

Frontotemporal Dementia Care Partners' Navigation of the Criminal Legal System

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BACKGROUND & METHODS

Individuals affected by frontotemporal dementia (FTD) may experience symptoms that violate social norms and may be considered "criminal." As a result, persons living with FTD may be more vulnerable and at risk for interactions with the criminal legal system, including arrests and incarceration. There is a paucity of data on the individuals' or their care partners' experiences in navigating the criminal legal system.

Aims



Learn about the experiences of people with FTD and their care partners with the criminal legal system, including with police, court systems, and in carceral settings.



Understand what specific barriers exist for people with FTD who have contact with the criminal legal system.

Methodology

- Semi-structured interviews with care partners of people living with FTD who have been in contact with the criminal legal system in the United States due to the accusation or conviction of a crime.
- Team-based thematic analysis using Atlas.ti with a codebook developed with inductive and deductive codes.

FINDINGS

Participants

Relationship of loved one with FTD to participant	n = 27
Spouse	18
Parent	5
Sibling	2
In-law	1
Adult Child	1

Region of U.S. of CLS involvement	n = 27
Northeast	7
Midwest	10
West	2
South	8
Northeast	7

Education Level of Participants	n = 27
High School	1
Some College	6
4-year degree	8
Post-graduate	11
Doctoral	1

Themes

There is limited education and awareness of FTD within the criminal legal system.

"...the policeman is yelling at my husband, and he's saying, 'Get your hands out of your pockets!' And I'm running up and saying, 'He doesn't understand you.' And he's like, 'Lady, get away. This guy's trying to break into cars.' And I'm like, 'This is my husband. He has dementia. He doesn't understand you...they ended up putting handcuffs on him and arresting him and locking him up in the local jail.'"

Care partners relied on their own background, education, and social capital to navigate the system and mitigate harms.

Care partners' credibility was questioned.

"... in the forensic psychologist report, she had said, 'His wife expresses concern... so maybe this should be considered in the future, but there's no need to do that now.' I think sort of waiting for things to get worse...nobody would buy into it."

"I don't say it as a credit to me or a tap on my back, but he's fortunate that he had me. It made me so reflective of the people that don't have someone who advocates...He would have been put in jail...because there's just no way. There's just no way he would have been able to articulate, comprehend..."

IMPLICATIONS

Conclusion

- FTD care partners are often under-resourced and unprepared to navigate the criminal legal system.
- The legal system lacks awareness and education on how to recognize and appropriately respond to dementia.
- Care partners are key in mitigating harms and navigating complex systems, often relying on social capital and education.

Recommendations

- Increase collaboration across systems.
- Expand dementia education for professionals in the criminal legal system.
- Prioritize inclusive research that reaches under-resourced or marginalized populations and minoritized racial and ethnic groups.

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