

Supporting Family Caregivers of People with Frontotemporal Dementia

Frontotemporal dementia (FTD) is an umbrella term for a group of disorders that primarily affect the frontal and temporal regions of the brain, areas that control personality and behavior. Even though there are many studies about dementia caregivers and about FTD, there is a lack of information regarding support for FTD caregivers and the unique challenges they face.

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The literature on dementia caregivers has grown exponentially since 1995,¹ yet little has been published about caregiver burden pertaining to the early-onset dementias.² This is despite research showing that dementia caregivers of younger people have greater perceived difficulties³ and greater level of caregiver burden.⁴

Early-onset dementia is a term used for people who develop dementia before the age of 65 years. In this age group, the most common diagnosis is of early-onset Alzheimer's disease (AD) and the second most common, frontotemporal dementia (FTD).⁵

The Alzheimer Society of Canada states that, of the 500,000 Canadians living with AD or a related dementia, up to 15% are younger than 65 years, and 2% of these people have FTD. The percentages are the same for Ontario.⁶

Frontotemporal Dementia

FTD is an umbrella term for a diverse group of rare disorders that primarily

affect the frontal and temporal areas of the brain generally associated with personality and behavior.⁷ The mean age of onset is between 52.8 and 56 years,⁸ but typically occurs between the ages of 40 and 70, and has a mean duration of eight years.⁹

Three clinical variants of FTD are currently recognized: behavioral variant (bv-FTD), and two language subtypes, semantic dementia (SD) and progressive non-fluent aphasia (PNFA).¹⁰

Behavioral variant of FTD. The prevailing presenting feature in bv-FTD is an alteration in the patient's social conduct and personality, as opposed to early-onset AD, where the initial problems are memory-related.¹¹

In bv-FTD, a cluster of symptoms form the diagnostic criteria include:

- apathy;
- disinhibition;
- aberrant social conduct;
- distinct lack of empathy;
- alterations in eating behaviors;
- development of motor or verbal stereotypies.¹⁰

The lack of inhibition results in impulsive or inappropriate behaviors, such as swearing at inappropriate

times or people, angry outbursts, or lack of social tact.¹² As the disease progresses, this may lead to criminal behavior, such as theft or inappropriate sexual behavior, which may bring people to the attention of the legal system.

FTD is generally misdiagnosed or mistaken for a mid-life crisis,¹³ and the lack of knowledge about the diagnosis can greatly contribute to caregiver stress.¹⁴

One of the reasons for focusing on the bv-FTD group is that the associated changes in personality and behavior make it extremely difficult for spouses and family members.⁵ In marked contrast to patients with SD and PNFA who commonly recognize their deficits, the bv-FTD group are disproportionately affected by impaired sight, neglect of self-care and basic activities of daily living (ADLs), such as hygiene and dressing. These patients also have problems with initiation, planning and execution of their instrumental ADLs (*e.g.*, dealing with finances, performing chores).¹⁵ Often described as "selfish" or "self-centered," bv-FTD patients have a distinct lack of empathy for the emotional con-

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cerns of others, leading to a major cause of distress to spouses.⁷

Issues and Clinical Intervention for Caregivers of FTD Patients

Numerous studies suggest that it is the patient's behavioral disturbance, not the cognitive decline (e.g., poor memory or mental disorganization) that is the most significant predictor of social and emotional distress for the caregiver.¹⁶ By virtue of the psychiatric and behavioral initial presentation of bv-FTD, caregivers are more likely to have more difficulties managing than spouses of patients suffering from early-onset AD.

Through my clinical experience, I have observed a number of cases where the marital relationship had essentially broken down prior to diagnosis or presentation to the Memory Clinic, due to the insidious onset of the disease, the difficulty obtaining an early diagnosis, personality changes and emotional changes in the patients.

Levels of stress and psychological morbidity are known to be particularly high amongst caregivers of people with younger-onset dementias.¹⁷ The reasons are associated with the developmental tasks related to the family life cycle and the lack of appropriate services for this population. This group also has to deal with forced early retirement, financial hardship due to loss of income, difficulty in obtaining a diagnosis, friends, family and employers not understanding, not fitting into adult day programs due to age restrictions, and lack of services for FTD clients.

Clinical intervention for caregivers. The approach in working with FTD caregivers needs to focus on three key areas: helping caregivers deal with the challenging behaviors with which the patient presents, providing emotional support for the caregiver, and provid-

ing appropriate support services and practical resources in the community.

In order to address these areas, the clinician should assess the following in order to provide proper interventions:

1. The psychological and physical well-being of the caregiver.
2. The caregiver's attribution and perception of their role.
3. The strength of informal and formal supports.
4. The quality of the premorbid relationship between the patient and the caregiver.
5. The cultural and spiritual beliefs of the caregiver.
6. The amount of knowledge that the caregiver holds about the illness.

Caregivers who do not feel understood by the clinicians will not come back, therefore not allowing for further support and intervention at a time that they need it most.

7. The types of coping strategies that the caregiver uses currently and has used in the past.
8. The presence of other potential stressors.¹⁸

Areas of intervention. Once the clinician is aware of which areas the caregiver needs help with, the interventions should be geared to address these areas. The number-one rule in dealing with families is "to start where the family is at" as opposed to where the clinician thinks the family needs help with. This is crucial, as caregivers will only accept help with areas that they recognize as "problem areas" and not the ones that the professionals think they need help with. For example, if a spouse states that her biggest difficulty is in dealing with her own embarrassment at her husband's inappropriate sexual behavior in front of others, but the clinician feels that actually the main issue is the wife's lack of acceptance of the disease and therefore poor lack of

supervision on her part, then the focus of the intervention should be on the wife's feelings of embarrassment.

Other issues can eventually be addressed once the caregiver feels heard and understood by the clinician. Caregivers who do not feel understood by the clinicians will not come back, therefore not allowing for further support and intervention at a time that they need it most. Clinicians should not be rigid in the way they provide help. Families will ask for support when they feel ready, and it is the role of the healthcare provider to be there when the family is ready to accept help.

After 18 years working in a Memory Clinic, I have found that the

most effective way to work with these families is to meet them initially at the time of diagnosis and to be available throughout the patient's disease process. It has been my experience that people are able to call in time of crisis or when support is needed if the initial therapeutic relationship was established early in the diagnostic process, and they feel that they can count on the clinician as issues arise.

Other areas that should be addressed with caregivers early in the disease are listed in Table 1.

Conclusion

Despite the large body of research concerning caregiving issues, there is little to guide clinicians in terms of assessing and managing these issues in the FTD population.

Medical advances in the early detection and assessment of early-onset dementias have brought to the attention of clinicians working in this area that

Table 1

Areas that Should be Addressed with the Caregiver Early in the Disease

- Power of Attorneys
- Understanding of the long-term care system
- Financial supports that are available to families through tax credits, social assistance, CPP and drug coverage
- Financial management issues and safeguards around excessive spending and gambling
- Safety issues (e.g., driving)
- Dealing with inappropriate or illegal behaviors

these patients and their caregivers have specific practical and emotional needs which cannot be addressed through services designed for older adults. Although mental-health workers possess a number of transferable skills in this area, they need to be alert to an emerging knowledge base concerning this population.

Working with caregivers of FTD patients is often challenging and difficult, even to the most experienced clinicians. Resources are scarce, public acknowledgement of the problem is quite limited, and treatments and interventions are not readily available. These cases require a lot of advocacy

on the part of the clinician, as these clients “fall through the cracks.” This is due to the majority of services being geared to an older patient population (e.g., adult day programs and drug coverage are geared to those over 65 years), which prevents seamless access to appropriate services.

As this disorder cuts across generational boundaries, the demands often include working with adolescents in the home (generally not an area of competency for clinicians in a Memory Clinic), working with schools, Children’s Aid agencies, adult day programs for patients, and sometimes issues related to patients’ or spouses’ parents,

who are aging as well and need support from their children. Furthermore, day programs and caregiver relief are not always provided for long enough hours to account for the needs of spouses who are still in the workforce.

In the future, more work should be done to provide prompt education and teach management strategies to deal with the difficult behaviors as these caregivers are at great risk of physical and mental health problems. Protocols should be developed in medical settings that all bv-FTD caregivers should be seen by social work/mental-health professionals at the time of initial diagnosis. This would hopefully provide intervention at a time that would be more beneficial than waiting for “the crisis point.” In this way, families could be given more education, could obtain emotional support earlier and could access help around practical issues sooner.

Clinicians working in this area will need to continue to find ways to work with this population in ways that are creative and based on the needs of this very vulnerable group of caregivers instead of the requirements of our institutions and support services currently available.

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