

## A sub-cohort assessment of the FTD Insights Survey

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www.FTDregistry.org



www.TheAFTD.org

### Background

Diverse representation in research participation is paramount to producing study outcomes that are generalizable to a broad population.

Despite efforts to promote inclusionary recruitment, racial/ethnic groups are underrepresented in FTD research.

Collecting insights from affected members of under-represented communities on early disease symptoms, the diagnostic journey, and the functional impacts of FTD will better elucidate health inequities, guide needed resources, and assist in the creation of more inclusive, person-centered research study designs.

### Methods

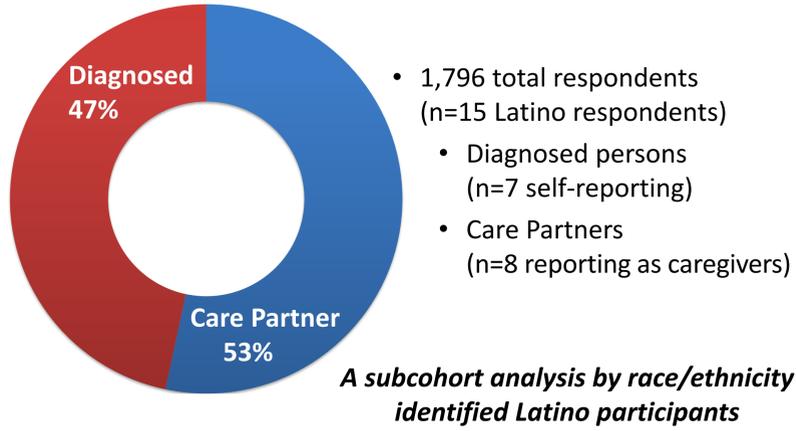
In preparation for an Externally Led Patient-Focused Drug Development meeting, the Association for Frontotemporal Degeneration (AFTD) and the FTD Disorders Registry (FTDDR) collaborated to develop the FTD Insights Survey.

This 191-question online survey was administered by the Registry and distributed through email and social channels by AFTD, FTDDR, and GENFI.\* Nearly 1,800 people completed the survey between October 2020 and March 2021. The primary geographic scope was the U.S. and Canada.

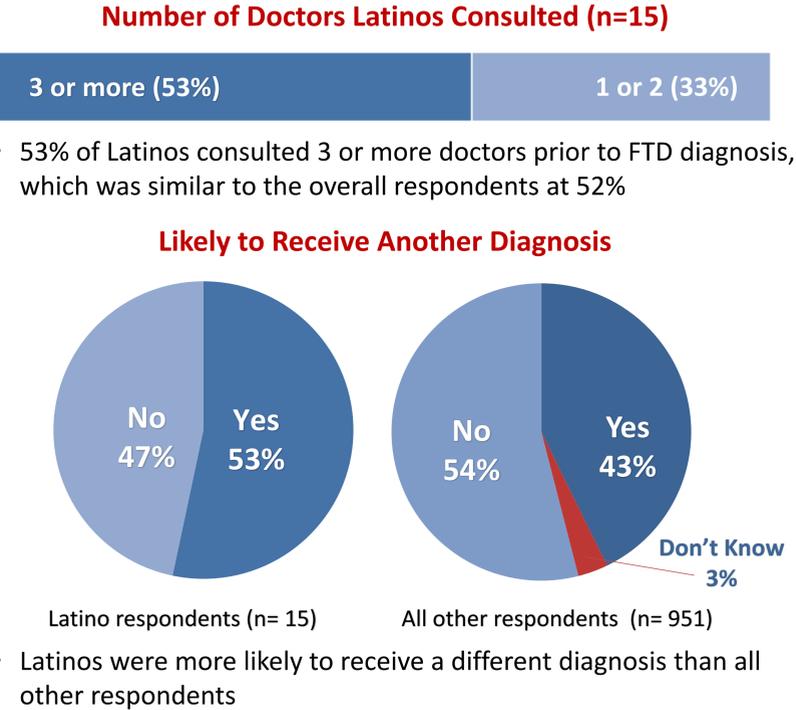
Persons impacted by FTD were invited to share their experiences from their perspective. Respondents were asked about diagnosis, symptoms, and willingness to participate in research and seek treatments.

**This online survey was designed to assess the lived experiences and perceptions of persons diagnosed with FTD, their family members, and caregivers.**

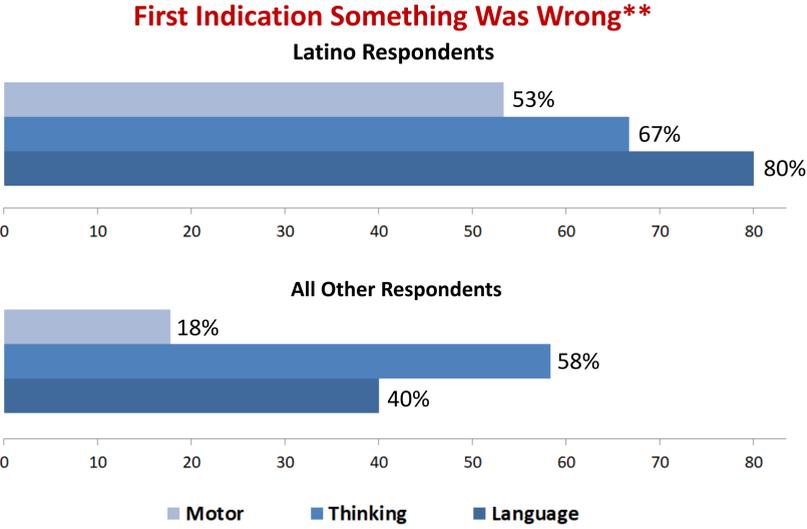
### Participant Survey Data



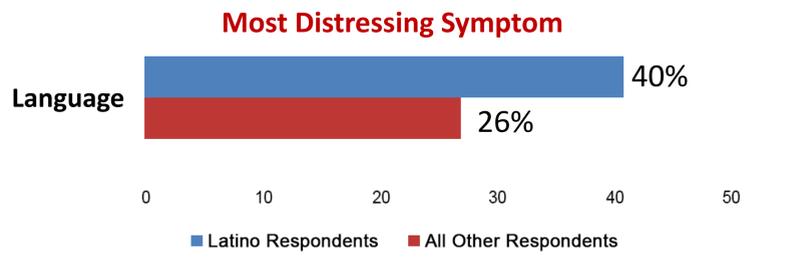
### Access and Diagnosis



### Symptoms

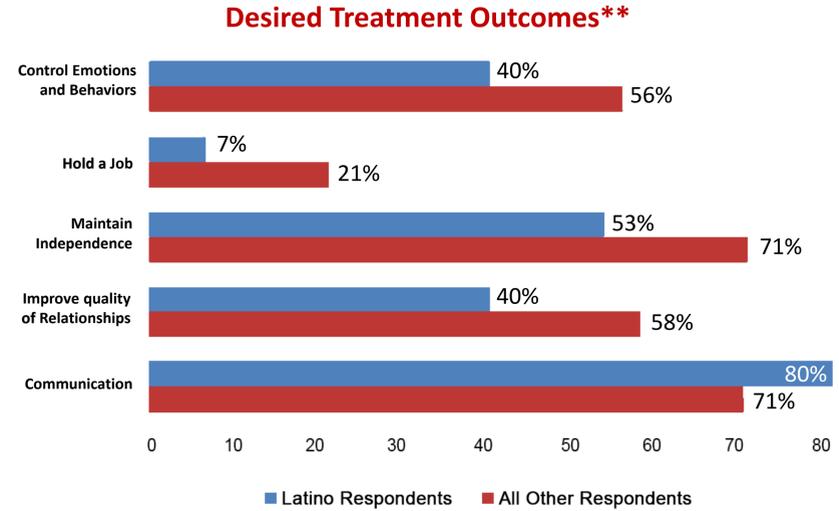


- Latinos were more likely to report motor, thinking and language as first symptoms compared to all respondents
    - Motor = tremor balance and performing movements
    - Language = speaking, finding words, and understanding
    - Thinking = solving problems, making judgement and organizing
  - Latinos had nearly equivalent representation of bvFTD, PPA, and PSP, whereas the overall cohort was comprised of 60% bvFTD
- \*\*Note: More than one response permitted*



- Latinos (40%) were more likely to indicate declines in language as a distressing symptom compared to all other respondents (26%)
  - Language = speaking, finding words, and understanding

### Disease Impact and Treatment



- Latinos were more likely to endorse treatment to improve the ability to communicate compared to all other respondents
- \*\*Note: More than one response permitted*

### Conclusions

The Latino perspectives reported on the FTD Insights Survey represent a small sample size of individuals. Their experiences overlap with other respondents, yet a key difference was more difficulty obtaining an accurate diagnosis.

Latino participants had an above average level of education (100% associates degree or higher), did access an FTD diagnosis/care, and were motivated to complete the survey, which may not represent Latinos in the general population.

Many questions remain regarding the lived experience of FTD in Latino populations. Addressing these issues is a key step to improve diagnosis, care, and access to research opportunities.

\*GENFI = The Genetic Frontotemporal Dementia Initiative – UK Cohort