

Frontotemporal dementia caregivers and researchers: Partnering for brain donation [Community-based participatory research project RFA]

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Specific aims:



1. To identify potential barriers to caregiver participation in brain donation programs among FTD families.
2. To design a questionnaire to assess the impact of issues, attitudes, concerns and barriers to brain donation as identified by the focus group content analysis.
3. Write a larger collaborative grant proposal to disseminate the questionnaire to a broader community of dementia caregivers and design and test an effective educational intervention strategy.

Methods



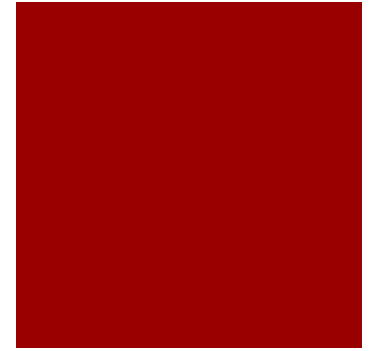
- Hold 2 focus groups (afternoon and evening) in three cities:
- Group A (Philadelphia) are members of an existing FTD caregiver support group who have access to a clinical research center where autopsy services are readily available.
- Group B (Indianapolis) no formal FTD caregiver support group but have local access to a clinical research center where autopsy services are available (less than 100 miles away).
- Group C (Boston) will consist of caregivers who are part of an FTD specific caregiver support group but do not have access to a clinical research center with available autopsy services (within 100 miles).

Participants



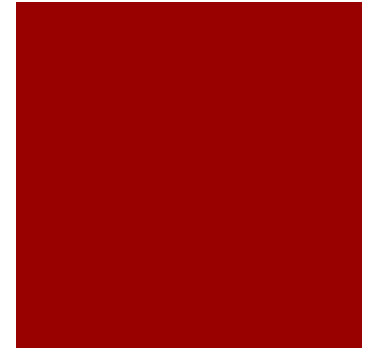
Gender	Race	N
Male	Caucasian	6
Female	Caucasian	22
	Asian	1
Missing	Multiple	1
Total		30

Relationship to Person with FTD



Relationship	N
Spouse	17
Adult child	8
Sibling	1
Missing	1
Other	3
Total	30

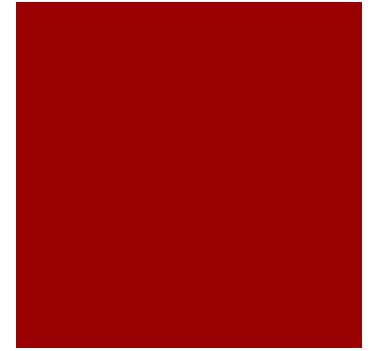
Religious Affiliation



Religion	N
Protestant	9
Catholic	13
Jewish	4
None	1
Other	2
Missing	1
Total	30

Collaborative process

- Requires time and attention
- Open lines of communication
- Mutual trust and respect
 - Community partner has much to offer
 - Invaluable access to persons with FTD and caregivers
 - Deep understanding of needs
- Worth the time and effort
 - Recruitment goals seem to be met easier
 - Synergy of ideas



Seven prominent themes emerged from transcripts:



- How interested and willing are you to participate in research?
- Who makes the decision about brain donation?
- Who initiates the discussion?
- When and how is the topic of brain donation presented?
- What factors contribute to [mis]understanding brain donation?
- What motivates brain donation?
- Barriers to brain donation.

How interested and willing are you to participate in research?



- Many families express an interest and willingness to participate in research but are naïve to the specifics of what it means and details of how to get involved.
 - *We want to help but we don't have enough information.*
 - *I always assume it makes sense to have a brain autopsy. What's the difference between the brain autopsy and brain donation?*
- Navigating the logistics of enrollment in a research program are complex and daunting
 - *And you say you can't have a brain autopsy unless you're affiliated with the research project?*
 - *I'm a scientific researcher. ...I'm in the field and it was still very difficult for me to figure out how to do this... I really had to keep... we had to keep at it.*

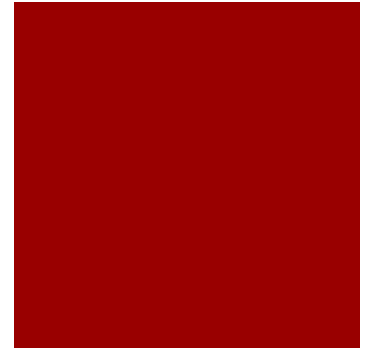
Who makes the decision about brain donation?

- Wide variation among families in terms of their comfort with the patient being involved in discussion on brain donation. Many caregivers are most comfortable if the topic is introduced early in the disease course so the patient can make his/her wishes known.
 - *My husband said absolutely from the very beginning that that was something that he wanted to do. He wanted to participate.*
 - *Hopefully the person that has been diagnosed will have some input and can say yes, I want my brain to be used for research.*

Who makes the decision about brain donation?

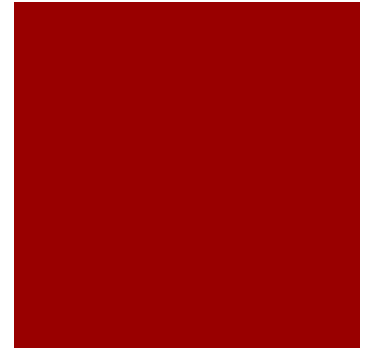
- However, if the issue is not raised until after the patient has lost the ability to make decisions, the topic should not be discussed in front of the patient.
 - *When she's in diminished capacity and can't respond to him he should have never brought that up.*
 - *I think if [the patient is] still able to consent and understand it then it definitely should be brought up. If [the patient is] incapable of giving any kind of opinion then it needs to be discussed separately, when they're not in the room.*

Who makes the decision about brain donation?



- If the patient is unable to express his/her own wishes, there is wide variability among families as to who should have a say in the decision.
 - *We talked about it as a family and we decided that this was definitely something we wanted to do.*
 - *Everybody has got to make the decision. It's got to be unanimous.*
 - *In terms of the people I would contact about decision making it would be a couple of my siblings only and then I would make a decision.*
 - *[He] does want to go talk to the Rabbi about donating his brain.*

Who initiates the discussion about brain donation?



- Little consistency as to who first introduces the topic of brain donation: physician, another member of the healthcare team; or a member of the family who first raises the subject.
 - *The assistant...talked to us about it.*
 - *Our neurologist definitely talked to us*
 - *Actually, I was the one who asked the question. The neurologist didn't approach me.*

When and how is the topic of brain donation presented?

- Families feel that it is inappropriate and insensitive to bring up the issue of brain donation at the first visit:
 - *The first thing that [the physician] said to [my parents] when he walked in was: "Have you considered brain donation?" They were really put off.*
 - *We were so blown away at the beginning that you could have talked us into selling shoes.*
- Neither should the topic be left till the patient is in end-stage disease, as family members may take this as a sign that their loved one is near death:
 - *After she was wheelchair ridden, the doctor [asked]... if we would like to donate her brain for research. My Dad, to him it's just like that's just a sign of death.*

When and how is the topic of brain donation presented?

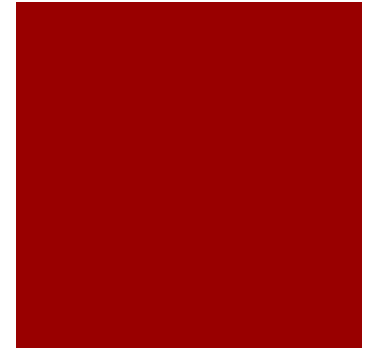
- Most families feel right time is during the second or third visit after diagnosis.
- The topic should be re-visited throughout course of illness, with informative written materials provided and family having opportunity to ask questions when they are ready, as the disease progresses.
 - *In terms of when you should bring it up would be ...maybe the second [visit] because ...by the second appointment I think [the reality of the diagnosis] sets in.*
 - *Yes, [revisit] it with the caretaker... I just feel like I need a little reminder and a little more explanation.*

Factors contributing to [mis]understanding brain donation?



- In all focus groups there was great confusion around what the brain donation procedure entails and what the caregiver must do at the time of death.
 - *I'm unclear about what to do, who to call, what to do at the time of death.*
 - *What are you physically going to get back? When is the report going to be due? When are you going to be able to get the final diagnosis?*
 - *And there's no charge for the family for that, is there?*
 - *[The brain] doesn't go back the funeral home?*

Factors contributing to [mis]understanding brain donation?



- *[The brain] doesn't go back the funeral home?*
- *What will happen at [the medical center]?*
- *Do you know how long it takes to...get the person's body back?*
- *I just feel like I need some correspondence or some reminders or something, some follow up periodically.*
- *I have too many things on my mind to wonder, to wonder okay what am I supposed to do. I need it black and white.*

What motivates brain donation?

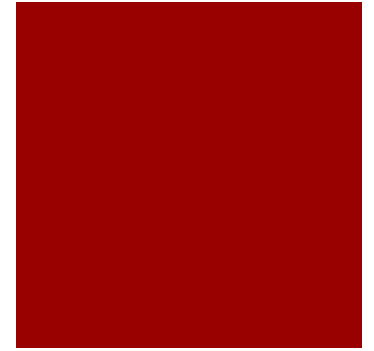
- Reasons for agreeing to brain donation include: getting a definitive diagnosis, providing risk information for family members, and to advance scientific knowledge:
 - *It's really the only way for them to know for sure what the diagnosis is.*
 - *Because there are so many in the next generation and now even grandchildren coming along that people...want to know [if there are] genetic factors there.*
 - *So one day, maybe not in my lifetime, but one day a doctor can look at families like us and not say "I don't know" and not say "I don't have an answer."*

Barriers to brain donation



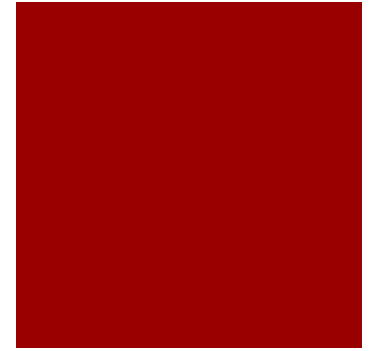
- Content analysis of the focus group transcripts revealed a number of underlying issues that act as barriers to the families' participation in research including brain donation:
 - Inappropriate and/or unmet expectations around clinical care;
 - Confusion about communication with clinical care team;
 - Lack of a rapport with clinical team;
 - Assumption that religion proscribes brain donation; and
 - Inconsistency among state laws around power of attorney.

Barriers to brain donation?



- *I still don't feel real comfortable and I thought she said she would get some information to me. She asked if we were a part of that and I said yes I think we signed papers but I felt like ok, they've lost this because she's asking me again.*
- *She said she would check but I've not heard anything. I've not heard from her...Another thing, a part of it I would like to hear results of when he was there for the appointment. I don't have to know all of the details but just a little summary of how they felt about him.*
- *As long as it doesn't cost us anything and that's another thing that I think should be mentioned. There is a cost factor.*
- *We were very blessed to have a rapport with our doctors, our family, our funeral director grew up and we were very, very, very blessed.*

Limitations



- Problems with technology in first focus groups
- Lack of minority representation
- Participants' emotional/social needs outweighed purpose of the focus group where no support groups are available
 - Develop appropriate support services

Conclusions



- Strong interest among many caregivers to participate in research and contribute to advancing knowledge about FTD. BUT a significant amount of miscommunication about brain donation exists among physicians and researchers and caregivers.
- In all focus groups—especially the ones conducted where caregivers do not have access to a support group—a significant proportion of the discussion was dedicated to the caregivers' sharing their stories, their feelings of isolation, and general frustrations around dealing with this rare disease.
 - Caregivers need support

Conclusions



- Brain donation is a very serious and important matter and researchers should treat it as such.
- Families would like to see a professional packet of material prepared for them—not poorly over copied photocopies mailed to the home.
- Consider the wording on the materials carefully.
 - Patient is still alive when the family is pre-planning for an autopsy, the paper work should reflect that.
 - The questionnaire for example, should not ask for “Name of Deceased”.

Conclusions



- Questions about religion and brain donation were raised.
 - Some caregivers not sure how their religion feels about organ donation in general nor brain donation specifically
- Families had many questions about the autopsy process itself.
 - Want information and specifics
 - Want a simple checklist of what to do when their loved one passes on

Conclusions



- No consensus emerged yet as to best time to introduce the subject of brain donation
 - Perhaps after 2 or 3 visits
- Does appear that the topic requires ongoing conversations between the caregiver and the clinician/researcher.
 - Some caregivers are not sure what they signed and what it means.
 - Would like some ongoing discussions.
- Pre-existing relationship between caregiver and the clinician who broaches the subject may be a salient factor in the caregiver's feelings about brain donation and the general attitude toward participation in research.

Next Steps



- Develop informative booklet for families—work with NIA and ADEAR
- Develop training materials for clinical staff on key communication issues
- Increase sharing of program specific information with AFTD as patient/family advocates
- Expand number of caregiver support groups available across the US
 - Explore collaboration between AFTD and ADRC/ADC centers

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