

An International Needs Assessment of Caregivers for Frontotemporal Dementia

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ABSTRACT: *Objective:* To guide development of public awareness and caregiver support resources for frontotemporal dementia (FTD) syndromes. *Methods:* We used an online survey to explore their needs. The survey was self-administered by self-identified, English-speaking caregivers for patients with FTD in several countries. *Results:* Of 79 caregiver respondents, approximately half were caring for patients with behavioural variant FTD or semantic dementia. The most common initial symptoms were Changes in Thinking and Judgment. Half of the respondents identified “failure to recognize the early stage of illness as a dementia” as the most troublesome aspect. Accordingly, over 40% of respondents had difficulty obtaining an accurate diagnosis for the patient. Caregivers prioritized family counseling and the public educational message that dementia can affect young people. *Conclusion:* The largest international survey of FTD caregivers to-date showed that support is needed for all family members adapting to the shock of early-onset dementia, and this may be most readily provided online.

RÉSUMÉ: *Une évaluation internationale des besoins des soignants dans la démence front temporeale.* *Objectif :* Le but de l'étude était de déterminer comment conscientiser le public au sujet des syndromes de démence frontotemporale (DFT) et aider à développer des ressources pour soutenir les soignants. *Méthode :* Nous avons effectué une enquête en ligne pour explorer leurs besoins. Cette enquête autoadministrée portait sur des soignants de langue anglaise, qui prenaient soin de patients atteints de DFT dans plusieurs pays et qui s'étaient eux-mêmes identifiés. *Résultats :* Parmi les 79 répondants, à peu près la moitié prenaient soin de patients qui étaient atteints de variantes comportementales de la DFT ou de démence sémantique. Les symptômes de début les plus fréquents étaient des changements au niveau de la pensée et du jugement. La moitié des répondants ont indiqué que le fait de ne pas reconnaître le stade précoce de la maladie comme une démence était l'aspect le plus perturbateur. Plus de 40% des répondants avaient eu de la difficulté à obtenir un diagnostic précis chez le patient. Les soignants priorisaient le counseling familial et les messages d'information destinés au public à l'effet que la démence peut atteindre des individus jeunes. *Conclusion :* L'enquête internationale la plus considérable jusqu'à maintenant auprès de soignants de patients atteints de DFT démontre le besoin de soutien de tous les membres de la famille qui doivent s'adapter au choc d'une démence à début précoce. Ceci peut facilement être disponible en ligne.

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Frontotemporal dementias (FTD) affect parts of the brain which regulate behaviours and insight, causing an early and dramatic impact on family members and other care partners. People with FTD experience intellectual decline which in the early stages usually is more subtle than the disruptive degree of disinhibition and other inappropriate behaviours affecting judgment, comportment in public, and eating habits.¹⁻⁴

A frontotemporal dementia usually declares itself in the 6th decade of life. The role of the caregiver in FTD is most frequently played by women, usually the patient's spouse.(Chow TW. Patient registry inquiry. Toronto: 2010, and⁵. As opposed to Alzheimer's disease, where the patient and spouse are typically advanced in years and living post-retirement, the patient-spouse dyad in FTD commonly is still an active part of the workforce and raising children, also sandwiched between these activities and caring for their own aging parents. Caregiving for FTD is difficult and different from Alzheimer's disease. In Canada, recognition of these differences is starting to gain more support from local, provincial and national organizations.⁶

The 2002 advent of the Association for Frontotemporal

Degeneration (www.theaftd.org), a non-profit organization to support caregivers for FTD, created advocacy for these caregivers, but this is still a relatively recent development. Exactly what constitutes the special need and challenges in caregiving in FTD is only slowly being understood. For this reason, we were interested to conduct a broadly-based study which could assay needs arising from the lived experience when a loved one has FTD. At the same time, we wanted to assay impressions about whether information provided online was felt to be useful. The main purpose of this survey was to help caregivers understand the natural history of symptoms in

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dementia as they have experienced them, and as other caregivers have experienced them. For this reason, we undertook an online survey that invited care partners of people with FTD to: 1) compare their impressions of caregiving with others caring for FTD, and; 2) track patient symptoms. The website platform for the survey and tracking instrument was provided by Dementia Guide, Inc., at <http://www.dementiaguide.com>.

METHODS

This study was reviewed and approved by the Research Ethics Committees at Baycrest and at the Capital Health District Authority, Halifax. Criteria for inclusion of participants included self-identification as a caregiver to someone with FTD (behavioural variant, primary progressive aphasia, corticobasal syndrome, or progressive supranuclear palsy); English-speaking, as the survey appeared only in the English language; and ability to access the internet for self-administration of the survey.

Caregivers from the US and Canada had previously requested at clinic or at lecture presentations on FTD that they be placed on a mailing list to receive periodic FTD news from co-author Dr. Tiffany Chow. Caregivers on this list received an email invitation to volunteer their participation for a web-based, anonymous survey developed specifically for FTD caregivers, hosted at www.dementiaguide.com. Participants were encouraged to invite other FTD caregivers to participate, so that more than one caregiver might have responded from each household. Even so, a review of the postal code and zip codes provided by respondents showed no repeats, indicating a lower likelihood of more than one respondent per patient. It is worth noting that only 69% of respondents gave their postal codes, so that respondents from the same household may be hidden in the aggregate dataset.

Volunteer participants logging onto the Dementia Guide website were informed that creating individual logins with passwords amounted to consent to have their anonymized data aggregated for reporting. Creation of a login was required in order to make any entries onto the website.

The survey questions appear in the Appendix. Multiple choice responses were provided, based on the co-authors' (TWC and KR) clinical experience in counseling caregivers. Fill-in-the-blank options were included in the survey to elicit any other responses. Dementia Guide did not charge these participants an access fee, and made the dataset available to each co-author independently.

While only the solicitation of postal code was designated on the website as an optional question, the survey software allowed caregivers to submit partially completed surveys.

DATA ANALYSIS

Responses were tallied and descriptive statistics applied. All the analyses were carried out in-house in the laboratory of the lead author (TWC).

RESULTS

Demographics

Seventy-nine participants responded to the survey from September, 2009 to July, 2010. This may represent 65% of the caregivers originally invited to participate or some mixture with secondarily invited caregivers. Approximately 41% (N = 26)

were men and 59% (37) were women (16 respondents skipped the question). Of respondents reporting where they lived (N = 64), 31 (62%) of the participants were from Canada (21 from Ontario), 20 (31%) from the USA, and the others from the UK and Europe.

Caregivers who identified their ages ranged from 28-78 years; the median was age 58. The most common FTD diagnosis was the behavioural variant of frontotemporal dementia with 22 responses (28%), followed by semantic dementia with 21 (27%). Other diagnoses are listed in Table 1. Only one caregiver gave no response to this question.

The rate of caregiver response to the remainder of the survey questions varied. Although 78 responded to the first question, only 62 respondents completed the entire survey. Thirty percent of respondents chose not to identify their postal code or US zip code.

Respondents most often (26%) recalled "Changes in Thinking and Judgment" as the first manifestation of illness (Table 2). Although 41 patients had diagnoses of progressive non-fluent aphasia, semantic dementia or logopenic progressive aphasia, only eight first symptoms reported were related to a change in language.

Table 3 lists the most troublesome aspects of caregiving selected by respondents. Write-in comments included:

- Poor insight: "the patient doesn't get that he has a dementia and tries to rationalize all the inappropriate behaviours as appropriate"; "the patient doesn't think there is a problem"; "the patient denied her disability, stating the confusion was due to menopause"
- Caregiver quality of life: "It's upsetting to watch that some days the patient is fine and others he acts like a child"; getting [other] family [members] to help care for the patient; [making] the transition from daughter to caretaker; loss of companionship/former partner or parent; loss of freedom in order to provide supervision; caregiver feeling "understimulated and resentful"; guilt over not moving back home to take care of the patient
- Family dispute about inheritance

Table 1: Diagnoses reported by caregivers

Diagnosis	Patients N=78
Behavioural variant frontotemporal dementia	22 (28.2%)
Semantic dementia	21 (26.9%)
Progressive non-fluent aphasia	14 (17.9%)
Don't have diagnosis yet	14 (17.9%)
Corticobasal Syndrome	13 (16.7%)
FTD-Amyotrophic Lateral Sclerosis	12 (15.4%)
Logopenic progressive aphasia	6 (7.7%)
Atypical type of Alzheimer's disease	4 (5.1%)
Parkinson's disease	3 (3.85%)
Progressive Supranuclear Palsy	2 (2.6%)

Table 2: First symptoms of FTD recognized by caregivers

Symptom Category	Sub-item	Patients N=65
Thinking and Judgment		17 (26.1%)
	Decision-making	9 (14.5%)
	Attention/Concentration	4 (6.15%)
	Insensitivity	2 (3%)
Memory	Judgment	2 (3%)
		15 (23%)
	Recent events	7 (10.7%)
	Names and faces	3 (4.6%)
Behaviour	Misplacing or losing objects	3 (4.6%)
	Past events	2 (3%)
		13 (20%)
	Inappropriate language and behaviour	8 (12.3%)
Language	Obsessive behaviour	2 (3%)
	Irritability/Frustration	1 (1.5%)
	Low mood	1 (1.5%)
	Wandering	1 (1.5%)
Personality changes		8 (12.3%)
	Word finding difficulty	7 (10.7%)
	Comprehension of speech difficulty	1 (1.5%)
	Generating speech/talking difficulty	0 (0%)
	Reading difficulty	0 (0%)
	Writing difficulty	0 (0%)
Everyday Activities		6 (9.2%)
	Lack of Interest/initiative	5 (7.6%)
	Restlessness	1 (1.5%)
	Anxiety	0 (0%)
	Low self esteem	0 (0%)
Physical changes	Problems with self-awareness	0 (0%)
		4 (6%)
	Financial management / Shopping for work or at home	2 (3%)
	Driving	1 (1.5%)
	Household chores	1 (1.5%)
	Eating	0 (0%)
	Operating gadgets/appliances	0 (0%)
	Personal care/ hygiene	0 (0%)
Sleep disturbances	0 (0%)	
Leisure activities disabled by FTD		1 (1.5%)
	Mobility	1 (1.5%)
Disability	Incontinence	0 (0%)
		1 (1.5%)
	Hobbies	1 (1.5%)
	Interaction with friends and family	0 (0%)
	Interaction with strangers	0 (0%)
	Looking after grandchildren	0 (0%)
	Spirituality and Religion	0 (0%)
Travel and Vacationing	0 (0%)	

To guide future public awareness campaigns, we surveyed the participants for things they wished they'd known earlier. The most common surprise to caregivers (27%) in the process of learning about FTD was that "Dementia can affect young people," e.g., "The age of onset of symptoms was 44." See Table 4 for other responses. Additional comments included:

- How complicated the simplest everyday activities have become for the patient
- How to cope and not cope at the same time
- The gravity of behavioural and personality changes
- How drastically life has changed for the family
- So few resources available for respite and financial help for young patients with dementia

Resources or interventions that had helped the caregivers the most were: the treating neurologist (18%); followed by information from the internet (14%); help from their own children (12%); day program staff and caregiver support groups

such as an FTD support forum each accounted for 9% of the answers. The nurse at the doctor's office; social workers, the Alzheimer's Society/Association and the Association for frontotemporal dementia were each cited by 6% of the caregivers. The family doctor was cited as a useful resource by 5%, along with the "None of the above: I need help" response. Religion and spiritual practice helped 3% of the caregivers and getting help from the psychiatrist was chosen by only 2% of respondents. Additional helpful resources included: legal counselling when the patient denied impairment; homecare; co-workers and employer; and the neuropsychologist.

Table 3: The most troublesome aspects of caregiving in FTD, according to 78 respondents

Concern	% of Respondents
Not knowing that it was a dementia or some other kind of neurological impairment	52%
Difficulty in acquiring a diagnosis	43%
Not knowing how to help the patient	25%
Not feeling adequate as a caregiver	24%
Patient persistence at driving unsafely or illegally	22%
Separation anxiety resulting in the patient constantly shadowing the caregiver	18%
Ineligibility for a day program	16%
Financial difficulties	10%
Legal proceedings related to former employment	4%

Table 4: The most unexpected aspects of caregiving in FTD, according to 64 respondents

Concern	% of Respondents
Dementia can affect young people	27%
Discovered strength in dealing with the problem	20%
Symptoms fluctuate	17%
Low availability of resources for young patients with dementia	13%
Learning that other people were also struggling with same diagnosis	11%
Feeling weaker in caregiving skills than they expected	5%
Caregiver difficulty accepting help	5%
Having to educate informal caregiver friends on how to help	3%

DISCUSSION

Caring for patients with dementia represents a significant burden to caregivers' well-being and quality of life. In the current study we addressed the first symptoms recalled by caregivers, the most troublesome and surprising aspects of caregiving, and the resources or interventions that helped the most in learning about FTD.

The most common initial symptom was Changes in Thinking and Judgment, reported in about one quarter of patients. Although behavioural disinhibition and aphasic changes have also been reported as first symptoms,⁷ Lindau et al reported loss of executive function as a first symptom occurring in 21% of FTD subjects, compatible with what we observed.⁸ An emerging literature on early diagnosis of FTD has highlighted the presence of memory complaints in early stages of this dementia.^{9,10} Until more clinicians accept that memory loss should not exclude FTD from the differential diagnosis, this feature may create a barrier to full assessment for FTD and provision of the most appropriate caregiver support.

Limitations of this web-based survey include recruitment bias: the first level of invitation to participate was sent from TWC to caregivers who have identified themselves in her clinics or at lectures as being keen to receive information. This does not represent all caregivers and excludes those who do not have internet access. As such, the respondents do not necessarily reflect the relative prevalence of FTD subtypes in the general population. Our response rate from caregivers for logopenic progressive aphasia, for example, is quite high compared with the lower rate of diagnosis at TWC's clinic and likely resulted from one or more of caregivers known to the clinic directly recruiting others also working with this type of aphasia into the survey.

It appears that education about FTD may need to begin with awareness of the neuropsychiatric disturbances as symptoms of a dementia or brain disorder. A top-down approach to education would aim to improve the diagnostic process, which otherwise constitutes a major source of caregiver distress. An Australian study showed that the time between onset of dementia symptoms and diagnosis is often prolonged, leading to years of uncertainty for patients and their families who recognize behaviour as unusual, but who have difficulty distinguishing it from the many other reasons by which judgment can be impaired in people. Factors contributing to this delay included: the insidious onset of the disease; under-recognition or uncertainty about, a lack of knowledge about or a negative attitude to earlier diagnosis by health professionals.¹¹

When we inquired about resources or interventions that helped caregivers the most, the neurologist was the most common source of information, followed closely by reading information on the internet, indicating that the internet should be the first medium for conveying information to caregivers (e.g. www.theaftd.org, www.dementiaguide.com, and lifeandminds.ca). Rosness et al's study on support to family caregivers showed that FTD caregivers are significantly less satisfied with the provision of information about the disease when compared with caregivers of early onset Alzheimer's disease and are in need of more and other forms of support.¹² In this regard, use of an online survey may have biased respondents about the

usefulness of the internet as a source of information. Even so, the growing ubiquity of online information about health problems, and the somewhat younger age of people with FTD, suggests that this is likely to be a useful tool for many people.

This study's strength is that it is the largest international survey of FTD caregivers to-date. The results, however, while in keeping with our clinical experience with caregivers, are not generalizable due to considerable recruitment bias inherent to our methodology. It is difficult to know, without obtaining the missing responses through another means, the impact of lack of completion of the survey on the general results. The lowest rate of response (69%) was to the location of the respondent; otherwise the nearly 80% response rate to the content items for the survey likely represents the sample.

In summary, caregivers from several countries who were invited to participate in an online interview identified changes in thinking and judgment as significant first symptoms of FTD, and identified several educational needs about how FTD is described and understood. The specific symptom descriptors which they selected suggested a more broadly construed dysexecutive function as an early presentation, as opposed to obsessive-compulsive or sexually disinhibited behaviours. Lack of awareness about early-onset dementias, even on the part of healthcare professionals and how to access resources contributed to caregiver burden. A related and burdensome aspect of caregiving was difficulty in getting a diagnosis. For people who are web users, the internet may be a medium well suited to educational efforts in FTD.

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DECLARATION

Dr. Rockwood receives personal compensation for his role as President and Chief Scientific Officer of DGI Clinical Inc.

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Appendix

Dementia Guide FTD Caregiver Survey. * denotes optional, non-required survey questions

Q1. The person with a frontotemporal dementia for whom I care has a diagnosis of: (please check all that apply, 99% responded)

- Behavioural variant frontotemporal dementia
- Corticobasal Syndrome
- Semantic dementia
- Progressive non-fluent aphasia
- Logopenic progressive aphasia
- FTD-ALS
- Parkinson's disease
- Progressive Supranuclear Palsy
- We haven't been given a diagnosis yet
- An atypical (unusual) type of Alzheimer's disease

Q2. What was the first symptom you can recall, now that you know more about the illness? To choose the symptom, select one of the eight categories (Q3-10) below. A list of symptoms within that category will appear on the next page, from which you can then choose one. (91%)

- Physical Changes
- Thinking & Judgment
- Memory
- Language
- Everyday Activities
- Behaviour
- Personality Changes
- Leisure Activities Disabled by FTD

Q2a. Physical Changes:

- Incontinence
- Mobility

Q2b. Thinking & Judgment:

- Attention/Concentration (lack of)
- Decision Making (problems with)
- Insensitivity
- Judgment

Q2c. Memory:

- Memory for Names and Faces
- Memory of Past Events
- Memory of Recent Events
- Misplacing or Losing Objects

Q2d. Language:

- Difficulty with Comprehension of Speech
- Difficulty with Generating Speech/Talking
- Difficulty with Word Finding
- Difficulty with Reading
- Difficulty with Writing

Q2e. Everyday Activities:

- Driving
- Eating
- Financial Management/Shopping for work or at home
- Household Chores
- Operating Gadgets/Appliances
- Personal Care/Hygiene
- Sleep Disturbances

Q2f. Behaviour:

- Aggression
- Delusions and Paranoia or Hallucinations
- Disorientation to Place or Time
- Inappropriate Language and Behaviour
- Inappropriate Sexual Behaviour
- Irritability/ Frustration
- Low Mood
- Obsessive Behaviour
- Repetitive Behaviour
- Wandering

Q2g. Personality Changes:

- Anxiety and Worry
- Interest/Initiative (lack of)
- Low Self Esteem
- Restlessness
- Self-Awareness (Problems with)

Q2h. Leisure Activities Disabled by FTD:

- Hobbies
- Interaction with Friends and Family
- Interaction With Strangers
- Looking after Grandchildren
- Spirituality and Religion
- Travel and Vacationing

Q3. Of the following what have been the most troublesome aspects of caregiving for you? (You may choose up to three, 85% responded)

- Getting a diagnosis
- Not knowing that this was a dementia or neurological
- He/she follows me around all the time
- He/she insists on driving and I'm afraid he'll or she'll hurt himself or herself or someone else.
- The rest of the family is in conflict with me about his/her care.
- I can't find a day program that will take him/her.
- Finances are terrible.
- His/her illness has led to legal proceedings related to former employment.
- I don't know how to help him/her.

- I don't feel adequate as a caregiver.
- Other (please specify)

Q4. What resource or intervention has helped you the most? (84%)

- The nurse at my doctor's office.
- My children.
- Social worker.
- The day program staff.
- The Alzheimer's Society/Alzheimer's Association.
- Religion/Spiritual practice.
- Caregiver support group.
- Information from the Internet.
- The Association for Frontotemporal Dementia.
- The family doctor.
- The neurologist.
- The psychiatrist.
- None of the above: I need help!
- Other (please specify)

Q5. What was your biggest surprise in the process of learning about FTD? (81%)

- Dementia happens to young people.
- I'm stronger than I thought I was.
- I'm weaker than I thought I was.
- The hardest thing is to accept help.
- The patient is not always out to lunch. Sometimes we have a great day or s/he sounds normal to someone we don't know. Is that possible in this disease?
- Other people we know are also struggling with this same diagnosis!
- There are so few resources available for respite for young patients with dementia
- Our friends are willing to help but they needed to be told what to do.
- Other (Please Specify)

*Q6. I live in: (81%)

- Canada
- Europe
- USA
- UK
- Other (please specify)

*Q7. My postal/zip code is: (69%)

*Q8. I am a: (80%)

- Man
- Woman

Q9. My year of birth is: (78%)