

Reported by Caregivers in the FTD Insights Survey

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Background

- FTD is a progressive neurodegenerative disorder, affecting the frontal and temporal lobes to impair behavior, language, and motor symptoms; FTD is remarkable for its early age of onset (45-65 years)^{1,2}
- Diagnosing FTD, especially bvFTD, can be challenging as the onset of symptoms is often insidious, and recognizing the early stages frequently relies on caregiver reports of behavioral changes³
- FTD is associated with diminished quality of life (QoL) and substantial caregiver burden⁴
- The AFTD and the FTD Disorders Registry collaborated on the development and execution of the FTD Insights Survey to better understand the lived experience of FTD⁵
- The FTD Insights Survey included questions on the diagnostic journey, symptom-related experiences, independence, QoL, and perspectives on current/future treatment options reported by the individual diagnosed with FTD, their biological relatives, or their caregivers⁵

Methods

- A subset of FTD Insights Survey data relevant to caregiver perceptions of the impact of FTD on the QoL of individuals with FTD was analyzed and compared to the impressions reported by individuals diagnosed with FTD
- The QoL indicators used to gauge impact on the individual diagnosed with FTD were as follows:
 - Loss of identity or sense of self
 - Loss of job or career
 - Loss of important family relationships
 - Loss of friendships
 - Loss of independence
 - Loss of financial security (retirement, savings, income)
 - Difficulty communicating
 - Reduced mobility
 - Anxiety about the future
 - I'm not sure
- The “symptoms affecting activities with others” indicators used to gauge impact on the individual diagnosed with FTD were as follows:
 - Play a game like cards or chess
 - Participate in conversations with family or friends
 - Attend social or other gatherings where there will be more people
 - Interact with new people in everyday life (in stores, on phone, etc)
 - Be intimate with a spouse or partner
 - Maintain friendships
 - Care for children or grandchildren
 - I don't have difficulties doing activities involving others
- The QoL and “symptoms affecting activities with others” indicators were compared between participants who only selected “I am or was a primary or secondary caregiver for someone with FTD” vs participants who only selected “I am diagnosed with FTD”
- Individual QoL and “symptoms affecting activities with others” indicators were analyzed using Pearson's chi-square test
 - Nominal *p* values were reported, and Cramér's V was used to assess effect size (0.15<*V*<0.33=Weak; 0.33<*V*<0.45=Moderately Weak)

Results

- Of the 1795 total respondents, 11.1% (n=200) responded that they were individuals diagnosed with FTD (ie, not relatives and/or caregivers) and 60.4% (n=1084) responded that they were caregivers (ie, not individuals diagnosed with FTD or their relatives)
- Greater percentages of caregivers reported loss of financial security and loss of important family relationships than individuals diagnosed with FTD (**Table 1**)
- The strongest effect size reported in the caregiver responses vs persons diagnosed was loss of financial security (nominal *p*<0.001, Cramér's V=0.358)

Results (Continued)

Table 1. Responders Who Reported Impact on QoL Indicators

QoL Indicator ^a	Caregiver, n (%) (n=1084)	Individual diagnosed with FTD, n (%) (n=200)
Loss of financial security (retirement, savings, income) ^b	449 (41.4)	31 (15.5)
Loss of independence	449 (41.4)	93 (46.5)
Loss of identity or sense of self	261 (24.0)	62 (31.0)
Difficulty communicating	255 (23.5)	85 (42.5)
Loss of job or career	216 (19.9)	61 (30.5)
Reduced mobility	163 (15.0)	52 (26.0)
Loss of important family relationships	150 (13.8)	17 (8.5)
Loss of friendships	91 (8.4)	26 (13.0)
Anxiety about the future	84 (7.7)	60 (30.0)
I'm not sure	18 (1.7)	10 (5.0)

^aResponders were able to select up to 3 answers; data reported as the number and percentage of responders who selected an indicator.

^bStrongest effect size reported in the caregiver responses (nominal *p*<0.001, Cramér's V=0.358).

- Greater percentages of caregivers than individuals diagnosed with FTD reported that the individual diagnosed with FTD had difficulty doing most measured “symptoms affecting activities with others” (**Table 2**)
- The strongest effect sizes reported in the caregiver responses vs persons diagnosed were:
 - Be intimate with a spouse or partner (nominal *p*<0.001, Cramér's V=0.365)
 - Play a game like cards or chess (nominal *p*<0.001, Cramér's V=0.357)
 - Care for children or grandchildren (nominal *p*<0.001, Cramér's V=0.353)

Table 2. Responders Who Reported Impact on “Symptoms Affecting Activities with Others” Indicators

Symptoms Affecting Activities with Others Indicator ^a	Caregiver, n (%) (n=1084)	Individual diagnosed with FTD, n (%) (n=200)
Participate in conversations with family or friends	700 (64.6)	92 (46.0)
Attend social or other gatherings where there will be more people	691 (63.7)	121 (60.5)
Be intimate with a spouse or partner ^b	625 (57.7)	63 (31.5)
Play a game like cards or chess	621 (57.3)	69 (34.5)
Interact with new people in everyday life (in stores, on phone, etc)	612 (56.5)	82 (41.0)
Care for children or grandchildren	577 (53.2)	56 (28.0)
Maintain friendships	553 (51.0)	65 (32.5)
I [the person I am caring for with FTD] don't [doesn't] have difficulties doing activities involving others	40 (3.7)	29 (14.5)

^aResponders were able to select all answers that apply; data reported as the number and percentage of responders who selected an indicator.

^bStrongest effect size reported in the caregiver responses (nominal *p*<0.001, Cramér's V=0.365).

Conclusions

- In this subanalysis of the FTD Insights Survey, caregivers more frequently reported certain indicators of impact on QoL and most “symptoms affecting activities with others” compared with responses of individuals diagnosed with FTD
- These data suggest that impact on certain indicators, specifically loss of financial security and intimacy with a spouse or partner, may be more apparent to caregivers than individuals with FTD, who may experience loss of insight
- These findings further support the importance of caregiver perspectives in fully assessing the burden of disease throughout the FTD patient journey
- Due to the exploratory nature of this study, more research is needed to characterize the impact of FTD on QoL and daily activities involving others to fully assess the unique perspectives of different stakeholders
- FTD Insights Survey data are available for researchers; for more information, contact director@FTDregistry.org or visit <https://ftdregistry.org/for-researchers>

References

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Abbreviations

AFTD, Association for Frontotemporal Degeneration; bvFTD, behavioral variant frontotemporal dementia; FTD, frontotemporal dementia; QoL, quality of life.

Disclosures

DMC, SM, and TWC are employees of Alector, LLC, and may have an equity interest in Alector, Inc. CFM, PAD, and RR are employees of the FTD Disorders Registry. PAD is an employee of AFTD.

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