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Organizing a Series of Education and Support Conferences for Caregivers of Individuals With Frontotemporal Dementia and Primary Progressive Aphasia

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Abstract

Frontotemporal dementia and primary progressive aphasia are relatively rare dementias, with average age of onset in the 40s to 60s, and cause initial degeneration in behavior and language, respectively. Caregivers of diagnosed individuals report that there is little information available about these diseases. In response to this need, we designed and implemented a 3-part series of conferences aimed to educate and provide support to these caregivers. This article introduces the reader to the 2 disorders, highlights the need for specialized resources, and describes the execution of the conferences. The need for similar resources to be offered in other regions is discussed.

Keywords

atypical dementia; Pick's disease; resources; semantic dementia

Frontotemporal dementia (FTD) and primary progressive aphasia (PPA) are 2 forms of dementia caused by progressive degeneration of the frontal and temporal lobes. Most researchers consider them to be related, under the umbrella of frontotemporal lobar degeneration.^{1,2} They are dementias in the sense that they cause progressive loss of cognitive and functional ability resulting from progressive neurodegeneration. When they initially

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occur, FTD and PPA have very distinct presentations. FTD is commonly characterized by change in personality marked by behaviors such as apathy and disinhibition and repetitive stereotyped behaviors, all combined with a loss of insight about these changes.²⁻⁵ PPA initially looks quite different, with a hall-mark breakdown in language functions in the context of an otherwise healthy, cognitively intact individual.^{6,7} Over time, however, patients with PPA tend to develop behavioral deficits, and their clinical presentation often eventually overlaps with that of patients with FTD.^{6,8,9} Presently, there are no effective treatments for either FTD or PPA.

In comparison with Alzheimer's disease (AD), the most common cause of dementia, a unique aspect of FTD and PPA are the age groups that they tend to affect. Both disorders are most common in the presenium, peaking in the 6th decade, but often occurring in individuals in their 40s or 50s.¹⁰⁻¹³ The families affected by these disorders are thus at a different stage in their lifecycle compared with those with AD; children may still be at home, and the individual who is affected may still be in the workforce. Families are faced with a myriad of challenges including replacing lost wages and insurance benefits, legal and financial planning, and coping with the eventual loss of a spouse or parent much sooner than anticipated.

There is no definitive life expectancy for an individual diagnosed with FTD or PPA, although studies suggest that individuals with these disorders live an average of 6 years from diagnosis, almost the same as in AD.¹⁴⁻¹⁶ However, one study indicates that many of these patients develop diseases such as motor neuron disease that shorten life even further.¹⁶ Even in the absence of motor neuron disease, the progressive neurodegeneration generally results in a life cut short. Thus, in addition to coping with changes in personality and cognition, the affected family has to cope with the eventual loss of their loved one sooner than they might have expected.

FTD appears to affect between 4% and 10% of patients presenting at dementia clinics, making it one of the more common forms of dementia.¹⁷ No prevalence estimates exist for PPA, although it does appear to be more rare than FTD. Families affected by these diseases often feel isolated, and yearn for the opportunity to talk with others in similar situations.

Diagnostic criteria for these disorders have been subject to a great deal of debate and change, making it difficult for families to find consolidated information, especially when the medical terminology is unfamiliar to them. What is today most commonly referred to as FTD has previously been referred to as Pick's disease.^{18,19} Another source of confusion comes from misreferral and misdiagnosis.²⁰⁻²³ The cluster of symptoms seen in FTD can masquerade as a mental illness such as the mania of bipolar disorder,^{24,25} and unsurprisingly many of these patients are first seen by psychiatrists.^{20,26} Because these disorders are rare, healthcare professionals are not always educated about the disorders, and patients are frequently misdiagnosed. It is not uncommon for a patient to have seen 3 specialists over 3 years, before being correctly diagnosed.²⁷ Getting the correct diagnosis can also be an expensive process, with diagnostic work up most often including neurological and neuropsychological examinations as well as neuroimaging and laboratory tests. By the time families reach a tertiary referral center, they are often confused, exhausted, and eager for as much information as possible. Unfortunately, there are limited resources available to help families understand and cope with these diseases.

Families dealing with FTD and PPA often turn to their local Alzheimer's Association chapter for support. Although the Alzheimer's Association may be helpful in addressing general questions regarding caregiving concerns, this organization is not very well equipped to offer specialized educational materials on non-Alzheimer dementias. A specialized association for FTD has been established,²⁸ but at this stage is mostly an Internet-based information

resource, without the nationwide local chapters and support groups' characteristic of the Alzheimer's Association.

In addition, these families have different needs compared with those who are dealing with AD. Alzheimer's is (usually) a disease of old age, affecting retired and relatively elderly individuals. In contrast, patients with FTD or PPA often are living at home, are preretirement age, and are valuable members of the workforce. Neither FTD nor PPA usually affects memory in the early stages, so a comparison with AD is quite insufficient.

There is a clear need for education and support specifically tailored to families dealing with PPA and FTD. Their situations are different from those with AD, and numerous questions go unanswered by standard dementia resources. Even among medical researchers, issues such as genetics, life expectancy, and etiology are unclear, given that the surge of research interest in FTD and PPA has been fairly recent. From a psychosocial perspective, managing finances, dealing with legal issues, and entering a nursing home at a young age are some of the challenges faced by these families.

The Northwestern University Cognitive Neurology and Alzheimer's Disease Center (CNADC) is 1 of 29 AD research centers funded by the National Institute of Health and the National Institute on Aging. A primary component of our center is our Neurobehavior and Memory Health Clinical Service, which includes behavioral neurologists, neuropsychologists, psychiatrists, and social workers. Diagnostic evaluation and ongoing care of persons with FTD and PPA are a clinical specialty of the CNADC.

In addition to providing clinical services for patients and families, as a designated AD research center, the CNADC has a memory research database composed of more than 600 active participants. Participants include people with a diagnosis of AD, FTD, and PPA as well as healthy older adults. The CNADC has one of the largest registries in the world of individuals diagnosed with PPA and FTD.

The need for both FTD/PPA education and the opportunity to meet others facing similar family situations was apparent from the questions our clinicians received and feelings of isolation expressed by many families affected by FTD and PPA who visit our clinic. Furthermore, as a specialized clinic, we felt a responsibility to educate our patients' families with the most accurate and up-to-date information available. During the initial conference planning meetings, we shared information and anecdotes gathered from families in our clinic. For example, we discussed adult children trying to balance caring for their own young families while coping with dramatic changes in their parent who had been diagnosed with FTD, or husbands and wives who retire only to find themselves in the new role of caregiver. We began to realize how important it might be to introduce these families to each other, allowing them to realize that they are not alone; furthermore, several families expressed an interest in meeting others who were facing similar challenges. Given the prevalent communication, insight, and neuropsychiatric symptoms experienced by those carrying the diagnoses, we decided to not only focus our efforts on caregivers but also include diagnosed individuals who were able to benefit from education and support.

As a result of these identified needs, a group of graduate students, social workers, and neuropsychologists designed a series of PPA and FTD Education and Support conferences to reach out to these families. The sessions were stretched out over the course of a year to allow for continuity of support and to permit several educational topics to be covered without overwhelming the participants. Each session was half-day in length, and began with an hour of educational lectures covering relevant topics about these relatively rare dementias (see below for the list of educational lecture topics). Each educational talk included time for the attendees to ask questions. Following the lectures, participants attended a support group facilitated by

social workers, psychiatrists, clinical neuropsychologists, and graduate students in clinical psychology and neuroscience. The support groups offered participants with an opportunity to discuss the challenges of providing care for an individual with FTD or PPA with other families living in similar situations. During the support group segment, family members separated into groups of 10 to 15 individuals, accompanied by 2 facilitators, in small, private rooms. For 90 minutes, the groups met for a semistructured session. The facilitators began by introducing themselves and suggesting that individuals say a little about themselves, their affected loved one, and their situation. Facilitators then mediated a discussion between the participants, bringing together common themes that they picked up during the introductions. Participants were encouraged to support each other and share common coping strategies and practical tips. In the few cases where crisis situations were identified, facilitators approached the participants after the group to offer a referral to an appropriate clinician. The program ended with a lunch, offering the families an opportunity to get to know one another in a less-structured setting, and also to interact with clinicians and researchers. In response to feedback from earlier sessions in which attendees told us that they would like more information on research, we displayed posters at the third conference detailing the research at our center currently being carried out with populations with FTD and PPA.

Initially, we sent invitations to all caregivers of patients with FTD and PPA who were in our research database. To reach out to more individuals, we placed information about the events on our Web site (www.brain.northwestern.edu). As our list of attendees and those interested in learning more about our program grew, we created a separate mailing list database specific to the conference.

Sessions were funded by a combination of departmental funds and a small charge to attendees. Later on, some funding was established from pharmaceutical companies. The overall costs of the conferences were kept to a minimum.

The conferences were designed to be independent, but also complimentary, to each other. We were aware that individuals may be able to attend some but not all sessions, and that families would be joining the conference series at various time points. Each session had a different theme dictated by the topics covered in the educational talks:

Session 1 “The ABC’s of FTD and PPA,”

Sandra Weintraub, PhD “Brain donation: Hope for the future,” Eileen Bigio, MD

Session 2 “Drug Treatment Options for PPA and FTD,” Deborah Reed, MD

“Coping With Common Communication and Behavioral Issues in FTD and PPA,”
Ann Oehring, MS, CCC-SP

Session 3 “Caring for the Caregiver,” Darby Morhardt, MSW, LCSW

The topics were quite diverse, and designed to be of interest to all attendees. Dr Weintraub’s talk served as an introduction to the disorders, with information on etiology, the role of the frontal and temporal lobes in language and behavior, and how the disorders are diagnosed. Dr Bigio spoke about the importance of research in developing treatments and gaining a better understanding of these diseases. Dr Reed talked about what kind of behavioral problems may emerge over the course of these diseases, and how they are treated from a neuropsychiatric perspective. Ann Oehring talked about language breakdown owing to dementia, and made suggestions on how to communicate more effectively with individuals diagnosed with these disorders. Finally, Darby Morhardt discussed the importance of caring for the caregiver. Her talk also featured a radio interview with a local family coping with FTD, and a guest panel composed of 2 individuals who themselves had been caregivers of an individual with PPA. The

presence of these caregivers along with a social worker allowed for interesting questions in an extended Q&A session.

The breakout support groups offered participants the chance to share their own tales of caregiving, and to receive and give support to others facing similar challenges. For many, this was their first opportunity to meet others coping with the impact of FTD or PPA. Some of the discussion topics that emerged included medications, challenging behaviors, taking away aspects of independence such as driving or family finances, legal issues, and discussion of their sadness in coming to terms with their loved one's condition.

At each conference, handouts were distributed detailing the content of the talks. Additional information on FTD and PPA and related resources were also included in the handouts. When people contacted us about the conferences, but were unable to attend, we offered to send out these packets. Feedback was positive from these families, suggesting that just receiving the additional information was useful. Overall, we had an impressive attendance rate of around 50 individuals per session. Attendance details are listed in Table 1.

Evaluation forms were collected at the end of each session, asking attendees to give ratings on various aspects of the events, from the quality of the learning facilities, to the content of the talks and support groups, to their satisfaction with lunch. Overall, the response was positive, and there were some helpful suggestions for future conferences. Particularly useful suggestions included topics for future lectures that would be most useful to caregivers such as presentations involving research updates, or advice on taking over the affected individual's responsibilities (eg, driving, financial affairs, use of potentially dangerous tools).

Some of the responses to each of the sessions are listed below:

Cleared up a confusing topic and terms for me. Excellent and easy to understand.

As with the session in October, this session was very helpful in providing new information, support, and access to experts in the field.

I can't begin to tell you how important your first series on FTD/PPA was for my daughter and me. It was good for both of us to see others dealing with the same issues. You have a tendency to think you're alone out there.

The speakers were very good and the information was helpful. Its good to have these things reinforced and helpful to know what others are experiencing.

As can be seen, we had an overwhelmingly positive response. There was some less-positive feedback, with attendees sometimes finding the content of talks too scientific or not of practical use to them. Feedback, both positive and negative, was used in planning discussions for future meetings.

In the coming year, we will be offering 2 more conferences and less formal monthly open-ended support groups. The idea to offer support groups came from feedback that there was not enough time to address the needs of everyone in the support groups offered at the conferences. We made an effort to keep the number of attendees per support group small enough for intimate discussion, allowing each member to have time to share his or her story. Nonetheless, it was difficult to terminate each session because they were so eager to interact with one another and had so much to share. As such, they requested that they would like to meet longer and more frequently. By offering monthly support groups, in the evening, it is hoped that more of the caregivers' needs will be met on an ongoing basis.

Perhaps, the most difficult challenge we faced in organizing these conferences was in deciding whether or not to include diagnosed individuals in addition to their caregivers. At the first 2 of

our 3 conferences, we did allow high-functioning patients to participate. We defined “high functioning” as those individuals who were able to function independently and able to communicate in an understandable fashion. However, it became apparent that our interpretation of these criteria differed dramatically from that of the family members. A broad range of abilities marked the first support group for diagnosed individuals, and the presence of individuals with severe impairment was unfortunately upsetting to some individuals who were in the earlier stages of the disease. Others, however, found the support group to be of great help, with friendship established between individuals who have continued to maintain contact via phone and e-mail.

For the most part, we discouraged patients with diagnosis of FTD, since they tend to have decreased insight, and often have behavioral symptoms not suitable for group attendance. Their decreased insight often results in denial of illness, and insistence that there is no change in their personality despite their families noticing pronounced changes,²⁹ and so many of these patients do not wish to attend support groups. Some caregivers were disappointed that they could not bring their loved one, often since they did not have appropriate respite care. In this situation, our social workers worked with the families to suggest local resources, allowing the caregiver time to attend this conference and other activities important to them. Other families already had a support system in place, and their loved one spent the day with friends or family members, or at a day center. This meant that the group was composed mostly of individuals with a PPA diagnosis. These are rare disorders, and the opportunity for an affected individual to meet and get to know someone experiencing the same disease can be invaluable. In the future, we intend to accommodate high-functioning diagnosed individuals by including activities appropriate for individuals with PPA, in collaboration with the speech and language pathology department. The inclusion criteria listed below were provided to caregivers who wished for the participation of diagnosed individual. Ultimately, the decision was left to the caregiver.

Inclusion participants with a diagnosis of FTD or PPA:

- must be aware of their symptoms and want help in coping with their symptoms;
- must not have any disruptive or socially inappropriate behaviors;
- must be able to communicate, that is, comprehend and express themselves to some degree;
- must be emotionally stable, and not likely to be upset by seeing others at different stages of the disease;
- must be able to function independently (ie, not require help with toileting); and
- must understand that educational talks will be frank in nature, and may talk about challenging behaviors, medications, and caregiver issues.

In conclusion, on the basis of the needs of families affected by FTD and PPA, we designed and executed a 3-part series of conferences for the education and support of caregivers coping with these disorders. Overall, each meeting was a great success, and allowed caregivers from diverse parts of the country (and the world) to meet each other, to learn more about the disorders, and to have their specific questions answered in a supportive environment. Feedback from these meetings highlights the need for additional meetings, as well as more frequent support opportunities. This program was innovative, but similar meetings are being set up in other parts of the United States, also in affiliation with research centers. We hope that these resources grow in depth and scope to meet the needs of diagnosed individuals and families who are coping with these less-recognized disorders, and that an increasing public awareness draws attention to the special needs faced by these families.

Practical considerations in planning education and support conferences include the following:

- Establish funding from your own center or from outside sponsors.
- Generate interest from colleagues and develop a planning committee, and to commit to running support groups and helping with practicalities.
- Find speakers, willing experts in the field who can communicate well with a lay audience.
- Specify a date, and make practical arrangements such as room bookings (conference room plus rooms for support groups, easy to find and close to parking), catering, etc.
- Three months before your conference date, mail out a flyer to families of affected individuals with an RSVP deadline at least 2 weeks prior to the date. Provide an RSVP phone number and a phone number for questions.
- Be prepared to commit time on the telephone as attendees call with RSVPs. Many attendees will have general questions about the disorders, as they have been recently given a diagnosis and are eager for information. Some family members require time to discuss whether their loved one is appropriate to attend the conference.
- On the day of the conference, have plenty of help for registration, answering any questions, and coordinating the catering and audiovisual staff as well as the speakers. One individual should “host” the event, welcoming participants, introducing the speakers, and guiding participants to the support groups’ sessions.
- Ensure that the support group rooms are conducive to a therapeutic environment, place chairs in a circle and make sure the room is soundproof and comfortable.
- Have clinician’s business cards and notepads on hand. We found that many families required some form of clinical follow-up or referral.
- At lunch, the host should thank the participants and the speakers, and staff should circulate making themselves available for questions, and distribute evaluation forms.

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Table 1
Demographics of attendees at each conference

	Session 1	Session 2	Session 3
# Caregivers and family members			
FTD	3	24	21
PPA	38	21	27
# Patients			
FTD	1	1	0
PPA	13	5	0
Total attended conference	55	51	48
Local	10 families	20 families	17 families
Out of state	11 families	7 families	7 families
Different home states/countries of attendees	Michigan, Illinois, Indiana, Texas, Massachusetts, Ohio, Kansas, Ireland, West Indies	Illinois, Indiana, Kansas, Ireland, Massachusetts, California, West Indies	Illinois, Massachusetts, Indiana, Louisiana, New York, West Indies