

Disease Impact of FTD

Understanding the lived experience of persons affected by frontotemporal degeneration (FTD) including those diagnosed, their families, and caregivers

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Disclaimer: Dr. Tatton contributed to this work while an employee at the AFTD, before her transition to Alector.

Poster #56556

The FTD Disorders Registry advances the science through surveys and connecting persons affected with FTD to research opportunities.

BACKGROUND

FTD is a group of rare brain diseases that cause myriad progressive changes to behavior, personality, language, and movement with onset typically before age 60. There are currently no treatments or cures.

The FTDDR is a regulatory-compliant, web-based portal that functions as both a Contact Registry and Research Registry for persons affected by FTD to amplify the patient/family voice and facilitate research.

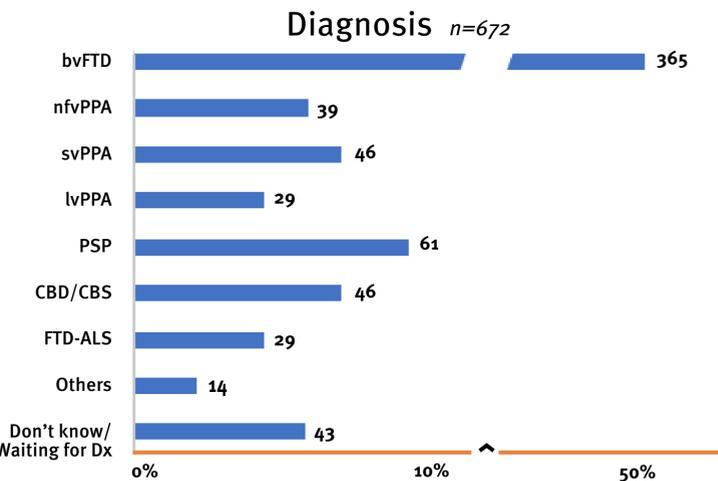
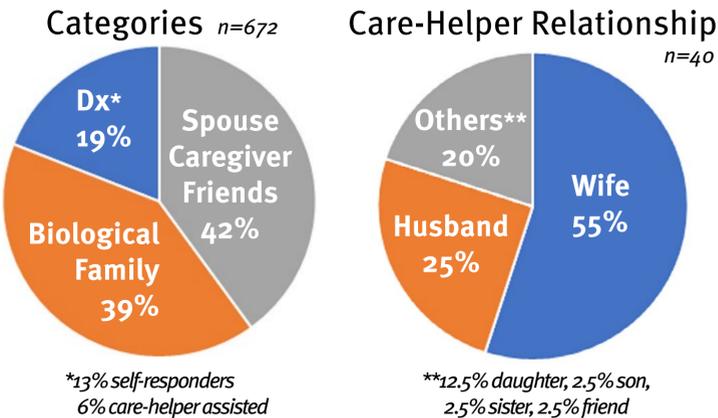
More than 4,000 registrants are enrolled in the FTDDR with 43% consented to ongoing research data collection via Registry surveys.

The Disease Impact Survey was designed to characterize person-centric perceptions of FTD disease manifestation and the impact to those diagnosed and others.

METHOD

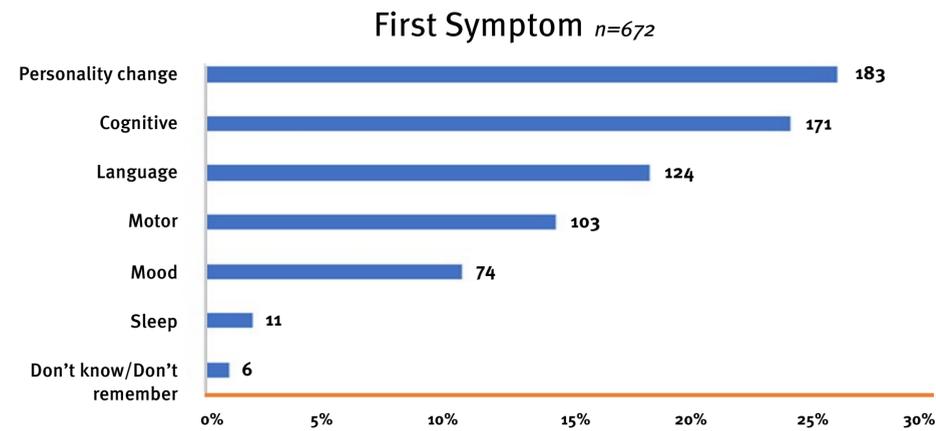
The 35-question survey was administered online via the Research Registry to 672 participants (205 male; 467 female) between March 2017 and January 2021. Multiple-choice style questions collected details about the diagnosis, symptoms, and daily life functionality. It also queried how the lives of people around diagnosed persons are affected.

SURVEY PARTICIPANT DEMOGRAPHICS

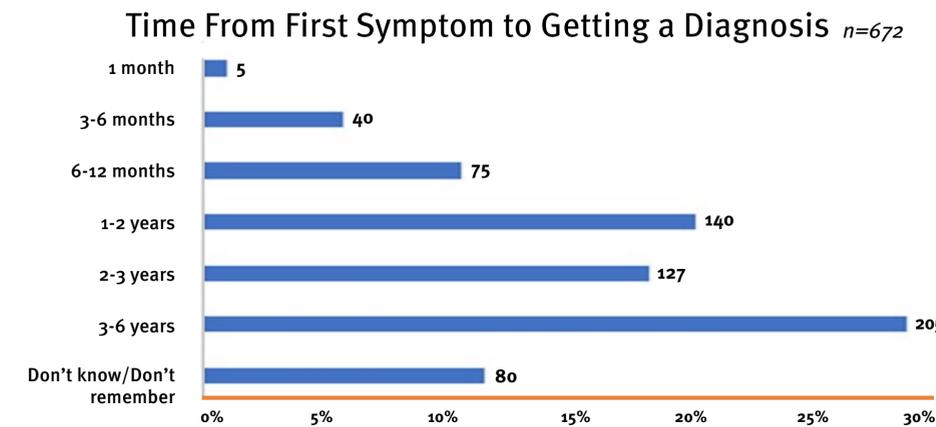


bvFTD = behavioral variant FTD
 nfvPPA = primary progressive aphasia: nonfluent agrammatic aphasia
 svPPA = primary progressive aphasia: semantic
 lvPPA = primary progressive aphasia: logopenic or logopenic dementia
 PSP = progressive supranuclear palsy or Richardson's syndrome
 CBD/CBS = corticobasal degeneration/corticobasal syndrome
 FTD-ALS = FTD with amyotrophic lateral sclerosis or FTD with motor neuron disease (MND)
 Others = include multiple system atrophy (MSA), non-specific FTD, genetic FTD, combination FTD

SYMPTOM ONSET and FTD DIAGNOSIS



- 51% reported first symptom onset at <60 years of age
- 78% noted more than one symptom before seeking a diagnosis

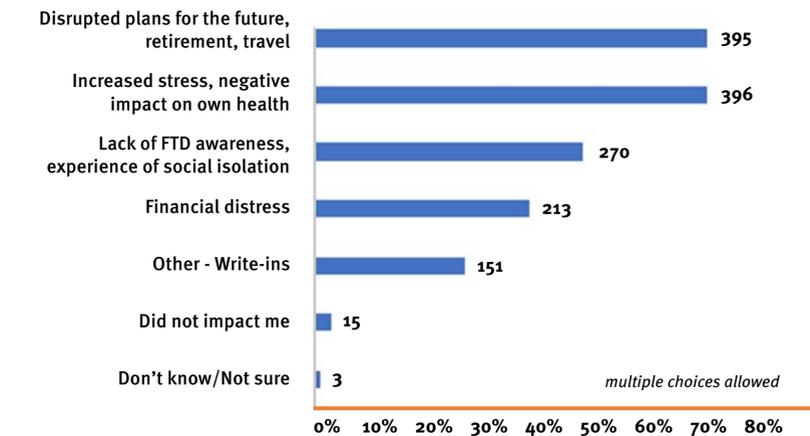


- 44% waited more than 6 months after the first symptom to see a doctor
- 52% required seeing 3 or more doctors before an FTD diagnosis was determined
- 53% were given a different diagnosis prior to FTD, including depression, anxiety, MCI, Alzheimer's, Parkinson's, bipolar disorder, mid-life crisis, menopause

IMPACT to DAILY LIFE

- 75% of FTD-diagnosed persons are living at home
- 30% FTD-diagnosed reported requiring assistance with one or more daily activities
- 43% family members, caregivers, and friends reported FTD-diagnosed required assistance with one or more daily activities
- Most difficult symptoms on a daily basis included language/communication, apathy, inability to plan/complete daily tasks, and lack of judgment/emotional control

Negative Impacts to Family Members and Friends



- Write-ins included criminal charges, emotional issues, fear of passing disease to kids, job issues, and the unpredictability of what to expect as the disease progressed
- One write-in respondent noted, "How did it not impact my life, is a better question."

CONCLUSION

FTD is a devastating disease that hinders a person in the prime of life from performing basic mental and/or physical daily tasks, and in most cases changes the person's personality and behaviors. The Disease Impact Survey captures these elements from the lived experience and demonstrates that FTD profoundly affects not only the person diagnosed, but also family, friends, and caregivers.