



SCHOOL OF MEDICINE

INDIANA UNIVERSITY

FTD Family Caregiver Research

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Outreach and Recruitment Core

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I have biases like everyone else.

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- Research on FTD, persons with FTD and their caregivers is growing.
- Intervention research vs examining burden and stress
 - Tailored Activity Program (O’Conner et al., 2017)
 - OT intervention with individualized activities for CG to engage the person with FTD in meaningful activities
 - Focus group study of FTD caregivers and brain donation (Austrom, Dickenson, Denny et al., 2011)
 - Identify barriers to research participation and brain donation and how to communicate with CG
- LEADS Study
- bvFTD and PPA Caregiver Needs Assessment (Austrom, Morhardt et al., 2018)



Tailored Activity Program (TAP)

(O'Conner et al., 2017)

- Successful randomized controlled trial helped reduce behaviors of concern in dementia
- Implementing participation in tailored activities preferred by and previously engaged in by PWD
- Protocol has scope to target both the person with FTD and CG
- PWD was engaged in meaningful activities; offers CG respite
- CG receives education about interventions and self efficacy
- using activities to reduce characteristic behaviors in FTD, improving quality of life and caregiving experience in FTD



FTD and LEADS

- If they meet diagnostic criteria for FTD or are found to have FTD mutations they will be sent to ALLFTD.
- What should happen is that ALLFTD sends us all that they recruit as clinical FTD who turn out to have amyloid and are reclassified as EOAD.
- We want all early onset disease.



Clinical Site	Principal Investigators
Butler Hospital	Stephen Salloway
Columbia University	Lawrence Honig
Emory University	Thomas Wingo
Houston Methodist Hospital	Joseph Masdeu
Indiana University	Liana Apostolova
Johns Hopkins University	Chiadi Onyike
Massachusetts General Hospital	Brad Dickerson
Mayo Clinic-Jacksonville	Neill Graff-Radford
Mayo Clinic-Rochester	David Jones
Northwestern University	Emily Rogalski
University of California-Los Angeles	Mario Mendez
University of California-San Francisco	Gil Rabinovici
University of Pennsylvania	David Wolk
Washington University	Gregory Day
Banner Health	Alireza Atri



There is an abundant literature regarding the experience of caregiving for persons with AD, however, there are very few studies examining the experience of caring for persons with FTD and none that have compared behavior and language variant caregivers. This qualitative study elicited the lived experience of caregivers specifically related to:

- Process of obtaining diagnosis
- Most challenging things participants had to deal with supporting/caring for the person with the diagnosis (PWD)
- What helped or hindered coping and day to day living
- What advice caregivers would offer healthcare providers

Semi-Structured Qualitative Interviews:

- Conducted 1X1, face-to-face or by phone
- All interviews were audio-recorded and transcribed. (Video-recorded: IN)
- Multiple, intentional readings of transcripts for content analysis and development of emerging themes.
- Researchers discussed emergence of themes noting areas of agreement/disagreement and similarities and differences between profiles

Sample:

- Purposive sampling was used to recruit caregivers (5) of persons with bvFTD (Indiana U) and (5) PPA (Northwestern U)



Diagnosis Journey

- Obtaining an accurate diagnosis was difficult and lengthy, multi-year process; with bvFTD taking an average of X more years than PPA.
- Finding knowledgeable healthcare providers, including neurologist, neuropsychologists, psychiatrists and other was a challenge for most



Most challenging aspects of caregiving

- Experiencing difficult and uncomfortable emotions: loneliness, depression, fear,
- Adapting to changing roles related to PWD inertia, lack of insight, and personality changes
- Experiencing significant financial and legal challenges; with bvFTD caregivers engaging legal remedies that changes marital/family structure to protect future
- Grieving developmentally non-normative losses due to younger age of onset



Key coping strategies

- All respondents identified support groups, individual counseling as essential avenues to talk and learn about the disease
- Develop a life outside of the diagnosis and the PWD
- Get respite care earlier rather than later
- Gain knowledge about diagnosis
- Develop good self-care habits



Advice for Healthcare Providers

- Without exception all respondents advise the neurologist and neuropsychologist to speak with care partner one-on-one, without the PWD present
- Provide a “roadmap” or “checklist” of what information needs to be provided for diagnosis and noting progression
- The concept of the progressive nature of the illness was not understood until far later in the diagnosis.
- Refer to social work early on to help with understanding of diagnosis, resources, and coping



Conclusions and Next Steps

- Preliminary analysis of in-depth interviews of bvFTD and PPA caregivers reveal both similarities and differences within the caregiving experience.
- Further analysis of this narrative data and further research is needed to more fully understand the experience of FTD caregivers and guide health care professionals in the development of appropriate interventions.



Care vs. Cure

Just because we cannot cure FTD, doesn't mean we don't care.



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Thank you
Any questions?

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We kept treating ... and managing symptoms... and symptom management was what allowed us to keep moving through the journey. We treated depression and we added another antidepressant. We added mood stabilizers, and they kept covering us for a season, but we just kept pursuing it, [the diagnosis] because the symptoms just kept expanding, which we now understand was the fact that it's a progressive disease. (F4)



Challenges of caregiving

You start to lose yourself. I can see that. One of my sisters says I've closed off a lot. I don't like to talk about this and sometimes I don't want to talk. I'm never not sad. (P1)

"I didn't get a chance to tell my mom goodbye, because I no longer have a mom.." (F1)

[the lawyer] was really careful to explain that it was a legal separation that would be dismissed after everything was done, that it wasn't a divorce, that we wouldn't have to file divorce papers or anything like that. After I understood it I'm like okay this is the system they have set up. (F5)



I think the support groups helped me understand what I'm going to be dealing with... hearing these stories....I'm a nicer person since I've been in therapy. (P5)

I have learned there is a next stage and that is giving yourself permission to think personally has only come about in the last 3-4 months where there is less guilt involved claiming your life... and I feel guilty a lot of the time. (P2)

My PPA support group most helpful. Monthly meeting was helpful but in the beginning I sat there in disbelief – there's no way that he will be incontinent, or have these behaviors. I sure learned quickly from my PPA sisters – some things were the same way, but others were not. (P4)



I think there have been so many little episodes where I want to share information that would be helpful but I'm worried I don't want to share it in front of J. Some days – I want to have in some of these initial meetings with the neurologist – have some time alone with the doctor....I think a checklist given to the family prior to an appointment would be helpful to the family. It would help families stay on track with relevant information, give families a preview of what they will most likely be facing, and reassure them that they didn't leave out any key information when they are meeting with the doctor/practitioners. (P5)



MEDICAL MANAGEMENT

Recommendations

- Holistic, person-centered approach
- Role of medical providers
- Common comorbidities of aging
- Non-pharmacologic interventions
- Pharmacological interventions when necessary
- Person-centered plan for possible medical and social crises
- End-of-life care discussions



Pharmacological Interventions

- Do have a place in the care and treatment of PWD
- Should be carefully considered once non-pharmacological interventions have been exhausted
- Most beneficial when used in combination with non-pharmacological interventions
- A plan to discontinue pharmacological interventions must be implemented after 3 – 6 months as many BPSD will resolve