional information regarding knowledge and perceptions of, as well as barriers and incentives to, brain donation.

To qualitatively analyze the focus group data and uncover emergent themes, we used consensual qualitative research (CQR) strategies (Hill et al., 2005). CQR takes a predominantly constructivist philosophical perspective and includes elements from phenomenology (Giorgi, 1985), grounded theory (Strauss & Corbin, 1998), and comprehensive process analysis (Elliott, 1989). Prior to analysis, two research assistants were thoroughly trained in CQR methods, which included (a) reading assigned literature outlining the method and examples in which the method was employed (e.g., Hill et al., 2005; Sue, Bucci, Lin, Nadal, & Torino, 2007) and (b) formally discussing the philosophical underpinnings and key components of CQR with the group facilitator. Analysis required five steps. In the first analytical step, the two research assistants, who had not previously seen the focus group transcripts, independently coded the transcripts using

CQR methods. Consistent with standard analytical methods for focus groups (Krueger, 1993), each research assistant reviewed the interview transcripts and developed domains (i.e., major themes or topic areas used to cluster or group data, Hill et al., 2005) and then coded focus group discussions according to these domains. Next, the research assistants' domains and qualitative analyses were reviewed by the group facilitator, who provided written feedback on overlap and discrepancies (e.g., a domain identified by one research assistant but not by the other). In the third analytical step, the research assistants collectively came to a consensus on a final list of domains and extracted core ideas (i.e., clearly and concisely worded data summaries for each domain, Hill et al., 2005). Next, they recoded the focus group transcript data so their coding reflected the collectively agreed-upon domains and core ideas. The group facilitator served as an internal auditor (i.e., an individual who is very familiar with the project, Hill et al., 2005) by checking that data were categorized in the appropriate domain and that all critical data were represented in the core ideas. The group facilitator revised domain names and core ideas for conciseness, as needed. Finally, the project director served as a second internal auditor to ensure that language used to describe critical domains and core ideas accurately captured the raw data.

Results

Participant Characteristics

On average, participants were 71 ± 11 years of age (range 58–88 years) with 15 ± 3 years of education (range 9–19 years). Focus group members had participated in the BU ADCC research registry for 4 ± 2 years (range 1–8 years). The sample comprised 66% women and 100% African American individuals. Of the 15 participants, three had agreed to donate their brains, six had refused to donate their brains, and six were considering donation at the time the focus groups were conducted. See Table 1 for complete demographic information.

Focus Group Themes

Table 2 includes focus group themes, descriptions, and whether the themes were solicited (i.e., part of the discussion guide) or spontaneously mentioned by participants.

Table 1. Focus Group Participant Characteristics

	<i>n</i> = 15
Age, years	71 ± 11
Sex, % female	66
Race, % African American	100
Education, years	15 ± 3
Length in registry, years	4 ± 2
Brain donation status	
Yes	3 (20%)
No	6 (40%)
Will consider	6 (40%)

Note: Data presented as $M \pm SD$ or frequency.

Perceptions and Misconceptions of Brain and Organ Donation Procedures.—A perception of brain donation procedures, specifically among individuals who were nondonors or undecided, was that it is too intrusive. One nondonor stated: “I don’t want them cutting my head open and taking my brain out.” Another nondonor explained: “I don’t want a knife or whatever, going, I know I’ll be dead . . . I won’t feel anything, but just the thought of somebody cutting . . . probably shaving my head or something, and then cutting my brain” Participants felt the request for brain donation was demanding, particularly when the request was made after a lengthy annual registry visit. One undecided participant said: “I gave you enough, and now you want more?”

One misconception about brain donation is that only a piece of the brain will be removed for autopsy. One donor recalled telling her sister about her brain donation decision: “[She asked] ‘They want to take your brain?’ I said, ‘Tissue, not brain. Tissue. That’s a little piece of the brain’.” Although focus group donors did not change their donation status after learning that the entire brain is used in autopsy, participants did report being surprised. In addition, participants expressed confusion about why researchers need both demented and nondemented brains for comparison. A nondonor said: “they wouldn’t need my brain if mine was healthy.”

Racial Minorities in Medical Research.—Focus group participants discussed ways in which racial mistrust related to African American human rights violations has been a barrier to both clinical research and brain donation participation. For example, an undecided participant stated that “Elderlys have that . . . study that they did . . . the [Tuskegee Study] . . . they know about that, and

Table 2. Focus Groups Themes

Themes	Descriptions	Solicited or spontaneous ^a
Perceptions and misconceptions of brain and organ donation procedures	Perceptions that brain donation is too intrusive and misconceptions that donation requires only pieces of brain tissue instead of the entire brain	Solicited
Racial minorities in medical research	Historical instances of discrimination are a major barrier to brain donation participation	Solicited
Racial disparities and discrimination in medical settings	Racial discrimination in hospitals is a barrier to participation	Unsolicited
Influence of religion and spirituality	Religious and spiritual values inform donor decisions	Unsolicited
Family perceptions of and involvement in donation	Family resistance to donation is a barrier to participation, and family discussions are important to donor decisions	Unsolicited
Family history of AD and desire to find a cure	Family history of AD and desire to contribute to finding a cure as primary incentives for participating in a brain donation program	Solicited
Exposure to medical and research settings	Familiarity with medical and research settings contributes to comfort participating in a brain donation program	Unsolicited
Culturally sensitive approaches to brain donation	Participants called for increased staff diversity and culturally relevant methods for donor recruitment	Solicited

Note: AD = Alzheimer's disease.

^aSolicited = themes that emerged in response to queries included in the discussion protocol; spontaneous = themes that emerged without related queries from the focus group facilitator.

what happened to those men. So that's always in the back of their head." A nondonor explained:

. . . African Americans traditionally do not participate in research studies, in research programs, and there are a lot of reasons for that, two of which are the Tuskegee institute men's program with the syphilis, and the women's sterilization program that they had in Alabama, and that impacted so many people for so long that it's very difficult to get Black Americans to participate in research studies because their foremost feeling is that they are guinea pigs and not being treated as a human research study participant.

Other participants stated that mistrust is related to disbelief that research will be used to benefit Black communities. One donor explained:

Yeah, I don't think it's that Black people don't want to take part of the study. I think [it's unclear that research is] really going to . . . help African Americans. It's going to help somebody else, another race besides . . . African Americans.

Participants also commented that, although they are aware of human rights violations against African Americans, participation among people of color is still critical. For example, a donor said:

Yes. Of course I'm aware of the negative . . . indications that were made here, I'm well aware of that. But my feeling has been that . . . things have

changed . . . We can learn from the past, but . . . we have to go on beyond the past and take advantage of what's happening in the present, and shape the future with that. That's my feeling about that, that we should go on, and things are going well in those areas as far as race relations are concerned and . . . the full participation of Black people and Asians and other minorities, so called other minorities.

Racial Disparities and Discrimination in Medical Settings.—Personal examples of racism within medical settings were interspersed with the discussion related to African Americans in clinical research. One donor stated: "I find that Black Americans do not get good healthcare, like other races . . . receive healthcare." Participants spoke at length about racial disparities within the local area and the need for reform. For example, a nondonor explained:

Well, that's that healthcare disparity that's just rampant in Boston. It is rampant in the whole medical system. They've had more commissions from the mayor's office come down . . . 'cause I've been on them. They've had more commissions about the healthcare disparity, but then that's where it ends. It needs to go further than that. They need to take these doctors and re-educate them into how to be human again, how to treat patients as patients.

Further, participants provided examples in which they have needed to advocate for themselves or their loved ones to receive adequate and culturally relevant care. One undecided participant discussed his family's experiences in the health care system:

[My father] had a doctor for a long time and, he used to always talk about his kids, and he would bring the doctor things you know, and then when he started to get sick, my sister went in there, and she was talking to the man, and she said I don't like the way that doctor talks . . . so she said, 'I'm going to find a Black doctor for him, then he'll understand.' So she found a Black doctor, and after that, things were different.

Another nondonor stated:

. . . they approach me differently than they do they do the Caucasians. Then they approach me in a manner that's suitable for the Caucasians but that doesn't work for me, and I have to constantly get in there and fight and fight and fight. And I'm telling them, 'Okay what you're telling me is not working for me. You need to come up with something that's working for me.' And I really need to talk to someone that's of my own ethnic background who will understand what it is I'm saying . . .

In addition to racial discrimination, participants spoke about age discrimination. For instance, a donor stated:

. . . I've told all my friends that are my age that if you go to the hospital, make sure that you bring one of your grandchildren, or your children, or something. Do not go to a hospital by yourself. If you go to a hospital by yourself and see a doctor, they act like you don't exist if you are old . . . They tell you things like you're a child. You're not the grown up. They're the grown up, you're the child, and it's dissenting [*sic*] because I've had my friends call me up and tell me that. I said, 'Didn't I tell you to take one . . . of your grandchildren or your children with you when you go to the hospital? Never go on an appointment by yourself. If you have to miss your appointment, don't go by yourself.'

Influence of Religion and Spirituality.—Participants spontaneously spoke about the influence of religion and spirituality on their donation decision. A nondonor mentioned a personal desire to remain intact: “. . . I came in this world with a . . . brain, I'd kinda want to leave with one.” Other participants spoke about the lack of support from churches for donation and African Americans'

desire to be buried intact. One nondonor suggested church involvement as a means to increase donation rates: “. . . really, you have to get to the churches and community groups and just talk about research that's been done in other areas, like they've discovered that Blacks have more hypertension than Caucasians do . . .” A nondonor stated: “African American persons are also more likely to believe in the importance of being buried intact . . . the Black church does not necessarily . . . advocate organ donations.” One donor stated that religious beliefs would not prevent him from donating because while his body will be buried, his spirit would be with the Lord.

Family Perceptions of and Involvement in Donation.—Focus groups included spontaneous discussions about the importance of getting families involved in donor decisions to provide input about the decision or ensure donor wishes are carried through. One participant, who was undecided about his donation decision, stated: “One thing that I haven't done that I think I would like to do, I have been asked each year if I wanted to donate, and I haven't mentioned this to my children yet. So I think I would just like to run this by them, not that it's going to ultimately affect my decision, but it would be interesting to see what they think . . .” Other participants noted that they have met, or anticipate meeting, resistance from their families and loved ones about their decision or potential decision to donate. A donor recalled: “My study partner was appalled when I said, 'Sure you can have it' . . . I mean, she could not believe that I was agreeing to this.”

Even when queried, participants were generally unsure why their family members experience negative reactions to brain donation. One donor postulated that brain donation might feel like an intrusion during a sensitive time or prevent a timely burial or open casket funeral. Other donors described their loved one's resistance and their responses, which included statements like: “Look. I'm already dead. I am going to be cremated. That's what I believe . . . so it's okay.”

Family History of Disease and Desire to Find a Cure.—Participants cited a family history of AD as the primary reason that they participate in AD research, including brain donation, as they have witnessed the disease progression and wish to contribute to prevention and cures to reduce the likelihood

that they or other family members will be affected by AD. Two different donors spoke about witnessing family members decline from AD:

. . . [my father-in-law] was an outstanding insurance executive—as I witnessed his gradual deterioration from Alzheimer’s . . . that has made an indelible impression on me. That fine mind went and finally he got to the point where he was unconscious and had to be fed like a baby. I . . . would do anything I could to help . . . to further the discovery of . . . either a cure or . . . arresting or curbing of the disease or anything that would help in the . . . study of Alzheimer’s that we need to [obtain] some relief from. And of course, the ultimate would be to find a cure for it.

Well . . . I had my father as an example of what Alzheimer’s . . . could do to a person. The last three years of his life, he didn’t know anything. He didn’t know where he was, so I wanted . . . to get some information on that so that’s why I joined . . . they talk about the brain having so many tangles . . . so that the person gets Alzheimer’s . . . and . . . the only way they can look at the brain is after a person dies and . . . they look at it that way. So, I said, well, I guess . . . this will be a good way to find out how it, how it works.

One undecided participant considered the benefit of brain donation to future generations of her family: “. . . if it’s [going to] benefit my children, my grandchildren, or my great grandchildren after I leave this earth, then . . . maybe I will participate.” Generally, nondonors felt as though their contribution to the ADCC registry study was enough, given their hesitations about brain donation: “I personally feel that getting involved in volunteer programs . . . [is] the . . . alternative for me to not get into organ donation because I feel I’m doing my part.”

Exposure to Medical and Research Settings.—Participants from both focus groups spontaneously spoke about the impact of medical and research setting exposure on their perceptions of research. Participants who worked in medical settings (e.g., as nurses) described comfort in these settings, which increased their willingness to participate in clinical research, including the BU ADCC brain donation program. One undecided participant explained: “Now a number of people in my family are from a medical background . . . and I’ve always as, even as a youngster, been comfortable around medical people.” A donor stated: “In our family, our kids grew up with my wife as

being the medical person, and of course, I had some medical background . . . so in our family we’ve always had a positive feeling toward teaching hospitals and medical research.”

Culturally Sensitive Approaches to Brain Donation.—In an effort to increase the BU ADCC brain donation program participation rates, the facilitator inquired about ways study staff can approach African Americans about brain donation and effective ways to relay information about donation to Black elders. Participants called on the Center to increase its racial/ethnic minority representation among staff. A nondonor responded: “I think it’s important to find someone you can relate to and often times that’s based on one’s ethnic background.” Similarly, a donor said:

. . . 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 personal. They want to talk to whatever their group is . . . because that person knows more about their culture and is more readily sensitive.

In addition, one undecided participant suggested that the Center increase opportunities for Black peer discussion: “. . . it is your peers that you listen to the most, more than hospital staff and skilled people . . .”

In terms of improving the dissemination of brain donation information, participants called for increased details related to how research in general, and brain donation in particular, can contribute to Black communities and future generations. A donor stated: “. . . just informing people about information that has already been gained that has helped Blacks about other research that’s been done . . . and from the brain we might learn even more.” An undecided participant explained: “. . . if we were assured that it would benefit the African American people . . . I think maybe more would be willing . . . to do this.”

Discussion

The present study was designed to provide a detailed, qualitative examination of African American elders’ knowledge of brain donation and identify incentives and barriers to participation in a brain donation program. Findings suggest there are some important knowledge gaps. First, participants were generally unaware of the need to compare

brains of demented and nondemented individuals with advance research, which supports our recent survey research in a larger cohort of African American elders (Jefferson et al., in press). A unique knowledge gap that we discovered was that participants believed only a piece of brain tissue, and not the entire brain, is required for donation. This misconception may be related to our Center staff's prior description of the brain donation program as a "brain tissue donation" program. The third knowledge gap that we discovered was that participants reported a lack of awareness of how research can benefit African American communities, which likely contributes to disproportionately lower rates of brain donation among Black elders.

As expected, we also uncovered a number of barriers to participation in the Center's brain donation program, some of which are consistent with prior literature on organ donation or autopsy. In particular, nondonors and undecided participants reported that brain donation is too intrusive, and a request for donation feels demanding, especially after a lengthy (i.e., 4 h) registry study visit. Prior work supports this barrier, as African Americans often refuse autopsy due to negative feelings about the surgical procedure (Bonner et al., 2000).

Another barrier to brain donation participation that we identified was racial mistrust due to historical human rights violations. This barrier is not surprising as prior work has reported that mistrust is a critical barrier to African American brain (Bonner et al., 2000) and organ donation (Minniefield et al., 2001). Participants reported that this barrier accounts in large part for African American underrepresentation in brain donation programs. Participants across all brain donation statuses (i.e., yes, will consider, no) cited the Tuskegee Syphilis Study, in particular, as contributing to African American mistrust of researchers. However, a unique finding of the current study is that some participants reported a desire to overcome mistrust as an "incentive" to participation in research and our brain donation program. In addition to historical episodes of discrimination, participants reported personal experiences with race and age discrimination in health care settings that have contributed to mistrust of research, including brain donation.

Religion and spirituality were also associated with African Americans' donation decisions, including a desire to be buried intact and the belief that churches in Black communities do not support organ donation. This latter finding is supported by our recent survey data in which African

Americans were more likely than White participants to incorrectly report that most religions do not support brain donation (Jefferson et al., in press). Other prior research suggests that African American elders want to understand how their church views donation before making a decision, more so than their White peers (Connell, Avey, & Holmes, 1994). Among a predominantly White sample, prior research has suggested that organ donation agreement is more likely when individuals believe their religious leader will support their decision (Skowronski, 1997). Future studies should assess whether African Americans believe their religious institutions and leaders support brain donation to better understand how these factors relate to donation decisions.

Familial influence was the last major barrier reported to be associated with brain donation program participation. Participants described experiencing, or believing they would experience, resistance from their families if they committed to brain donation. Most participants, however, had not yet discussed the donation opportunity or their donation decision with their loved ones. Possible family objection is not a surprising barrier, as prior organ donation research suggests that individuals may be hesitant to speak with their families about their donation decisions (S. E. Morgan, 2004) because they anticipate having to defend these decisions (Afifi et al., 2006). Autopsy research among African Americans indicates that family member agreement is critical in the decision to donate (Bonner et al., 2000), particularly because donation wishes often require family follow through. Therefore, supportive families may be an incentive to organ donation, as African Americans who have spoken with their families about donation are more likely to have also signed an organ donor card than those African Americans who have not spoken with their families (S. E. Morgan, 2004).

The primary incentive for participating in our brain donation program was the possibility of family benefit. Specifically, family history of AD was cited as the primary reason for participating in both AD research in general and our brain donation program in particular. Donors and undecided participants expressed an interest in contributing to finding a cure for AD, especially after the personal experience of watching a loved one decline from the disease. Consistent with the autopsy literature (Bonner et al., 2000; Connell et al., 1994), participants stated also that brain donation may

help prevent future family generations from being affected by AD. Previous research indicates that because of concerns related to the heritability of AD, individuals are particularly motivated to donate if it might benefit their children and grandchildren (Connell et al., 1994). Finally, a unique incentive identified in the current study was that past exposure to medical research settings contributes to trust and willingness to donate one's brain.

Based on the aforementioned knowledge gaps and barriers and incentives to donation, our participants offered three recommendations to increasing African American representation in the Center's brain donation program. First, they advocated for an increase in racially and ethnically diverse staff with whom participants can relate and discuss the sensitive issue of donation. Second, because the opportunity to share views and experiences among peers might be more influential in donation decisions than one-on-one conversations initiated by study staff, they suggested peer discussion groups be held. Finally, they recommended promoting awareness both among Center participants and among community leaders (e.g., religious leaders) about ways in which brain donation research will directly benefit African American communities.

The present findings, taken together with our previous research (Jefferson et al., in press), suggest that brain donation programs would benefit from the development and implementation of culturally relevant educational protocols for use with African American participants. We propose the inclusion of several key elements for such educational protocols as well as details on how our Center has begun implementing these elements into our own recruitment practices. First, information about procedural elements should be covered, including the fact that the entire brain is required for donation and the procedure will not delay or alter traditional funeral arrangements. To ensure that all participants receive consistent, accurate information, we have implemented a staff/faculty training session in which the neuro-pathologist directing our Center's Brain Bank covers brain donation procedures, including extraction details, tissue processing methods, and family feedback practices. Our second recommendation is that discussions include the fact that most religions support donation, and religious leaders should be incorporated in brain donation education programs whenever possible. Third, information on how brain donation specifically benefits Black communities should be covered.

Locally, our brain donation discussion protocol has been augmented to include details about clinical research progress for treating hypertension among African Americans, who are at higher risk for this disease than their White counterparts (e.g., Schmidlin, Forman, Sebastian, & Morris, 2007). Fourth, family members should be invited to participate in the brain donation conversation, something that organ donation programs have previously emphasized for donation decision making (Guadagnoli et al., 1999). These conversations are not only critical to formulating an individual's initial donation decision but also vital to increasing family members' follow-through on their loved one's donation decision at the time of death (Afifi et al., 2006). Finally, protocols must address mistrust related to historical and current experiences of discrimination within research and health care settings. African American brain donation requests are known to be more successful when culturally relevant approaches are employed (Bonner et al., 2000), including discussions of the Tuskegee Syphilis Study (Brandt, 1978; Schuman, Olansky, Rivers, Smith, & Rambo, 1955). Locally, we have formally presented transcript excerpts from the current study that reflect racial disparities and discrimination in medical settings along with cultural mistrust in an effort to familiarize our research team with barriers to brain donation among African American participants and highlight the need for culturally relevant discussions with participants.

Conversations related to racial mistrust, however, may be uncomfortable for staff who have not been trained in appropriate methods for approaching African American patients or participants about health care disparities, racial discrimination, and human rights violations. To address this barrier, we have hosted a cultural competence training aimed at increasing staff comfort facilitating race-related discussions and providing strategies to acknowledge and provide opportunities to discuss issues related to mistrust. Furthermore, our Center has hired additional racial and ethnic minority staff, per participants' requests, and appointed an African American woman as the brain donation liaison for all African American participants. In conjunction with cultural competence trainings, staff may benefit from training related to discussing brain donation more generally, as donation is a potentially uncomfortable topic of discussion for study staff, participants, and their families (Siminoff, Burant, & Ibrahim, 2006).

The present study is among the first to narrow the knowledge gap about brain donation program participation among African American elders by extending prior work in several ways (Bonner et al., 2000; Jefferson et al., in press). First, several aspects of the brain donation process need to be emphasized when recruiting individuals from any racial/ethnic group into a donation program, and those programs recruiting African American participants should provide information about how brain donation benefits the Black community. Second, racial mistrust and family objections, which are factors influencing organ donation and clinical research participation among African Americans (Afifi et al., 2006; Minniefield et al., 2001; S. E. Morgan, 2004), function as barriers to brain donation. Third, consistent with the autopsy literature (Bonner et al., 1997; Connell et al., 1994), the potential to benefit younger family members through participation in brain donation research was cited as the primary incentive to participation.

Although this study has a number of strengths, several factors associated with the generalizability of our sample should be considered when interpreting our findings. First, due to the relatively small sample size and few focus groups held, findings may have limited generalizability to a larger population of African American older adults. Second, African American participants in our registry were purposefully and not randomly selected to participate in this study, so it is possible that extremely motivated participants, with unusually high levels of comfort in research settings, attended the focus groups. Third, our focus group participants, who are existing members of a large research registry, are likely savvier about the importance of research than the average prospective brain donor not enrolled in a clinical research program who may be more likely to have misconceptions and misinformation about brain donation. Also, all participants were free of dementia, so we did not gather information about ways to recruit African Americans with AD via family members or health care proxies (Bonner et al., 2000).

There are several important areas of inquiry for future research. Additional studies are needed to clarify the role of religious and spiritual values in Black older adults' decisions to donate or not donate one's brain. Researchers should explore the ways in which peer education may provide opportunities for African American elders to overcome barriers to brain donation program participation. Research related to the perceptions of and attitudes about

donation among donor's family members should also be examined, particularly because loved ones are responsible for carrying out donor decisions postmortem. Finally, similar to Bonner and colleagues (2000), culturally relevant brain donation educational interventions should be created and evaluated for use with Black older adults and their families.

Funding

Paul B. Beeson Career Development Award in Aging (K23-AG030962 to A.L.J.); BU ADCC (P30-AG013846); Boston University Medical Center General Clinical Research Unit (UL1-RR025771); U.S. Department of Veterans Affairs, New England Geriatric Research, Education, and Clinical Center.

Acknowledgment

The authors would like to thank the focus group participants who made this research possible.

References

- Afifi, W. A., Morgan, S. E., Stephenson, M. T., Morse, C. R., Harrison, T., Reichert, T., et al. (2006). Examining the decision to talk with family about organ donation: Applying the theory of motivated information management. *Communication Monographs*, 73, 188–215.
- Bonner, G. J., Darkwa, O. K., & Gorelick, P. B. (2000). Autopsy recruitment program for African Americans. *Alzheimer Disease and Associated Disorders*, 14, 202–208.
- Bonner, G. J., & Miles, T. P. (1997). Participation of African Americans in clinical research. *Neuroepidemiology*, 16, 281–284.
- Boulware, L. E., Cooper, L. A., Ratner, L. E., LaVeist, T. A., & Powe, N. R. (2003). Race and trust in the health care system. *Public Health Report*, 118, 358–365.
- Brandt, A. M. (1978). Racism and research: The case of the Tuskegee Syphilis Study. *Hastings Center Report*, 8, 21–29.
- Callendar, C., & Miles, V. (2001). Obstacles to organ donation in ethnic minorities. *Pediatric Transplantation*, 5, 383–385.
- Connell, C. M., Avey, H., & Holmes, S. B. (1994). Attitudes about autopsy: Implications for educational interventions. *Gerontologist*, 34, 665–673.
- Corbie-Smith, G., Thomas, S. B., & St. George, D. M. (2002). Distrust, race, and research. *Archives of Internal Medicine*, 162, 2458–2463.
- Doak, C. C., Doak, L. G., & Root, J. H. (1996). *Teaching patients with low literacy skills*. Philadelphia: J.B. Lippincott Company.
- Elliott, R. (1989). Comprehensive process analysis: Understanding the change process in significant therapy events. In M. J. Packer, & R. B. Addison (Eds.), *Entering the circle: Hermeneutic investigations in psychology* (pp. 165–184). Albany, NY: SUNY Press.
- Freimuth, V. S., Quinn, S. C., Thomas, S. B., Cole, G., Zook, E., & Duncan, T. (2001). African Americans' views on research and the Tuskegee syphilis study. *Social Science & Medicine*, 52, 797–808.
- Froehlich, T. E., Bogardus, S. T., Jr., & Inouye, S. K. (2001). Dementia and race: Are there differences between African Americans and Caucasians? *Journal of the American Geriatrics Society*, 49, 477–484.
- Giorgi, A. (1985). Sketch of a psychological phenomenological method. In A. Giorgi (Ed.), *Phenomenology and psychological research* (pp. 8–22). Pittsburgh, PA: Duquesne University Press.
- Glasgow, M. E., & Bello, G. (2007). Bone marrow donation: Factors influencing intentions in African Americans. *Oncology Nursing Forum*, 34, 369–377.
- Guadagnoli, E., Christiansen, C. L., DeJong, W., McNamara, P., Beasley, C., Christiansen, E., et al. (1999). The public's willingness to discuss their preference for organ donation with family members. *Clinical Transplantation*, 13, 342–348.
- Hall, L. E., Callender, C. O., Yeager, C. L., Barber, J. B., Jr., Dunston, G. M., & Pinn-Wiggins, V. W. (1991). Organ donation in blacks: The next frontier. *Transplantation Proceedings*, 23, 2500–2504.
- Harris, M. I. (1998). Diabetes in America: Epidemiology and scope of the problem. *Diabetes Care*, 21(Suppl. 3), C11–C14.

- Hill, C., Knox, S., Thompson, B., Williams, E., Hess, S., & Ladany, N. (2005). Consensual qualitative research: An update. *Journal of Counseling Psychology, 52*, 196–205.
- Jefferson, A. L., Lambe, S., Cook, E., Pimontel, M., Palmisano, J., & Chaisson, C. (in press). Factors associated with African American and White elders' participation in a brain donation program. *Alzheimer's Disease and Associated Disorders*.
- Kitzinger, J. (1995). Qualitative research: Introducing focus groups. *British Medical Journal, 311*, 299–302.
- Krueger, K. (1993). Quality control in focus group research. In D. Morgan (Ed.), *Successful focus groups: Advancing the state of the art* (pp. 65–85). Newbury Park, CA: Sage Publications.
- Luchsinger, J. A., Tang, M. X., Stern, Y., Shea, S., & Mayeux, R. (2001). Diabetes mellitus and risk of Alzheimer's disease and dementia with stroke in a multiethnic cohort. *American Journal of Epidemiology, 154*, 635–641.
- McNamara, P., Guadagnoli, E., Evanisko, M., Beasley, C., Santiago-Delpin, E., Callender, C., et al. (1999). Correlates of support for organ donation among three ethnic groups. *Clinical Transplantation, 13*, 45–50.
- Minniefield, W. J., Yang, J., & Muti, P. (2001). Differences in attitudes toward organ donation among African Americans and whites in the United States. *Journal of the National Medical Association, 93*, 372–379.
- Morgan, D. (1997). *Focus groups as qualitative research* (2nd ed.). London: Sage.
- Morgan, D. (1998). Planning focus groups. In D. Morgan, & K. Krueger (Eds.), *The focus group kit* (Vol. 2). London: Sage Publications.
- Morgan, S. E. (2004). The power of talk: African Americans' communication with family members about organ donation and its impact on the willingness to donate organs. *Journal of Social and Personal Relationships, 21*, 112.
- Park, M. A. (1998). A statewide assessment of attitudes, beliefs, and behaviors among blacks toward donation. *Journal of Transplant Coordination, 8*, 25–29.
- Plassman, B. L., Langa, K. M., Fisher, G. G., Heeringa, S. G., Weir, D. R., Ofstedal, M. B., et al. (2007). Prevalence of dementia in the United States: The aging, demographics, and memory study. *Neuroepidemiology, 29*, 125–132.
- Robbins, M. (2001). Assessing family members' motivational readiness and decision making for consenting to cadaveric organ donation. *Journal of Health Psychology, 6*, 523–535.
- Schmidlin, O., Forman, A., Sebastian, A., & Morris, R. C., Jr. (2007). Sodium-selective salt sensitivity: Its occurrence in blacks. *Hypertension, 50*, 1085–1092.
- Schuman, S. H., Olansky, S., Rivers, E., Smith, C. A., & Rambo, D. S. (1955). Untreated syphilis in the male negro; background and current status of patients in the Tuskegee study. *Journal of Chronic Diseases, 2*, 543–558.
- Siminoff, L. A., Burant, C. J., & Ibrahim, S. A. (2006). Racial disparities in preferences and perceptions regarding organ donation. *Journal of General Internal Medicine, 21*, 995–1000.
- Skowronski, J. J. (1997). On the psychology of organ donation: Attitudinal and situational factors related to the willingness to be an organ donor. *Basic and Applied Social Psychology, 19*, 427–456.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Grounded theory procedures and techniques* (2nd ed.). Thousand Oaks, CA: Sage.
- Sue, D. W., Bucceri, J., Lin, A. I., Nadal, K. L., & Torino, G. C. (2007). Racial microaggressions and the Asian American experience. *Cultural Diversity and Ethnic Minority Psychology, 13*, 72–81.
- Terrell, F., Moseley, K. L., Terrell, A. S., & Nickerson, K. J. (2004). The relationship between motivation to volunteer, gender, cultural mistrust, and willingness to donate organs among Blacks. *Journal of National Medical Association, 96*, 53–60.