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Research Article

Will My Soul Go to Heaven If They Take My Brain? Beliefs and Worries About Brain Donation Among Four Ethnic Groups

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Abstract

Purpose of the Study: Studying the brain through autopsy is an essential component of Alzheimer's disease research. Racial and ethnic minorities are underrepresented in Alzheimer's research generally and, in particular, in the number of completed brain autopsies. We explored beliefs about and attitudes toward brain donation among African American, Chinese, Caucasian, and Latino research subjects and their family members through focus groups at 4 NIH-funded Alzheimer's Disease Centers.

Design and Methods: Eighteen focus groups were conducted with 61 research subjects and 34 family members. Because the primary purpose of the focus groups was to identify the range of considerations that may influence the decision to participate in brain donation, data from focus groups were pooled and then analyzed.

Results: We found that many of the concerns, attitudes, and beliefs about brain donation were similar across the 4 ethnic groups. Concerns and attitudes fell into 3 categories: (a) concerns and misconceptions about brain research and the process of brain removal, (b) religious beliefs, and (c) the role of the family.

Implications: Our findings suggest that interventions to enhance enrollment in brain donation that target factors identified in this study are likely to be relevant to people from a broad range of backgrounds and ethnicities. Nonetheless, we observed some potential differences among racial/ethnic groups that may affect how research volunteers and their families approach a decision about donating their brain for research. Further study is warranted to explore these and other possible culturally distinct attitudes and beliefs about brain donation.

Key words: Qualitative analysis: Content analysis, Focus groups, Diversity and ethnicity, Dementia, Brain donation

Studying the brain is an essential component of Alzheimer's disease research (Kaye, Dame, Lehman, & Sexton, 1999). At the 27 NIH-funded Alzheimer's Disease Centers (ADCs) in the United States, many of the research studies rely on neuropathological data that are correlated with clinical data collected on research subjects for months, often

years. In recent years, there has been increasing emphasis on including persons from diverse ethnic groups in study cohorts to address the historic lack of knowledge about how race and other cultural characteristics interplay with genetic, behavioral, social, and environmental factors to affect the prevalence and trajectory of Alzheimer's disease

and other dementias (Kaye et al., 1999). Although many researchers have developed effective strategies and programs to recruit persons from diverse ethnic groups to participate in research, minorities are still underrepresented. Additionally, among minority research participants lower rates of agreement for brain autopsy persist. For example, across NIH-funded ADCs, the cumulative proportion of white deceased research participants whose brains were autopsied was 60% compared with 47% of Hispanic subjects, 24% of African American or black subjects, and 15% of Asian subjects (Morris, Cairns, & Taylor-Reinwald, 2014).

Most research on brain donation among minorities has focused on African Americans. In a study of African Americans, Bonner, Darkwa, and Gorelick (2000) identified lack of understanding of the rationale for brain autopsy, fear of mutilation from the surgical procedure used for brain removal, and the lack of receptivity of family members to brain donation as factors that may influence willingness of research volunteers to agree to brain donation. More recent studies have identified misconceptions about brain donation procedures, concerns about racial discrimination in medical settings, and the influence of religion and spirituality as additional factors (Bonner et al., 2000; Jefferson et al., 2011). Several research centers have implemented programs aimed at improving African American subjects' rates of brain donation. An intervention using educational interviews at the Sanders-Brown Center on Aging (Danner, Darnell, & McGuire, 2011) resulted in a 71% agreement by recruits to participate in a longitudinal study. Half of those who enrolled agreed to brain donation, a significant increase from the proportion of subjects who had agreed before the intervention. Bonner and colleagues (2000) incorporated discussion of brain donation within the context of end-of-life treatment decisions that resulted in an increase in autopsy completion rate from 2% to 29%. Both studies demonstrated the value of focused programs designed to improve African American autopsy rates as well as the need, given the relatively low autopsy rates despite these programs, to further investigate barriers to autopsy.

Although no prior studies have examined attitudes among Latinos or Asian Americans toward brain donation, studies of these groups' attitudes toward research in general have found that cultural factors may influence receptivity to serving as a research volunteer and, by implication, their willingness to agree to brain donation. For example, culturally shaped conceptions of dementia and concerns that participating in research might be harmful for a cognitively impaired person were found to influence attitudes of Chinese Americans about participating in dementia research (Hinton, Guo, Hillygus, & Levkoff, 2000). Chinese subjects have also been reported to believe that when a person dies, their body should remain whole, presumably creating a barrier to brain donation (Barry, 2013). In a study of Latinos and African Americans living in Los Angeles, Latinos expressed greater desire for health

information as a prerequisite for participation in research, whereas African Americans expressed more concerns about trust and quality of care (Calderon et al., 2006).

Prior research also suggests that individual and family approaches to decision making about matters such as consenting to brain removal and autopsy may be rooted in cultural tradition. A study of attitudes toward patient autonomy found that Korean Americans and Mexican Americans were more likely to hold a family-centered model of medical decision making than African American and European American respondents (Blackhall, Murphy, Frank, Michel, & Azen, 1995). In another study, Chinese elders were found to be more likely than non-Chinese elders to agree to participate in a research study if asked by their son or daughter, suggesting the important role of family members in this decision (Brugge, Kole, Lu, & Must, 2005). Gallagher-Thompson, Solano, Coon, and Areán (2003) identified similar cultural values of family cohesiveness and responsibility, or "familismo" among Latinos (Calderon et al., 2006). How decisions are made within families may be especially important for brain donation given that research subjects only give assent to autopsy, whereas actual consent must be given by the next of kin after the subject dies (Calderon et al., 2006).

Thus, although much is known about ethnic differences in research participation, substantial gaps in understanding of research subjects' attitudes and beliefs about brain donation remain, especially among Asians and Latinos. Qualitative methods are an effective approach for gaining insight and generating hypotheses when there has been limited prior research (Barry 2013; Calderon et al., 2006). One strength of the qualitative approach is that it allows the researcher to elicit the experiences and meanings associated with the topic of interest from the perspectives of key stakeholders, including research subjects and family members. Focus groups are a qualitative method that allows for data collection from a number of participants in a relatively limited period of time and is especially suited to gathering data on attitudes and beliefs (Morgan, 2010). To guide the development of a survey on attitudes toward brain donation across NIH-funded ADCs, our team conducted focus groups designed to explore the range of viewpoints, attitudes, and experiences of African American, Chinese, Caucasian, and Latino research subjects and family members that may affect willingness to agree to brain donation. The focus group component of the study, reported on here, contributes to the literature by offering insights on attitudes toward and beliefs about brain donation across a multiethnic sample that includes two previously understudied groups (i.e., Latinos and Asian Americans).

Methods

Study Participants

A convenience sample of nondemented African American, Caucasian, Chinese, and Latino research subjects enrolled

in longitudinal studies and/or serving as controls in clinical trials from four NIH-funded ADCs participated in the focus groups. Family members of the research subjects who participated in the focus groups were invited to participate in groups separate from the subjects. The four centers included (names of four centers). They were chosen to ensure sufficient representation of the four ethnic groups of interest. The focus groups were organized by subject or family member status, ethnicity, and brain donor/non-brain donor status. Brain donor status for subjects was defined as persons who had signed an assent to brain autopsy. As the Chinese subjects were drawn from a relatively new study cohort and few had yet signed an agreement for brain donation, Chinese subjects included in the “donor” group were those who had expressed willingness to consider assenting to brain donation when they were provided an “Autopsy Program Enrollment” packet during their annual study visit, whether or not they had signed an assent form.

Procedures

Research subjects were invited to participate in a focus group by a personal phone call or during a regularly scheduled study visit. Family members of these research subjects were invited to participate in separate groups. The focus groups were held at community sites such as a local clinic, adult day care center, church, or retirement home and lasted between 1 and 2 hr. Of the 18 focus groups, one group of non-donor subjects was conducted in Spanish, one of the Chinese subject groups was conducted in Cantonese and one was conducted in Mandarin, and one family-member group was conducted in Cantonese.

The semistructured interview guide was developed by the coauthors and reviewed by research assistants who had experience working with the populations of interest. The questions were based on prior research and recommendations by research staff from the four collaborating centers. Focus group interviews with Chinese participants were conducted by Chinese research staff, Latino groups were conducted by a Latino staff person, and the African American groups were conducted by African American staff. For the groups conducted in Mandarin, Cantonese, or Spanish, a native speaker conducted the interview using the English interview guide with on-site translation. Facilitators of the focus groups were instructed to secure signed consent before beginning the interview, to make sure that the tape recorder was functioning, to follow the prepared interview schedule (allowing flexibility with respect to time limitations and to skip over questions that had already been spoken to), and to ensure that all participants had an opportunity to voice their thoughts and opinions.

We developed a set of concepts and ideas to be explored along with additional open-ended questions designed to uncover specific ideas that may not have already been discussed. During the interview, we first described the purpose of the study and obtained signed consents. Guidelines for

participation in the discussion were then reviewed. After these preliminaries, participants were asked, as a warm-up question, how they came to be involved in research. They were then asked how they think about brain donation (“What comes to mind...”) and what they thought were the “benefits” and the “downsides” of brain donation.

African American, Chinese, and Latino participants were then asked to consider how people from their own racial/ethnic group might differ from other racial/ethnic groups in their willingness to participate in a brain donation program. In the Caucasian groups, this question was asked in general, without reference to a specific ethnic or cultural group. Participants were given an opportunity first to respond to this question without prompting. If certain topics were not mentioned, they were then asked about them. Topics included “religious or spiritual beliefs or practices,” “feelings about the body and how the body is treated when someone dies,” “feelings about participating in research in general,” “how people feel about hospitals or about research centers,” and “anything else?” Finally, participants were asked what might make brain donation more appealing for them, their family, and their community. Participants were thanked and given a \$25 gift card. The interview guide for the family members followed a similar outline with questions tailored to companions of research subjects. Focus group interviews were audio-taped, transcribed, then translated into English if conducted in another language. Transcribers were instructed to delete extraneous words such as “you know” or “uh” as long as these deletions did not change the meaning of the comments.

Data Analysis

Computer-assisted data analysis (i.e., data management and coding) was conducted using NVIVO® qualitative software (NVIVO, 2010). Analysis involved multiple steps that included open coding and constant comparison, following an accepted approach for descriptive qualitative studies (Cohen & Crabtree, 2006; Sandelowski, 2000). As the primary purpose of the focus groups was to identify the range of considerations that may affect willingness of research subjects to agree to donate his/her brain, the data from all focus groups were pooled and then analyzed. The principal investigator (PI; L. Boise), coinvestigators (L. Hinton, H. Rosen), research associate (M. Ruhl), and four research assistants participated in a systematic process for coding the transcripts. First, using the topics asked about in the interviews as a basic frame for coding the data, the principal investigator and coinvestigators coded two transcripts of interviews with research subjects and two transcripts of interviews with family members to create preliminary coding schemes of themes and subthemes. The preliminary coding schemes were reviewed, modified several times, and then finalized by the research team. The data coder used the final coding schemes to create a codebook for the research subject transcripts and a codebook for the

family member transcripts and input the codes in NVIVO. Each transcript was then coded according to the codebook by two members of the team. The PI then reviewed the coded transcripts, identified inconsistencies between the two coders, and asked the original coders to reconcile the code differences. In cases where the two coders were unable to agree on coding, the PI made the final decision as to most appropriate coding.

Results

Participant Characteristics

A total of 61 subjects and 34 family members participated in the 18 focus groups. As reported in [Table 1](#), roughly equal numbers of persons from each of the four racial and ethnic groups participated in the research subject focus groups. The mean age of research subject participants was 81 (range 48–95) and 74% were female. There was a broad range of education among the research subject participants, although the majority had a least high school education. Fifty percent of these participants were Protestant and 31% identified themselves as Catholic (the majority of Catholics were Latino and all except one of those who identified themselves as having no religion were Chinese). The majority of the research subject participants were married. The family member participants also included roughly equal numbers of participants from each of the four racial/ethnic groups. Sixty-five percent were female and the mean age of family member participants was 64 with a range from 32 to 94 years. The average years of education was 14, with a range from 11 to 20 years. Equal numbers of family members identified themselves as Protestant or Catholic (the majority of the Catholic participants were Latino). The majority of family members were married.

Focus Group Discussions and Themes

In response to the opening question, that is, reasons for participating in research, frequently mentioned reasons included a desire to help scientists better understand Alzheimer's disease, interest in the hope of helping family members, and the benefit of receiving health assessments that often go along with serving as a research subject. Some participants appreciated that their involvement provided the opportunity to learn about Alzheimer's disease and research. Others enrolled in studies because members of their social group (e.g., other Latinos) were involved. Discussion then turned to brain donation. Through our analysis, we identified 6 topic areas and 12 themes. Although the topics fall generally in line with the questions we posed, our analysis revealed a range of perceptions and perspectives on these topics. These are presented in [Table 2](#) along with comments for each theme that illustrate the varying perspectives with emphasis on perspectives and views that were frequently expressed or, when indicated,

comments expressed by one or few individuals that were in contrast to the prevalent view.

Understanding the Rationale for Brain Donation and the Process of Brain Removal

In discussing the benefits and downsides to brain donation, a wide range of understandings and attitudes about the rationale for brain autopsy and the process of brain removal were revealed ([Table 2](#), Section A). Some participants, especially those with scientific backgrounds or relatives who worked in health care or research, understood that studying brain tissue is an integral part of dementia research; this understanding seemed to facilitate a willingness to agree to brain donation (A1(a),(b)). A number of participants, however, reported misconceptions about how studying brain tissue contributes to understanding of the disease process or how the brain is removed from the body for analysis (A2). Given that the participants in the focus groups were generally cognitively healthy, some thought that their brain would be of little value to researchers studying Alzheimer's disease or other dementias (as reflected in A2(a)). Many participants were curious about the procedures for brain removal and many had questions about it, such as where the incision was made, how long it took to complete the process, what would happen if the person was away from home when they died. Some found the subject of brain removal unfathomable, even repugnant (A2(b)). Participants expressed a desire for information in relation to what would be needed to carry out the brain donation process as well as information about the results of the research (A3). For example, not knowing the details about transport of the deceased person to the lab for brain removal and return to the funeral home caused a family member to worry that brain donation might delay funeral arrangements (A3(a)). Having information about brain donation before someone died was also mentioned as helpful for family members who otherwise might be distressed by the autopsy consent process at the moment of loss (A3(b)). Although many people were curious and interested in the process of brain donation and removal, some preferred not to know the details (A3(c)). Several participants also spoke about the need for information to be disseminated to the community, for example, to report the results of research related to brain autopsies (A3(d)) and to let people know the benefits of research participation (A3(e)).

Personal Reactions to Brain Donation

Participants' personal views on brain donation stemmed from two primary sources: value perspectives and emotional reactions ([Table 2](#), Section B). A number of participants said that their desire to help others was an important reason for agreeing to donate their brain (B1(a)). Not all participants agreed with this assessment, however. The discussion between two research subjects in a Chinese group

Table 1. Characteristics of Focus Group Participants

Group #	N	Ethnic group	Family/subject	Donor/ non-donor	Language used in focus group	Gender		Age	Years of education	Religion ^a
						Men	Women			
1	8	African American	Subjects	Donors	English	—	8	64–84	12–16	6 Protestant 1 Catholic 1 No religion
2	7	African American	Subjects	Non-donors	English	—	7	83–91	12–18	6 Protestant 1 Catholic
3	7	African American	Family	Donors	English	3	4	32–60	11–16 ^a	3 Protestant 3 Catholic 1 “Other”
4	3	African American	Family	Non-donors	English	1	2	48–51	Missing	Missing
5	6	Chinese	Subjects	Non-donors	English	3	3	61–79	18–20	2 Protestant 4 No religion
6	5	Chinese	Subjects	Donors ^b	Mandarin	3	2	65–75	11–18	1 Protestant 4 No religion
7	4	Chinese	Subjects	Non-donors	Cantonese	1	3	60–82	12–20	2 Protestant 1 Catholic 1 Daoist
8	4	Chinese	Family	Donors ^c	Cantonese	—	4	35–70	12–20	2 Protestant 1 Buddhist 1 None
9	3	Chinese	Family	Non-donors	English	—	3	39–68	12–20	2 Protestant 1 No religion
10	7	Latino	Subjects	Donors	English	1	5	73–95	4–20	2 Protestant 5 Catholic
11	4 ^b	Latino	Subjects	Non-donors	Spanish	2	2	70–77	5–7	1 Protestant 4 Catholic
12	4	Latino	Subjects	Non-donors	English	2	1 ^d	74–89	8–14 ^d	1 Protestant 3 Catholic
13	6 ^e	Latino	Family	Donors	English	2	4	64–78	12–16	2 Protestant 4 Catholic
14	2 ^e	Latino	Family	Non-donors	English	1	1	73–91	12–13	2 Catholic
15	6	White	Subjects	Non-donor	English	2	4	72–90	12–18	Missing
16	10	White	Subjects	Donor	English	5	5	62–94	12–18	1 Protestant (others missing)
17	7	White	Family	Donors	English	—	7	64–94	12–18	Missing
18	2	White	Family	Non-donors	English	1	1	45–62	Missing	Missing

Notes: ^aPersons identified as non-Catholic Christians categorized as Protestant (includes “Protestant,” “Christian,” Methodist, Baptist, Episcopalian).

^bOne family member attended this subject focus group (data for family member not included in demographic data).

^cChinese “donor” groups included some subjects who had not signed assent forms (or family members of subjects who had not signed assent forms) but were considered by staff to be positively inclined to agree to brain donation.

^dData missing for one participant.

^eOne subject attended each of these family focus groups (data for subject not included in demographic data).

illustrates two opposing value perspectives: one participant felt that donating an organ to a living patient would be of greater value than donating one’s brain for research, whereas another participant countered that the potential to help thousands of people through donating one’s brain for research had much greater value (B1(b)). With respect to emotional reactions, some participants were comfortable with the idea of brain donation and expressed no hesitation about it (B2(a)). Others reported negative, ambivalent,

or uncomfortable feelings. News reports or stories participants had heard about organ harvesting or memories of reports from Nazi Germany or other periods in the past left some with negative feelings about the topic. Often, though, the very idea of brain removal and autopsy was simply distasteful (B2(b)). Some study subjects struggled with a desire to accept brain donation, yet were unable to eliminate their discomfort with it (B2(c)). One man pinpointed this discomfort for himself and his wife with the fact that

Table 2. Topics and Themes Discussed in Focus Groups

Topic	Themes	Representative comments
A. Purpose and process of brain autopsy in AD research	A1. Understanding the purpose of studying the brain facilitates receptivity to brain donation	<p>(a) <i>Since we have all studied biology, we know what autopsy is all about. Of course, this is a procedure where a brain is taken out to be observed if there are any pathological changes inside, or if it is normal. Therefore, after I heard about it, I thought to myself, it is what should be done.</i></p> <p>Chinese donor subject</p> <p>(b) <i>Well, I feel when you're gone, you're gone, and you take the brain. And the researchers or scientists will study the cells or parts of the brain that causes the illness that appears, and will benefit from that knowledge. So they will be able to, with their research, maybe they can come up with some medications or something that will slow down the process.</i></p> <p>Latino family member of non-donor subject</p>
	A2. Misunderstandings of how the brain is used in or harvested for AD research	<p>(a) <i>So when they do the autopsy in the brain, they know a certain specific spot, the hippocampus, the part of the brain they're looking for this protein, right? So what do they do with what they find? Because I was wondering about that, if you don't have the disease, I guess they just sew you back up, and if the findings are positive, what do they do with it?</i></p> <p>African American donor subject</p> <p>(b) <i>Someone might think when you donate your brain, they are going to cut off your head, open it and remove the brain...if people think that way, then I think there will be even less people who want to donate... Would you mind answering my question? Will the head be cut off? Or, is it just cutting open the head and removing the brain? What is going on?</i></p> <p>Chinese (potential) donor subject</p>
A3. Need for information about brain donation and research	A3. Need for information about brain donation and research	<p>(a) <i>Do we need to make a phone call? And then does somebody come and pick up the body? How long does it take? I don't know enough to say there's a downside... If you told me it's going to take three, four, or five days, then I'll be like, "Well, that's a downside right there."</i></p> <p>Latino family member of donor subject</p> <p>(b) <i>... had she just passed, and then you guys brought a paper to me saying, "Your mom's agreed to donate," that would be very hard for me. So not knowing, you know, you want to do their wishes, and this is a little bit easier ahead time, this is great – really great. I don't like being surprised the day of something, so I appreciate you guys taking the time to do this.</i></p> <p>Latina family member of donor subject</p> <p>(c) <i>...as long as they look presentable and in that open casket, however they do it, I don't care, I don't want to know...</i></p> <p>Chinese family member of non-donor subject</p> <p>(d) <i>...nobody comes out into our community and says, as a result of these studies, we have now found that maybe this might be a better way to help to live in a healthy way, it doesn't happen..</i></p> <p>African American donor subject</p> <p>(e) <i>I think we need to hear more information in this area [about brain donation] and let them know what the benefits are.</i></p> <p>Latino donor subject</p>

Table 2. Continued

Topic	Themes	Representative comments
B. Personal views on brain donation	B1. Value perspectives on brain donation	(a) <i>I think it's good for research, for instance, what [Center] does here with the Alzheimer's disease, and all of that, and doing the research on it, I think that's a good thing. They know what they're looking for, and they know what they're going to do with it. To me, I don't look at it in no way but a good thing.</i>
		Latino family member of donor subject
		(b) <i>Participant 1: Theoretically it [brain donation] helps the study. However ... I would say, it will be helpful to another person directly if I donate a brain, the organ to him/her; that is easier to accept. However, if it is just for a study on brains, checking whether there is protein, or whatever, then I would not consider it very worthy ..., just as I said before, for the purpose of torturing the body after one has died, it is not worthy.</i>
		Participant 2: <i>Mmm, I mean that donating when one is alive is to save a person, just as if you donate a kidney to someone, is to save a person. However, when your brain is used for a study, the results of the study, putting all the data together and coming to a conclusion, that will save thousands and thousands of people.... donating the brain is for the future, many contributing to the human race.</i>
		Chinese non-donor subjects
		(a) <i>Well, my mom's been very proud to be a part of this study, you know, all the way along. She's doing it because she's just proud to be part of the study, and she's been treated really well throughout it.</i>
		Latino family member of donor subject
		(b) <i>Well, I think for some people it just totally grosses them out, the whole concept. I know when I brought up to my kids it was kind of: "Oh, Mom," you know, "ick." But they're rallying around. As my daughter says, "I'll give permission, but I don't want to think about it."</i>
		White non-donor subject
		(c) <i>I can't quite put my finger on my discomfort. I don't tolerate superstition, and yet I don't understand why I'm uncomfortable with the idea. And I do think that very often if I'm uncomfortable with something, that if I keep on thinking about it, or talking about it, or discussing it, that I might be able to overcome it. ... I can be fairly objective about a lot of things, but this one puzzles me.</i>
Chinese non-donor subject		
(d) <i>[speaking about his wife] I think she could live with this if this was a different program and [Center] stole my liver, you know and returned everything else. But not the brain, because that's the seed of my behavior, how I related, you know, how I act, feel, everything is in this one organ. And to have it missing, it's like I don't know why I'm thinking of the word "fraudulent," but it's as if I were to then be cremated, it's not the same because it's not whole.</i>		
Chinese non-donor subject		
(e) <i>I could weep and mourn for a long time over the personality that's lost or the soul, whatever, but not the body. I don't feel any sentiment about that, that it has to be preserved or treated in any special way.</i>		
Caucasian non-donor subject		
C. Handling of the body after death	C1. Worries about respectful handling of body by researchers	(a) <i>Participant 1: ... about the body, you really have to explain to people about the body because people think that if you take part of it, when the person dies and the person has to be viewed, the person might look all terrible and things, so you have to explain to people that the body is going to be treated... you know.</i>
		Participant 2: <i>In a respectful way...</i>
African American donor subjects		

Table 2. Continued

Topic	Themes	Representative comments
C2. Presentation of the body at the funeral if the brain has been removed		<p>(b) Well, my son-in-law is a doctor, and when I discussed with him my interest in donating my body, he said it was fine but I should just be aware that students are not very respectful of the cadavers that they work on. Now I thought it was interesting, I didn't pursue it further, but, you know, after I'm dead, what does it matter? But he thought it was something that I might like to think about I guess.</p> <p>Chinese non-donor subject</p> <p>(a) Well, I know I have already paid to be cremated, so to me whatever is left of me can be used for good, and so, I have no qualms about pieces of me or religious problems with this sort of thing. But I think it would just comfort me to know that somebody can benefit.</p> <p>White non-donor subject</p> <p>(b) Interviewer: Do you feel that feelings about the body and how the body is treated when someone dies can influence a person's decision to donate their brain? Or would that not be a factor?</p> <p>Participant: Well, I think that's a part of it, because, just like the question you were asking, would an open casket be available?</p> <p>African American non-donor subject</p> <p>(c) When I told my daughter about donating my brain, she asked me what state it would leave my body in after the surgery.</p> <p>Latino non-donor subject</p>
D. Religion and spirituality	D1. Influence of religious beliefs and metaphysical questions on attitudes toward brain donation	<p>(a) Where is my wife's concern then? She feels that.... she is a firm believer of resurrection, firm indeed. You cannot be a Christian if you have doubts about this. As a Christian, you call God a true God who is omnipotent, omnipresent, and omniscient because He is a living God. However, my wife's concern is that before your resurrection, you have to be a person, a person that is intact, then you can resurrect as a complete being as well. In the event you have become imperfect, then what will be your condition, possibly imperfect, after your resurrection? This is where her concern is.</p> <p>Chinese subject (potential) donor subject</p> <p>(b) What comes to my mind is in the resurrection does my brain got to be there, or is God able to collect everything and do it. And I think, will be able to put all the things together, and the resurrection will not be complete even though my brain is here and my body's somewhere else. So that really doesn't bother me in that part. ...so I don't have any reservations in giving my brain out for this.</p> <p>Latino donor subject</p> <p>(c)...what do you think would happen to the soul if you donate your brain, and your soul is a part of your brain—is the brain? What happens to your soul?</p> <p>African American non-donor subject</p>

Table 2. Continued

Topic	Themes	Representative comments
E. Family's role in brain donation	E1. Honoring the subject's preferences vs leaving decision to family	<p>(d) Participant 1: <i>In my family, we don't have a viewing service.</i> Interviewer: <i>Okay.</i> Participant 1: <i>We're Unitarians and we just don't do that. But we do have a memorial service and sometimes it's six months or so after the person has died.</i> Interviewer: <i>Right. Okay. You think about that when you think about brain donation, so it's not a concern?</i> Participant 1: <i>Nobody's going to know what's in my head by the time...</i> Interviewer: <i>By that time.</i> Participant 1: <i>They won't even see me to actually—you know. They'll have a nice picture of me when I was sixteen.</i> Participant 2: <i>Many churches now have the alternative of memorial services. Most people in our church, the United Methodists, have memorial services rather than the funerals. I've gone to very few funerals...</i> Caucasian donor subjects (a) <i>Well, I think I had more of a problem with it than my mom did, because I had hope for everything. It's like, if my mom has a really good brain, I don't want 'em to take it. What if she wakes up? If it was damaged, it would be easier for them to get rid of it for her. But it's her choice...my mom is very sweet, and can be very passive, but once in a while she'll say, "Oh I've already decided that I'm going to do this, and you're going to abide by my wishes." I'm like okay.</i> Latino family member of donor subject (b) <i>...when the parents are still alive, when they are still conscious, when you chat with them, you should be able to know their wishes. In fact, when they say, "I am not donating, oh definitely I will not donate." Then, you do not really even need a form to sign. You will not even give it a second thought. When you hear, "It's not a big deal. I will donate to others." Then the children will act accordingly to their wish, saying, "Oh, I do recall dad mention it, mom said so." Well then they will actually go ahead and donate without feeling guilty.</i> Chinese family member of (potential) donor subject (c) <i>...in some of your questions—you are bringing up a good point—that it made it sound like would we have objections, while that shouldn't even be on the table if it's something that individual has made a request for. ...If you have a family where there's dissension on that, I would think that the family members that are supporting the wishes that have been documented, and if [University] decides to not go through with it, that they are actually setting themselves up for some liability, because you could actually have the family members that are in support of that sue that those wishes were not followed. Especially if there's good documentation.</i> Caucasian family member of donor subject (d) <i>I'm fine with it. They can have anything, you can have whatever you want when I'm dead: organs, brains, I don't care, I'm dead. But I would just leave the decision to my family. I don't want to cause my family anymore undue stress and burden already, you know.</i> Chinese family member of non-donor subject</p>

Table 2. Continued

Topic	Themes	Representative comments
E2. Family decision-making dynamics		(a) <i>I told them [that I had consented to brain donation] and they look at me and they say, "Mom, that's not going to happen." I said, "There's nothing you can do about it. I already signed the [form." The say, "It's not going to happen." I say, "You can't – that's my wish. That's what's going to happen.</i>
	African American donor subject	(b) <i>Participant 1: We're the ones who have to enforce—you'll be in charge, and you'll be in charge, and you'll be in charge—you have to enforce, you know – or "enforce" maybe a harsh word. Maybe lead..</i>
F. Ethnicity and cultural values		Participant 2: <i>...follow through on your wish [about brain donation] ... there may be some resistance, where if you show the paperwork ahead of time, and he signed it and this year, we're fine, you want to make sure that he's not progressed to a point where they say, "you know, he wasn't thinking right when he did this." You want to have all your paperwork lined up.</i>
	Latino family member of donor subject	(c) <i>You do not want to cause any quarrels with your family while you are still alive, because of this issue after death. I can say I am more than willing to donate, however, my wife says no way.... Well, no one wants to deal with things like this. Nevertheless, not only the donor himself or herself has to think it through and consent to it, but also the family, your wife, your husband, and your children, they all have to come to a unanimous agreement. Otherwise, you and your family will be on bad terms.</i>
F1. Traditional and shifting cultural beliefs and values		Chinese non-donor subject
	(d) <i>...given the stage in which my mom is in her Alzheimer's... It is a decision of the family. And, as both of us are the eldest of our siblings, and we have a very close family, and so that consensus building, and it really is consensus, is important because you don't want one of the five or six to be dissenting and be very vocal about it.</i>	
F1. Traditional and shifting cultural beliefs and values		Family member of Chinese (potential) donor
	(a) <i>[If I agreed to brain donation] I would be ignoring the cultural sensitivity that the bodies be kept whole. Chinese non-donor family member</i>	
F1. Traditional and shifting cultural beliefs and values		Chinese (potential) donor subject
	(b) <i>...my family member did not say they don't trust [the doctors or researchers]. They just reject the idea [of brain donation]. This may be because they want my whole body as an integral part to go to the furnace.</i>	
F1. Traditional and shifting cultural beliefs and values		Chinese (potential) donor subject
	(c) <i>Well, I'm a Catholic. So I feel the Catholic church teaches you things: that you don't donate your body; that when you die you give your body back to Jesus.</i>	
F1. Traditional and shifting cultural beliefs and values		Latino non-donor family member
	(d) <i>The more you understand about anatomy, biology, and human body anatomy, the less and lightly you will consider this matter [of brain donation] and the more you will feel it is not an issue. However, to common people, this is not the case, absolutely not.</i>	
F1. Traditional and shifting cultural beliefs and values		Chinese (potential) donor subject
	(e) <i>I think it's a modern way of thinking...it's like being educated and knowing it's going to benefit, and I think that's where it's at. And that's why I'm proud of my mom for being – she's always like one step ahead, she's involved in today's news topics, you know, this and that, and what going to benefit. She doesn't have old-way thinking, like maybe one of my aunt's does... Maybe not so much the Hispanic race, it's where they are with their thinking.</i>	
F1. Traditional and shifting cultural beliefs and values		Latino family member of donor subject

Table 2. Continued

Topic	Themes	Representative comments
F2. Group identity in social and historical context		(f) <i>I'm ok with it [brain donation], you know...different from my dad. He doesn't know why I'm here. And I can tell, he would totally flip out. ... my dad was born in Hong Kong, he didn't come until he was a little kid. But he's what I call, "more Chinese-y."</i>
		Chinese family member of non-donor subject
		(a) <i>I think about, you know, the feelings about participating in research in general, because you know there was that study with the syphilis study, yes, the Tuskegee and people trusted and then didn't so there's that level of trust and people are just not willing to because they don't think... umm trust as I said.</i>
		African American family member of donor subject
		(b) <i>I am so ambivalent about studies that are being done on Black Americans that don't seem to have benefitted us to any great degree. I'm not a medical person but I have some real reservations just about, again, are we going to be used in a very more sophisticated way as we have been in the past in not such a sophisticated way and just bluntly been used, and that's what took me two or three years to make up my mind and to get a better feeling about [study research assistant] and the group...</i>
		African American donor subject
		(c) <i>A lot of people have a problem with you donating an organ, a brain, whatever. What else are you going to use it for? Are you going to use it to see how dumb I am? Are you going to see this and that, you know, at the same time? I'm just being real with you.</i>
		Latino family member of donor subject
		(d) <i>I'm very grateful for the opportunity to sit around the table and discuss it because ... studies prior to, ... we were excluded, ok, so I think this is, whoever decided that this is what we need to do to bring more Afro-Americans into these studies, I think it's a wonderful idea, and so I'm grateful.</i>
		African American donor subject
	(e) <i>Three years ago, I learned of this research, and that it is focused on Asians. I find it very touching to have such research that focus on Asians. Therefore, I hope I can at least somewhat contribute to this, no matter how little it will be.</i>	
	Chinese non-donor subject	
	(f) <i>...the reason why I participate also is because there's a lot of Latino and Latinas working here. So you feel more comfortable that you can relate to each other and communicate. If you were an Anglo, I would never have participated. I would have said, no, forget it.</i>	
	Latino non-donor subject	

Note: AD = Alzheimer's disease.

the autopsy involved the brain, which, he said, is the source of one's "behavior," one's self (B2(d)). Another participant had a different view: she attached no special significance to the body, including the brain, and did not feel it was necessary to treat it "in any special way" (B2(e)).

Handling of the Body and Brain After Death

Many participants engaged openly in discussing death and the disposition of the body (Table 2, Section C). Chief concerns were how one's body would be treated by researchers and the appearance of the head and body after brain removal. Although there was much talk about the potential for their body to be treated disrespectfully during the autopsy procedures (C1), much of this was in relation to concerns related to medical students "dissecting" of cadavers (C1(a),(b)). This concern did not necessarily dissuade them from agreeing to brain donation (C1(b)). A topic of great interest to a number of participants was concern about the appearance of the body at the funeral. In several of the focus groups, cremation was the norm; this practice was often associated with a nonchalant view of brain donation (C2(a)). When the person or family anticipated burial, especially if an open casket was expected, there was greater concern about how brain removal might affect the appearance of the body, for example, whether incisions would be visible (C2(b),(c)).

Religion and Spirituality

Discussion about religious beliefs in relation to brain donation reflected a complex set of dimensions (Table 2, Section D). Few participants professed to specific knowledge about the tenets of their religion on brain donation; rather, most spoke from the vantage point of their personal religious beliefs. Some people who professed to strong fundamentalist religious belief stated that their beliefs kept them from agreeing to donation; others saw no contradiction between belief and brain donation. One man spoke about his wife's concern with the incongruity between resurrection and separation of the brain from the rest of the body (D1(a)). Another man wondered whether God would be able to put the body together with the brain so that resurrection could take place; he concluded, apparently, that an omnipotent God would be able to accomplish this (D1(b)). A woman was more circumspect about the consequences of brain donation for life after death: she posed the question of whether the soul resides within or actually is one's brain (D1(c)). "What happens to your soul?" she asked, if the soul is the brain. Persons with more liberal theological beliefs had a more flexible attitude about the necessity of retaining the brain in the body after death (D1(d)).

The Family's Role in Brain Donation

Ultimately, the next of kin will be faced with the decision to consent to brain autopsy after a research volunteer dies (Table 2, Section E). As such, subjects and family members tended to address the family's role and responsibilities

within the framework of two dimensions: first, whether the subject's or the families preferences should prevail, and second, how the decision should be made within the context of family dynamics. With respect to the first dimension, a number of family members reported that they respected the subject's decision to donate their brain despite their own hesitations (E1(a)). Knowing the subject's preferences made it easier to support his or her decision and eased potential guilt feelings (E1(b)). One family participant strenuously asserted that family members were obligated to comply with an individual's desire to donate his/her brain and stated further that it was the responsibility of the research center to comply with the subject's expressed desire (E1(c)). In some cases, however, subjects said they would defer to family members because it would be they who would ultimately be faced with the decision whether or not to consent for autopsy (E1(d)). Many acknowledged that, though this was an important matter for discussion, it was a difficult topic to talk about, especially with younger family members.

The second dimension affecting decision making about brain donation was the style of communication dynamics within the family (E2). In some families, the subject clearly asserted his or her position on brain donation and expected family members to abide by it (E2(a)). One family member recommended that the primary caregiver make sure all paperwork assenting to brain donation was signed and communicated to other family members and that this needed to be done before the subject's cognitive decline had progressed too far (E2(b)). Alternatively, some participants emphasized consensus decision making as an essential foundation for good relationships among family members. One subject mentioned that, although he was willing to donate his brain, his wife was opposed to it and that all family members need to "come to a unanimous agreement" (E2(c)). An added consideration for the dynamic process of decision making about brain donation is the subjects cognitive status: one family member whose mother's dementia was progressively deteriorating emphasized the need for "consensus building" to avoid dissent among siblings (E2(d)).

Ethnicity and Culture

During our interviews, we asked participants how they thought people from "religious, ethnic, and cultural" groups may differ in their willingness to participate in a brain donation program (Table 2, Section F). Although comments in the sections above may have originated from the spokesperson's ethnicity or cultural traditions, they were not always articulated as such. In this section, we focus on participant comments that specifically refer to one's own ethnic group. Comments center around two main areas: traditional and shifting cultural beliefs and values, and the social and historical context of racial and ethnic group experience and attitudes. A third area that may relate to culture, although not discussed as such, is the dynamics of communication

and decision making about important issues within families. In terms of culturally based beliefs and values (F1), the topic most often discussed was that of funerals and the disposition of the body. This was especially apparent in the groups of Chinese participants. In all five focus groups of Chinese subjects or families, the desire to maintain the wholeness of the body was discussed (F1(a),(b)). The view expressed by Chinese participants that the body should remain whole was not necessarily associated with religious belief. In contrast, the concerns and beliefs about the disposition of the body were generally discussed by Latinos and African Americans within the context of their religious beliefs. For example, the Latino subject in F1(c) discussed his belief as a Catholic that keeping the body intact was necessary in order to “give your body back to Jesus.”

As participants discussed cultural traditions, they often acknowledged that individual differences, such as exposure to Western medicine or science as well as age and life experience, might result in some people within their racial or ethnic group being more accepting of research participation and brain donation (F1(d)). One woman expressed pride that her mother was very forward thinking and aware of current issues, pointing out that the key factor influencing Hispanics’ attitudes toward brain donation may not be “so much the Hispanic race, it’s where they are with their thinking” (F1(e)). In contrast, a Chinese family member described her father’s more traditional views that would make it difficult for him to accept the idea of brain donation (F1(f)).

Another area rooted in race and ethnicity is the social and historical context of identify and experience. Awareness of the history of racism in society and, in particular, in health research caused participants from African American, Latino, and Chinese groups to be cautious about participation in research and, by implication, brain donation. African Americans spoke of the “Tuskegee syphilis” studies (Katz et al., 2006) as evidence of the history of maltreatment by researchers (F2(a),(b)). One African American mentioned the recently published “Henrietta Lacks” book about an African American woman whose genes were harvested by doctors at the health institution treating her for cancer without her knowledge during the 1950s (Skloot, 2010). Several Chinese participants spoke of policy changes in China in favor of cremation despite the cultural tradition of whole-body burial. One Latino man, who spoke at some length about the ways Mexicans have been mistreated by white people (“gabachos”), reflected the sentiment that Latinos might feel they would be looked down upon or their brain might be inappropriately used due to their ethnicity (F2(c)).

Although concerns about racism seemed especially salient for African American participants, several African Americans expressed appreciation for the opportunity to participate in research that could increase knowledge about how Alzheimer’s disease manifests in African Americans (F2(d)). Similarly, individuals from Chinese and Latino

groups expressed appreciation that the studies they were involved in focused on and employed researchers and staff from their ethnic group (F2(e),(f)).

Another topic that may be culturally based is the ways families make important decisions. Although not discussed by Chinese participants as a uniquely culturally based value, we found that Chinese subjects and family members in all five focus groups were especially reflective about the need for family consensus in this decision. As described above in the section on family roles and decision making, comments such as that made by a Chinese subject and one by a Chinese family member suggest that consensus within the family about brain donation was based on a central value for Chinese families.

Discussion

This study is unique in exploring the attitudes, beliefs, and experiences that may influence receptivity to donating one’s brain for research across four racial/cultural ethnic groups. Our findings suggest that there are broad similarities in the types of concerns, attitudes, and beliefs toward brain donation across the four racial/ethnic groups we studied. Significantly, our study is the first to assess attitudes toward brain donation among Latinos and Asian Americans and to demonstrate a core of shared concerns with African Americans and white non-Hispanics. In all groups, a strong motivation for participation in research and for willingness to donate one’s brain was the belief that by participating, research subjects may help future generations and, possibly, their own families. The concerns and attitudes related to brain donation that were identified in this study fell into three categories: (a) concerns and misconceptions about the value and logistics of brain removal and autopsy, (b) religious beliefs, and (c) the role of family. Although each of these areas have been identified and discussed in prior studies, which often focused on one or two ethnic and racial groups, their emergence in our study that included a wider range of ethnicities represents an important extension of prior findings.

Concerns and misconceptions related to brain removal and autopsy were prominent across groups. An important discovery in this study is the pervasive lack of understanding of the ways studying the postmortem brain aids Alzheimer’s disease research. For instance, some participants expressed the opinion that brains from cognitively normal individuals are not valuable for research. It was apparent from the groups that many subjects had never had this discussion before, and many appreciated the opportunity to discuss the value of brain donation. We also found that the participants from all four groups had many questions as well as misconceptions about the logistics and procedures associated with brain removal and autopsy. Concerns were expressed about the procedures used to transport a body to the research institution for brain removal, how brain removal is performed, and how the brain is used for research. Another

topic was the concern that brain removal would result in disfigurement. The preference for burial and, in particular, open casket funerals stimulated worries about how the deceased person might look. In contrast, participants who planned for cremation often seemed rather cavalier about brain donation. These observations are consistent with studies of African Americans (Bonner et al., 2000; Lambe, Cantwell, Islam, Horvath, & Jefferson, 2011). An added consideration, shared primarily by Chinese participants, was a cultural value that the body must remain whole (Hinton et al., 2000).

One concern, well known among African Americans (Katz et al., 2008), is the pervasive history of racism in medical research. Consistent with Lambe and colleagues (2011), we found a high degree of awareness about this history among the African Americans in our groups and a corresponding reluctance to agree to brain donation. However, this concern was not unique to African Americans. Similar concerns were expressed by several Latino and some Chinese participants but not to the degree as with African Americans. Despite this prevalent perspective, some African Americans also recognized the need for inclusion of African Americans in research studies to fill critical gaps in knowledge.

Religious beliefs and practices were another important topic of discussion. In some of our focus groups, discussion turned to the enigma of what happens to the body after death, something the participants may not have considered previously. Some wondered whether brain removal would interfere with the transition from living on earth to the place where the body—or the soul—rests after death. Nonetheless, despite the tendency for strongly religious participants to raise concerns about brain donation, some participants seemed able to formulate a concept of death and afterlife that was not an impediment to agreeing to brain removal. The variety of responses on the topic of religious beliefs and the impact of deeply felt religious views on autopsy rates provides a rich and complex area that warrants further study.

Another key area that may affect attitudes toward brain donation is the role of the family in decisions on brain donation. In our groups, there was much discussion about whose preferences should prevail: some groups emphasized the obligation of family members to honor the wishes of the elder research subject. On the other hand, some research subjects deferred to family members who would ultimately be asked for consent for brain removal and autopsy after the subject died. Another dimension revealed during our discussions is the way families interact around important decisions. Chinese focus group participants, in particular, appeared to be sensitive to how family members would feel about brain donation and expressed a strong desire to arrive at a decision by consensus. These sentiments are consistent with those reported by Sun, Ong, and Burnette (2012) who found a central importance of family harmony among Chinese Americans in their caregiving decisions. For

families that put a high value on family harmony, divergent perspectives could be a challenging barrier to obtaining assent to brain donation or consent to autopsy of the next of kin after the subject dies. It was apparent from the discussions in all of our groups that brain donation can be a difficult topic to discuss with family members and others because it brings up unanswered or unanswerable questions, touches on one's mortality or the experience or anticipation of loss of a parent or other close relative, and can push individuals to evaluate their beliefs about death and afterlife. These concerns have also been touched on by other researchers who studied whites and African Americans (Bonner et al., 2000; Lambe et al., 2011). Our findings suggest that they are not unique to those groups and in fact may be more important in Chinese individuals.

Viewed in the context of prior work, our study adds important observations to the literature. Although we did not attempt to draw definitive conclusions about the similarities and differences between racial or ethnic groups in attitudes toward brain donation, our general conclusion is that issues that were raised in previous studies of Caucasians and African Americans are relevant in other ethnic groups such as Latinos and Chinese Americans. Our findings suggest that interventions designed to enhance enrollment in brain donation programs should target factors outlined above, which are likely relevant to people from a broad range of backgrounds.

Nonetheless, there were some indications that ethnically specific cultural traditions and beliefs may influence the degree of importance and relevance of individual factors in different ethnic groups. Our preliminary observations suggest some potential differences that related to ethnicity, such as more frequent concern about body integrity and less mistrust of research in Chinese Americans, and greater interest in receiving information about the rationale for brain donation among Latinos. Furthermore, beliefs and attitudes were not constant across all members of a given ethnic group and are likely attenuated by age or by exposure to western society, the health professions, or the sciences. Further comparative research should be carried out to confirm this and may yield meaningful differences among ethnic groups or subgroups that might be used to guide intervention programs.

This qualitative study has important limitations that must be considered when interpreting our findings. First, as persons with dementia were excluded, our findings do not apply to this important group of study subjects. Second, subjects and family members who declined to attend a focus group may have different views than those who did participate. Third, our findings suggest a wide-ranging set of considerations of research subjects and their families about donating one's brain for research but they do not allow for the identification of actual predictors of assent to brain donation. To pursue the identification of predictors of willingness to donate one's brain for research across ethnicities, we have developed and carried out a survey with

research subjects at ADCs across the United States. Further research with family members of research subjects as well as with other ethnic groups is needed to better understand this important question. Finally, this study might have been enriched by exploring self-perceptions of culture and race among different white ethnic groups.

Despite the limitations of this study, our findings offer much to ponder as researchers consider how best to approach the topic of brain donation with research subjects and their families. The reflection of one Chinese family member thoughtfully summarized some things to consider when talking with research subjects about brain donation.

...regarding this research, the more you know, the more confidence you have. ...they will feel more comfortable when they have a better idea about the details of the procedures. To feel settled and comfortable is most important. Basically, it is respect for the deceased. Then, I would say they would consider donating, then all factors add up to be positive. Nevertheless, if there is any of the slightest negative, that is negative, definitely, they will not donate.[Chinese family member, Cantonese group]

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