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Behavioral Variant Frontotemporal Degeneration (bvFTD): Exploring the Diagnostic Journey

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BEHIND EVERY DELAY IS A FAMILY WAITING FOR ANSWERS

INTRODUCTION

Behavioral variant frontotemporal degeneration (bvFTD) is a form of FTD characterized by progressive changes in behavior, personality, and executive function. Key symptoms include apathy, disinhibition, loss of empathy, lack of insight, and speech and language difficulties. The overlap of these symptoms with psychiatric and other neurological disorders frequently leads to misdiagnosis and substantial delays in obtaining an accurate diagnosis, causing frustration and distress for patients and their families.

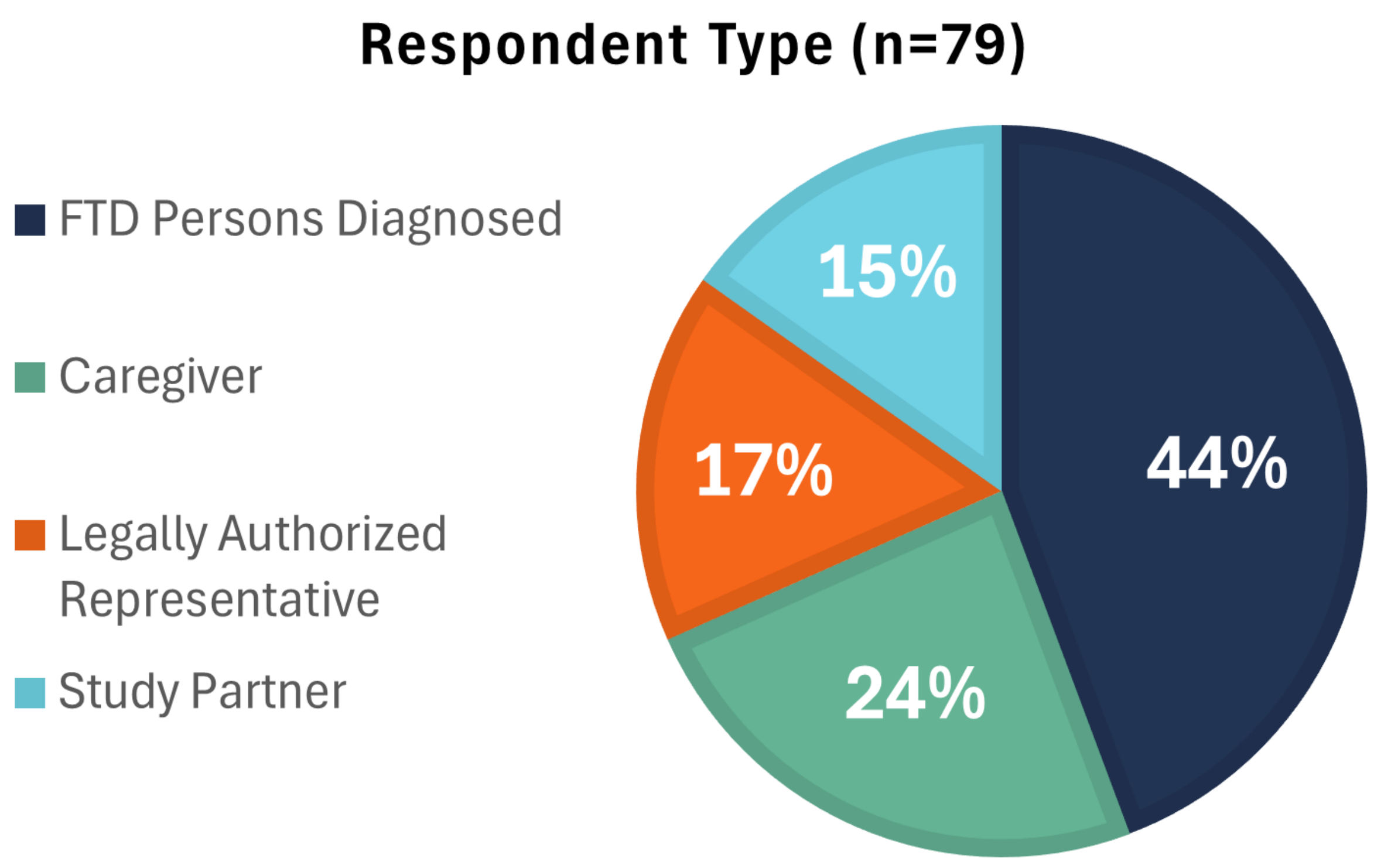
OBJECTIVE

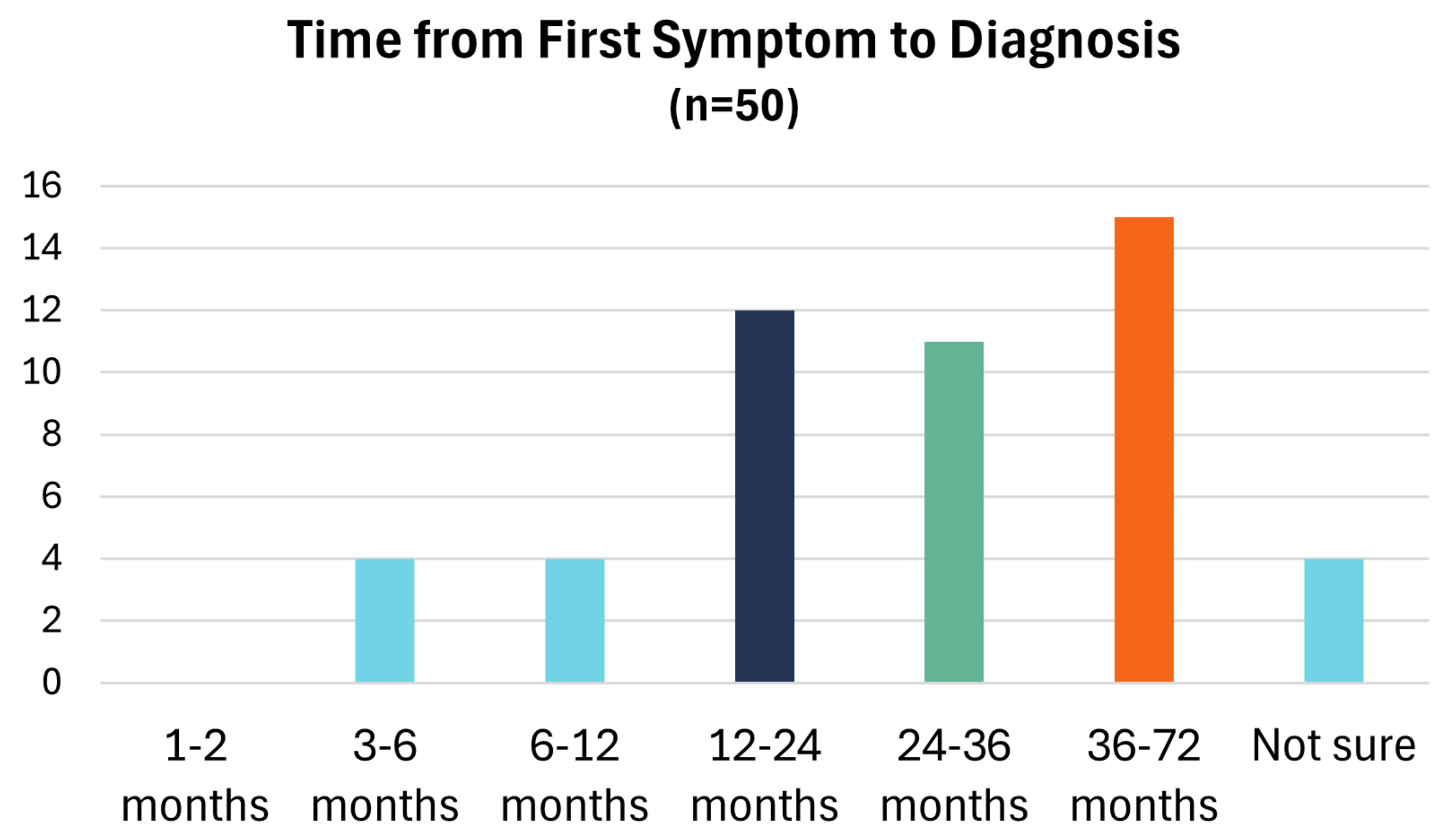
Characterize and describe the diagnostic journey of individuals impacted by bvFTD.

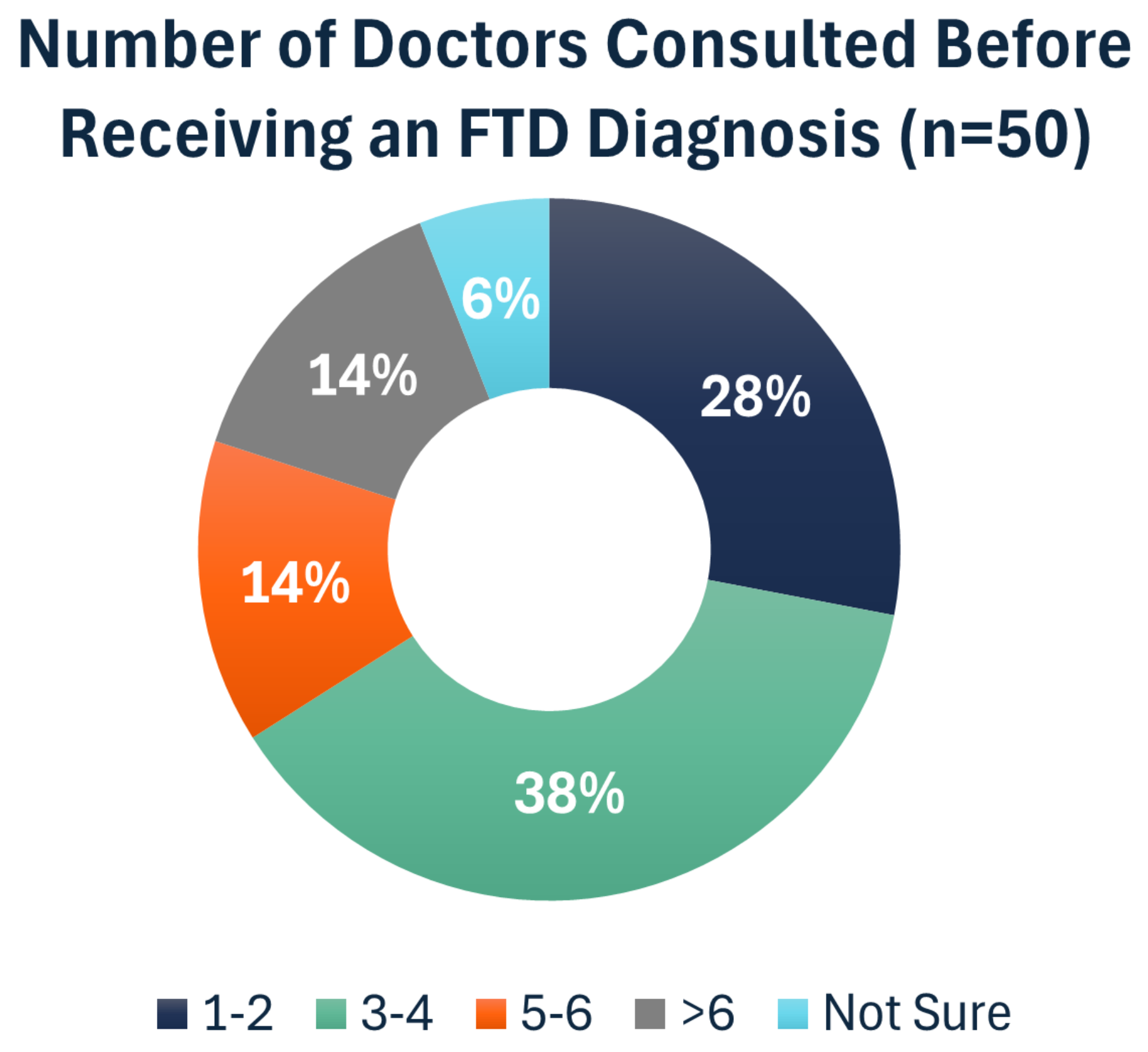
KEY FINDINGS

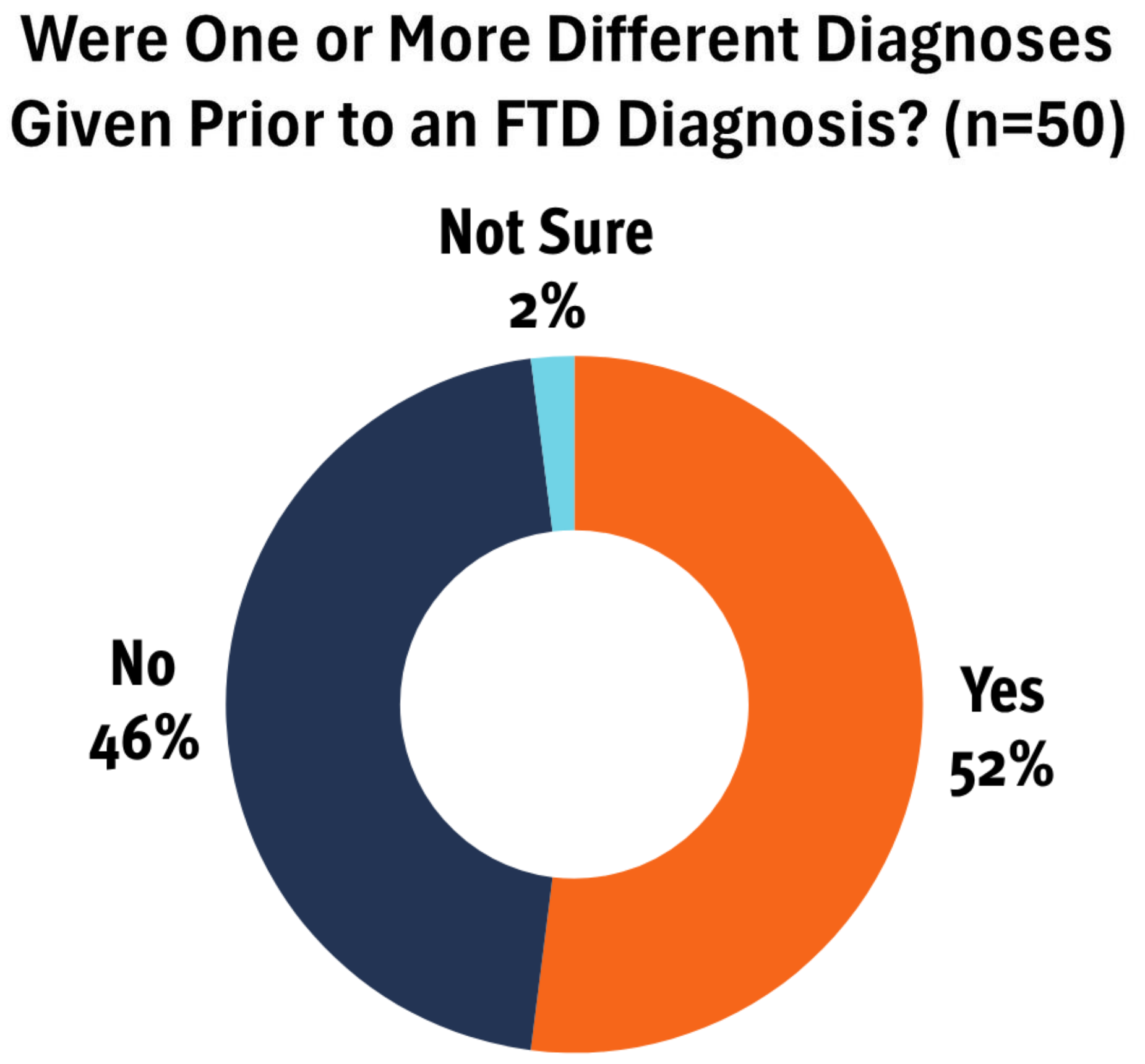
Results highlight the significant challenges individuals face in receiving a timely diagnosis of bvFTD. The key findings, based on 50 survey respondents show:

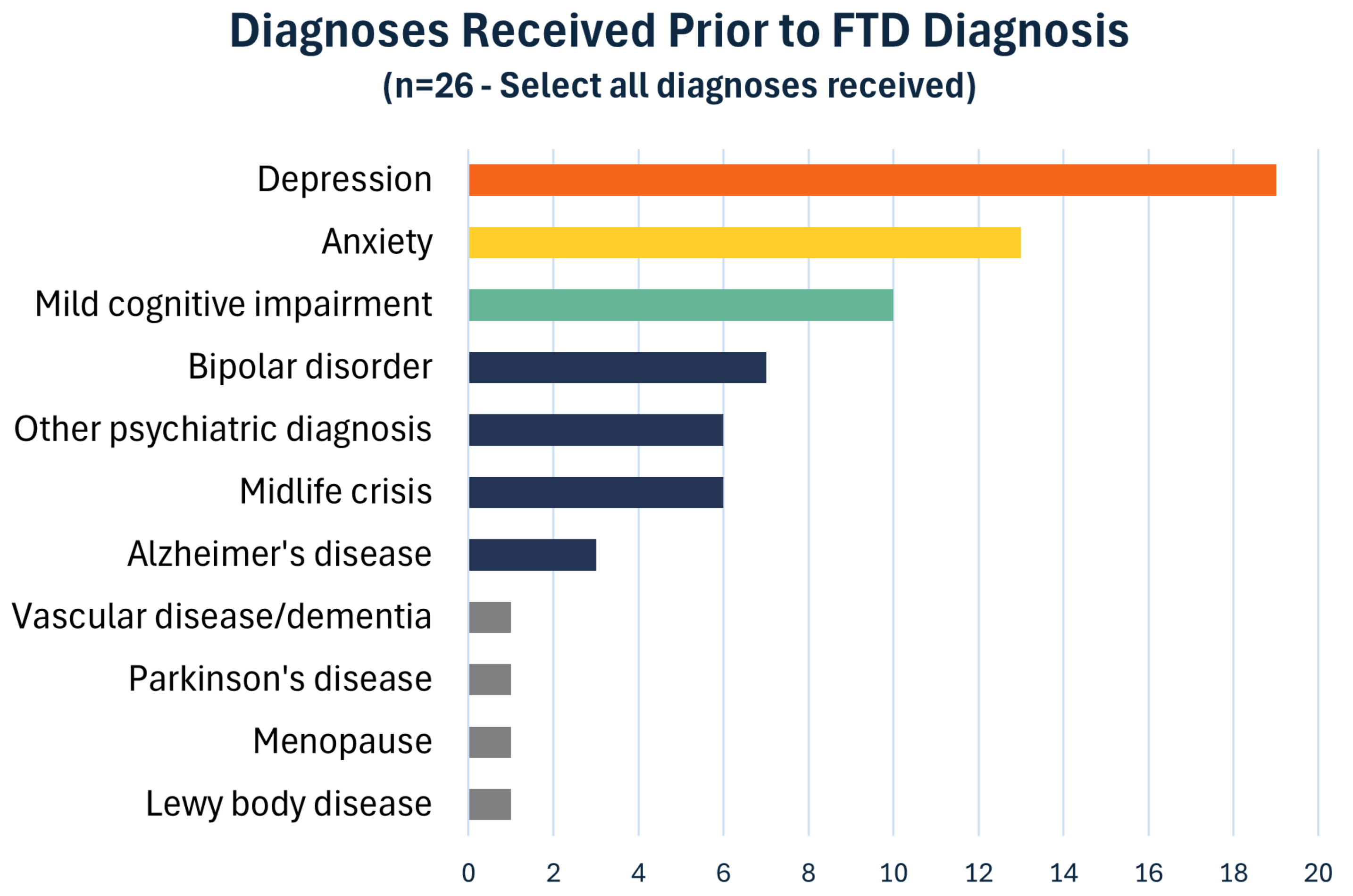
- 76% of respondents reported waiting over a year from symptom onset to diagnosis with 30% experiencing delays of 3-6 years
- 52% were diagnosed with other conditions prior to receiving an FTD diagnosis
- The most distressing early symptoms reported were:
- Mood changes (46%)
- Problems with thinking and judgement (40%)
- Memory issues (36%)
- Personality changes (36%)

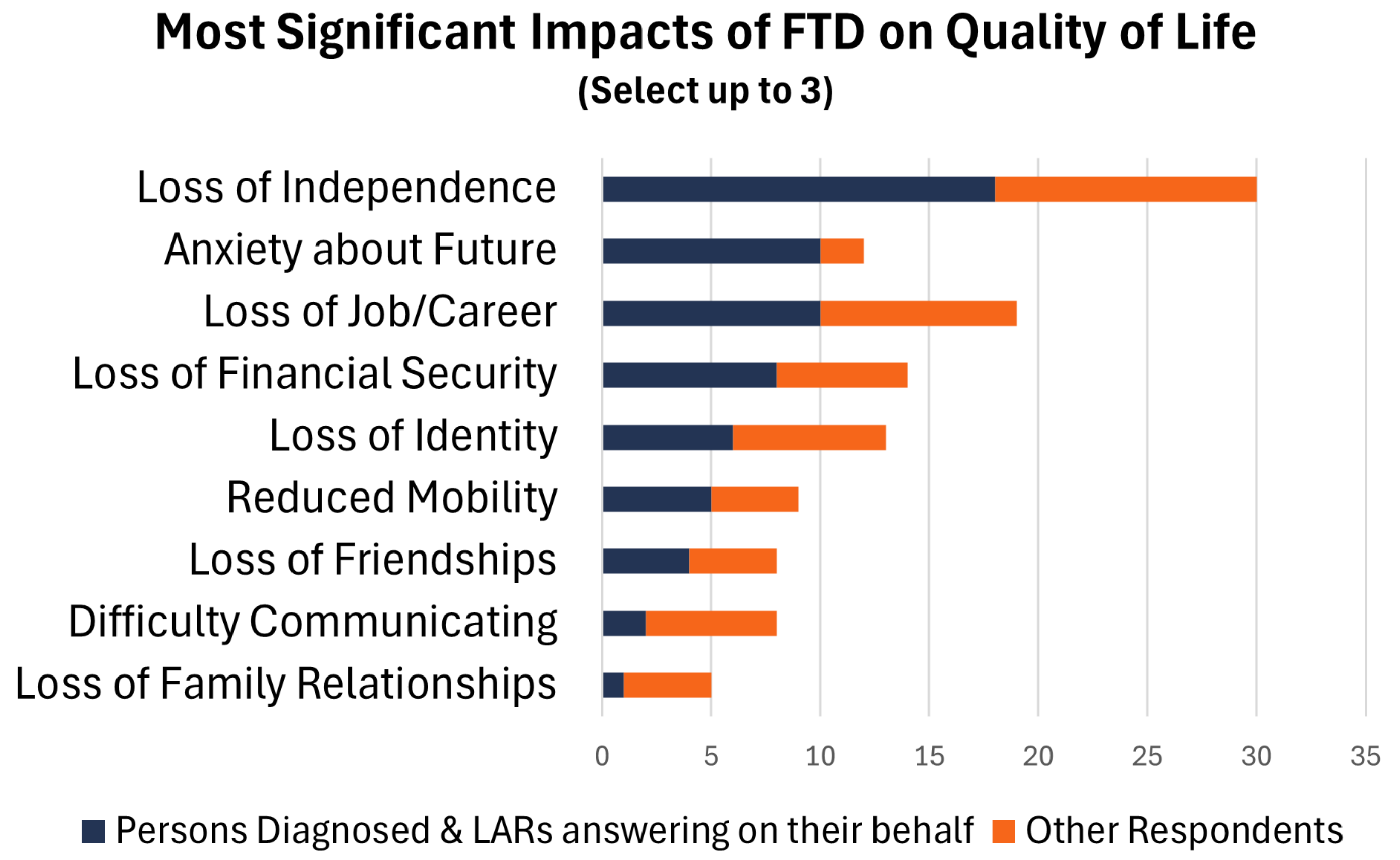

Respondent Type (n=79)


Time from First Symptom to Diagnosis (n=50)


Number of Doctors Consulted Before Receiving an FTD Diagnosis (n=50)


Were One or More Different Diagnoses Given Prior to an FTD Diagnosis? (n=50)


Diagnoses Received Prior to FTD Diagnosis
(n=26 - Select all diagnoses received)


Most Significant Impacts of FTD on Quality of Life
(Select up to 3)

METHODOLOGY

The FTD Disorders Registry is a non-profit, direct-to-participant registry relaunched in 2024 with an updated platform, research protocol, and electronic remote consent. Between May 2024 and the data freeze on January 3, 2025, 205 participants in the United States and Canada completed a survey on the diagnostic journey, of whom 50 specified bvFTD as the current known diagnosis.

CONCLUSION

Given that respondents were more likely to live in urban, less disadvantaged areas and that research participants tend to be more healthcare literate and proactive than the general population, the diagnostic challenges reported here likely underestimate the broader difficulties faced by individuals navigating the FTD diagnostic journey. While based on a limited sample size, these data align with findings from the FTD Insights survey of 1800 participants. They underscore the challenges and complexities involved in diagnosing bvFTD, the prevalence of misdiagnosis, and the significant impact it can have on patients' and caregivers' lives. These findings highlight the need for targeted clinician education to recognize early signs of bvFTD and incorporate it into the differential diagnosis for patients with unexplained mood, cognitive, or personality changes. Future analyses will focus on larger sample sizes and utilizing validated tools to understand respondents' socioeconomic and geographic factors correlate with diagnostic journey.

CONTACT

Registry Director:

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☎ 888-840-9980

AFTD and the FTD Disorders Registry have information and resources for people interested in participating in research as well as researchers who want to better understand the lived experience of FTD.

www.FTDRegistry.org

www.theaftd.org

WE THANK ALL FTD DISORDERS REGISTRY PARTICIPANTS FOR SHARING THEIR EXPERIENCES