Frontotemporal dementia caregivers and researchers: Partnering for brain donation

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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.

Collaborative process

- Requires time and attention
- Open lines of communication
- Trust and respect
- Worth the time and effort
    - Recruitment goals seem to be met easier
    - Synergy of ideas

Conduct focus groups

- 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 not part of an FTD specific caregiver support group but do have access to a clinical research center with available autopsy services (within 100 miles away).

Findings to date

- Surrogate decision-making is difficult for some families but not all.
- Some family members are quite comfortable in making the decision to consider brain donation.
- Others described difficulty in making that decision on behalf of the patient if the patient had not specifically been involved in the discussion, consent process or had mentioned an interest in research in the past.

Findings to date

- 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”.

Findings to date

- No consensus emerged yet as to best time to introduce the subject of brain donation
- Does appear that the topic may require ongoing conversations between the caregiver and the clinician/researcher.
- 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

- Focus groups scheduled for Indianapolis October 15th and Boston October 28th.
- Meeting scheduled at NIH with program officers and all grantee partners
- Paper presentation at GSA November 18th