

Background

- Clinical research coordinators (CRCs) serve a critical role in the execution of clinical research.
- It is a role with high turnover, yet coordinator comfort, empathy, and expertise in both the disease and the research protocol can all facilitate or worsen participant retainment in clinical research.
- Their importance is even more pronounced in rare diseases like frontotemporal degeneration (FTD) where the challenges of study recruitment and retention are heightened and where there is less community understanding of disease.
- The training adequacy, job satisfaction, and retention of FTD CRCs have not been systematically examined.

Methods

- In 2024, the Association for Frontotemporal Degeneration (AFTD), a patient advocacy organization dedicated to FTD, conducted an advisory panel to explore issues related to FTD, including barriers to clinical research participation.
- Through these, as well as conversations with people with lived experience of FTD and with clinical research professionals, the critical role of CRCs was highlighted.

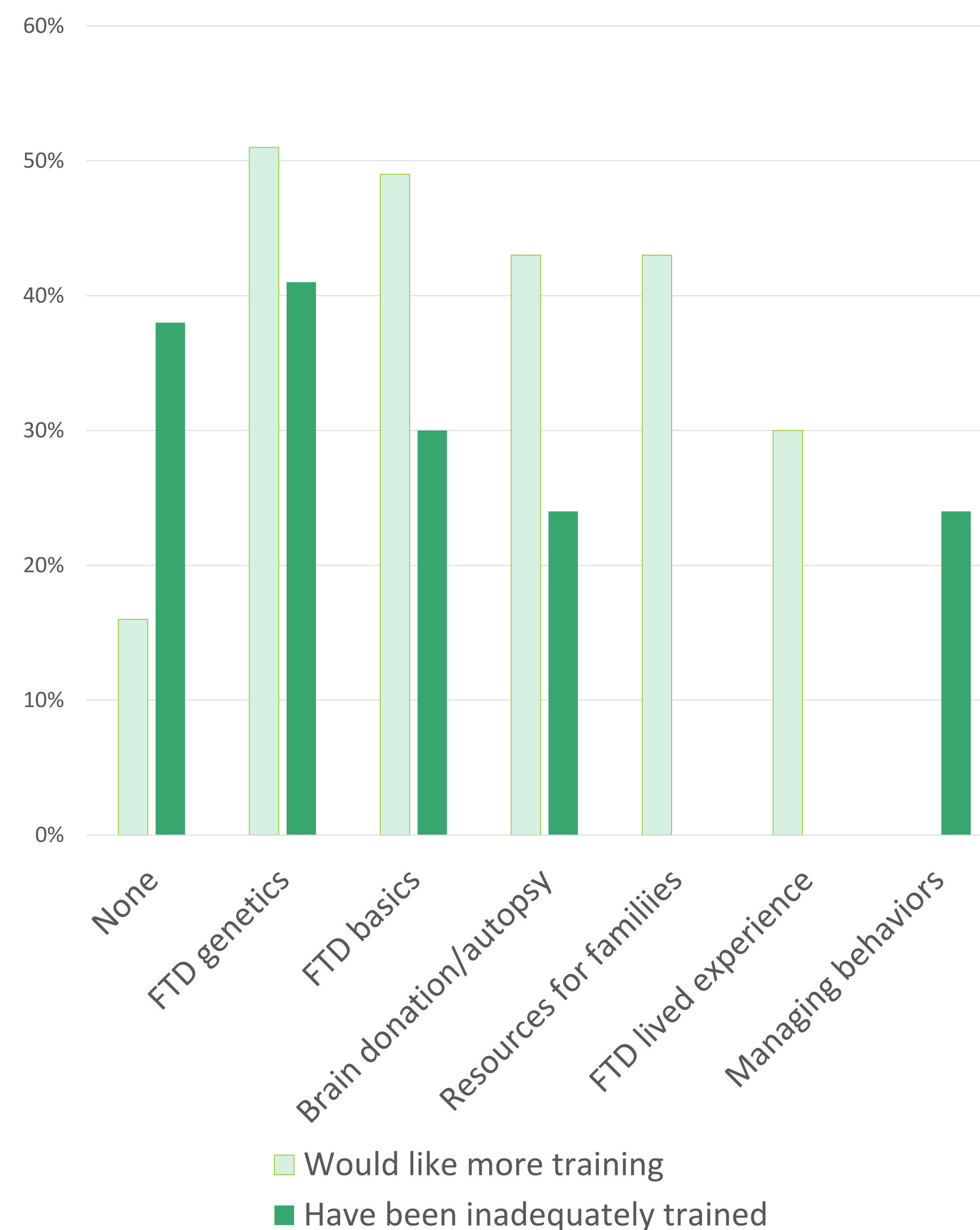
“That site went through 5 study coordinators...the study coordinators all sounded like they were about 14 years old. They may have been quite competent, but their communication skills weren’t.”

- In 2025, AFTD launched a survey of CRCs to better understand their experiences, gaps in training, and factors related to job satisfaction.
- The anonymous, online survey was created by the FTD Disorders Registry, was approved by the North Star Review Board, and distributed to study coordinators working across the US and Canada.

Results

- Forty FTD CRCs across 26 sites completed the survey.
- Prior to their current role, 45% were not familiar with FTD, 42% had worked in related disorders, and fewer had some training (20%) or personal experience with FTD (10%).
- 53% worked primarily in FTD research in addition to other diseases, 33% primarily in other diseases but on FTD studies as well, and 14% exclusively in FTD research.

Respondents were asked to identify areas in which they would like more training and topics that arise in study visits for which they’ve felt inadequately trained to address:



Results (cont)

CRCs report enjoying interacting participants and families:

“The most rewarding part of my role is working with patients and learning how they are affected by FTD.”

“I like interacting with and supporting my research participants. I've grown to know and care for them so it's nice to be able to support them when possible and learn from them.”

As well as challenges related to the emotional burden and logistics of working in FTD research:

“Seeing our patients decline fast and passing within a short time, especially when children are involved.”

“While compiling multiple facets of research within one study is helpful to the researcher, it isn't always what's best for the patient.”

64% reported they’d like to stay in the FTD field. For those hesitant to stay in FTD, the primary drivers are a lack of room for growth at their institution (46%) and adequate pay (38%).

Conclusions

- While there are challenges to conducting research in a rare progressive disorder, CRCs elucidated a number of modifiable factors that can potentially increase coordinators’ proficiency and job satisfaction, leading to better experiences for research staff as well as participants.
- AFTD is developing a modular training curriculum to standardize CRC competency, aiming to improve both workforce stability and the participant experience in FTD research.