



Building a Legacy Through Brain Donation...Gone but Not Forgotten

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Background

- **Certain communities have been historically racialized and minoritized** by society such as communities with members with racial, ethnic, religious identities as well as disability status.
- In Alzheimer's disease and related dementias research it is estimated that **only 4% of brain donation program participants self-identify as non-Hispanic white.**
- People with differing abilities and disabilities are also **significantly underrepresented in brain donation programs.**
- **Few studies have recorded, tracked and shared data denoting the actual percentage of brain donation program participants and biomedical studies with a disability.**
- **Intentional inclusive** outreach, engagement, recruitment and retention efforts are not optional but **essential to advancement of science.**
- **Minoritized** participants say **yes at a lower rate** than their non-Hispanic white peers.
- Brain donation participation barriers among members of **Minoritized Communities** and their family members include:
 - Concerns and **misconceptions about brain research** and the **process of harvesting** the brain
 - **Mistrust**
 - **Religious beliefs**
 - **Role of family members**

Study Objective

To utilize the power of storytelling to honor and elevate the lives of a diverse group of community-dwelling brain donation participants with intersectional vantage points.

Participant Demographics

3 Community-Dwelling Adults from Diverse Backgrounds
Study participants (n=3) had a **mean age of 60.67 years** (SD±8.33)
Male participants comprised (n=1)
Female participants comprised (n=2)
Participants were living with either Parkinson's disease, Down syndrome or bipolar disorder *and* Alzheimer's disease or a related dementia

Thank You to Our Gracious Donors:
Michael, Jill, and Toni



Examples of the Semi-Structured Interview Questions

- What are some of your *favorite memories with your loved one* that really captured their personality?
- How did your loved one and your family *decide to participate in the brain donation* research program?
- What do you hope *science, researchers, and future families will gain* from your loved one's gracious gift?
- What would you want, especially those who never got the chance to meet him/her? *people to remember or know about your loved one*

Exemplary Quotes

- “Well, it's very, very simple. I was not ready to give up. I just and I'm still not ready to every once in a while, I check with my daughter [Annie] and make sure his brain is being taken care of. Was not ready to give up, and if that somehow leads to something that will put an end to this horrible, I mean, you can't even, you can't, you just don't have any idea what it's like to see the way a disease can just destroy a person. I mean, every single aspect of that person, he didn't look the same, he didn't act the same. It just. I just don't, I just don't want to see this fight ended until somebody wins.” **Spouse & Primary Caregiver**
- “not all Jill's friends had down syndrome, because they were all in Special Olympics and did many different things, but at the same time, the focus was let them do their thing, but if you want them to act like, quote-unquote, and I hate the word normal, a normal child, or adolescent, or teenager, they have to be exposed with these other normal kids. Yeah, and so they... the student body and the other kids in the school really, embraced everybody and loved them, and they weren't just gonna let them be, like, off to the side, like, that just wasn't gonna fly. But I just thought that was so beautiful, and I think it kind of...maybe broke some of the mold of that stigmatism” **Sibling & Primary Caregiver**
- “When Toni was diagnosed, she had always said she wanted to donate her brain. It wasn't even a discussion and to be honest we didn't think about it until she died, and I, you know, I told her daughters and said your mom wanted to donate her brain because she wants to further the study...It wasn't up for discussion. It's what she wanted. You know, when she was diagnosed and it was just very matter of fact. She's like, I'm gonna donate my brain. And I said, I think that's great.” **Sibling & Primary Caregiver**

Methods

- One-on-one semi structured interviews were conducted to glean insight into our research question; how did your loved one and their family members decide to participant in the brain donation program among community-dwelling adults with multiple overlapping social identities.
- Participants were asked to complete either an in-person or virtual 90-minute semi structured interview. Logistics based on preferences of the participant.
- The primary interviewer (LAW) self-identifies as an African American female interdisciplinary clinician and research scientist. The second interviewer (HS) self-identifies as a Mexican American male nurse and emerging scholar. Both are associated with the University of Pittsburgh.

Conclusion

The unique perspectives and lived experiences of each donor and their loved ones were grounded in the collective desire to make a difference in the fight against AD/ADRD. The commitment to building a legacy and advancing the scientific strides against AD/ADRD is unmeasurable. Each ethnographic narrative shared reiterates the need to identify effective, sustainable means to irradicate AD/ADRD.

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