

2-question FTD impact survey for caregivers and patients

Analysis Report

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1 BACKGROUND

Frontotemporal Degeneration (FTD) refers to a group of clinical syndromes that display degenerative and progressive changes in behavior, personality, language, cognitive skills and motor function. FTD is considered an early onset dementia and occurs most commonly in those aged 45-65. It is also a rare disease, and our current best estimate of FTD prevalence is that approximately 60,000 persons in the United States are affected (1). Neuroimaging reveals significant brain atrophy in the frontal and temporal lobes of persons diagnosed. FTD progresses rapidly, mean survival after symptom onset is about ten years. Persons affected can present with an array of clinical symptoms (2) which are challenging not only for obtaining an accurate diagnosis; but also for the individual affected, and family members, to manage on a daily basis (3).

2 SURVEY OBJECTIVES

In the summer of 2014 we posted the following request on our AFTD webpage:

AFTD 2-Question Impact Survey - We need your help!

If you are a person diagnosed with FTD, or a primary caregiver/former caregiver/family member of someone with FTD, please answer this short on-line survey (2-questions) that will help AFTD advocate with public policy and healthcare providers.

The primary objective of this survey was to learn more about the impact of FTD symptoms on daily activities of life for persons diagnosed as well as for their caregivers or family members. We also wanted to learn more about how the disease has impacted the quality of life in general for individuals and/or family members. We sought to create a 2-question survey that allowed for multiple selections but at the same time was easy and quick to complete. We did not ask responders to prioritize their selections. We did not ask for self-identified persons-diagnosed to provide any further details regarding their diagnosis. Participation was voluntary and anonymous.

Our plan was to summarize the responses and use this information to help us in our advocacy efforts. One such effort is lobbying the Food and Drug Administration (FDA) to select frontotemporal degeneration as one of the diseases that will be the focus of public meetings in 2016/17 as part of the Prescription Drug User Fee Act (PDUFA), and FDA's effort to inform their reviewers about the impact of underserved diseases on persons diagnosed and their families.

3 PARTICIPANTS

Responders to the survey were asked to identify themselves as a primary caregiver, former caregiver or family member of someone diagnosed with FTD; or, as a person diagnosed with an FTD disorder. Notice of the survey was posted on the AFTD website <http://www.theaftd.org/>;

Facebook page <https://www.facebook.com/TheAFTD>; and Twitter @AFTDCure, <https://twitter.com/AFTDCure>. A total of 937 individuals visited the survey, and 65 of these self-identified as persons diagnosed with FTD.

4 METHODOLOGY

The survey was conducted via Wufoo, a web application that helps to build online forms for survey (3). All submitted forms were collected from June 2014 to mid-September 2014 and data was downloaded from the Wufoo application at the end of the survey period. The survey was designed as a 2-question multiple choice answer questionnaire. Primary caregivers, former caregivers or family members of someone diagnosed with an FTD disorder were presented with two questions and asked to select from the multiple answer options that applied to his/her situation. The question/answer set for caregivers and family members were:

- **What FTD symptoms cause the most difficulty on a daily basis?**
 - ✓ Unpredictable, compulsive, inappropriate behaviors
 - ✓ Problems with language and communication
 - ✓ Apathy and loss of feelings for others
 - ✓ Loss of judgment and/or lack of emotional control
 - ✓ Inability to plan and complete regular daily tasks
 - ✓ Other
- **How has FTD impacted you/your family?**
 - ✓ Financial distress
 - ✓ Altered roles and relationships within family
 - ✓ Disrupted plans for the future, retirement, delaying college
 - ✓ Lack of FTD awareness/understanding, social isolation
 - ✓ Increased stress, negative impact on own health
 - ✓ Other

A related set of two questions with multiple answer options was offered to individuals diagnosed with an FTD disorder:

- **What symptoms are the hardest for you to deal with?**
 - ✓ Not being able to plan and complete regular daily tasks
 - ✓ Inappropriate or repetitive/compulsive behaviors
 - ✓ Problems with language and communication
 - ✓ Loss of interest in activities and/or feelings for others
 - ✓ Angry and/or emotional outbursts
 - ✓ Other

- **How has FTD impacted your life?**
 - ✓ Loss of job and income
 - ✓ Disrupted relationships with family, friends
 - ✓ Loss of decision-making ability, future planning
 - ✓ Lack of FTD awareness/understanding, social isolation
 - ✓ Loss of independence, ability to care for self
 - ✓ Other

Participants were asked to select the answers that applied to their situation (from a minimum of 1 choice to a maximum of 3 choices), and no ranking of answers was requested. Appendix A contains a word document version of the online survey.

5 RESULTS

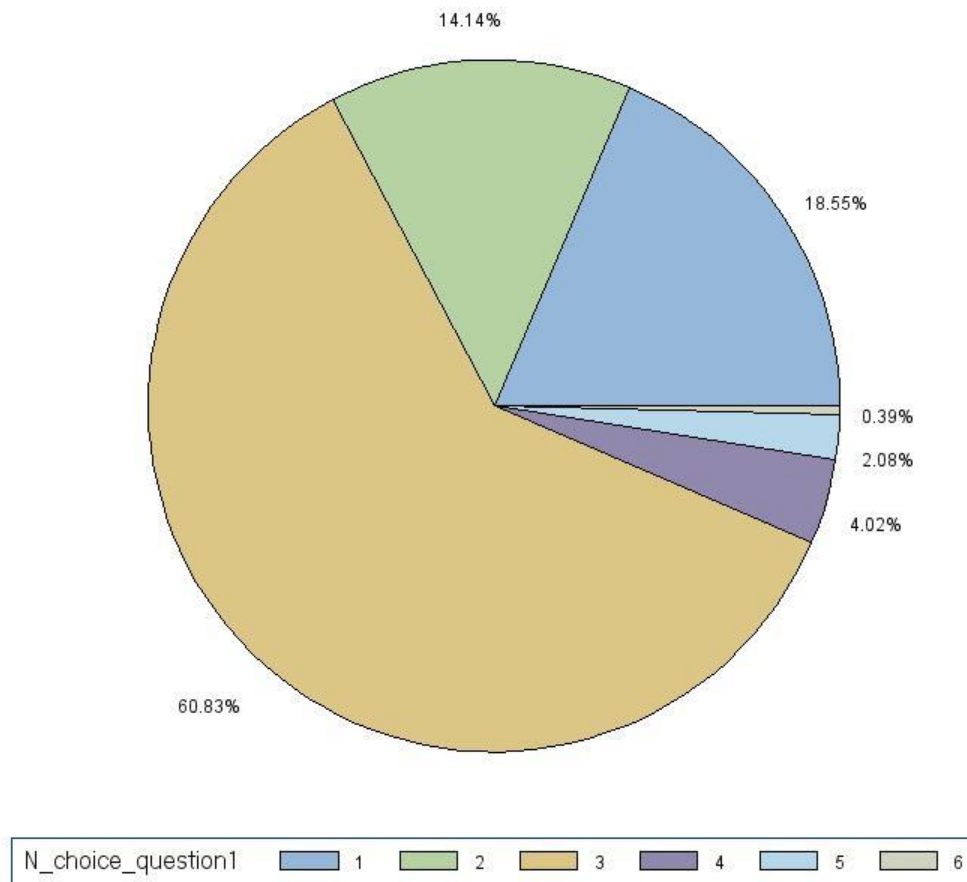
In this report the multiple choice answers submitted by an individual are represented by frequency and percentage of each category.

The total number of individuals who submitted a survey was 937, approximately 8-9 individuals per day visiting the online site. Of those, 872 (93%) were primary caregiver/former caregiver/family member of someone diagnosed with FTD and 65 (7%) were diagnosed with an FTD disorder (one missing information). In the Caregiver group, 11.6% (n=101) did not select any multiple choice answers, and the surveys were ruled as submitted in error and not included in this analysis. In the Persons Diagnosed group, 12.3% (n=8) did not select any multiple choice answers to the questions, and ruled as submitted in error and not included in this analysis. Therefore the total number of forms collected and considered in this analysis is 828, (771 Caregiver and 57 Persons Diagnosed).

5.1 Caregiver

For question 1, the majority of Caregivers checked three top choices from the answer set (61%), 14% made two choices, and 19% made one choice. The remainder selected four or more options (Figure1).

Figure 1. Number of choices for question 1 by Caregiver

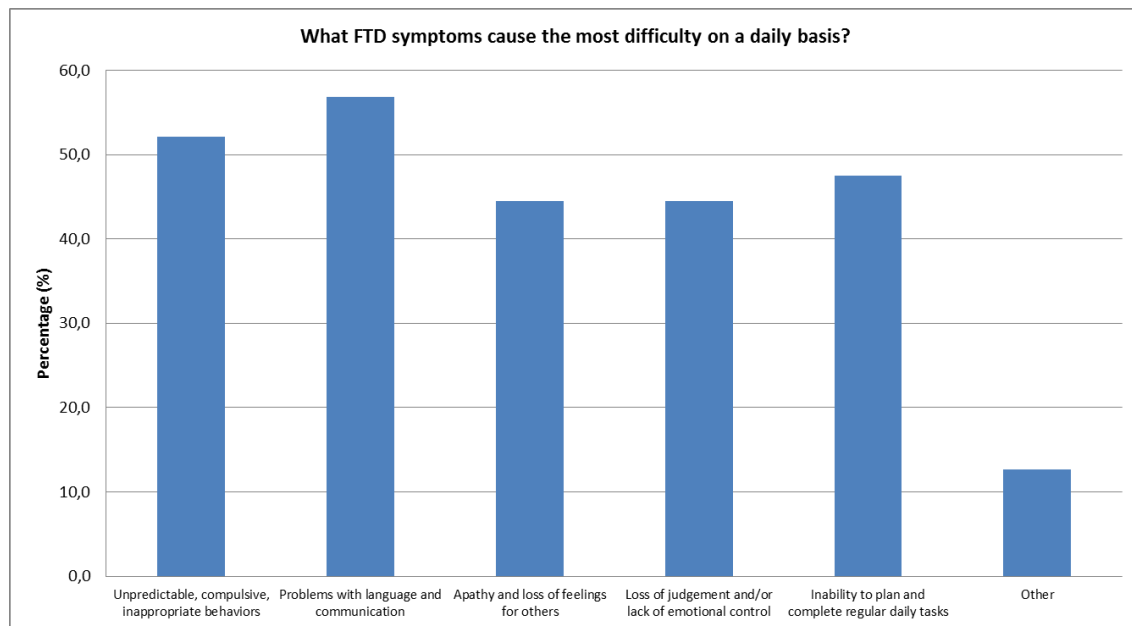


For question 1 ‘What FTD symptoms cause the most difficulty on a daily basis?’ caregivers and family members responded to all categories (Figure 2), but the most frequent choices were “Problems with language and communication” (56.8%) followed by “Unpredictable, compulsive, inappropriate behaviors (52.1%) (Table1).

Table 1. Question 1 – Caregiver

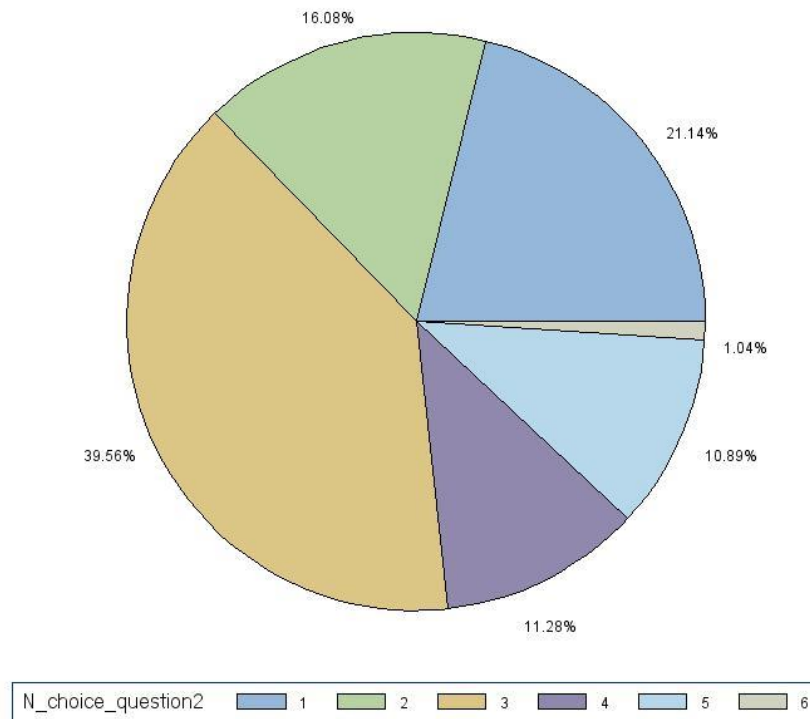
What FTD symptoms cause the most difficulty on a daily basis?	N	%
Unpredictable, compulsive, inappropriate behaviors	402	52.1
Problems with language and communication	438	56.8
Apathy and loss of feelings for others	343	44.5
Loss of judgment and/or lack of emotional control	343	44.5
Inability to plan and complete regular daily tasks	366	47.5
Other	98	12.7

Figure 2. Distribution of choices for question 1 by Caregiver



For Caregivers/family members responding to question 2, the majority checked 3 answer options (40%), 21% made one choice, 16% two choices, and the rest selected 4 or more options (Figure2).

Figure 3. Number of choices for question 2 by Caregiver

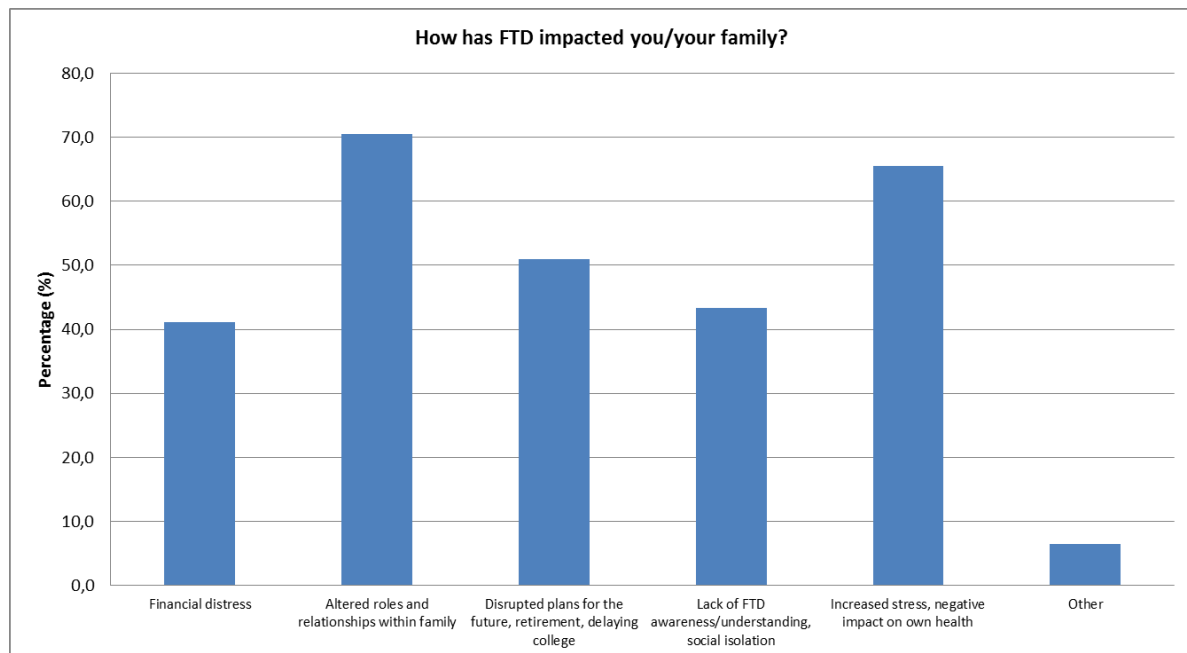


For question 2 ‘How has FTD impacted you/your family?, caregivers and family members responded to all categories, but the most frequent choices were “Altered roles and relationships within family” (70%) followed by “Increased stress, negative impact on own health” (66%) (Table2).

Table 2. Question 2 – Caregiver

How has FTD impacted you/your family?	N	%
Financial distress	317	41.1
Altered roles and relationships within family	543	70.4
Disrupted plans for the future, retirement, delaying college	393	51.0
Lack of FTD awareness/understanding, social isolation	334	43.3
Increased stress, negative impact on own health	505	65.5
Other	50	6.5

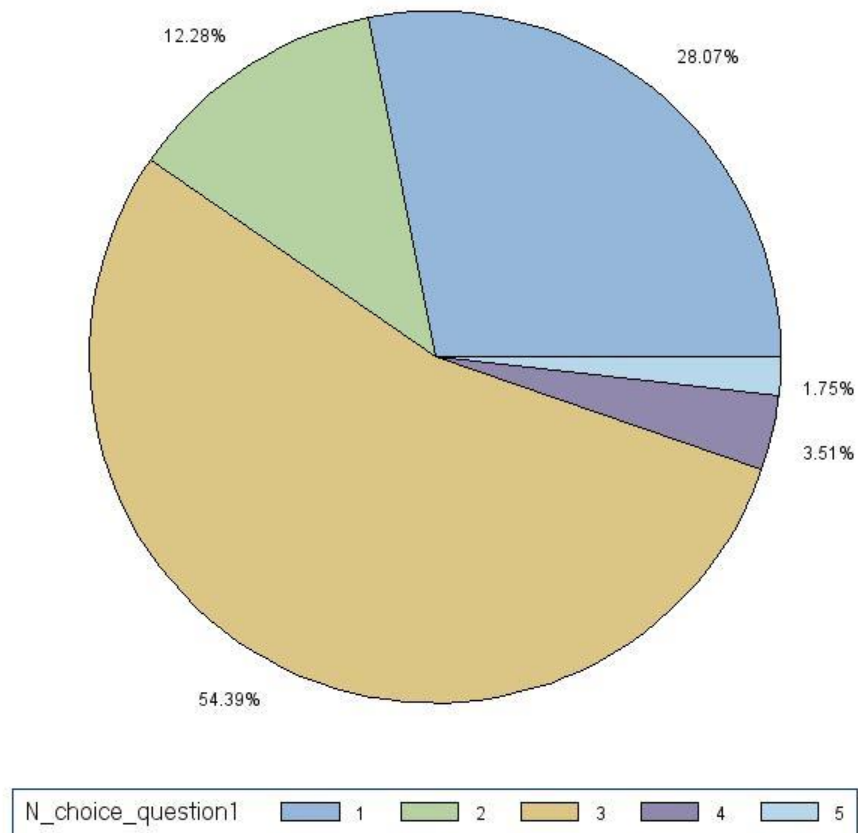
Figure 4. Distribution of choices for question 2 by Caregiver



5.2 Person Diagnosed

For question 1, the majority of persons diagnosed checked 3 top choices from the answer set (54%), 28% made one choice, 12% made two choices and the remainder selected four or five answers (Figure3).

Figure 5. Number of choices for question 1 by Person Diagnosed

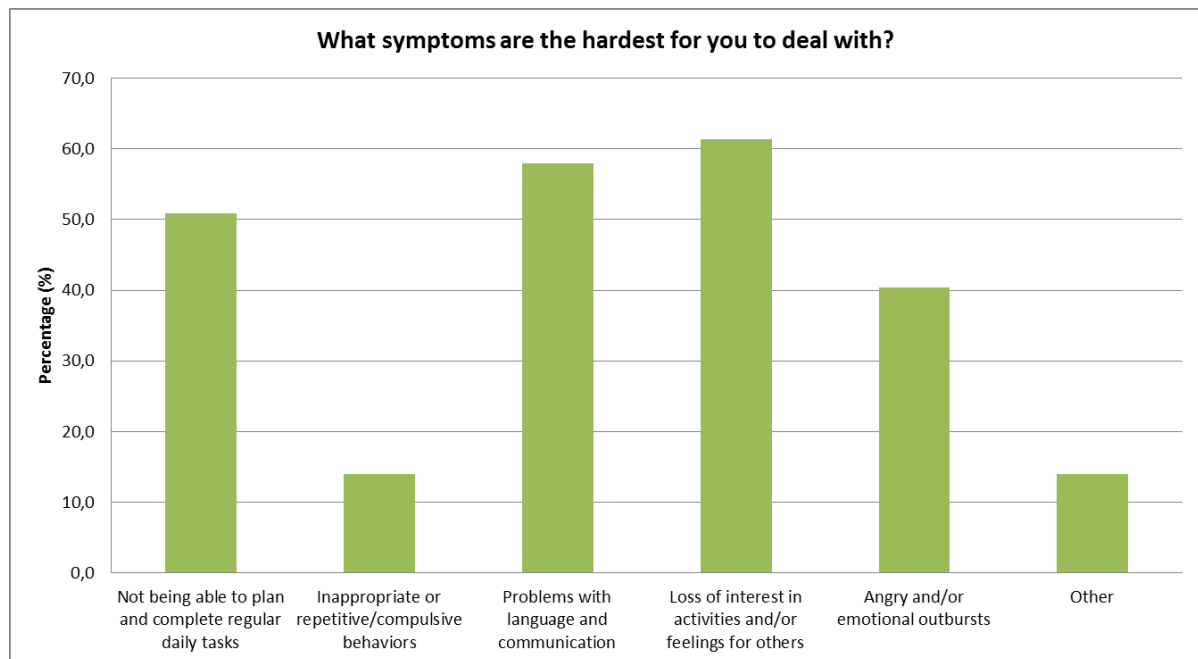


For question 1: ‘What symptoms are the hardest for you to deal with?’, persons diagnosed checked all categories, but the most frequent choices were “Loss of interest in activities and/or feelings for others” (61%), followed by “Problems with language and communication” (58%) (Table3).

Table 3. Question 1 – Person Diagnosed

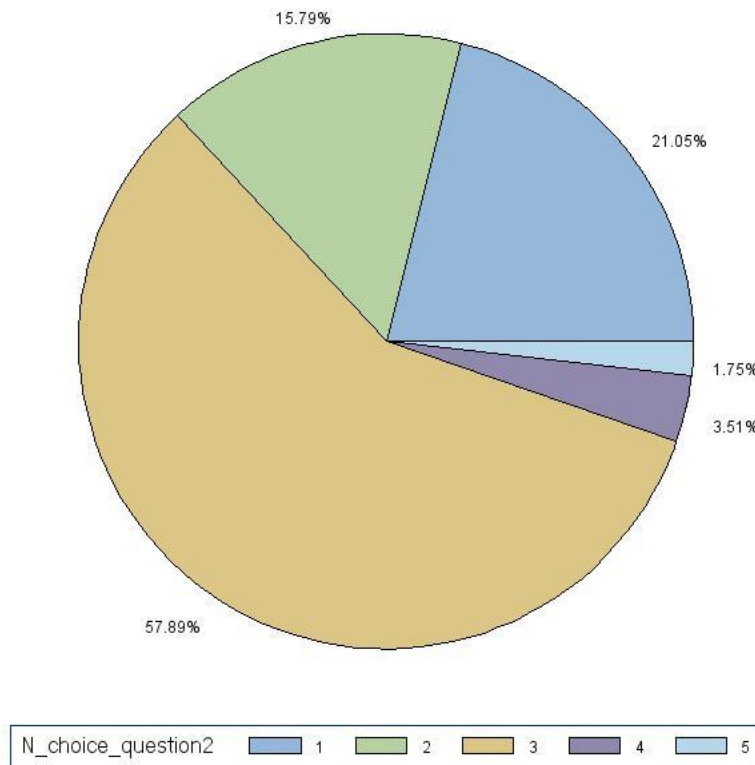
What symptoms are the hardest for you to deal with?	N	%
Not being able to plan and complete regular daily tasks	29	50.88
Inappropriate or repetitive/compulsive behaviors	8	14.04
Problems with language and communication	33	57.89
Loss of interest in activities and/or feelings for others	35	61.40
Angry and/or emotional outbursts	23	40.35
Other	8	14.04

Figure 6. Distribution of choices for question 1 by Person Diagnosed



For question 2, the majority of persons diagnosed responded with three selections (58%), 21% made one selection, 16% made two selections, and the remainder made four or five choices (Figure4).

Figure 7. Number of choices for question 2 by Person Diagnosed

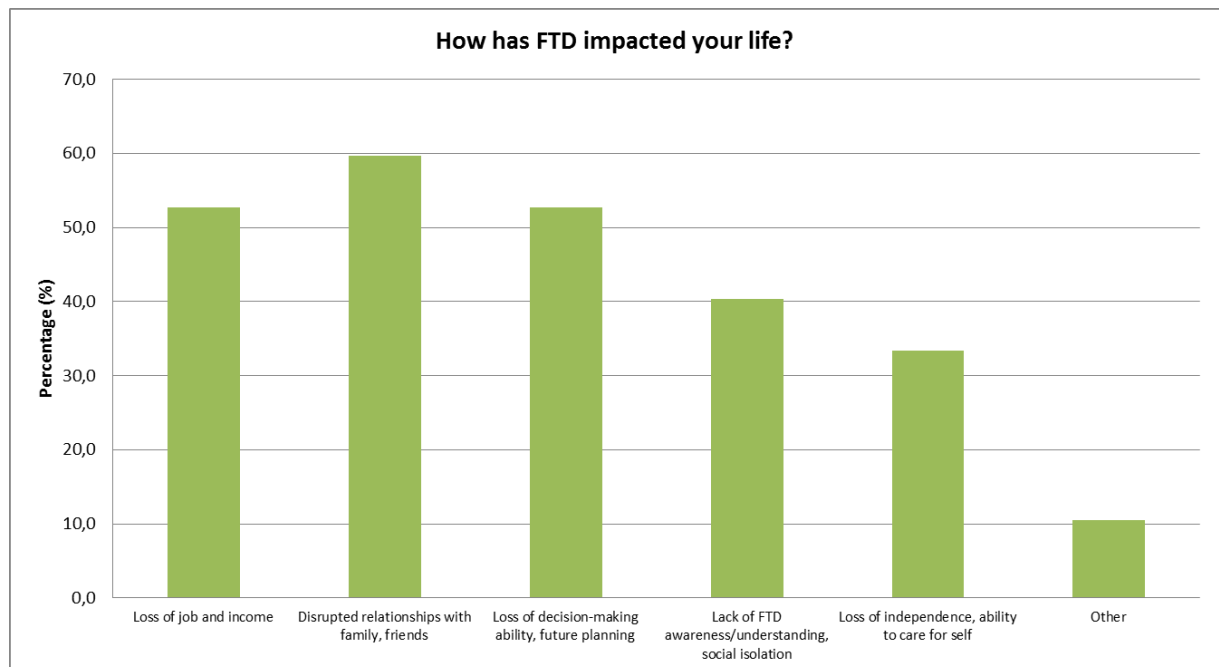


For question 2 ‘How has FTD impacted your life?’ all categories were selected, but the most frequent were “Disrupted relationships with family, friends” (60%), followed by “Loss of job and income” and “Loss of decision-making ability, future planning” (tied at 53%) (Table4).

Table 4. Question 2 – Person Diagnosed

How has FTD impacted your life?	N	%
Loss of job and income	30	52.63
Disrupted relationships with family, friends	34	59.65
Loss of decision-making ability, future planning	30	52.63
Lack of FTD awareness/understanding, social isolation	23	40.35
Loss of independence, ability to care for self	19	33.33
Other	6	10.53

Figure 8. Distribution of choices for question 2 by Person Diagnosed



6 CONCLUSIONS and RECOMMENDATIONS

We formulated the questions and answers based on our experience from the AFTD Helpline, our yearly Education Conference for FTD caregivers and persons diagnosed, and contact with FTD support groups. This was our first attempt at soliciting information via an online survey and promoting the survey through online media (AFTD website, Facebook and Twitter). While most of the responders were US-based according to Wufoo analytics support, individuals from Europe as well as Australia also took part.

Our intent was to create a survey that would allow persons diagnosed as well as caregivers and family members to respond; and that could be completed easily and quickly. We also wanted to collect useful information on the impact of FTD that we could submit to the FDA's request to nominate diseases for their next round of public meetings as part of the Prescription User Fee Drug Act (PDUFA) due in December 2014.

Some concerns remain unanswered. It is not clear why many of the responders were unable to follow the instructions and made more than three selections from the multiple choice answers. It is interesting that this occurred in both the caregiver/family member and persons diagnosed groups. It may be that the directions needed to be framed differently.

We believe that the excellent response to the FTD impact questionnaire reflects an engaged community and we were encouraged that so many persons diagnosed with FTD were able to complete and submit surveys. The distribution of selected options was very interesting and we believe merits further study, particularly those responses selected by persons diagnosed.

7 REFERENCES

- (1) Knopman, DS and RO Roberts. Estimating the number of persons with frontotemporal lobar degeneration in the US population. *J Mol Neurosci*. 2011, **45**:330-5.
- (2) Jicha, GA and PT Nelson. Management of frontotemporal dementia: targeting symptom management in such a heterogeneous disease requires a wide range of therapeutic options. *Neurol Dis Manag*. 2011, **1**:141-56.
- (3) Diehl-Schmid, J. Caregiver burden and needs in frontotemporal dementia. *J Geriatric Psych Neurol*. **26**:221-9.
- (4) Wufoo site: <http://www.wufoo.com/>

8 APPENDIX A – SURVEY TEXT

AFTD 2-question disease impact survey

If you are a person diagnosed with FTD, or are a primary caregiver/former caregiver/family member of someone with FTD – we need your help. Please answer this short survey that will help AFTD advocate with public policy and healthcare providers.

1 Who am I?

I am

- A primary caregiver/former caregiver/family member of someone diagnosed with FTD
- A person diagnosed with an FTD disorder

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Primary Caregiver/Former Caregiver/Family Member

Please answer the following 2 questions.

▶ What FTD symptoms cause the most difficulty on a daily basis? Check the top 1-3 choices that apply. *


- Unpredictable, compulsive, inappropriate behaviors
- Problems with language and communication
- Apathy and loss of feelings for others
- Loss of judgment and/or lack of emotional control
- Inability to plan and complete regular daily tasks
- Other

▶ How has FTD impacted you/your family? *


- Financial distress
- Altered roles and relationships within family
- Disrupted plans for the future, retirement, delaying college
- Lack of FTD awareness/understanding, social isolation
- Increased stress, negative impact on own health
- Other

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Please answer the following 2 questions.


 What symptoms are the hardest for you to deal with? Check the top 1-3 choices that apply *

- Not being able to plan and complete regular daily tasks
- Inappropriate or repetitive/compulsive behaviors
- Problems with language and communication
- Loss of interest in activities and/or feelings for others
- Angry and/or emotional outbursts
- Other

 How has FTD impacted your life? Check the top 1-3 choices that apply *

- Loss of job and income
- Disrupted relationships with family, friends
- Loss of decision-making ability, future planning
- Lack of FTD awareness/understanding, social isolation
- Loss of independence, ability to care for self
- Other

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 Thank you for supporting AFTD's advocacy efforts. We will post the results of the survey on our website later this summer.