

PERCEIVED IMPEDIMENTS TO COMPLETED BRAIN AUTOPSIES AMONG DIVERSE OLDER ADULTS WHO HAVE SIGNED A UNIFORM ANATOMICAL GIFT ACT FOR BRAIN DONATION FOR CLINICAL RESEARCH

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Background: A small number of older adults in the United States who agree to brain donation for clinical research belong to diverse racial, ethnic, and economic groups. Those who agree, however, are less likely to have completed brain autopsies compared with older non-Latino Whites of higher socioeconomic status. As such, our understanding of Alzheimer's disease and related dementias remains limited in these underrepresented and understudied populations. Here, we examine perceived impediments to completed brain autopsies among diverse older adults who have agreed to brain donation for clinical research.

Methods: Participants (N=22) were older adults (mean age=77 years) who self-identified as African American (n=8), Latino (n=6), or White of lower income (n=8). All participants had previously agreed to brain donation via the Uniform Anatomical Gift Act. Each participant took part in a one-time, semi-structured focus group. Data were analyzed using a Grounded Theory Approach with both Open Coding and Constant Comparative Coding.

Results: Perceived impediments to completed brain autopsies varied by group. Older African Americans and older Latinos expressed concern about a lack of follow-through by family members regarding their brain donation wishes. Older Whites of lower income indicated that their own uncertainty surrounding the processes of brain donation and brain autopsy might serve as an impediment.

Discussion: Diverse older adults expressed different perceived impediments to having brain autopsies completed upon their death. Continuous education for diverse older adults and their family members regarding brain donation for clinical research,

INTRODUCTION

Biomarkers yielded from cerebrospinal fluid (CSF) analysis, magnetic resonance imaging (MRI), and positron emission tomography (PET) data represent acceptable assessments of Alzheimer's disease (AD) while persons remain alive.¹ However, a definitive diagnosis of AD or related dementias still requires brain autopsy. Furthermore, brain autopsy and resultant brain tissue from persons in longitudinal studies on aging remain critical to developing and improving strategies to address Alzheimer's disease and related dementias (ADRD).²⁻⁴ Available brain tissue in the United States largely originates from non-

Latino Whites of higher socioeconomic status. Despite persistent and continuous efforts, persons who represent diverse populations – including African Americans, Latinos, and Whites of lower socioeconomic status – face well-documented barriers to agreeing to brain donation.⁵⁻¹⁰ Of the smaller number of diverse older adults who do agree to brain donation, even fewer will have completed brain autopsies upon death compared with those who are non-Latino White.⁶ As such, subsequent brain tissue does not represent the racial, ethnic, and economic diversity of older adults.¹¹ As older African Americans and older Latinos face an increased risk of AD compared with their non-Latino White counter-

including clear guidelines and processes, may facilitate completed brain autopsies among diverse older adults. *Ethn Dis.* 2020;30(Suppl 2):709-718; doi:10.18865/ed.30.S2.709

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parts,¹² insufficient brain tissue limits our understanding of and ability to address the disproportionate burden of ADRD for these underrepresented and understudied populations.

Previous studies have identified factors associated with agreeing to brain donation among diverse older adults, predominantly older African Americans, largely using qualitative research methods such as focus groups.^{2, 7-10,13,14} Qualitative research

the cooperation of others, such as family members, remains instrumental for successful or completed brain autopsies. Given the well-documented salient role of family among diverse older adults, family members and other factors may serve as potential impediments to completed brain autopsies for these populations who have agreed to brain donation.^{6,8,17-19}

To our knowledge, prior studies have not examined possible challenges to subsequent completed brain autopsies among diverse older adults who have agreed to brain donation. The purpose of this article, reporting on research using a qualitative focus group methodology, is to identify perceived impediments to completed brain autopsies among diverse older adults who participate in longitudinal studies on aging and have agreed to brain donation. For this research, diverse older adults self-identified as African American, Latino, or White of lower income. Study findings may provide the foundation for designing and implementing culturally compatible educational tools and engagement strategies to increase brain autopsy completion rates among diverse older adults.

consist of older African Americans, one solely pertains to older Latinos, and the final cohort study includes all races and ethnicities but is predominantly non-Latino White. All cohort studies are based in and around Chicago, with all participants tested individually within their residences. All participants are free of dementia at baseline, as previously described.^{5,20} All participants report their race (eg, African American/Black) and ethnicity (ie, Hispanic: yes or no) based on categories from the 1990 United States Census Bureau,²¹ as well as their sex (ie, male or female), date of birth, years of education, and income. Annual income is measured using the Show-Card Method from the Established Populations for Epidemiologic Studies of the Elderly, in which participants were asked to select 1 of 10 levels of total annual family income.²²

Eligible persons for the current study must have previously agreed to brain donation for clinical research via the Uniform Anatomical Gift Act as part of their cohort study participation. The Uniform Anatomical Gift Act is a legal document in all 50 states that allows persons to agree to donating their organ(s) and tissue at the time of death to institutions for research and other purposes (eg, transplantation).²³ Other eligibility criteria of the current study included: 1) aged ≥ 60 years; 2) free of dementia; 3) proficient in English – oral and written; and 4a) self-identified as either African American or Latino, or 4b) non-Latino White with a self-reported income level at or below approximately 150% of the 2018 Federal Poverty Lev-

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methods provide in-depth insight into people's attitudes, beliefs, and behaviors.^{15,16} Motivating factors for agreeing to brain donation among diverse older adults include altruism and perceptions of brain donation as beneficial to the person or future generations.^{13,14} However, while a person can agree to brain donation,

METHODS

Participants

Participants were recruited from four community-based longitudinal cohort studies on aging. Three studies include brain donation as an optional component and one study requires brain donation as a condition of entry into the study. Of the four cohort studies, two exclusively

el,²⁴ or a yearly income \leq \$19,999.

Participants took part in qualitative focus groups regarding the broader topic of facilitators to brain donation among diverse older adults who have agreed to brain donation. Within those focus groups, participants discussed potential impediments to completed brain autopsies and related suggestions for future engagement with diverse older adults regarding brain donation. From a pool of 535 eligible persons, 69 persons were contacted regarding their potential interest in focus group participation, with 24 persons subsequently scheduled and confirmed for focus groups. Two persons either cancelled or were absent the day of the focus group. A total of 22 participants (8 older African Americans, 6 older Latinos, and 8 older Whites of lower income) participated in one of three focus groups. An Institutional Review Board at Rush University Medical Center approved the current study. All procedures were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all participants included in the study.

Focus Group Guide

Prior to conducting focus groups, a Focus Group Guide²⁵ was developed for specific use with diverse older adults who have agreed to brain donation, as previously described.²⁶ The Guide set forth seven content areas (eg, altruism and thinking of

the future [family and future generations]). The content areas and related questions were developed by reviewing previous literature, conducting clinic observations, and community-based engagement with diverse older adults. We designed the Guide to systematically gather participant perspectives regarding, in part, potential impediments to completed brain autopsies among diverse older adults who have agreed to brain donation. Sample questions from the Guide included: "What did your family say about your decision to donate your brain?" and "When talking about brain donation, what should researchers consider?" Focus groups were semi-structured; hence, the Guide provided content areas and related questions to be addressed, but participants shaped the flow of discussion.

Recruitment for Focus Groups

We used two methods to recruit participants, as previously described.²⁶ Briefly, for the first method, study staff identified eligible persons based on study criteria and used a variety of direct outreach approaches (ie, phone calls, letters, and in-person visits). The second method included more passive outreach approaches, such as posting flyers and holding presentations where eligible persons frequented, including churches, libraries, health centers, and senior living facilities. All current study participants were recruited using the first method. Prior to each focus group, study staff provided reminder calls to participants regarding the date, time, and location of focus groups.

Focus Group Procedures

Each participant took part in one focus group. Three separate focus groups were conducted and consisted of: 1) older African Americans who had agreed to brain donation, 2) older Latinos who had agreed to brain donation, and 3) older Whites of lower income who had agreed to brain donation. Based on a qualitative sampling algorithm,²⁵ each focus group consisted of 5-8 participants, for a total of 15-24 diverse older adults who had agreed to brain donation.

Each focus group included an explanation of the purpose of the focus group and what comprised participation, orally leading participants through informed consent and HIPAA documents, and the use of audio-recorders. All participants provided written informed consent prior to the activation of audio-recorders. At the commencement of each focus group, each participant was given a \$25 Visa gift card as a token of appreciation. All focus groups were conducted in English. Focus groups lasted an average of 90 minutes.

All focus group data, including audio-recordings, were uploaded to a secure server at the Rush Alzheimer's Disease Center behind the Rush University Medical Center firewall. Audio-recordings then were electronically transferred to a medical transcription agency. Transcription included the de-identification of participants and the deletion of any names and other protected health information. Across all focus groups, CMG (the first author) served as the moderator and was accompanied by at least two trained study staff members.

Analyses

Transcripts served as the basis for data analyses. The unit of analysis was the focus group. To ensure inter-rater agreement, CMG and a trained study staff member conducted all data analyses, which consisted of two phases. For the first phase, data were analyzed across all focus groups or, more specifically, across racial, ethnic, and economic groups. An inductive Grounded Theory Approach^{27,28} with Open Coding³⁰ was used for the first phase. Grounded Theory Approach aims to produce novel theories and related hypotheses regarding the social world and how people navigate existing phenomena or issues.^{29,30} Analyses consisted of five steps.³¹⁻³³ First, analysts read each transcript to become familiar with the data. Second, analysts identified key passages within each transcript. Third, analysts developed and assigned codes to key passages. Fourth, analysts identified subthemes from the codes. Finally, analysts created overarching themes from the subthemes. At each step, analysts discussed and reached consensus.

For the second phase, group categorization (racial, ethnic, and income status) served as the unit of stratification and data were analyzed using an inductive Grounded Theory Approach with Constant Comparative Coding.³⁰ The five steps of the first phase were performed; however, divergent or distinctive elements for each group were of exclusive focus.

RESULTS

Participant Characteristics

All participants (N=22) had previously agreed to brain donation for

clinical research via the Uniform Anatomical Gift Act as part of their cohort study participation. Participants who self-identified as African American (n=8) or Latino (n=6) took part in cohort studies with optional brain donation. Participants who self-identified as White of lower income (ie, with a self-reported income \leq \$19,999) (n=8) belonged to a cohort study with brain donation as a requirement for cohort study participation. Participants were 92% women, with a mean age of 77 years, and had a median income range of \$30,000-\$34,999. Participants who self-identified as White of lower income had a median income range of \$15,000-\$19,999. Additional demographic characteristics, including median income levels and mean years of education, for the total study sample and by focus group are shown in Table 1.

Perceived Impediments to Brain Autopsy Completion

Participants discussed their postmortem preparations and outlined related plans, including interment and financial planning, previously shared with their loved ones. Notably, brain donation was included in their end-of-life plans. Across all groups, participants altruistically spoke of brain donation and espoused the belief that brain donation would benefit future generations, including family members. One participant noted, "...that's the one reason why I decided to donate my brain is because it may not save me, but it may save somebody's grandchild."

While all participants had agreed

to brain donation, they indicated potential impediments to completed brain autopsies upon death. Furthermore, each group identified specific perceived impediments to completed brain autopsies (Table 2).

Older African Americans and Older Latinos: The Role of Family

Both older African Americans and older Latinos voiced concerns that family members may not carry out their brain donation wishes due to family members' desires to have traditional interments for participants. Participants also expressed that family members may perceive brain donation and resulting brain autopsy as added inconveniences during the grieving process and interment procedures. Hence, both older African Americans and older Latinos questioned whether their loved ones would complete their brain donation plans. Older African Americans stated that their brain donation decision was discordant with their family members' intentions and worried that the lack of family buy-in may lead family members to not honor participants' brain donation wishes upon death. Older Latinos expressed concern that their brain donation wishes would not come to fruition due to a lack of family follow-through, although their loved ones had already expressed support for their brain donation decision.

Older Whites of Lower Income: The Role of Uncertainty

Older Whites of lower income spoke of their own uncertainty surrounding the processes of brain

Table 1: Participant characteristics by demographic group and total, N=22

	Number of participants	Women, %	Income, median	Age, mean	Years of education, mean
Older African Americans	8	88%	\$50,000 - \$74,999	75.5 years	18 years
Older Latinos	6	100%	\$20,000 - \$24,999	75.8 years	13 years
Older Whites of lower income	8	88%	\$15,000 - \$19,999	79.9 years	14 years
Total	22	92%	\$30,000 - \$34,999	77.1 years	15 years

donation and subsequent brain autopsy, such as who and when loved ones should call once a participant passes away. Due to their own lack of clarity, older Whites of lower income expressed an inability to outline to loved ones how to fulfill their brain donation wishes. Although loved ones knew of and supported their brain donation decision, older Whites of lower income believed family would be unclear as to how to carry out those wishes, and this would inhibit brain procurement at the time of death.

Participant-Identified Next Steps to Address Perceived Impediments to Brain Autopsy Completion

Participants led active lives with continuous education and learning as important values. Research served as another form of activity for participants as well as a mechanism for education and learning for themselves, their families and communities, and society at large. Participants, specifically older African Americans and older Latinos, indicated that education and learning assisted them with combatting

fear associated with AD and related suffering for both themselves and their family members. Older African Americans viewed education and learning as a means of “progression” for their communities, especially regarding AD. As such, older African Americans indicated that they spread information and awareness about AD to their families and communities, in part, through their research participation and plans for brain donation. Older Whites of lower income viewed research and brain donation as knowledge-building for

Table 2. Perceived impediments to completed brain autopsies and potential ways to address

Perceived impediment	Most affected population	Representative quote	A sample of potential ways to address
Uncertainty surrounding the processes of brain donation and brain autopsy	Whites of lower income	“There’s a process there when I’m dead or die. Hopefully, they’ll be there to know what this next step is. I’ve written it all down, but just so that they know.”	Continued engagement - brain donation Continued education - brain donation/ brain autopsy Printed materials - brain donation/brain autopsy Potential simulation - brain autopsy
Lack of family buy-in	African Americans	Participant 1: “It’s just something they didn’t want to—well, I had already done it. I told them it was—it’s already done.” Participant 2: “But the issue though with that is, will they honor your wishes?”	Family as participant Family engagement - loved one’s research participation Family education - role of research/brain donation Family education - process of brain autopsy
Lack of family follow-through	Latinos	“And so the children have to know that because my son said—one of my sons said, ‘I’m glad you’re telling me this. And I’m glad it’s written down because I would’ve fought hard not to have any of this done.’”	Family as participant Family engagement - loved one’s research participation Family education - role of research/brain donation Family education - process of brain autopsy

themselves and future generations.

Although all participants had previously agreed to brain donation, they expressed a need for continuous engagement and education regarding brain donation. Participants, specifically older Latinos and older Whites of lower income, wanted more information on the process of brain donation and subsequent brain autopsy, including the timeline of events from time of death to brain autopsy to interment. Older Latinos sought more information regarding brain donation considering their plans for cremation. The need for more engagement and education led participants to provide suggestions for researchers and their future engagement efforts regarding brain donation. Older Latinos indicated that researchers must make research “personal” and straightforward to illustrate the role and need for research and brain donation. Furthermore, older Latinos suggested aiming educational materials regarding research and brain donation toward adult children of older adults. Older Whites of lower income expressed an interest in viewing a simulated brain autopsy to facilitate their understanding. Older Whites of lower income also suggested that researchers provide methods for participants to advertise their involvement in research and brain donation to others in their communities, in part, to alert medical staff and other community members if they were to die (Table 2).

DISCUSSION

Older adults who are African American, Latino, and White of

lower income are underrepresented and understudied in longitudinal studies on aging with brain donation. Hence, a lower number of completed brain autopsies and resultant brain tissue exist for diverse older adults compared with those who are non-Latino White of higher socioeconomic status. Using qualitative research methods, we identified several perceived impediments to completed brain autopsies among older adults who self-identified as African American, Latino, or White of lower income and who have agreed to brain donation for clinical ADRD research. Across all groups, participants voiced concerns about their subsequent brain autopsies. Older African Americans and older Latinos expressed that a lack of family buy-in and a lack of family follow-through, respectively, may serve as impediments to subsequent completed brain autopsies. Older Whites of lower income spoke of their own uncertainty regarding the processes of brain donation and subsequent brain autopsy as a potential impediment to completed brain autopsies.

We are not aware of prior studies that have used qualitative focus groups to exclusively identify perceived impediments to completed brain autopsies as indicated by diverse older adults who have agreed to brain donation for clinical ADRD research. Previous studies on brain donation among diverse older adults have largely focused on the identification of barriers to brain donation agreement, not barriers to completed brain autopsies once agreement has been obtained.^{6-10,17,18} Potential participant-identified impediments

to completed brain autopsies can provide insight into postmortem challenges and can allow for the development and implementation of possible ways to address these perceived impediments to completed brain autopsies beforehand. Older African Americans indicated that a lack of family buy-in at the level of brain donation decision making may impede subsequent completed brain autopsies. Older Latinos identified a lack of family follow-through as a possible impediment to future successful brain autopsies, despite initial and explicit family member support regarding older Latinos’ brain donation decision.

Overall, both family buy-in and family follow-through are required for completed brain autopsies. Previous research has elucidated the important role of family members of older African Americans and older Latinos throughout the brain donation process – from engagement and education regarding brain donation to brain donation decision making to postmortem interment plans and brain autopsy completion.^{7,10,14,19} With the knowledge and agreement of older adults, researchers may consider increasing engagement with the families of older African Americans and older Latinos regarding the entire brain donation process - from engagement, education, and agreeing to brain donation to the completion of brain autopsies. More specifically, it is especially essential that family members of older African Americans are involved in decision making about brain donation (eg, reviewing, discussing, and signing the Uniform Anatomical

Gift Act), while it is particularly important that family members can easily access information regarding the brain donation wishes and interment plans of older Latinos.

Directly stemming from impediments and related methods to address the impediments as identified by older African Americans and older Latinos in the current study, we suggest that researchers continuously engage with the families of diverse older adults regarding the following topics: 1) research participation and what it entails; 2) the purpose of brain donation and its relation to ADRD research; 3) the brain donation wishes of older adults; 4) why it is important for diverse older adults to agree to brain donation and subsequent brain autopsy in relation to researchers' understanding and addressing ADRD among diverse older adults; 5) potential benefits of brain donation and subsequent brain autopsy to family members – such as more information regarding family health history- and future generations; and 6) the process of the brain autopsy itself, including what occurs during the brain autopsy to address potential fears regarding interment plans. Researchers may address the above topics using printed educational materials when engaging with families. For example, researchers may create brochures on brain donation that specifically address these topics. Brain donation brochures must be culturally and linguistically compatible with the family members of diverse older adults, including materials in the language spoken by the family members of diverse older adults and using images that

resonate with diverse populations. Researchers may also host a series of small gatherings comprising the family members of diverse older adults to address each of these topics. Moderators who are bilingual should conduct the small gatherings to meet the linguistic needs of the family members of diverse older adults. Most importantly, researchers may further develop or tailor suggested educational materials and activities to address the cultural needs of the family members of diverse older adults who have agreed to brain donation in their communities.

Older Whites of lower income in the current study also spoke of potential impediments to completed brain autopsies, including their own uncertainty surrounding the processes of brain donation and brain autopsy. They expressed concern that they may not be adequately able to outline the processes of brain donation and brain autopsy to loved ones. Hence, they feared that their brain donation wishes may be in jeopardy due to their own lack of understanding. Directly stemming from perceived impediments indicated by older Whites of lower income in the current study and their suggested ways to address these impediments, we recommend that researchers continuously engage with older Whites of lower income to discuss the following topics: 1) step-by-step instructions for loved ones once an older adult passes away, including who needs to be contacted; 2) a timeline of the brain autopsy, including the timeframe for initial contact with research staff once an older adult passes away and when

the funeral home or family will receive the older adult's body for interment; and 3) a visual simulation of a brain autopsy. Researchers may develop and use printed educational materials and audiovisual tools, and host small gatherings to address these topics with older Whites of lower income. Researchers may also discuss these topics and share the related materials with family members

Our current study findings elucidate that, while diverse older adults believe in and have agreed to brain donation for clinical ADRD research, they also identify ... the iterative need for family engagement and the need for continued education.

of older Whites of lower income to ensure the successful completion of brain autopsies. Above all, researchers may continue to create and modify educational materials and related activities to meet the needs of diverse older adults who have agreed to brain donation in their communities.

Although researchers are actively engaged in increasing brain tissue from underrepresented and under-

studied populations, a dearth of diversity in brain tissue persists, even with diverse older adults who have agreed to brain donation for clinical ADRD research. Our current study findings elucidate that, while diverse older adults believe in and have agreed to brain donation for clinical ADRD research, they also identify potential impediments to completed brain autopsies, including the iterative need for family engagement and the need for continued education. Hence, culturally compatible engagement approaches and related educational materials are required for all diverse older adults and their family members regarding brain donation and subsequent brain autopsy. With such information, researchers may effectively address potential impediments and facilitate increased rates of completed brain autopsies among diverse older adults who are underrepresented and understudied in clinical ADRD research with brain donation.

Study Limitations

The current study has limitations and strengths. One limitation pertains to the low participation rate among diverse older men. Future research may implement strategies, such as conducting focus groups exclusively comprising diverse older men who have agreed to brain donation, to understand their perspectives regarding potential impediments to completed brain autopsies. A second limitation relates to the exclusive recruitment of older Latinos who were English-proficient. Future research should explore potential impediments to

completed brain autopsies among older Latinos who have agreed to brain donation who prefer conversing in Spanish or Portuguese as well as among other subgroups of older Latinos who have agreed to brain donation. A third limitation concerns older African Americans in the current study, as they tended to have a higher median income level and more mean years of education than typical older African Americans. Hence, current study findings may not be generalizable to older African Americans across the United States. A fourth limitation pertains to one focus group being conducted for each group of diverse older adults, which likely precludes qualitative saturation regarding the identification of a complete array of potential impediments to completed brain autopsies among diverse older adults who have agreed to brain donation. Lastly, researchers should note that perceived impediments to completed brain autopsies and suggested methods and materials of engagement may be of utility when engaging with diverse older adults and their families regarding brain donation and subsequent brain autopsy – regardless of racial, ethnic, or economic categorization.

This study also has several strengths, including a well-characterized sample of diverse older adults who are community-dwelling and previously agreed to brain donation for clinical ADRD research. We used an established qualitative sampling algorithm; developed a focus group guide based on previous literature, clinic-based observations, and community-based exposure to and en-

agement with potential focus group participants; and executed high-fidelity qualitative data analyses.

CONCLUSION

In sum, further research is required to fully understand potential impediments to completed brain autopsies among diverse older adults who have agreed to brain donation for clinical ADRD research. Current study findings provide the foundation for understanding these diverse participant perspectives regarding potential impediments to completed brain autopsies. Our research also sets forth participant-identified next steps and related recommendations to assist researchers and others with designing and implementing culturally compatible engagement strategies and educational tools with the purpose of increasing brain autopsy completion rates among diverse older adults who have agreed to brain donation for clinical ADRD research.

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CONFLICT OF INTEREST

No conflicts of interest to report.

AUTHOR CONTRIBUTIONS

Research concept and design: Glover, Shah, Bennett, Wilson, Barnes; Acquisition of data: Glover, Bennett, Barnes; Data analysis and interpretation: Glover, Barnes; Manuscript draft: Glover, Shah, Bennett, Wilson, Barnes; Statistical expertise: Glover; Acquisition of funding: Glover, Bennett, Barnes; Administrative: Glover, Bennett; Supervision: Glover, Shah, Bennett, Wilson, Barnes

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