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Advanced Practice Nursing: Meeting the Caregiving Challenges for Families of Persons with Frontotemporal Dementia

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Abstract

Frontotemporal dementia (FTD), once thought to be a rare cause for dementia, is now acknowledged to be the most common presenile (before age 65) cause of dementia (1). FTD is associated with profound changes in behavior, personality, emotions, and cognition. The purpose of this paper is to describe two cases of patients with FTD in order to illustrate salient aspects of the caregiving experience. Issues faced by caregivers are organized into 6 categories: diagnosis, behavioral symptoms, function, communication, long term management and care, and maintenance of the caregiver's emotional and physical health. Examples of interventions directed by advanced practice nurses are described. We suggest that management of FTD requires expertise as scientific advances and discoveries about FTD continually change the landscape of care.

Keywords

Frontotemporal dementia; dementia family caregiving; advanced practice nurse; clinical nurse specialist

Introduction to FTD

Perceptions of what constitutes the dementia family caregiving experience are rapidly changing. Public understanding of dementia is based largely on Alzheimer's disease (AD). Patients with AD typically show evidence of memory loss, visual-spatial problems, and word finding deficits. Yet, non-AD dementias manifest symptoms that are unique and different. Patients with FTD may demonstrate strong memory, visual, and navigational skills, yet be profoundly impaired due to changes in judgment, executive skills, behavior, emotions, and personality (2,3), all of which create unique experiences for the family caregivers.

FTD results from atrophy in distinct areas of the brain, the frontal and/or anterior lobes. FTD refers to a spectrum of diseases and is categorized as either a behavioral or an aphasic subtype. The first subtype is commonly referred to as the behavioral variant of FTD (bvFTD), the most common subtype. Neuronal loss and tissue atrophy in the frontal lobes manifest as behavioral, personality, and emotional changes and a dysexecutive syndrome. Disinhibition and deficits in personal and social misconduct are often seen. The aphasic subtype is comprised of two conditions, semantic dementia (or temporal variant) and progressive non-fluent aphasia (PNFA). Tissue loss in SD occurs in the anterior temporal lobes and causes a progressive loss of word and object knowledge. Behaviorally, patients with SD can exhibit changes that include

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rigidity, obsessive-compulsive activities, and self-centeredness (2,4–8). Since behavioral changes are not as predominant in PNFA, this subtype will not be included in this paper. FTD is recognized as the most common presenile dementia, typically occurring between 50 and 60 years of age and represents approximately 10–20% of dementia cases (9). FTD occurs in 3.5–4.8/100,000 people aged 45–64 compared with 4.2/100,000 in that age group afflicted with AD (1,10). FTD progresses to death more rapidly than AD (11) with a mean survival of 6 (12,13) to 8 years (14). The cause of death is not typically known (15), although in clinical experience, injury from falls and aspiration due to swallowing deficits are implicated. Tau-positive and negative proteins have been identified as the cause for characteristic neuronal and glial protein inclusions. Specific clinical features, functional abilities, and survival are associated with FTD neuropathology (13,16). For example, tau-negative FTD has been associated with more disruption in behavior, social conduct, language, and executive dysfunction (17). To date, there is no cure for FTD and treatment focuses on symptom management.

FTD has an important impact on functional skills. Patients with FTD typically have difficulty managing responsibilities and decision-making at home and in the workplace. These patients may be at more risk for injury from a variety of safety issues in the home or institutional environment. Falls due to impulsivity or lack of judgment, ingestion of toxins, burns from fires, appliances or the sun, injury from sharp objects or weapons and inability to respond appropriately to emergency situations are all risks for these patients (18).

There is heterogeneity in both the presentation and progression of FTD that reflects differences in affected brain regions and cellular pathology. The cases described here reflect common issues that we have observed in our clinical experience in patients with these diagnoses. Actual patient and family names have not been used. Various interventions made by the Advanced Practice Nurse (APN) familiar with FTD are included.

Case 1-Frontotemporal Dementia (FTD)

Jackie was first evaluated at the age of 54. She presented with a 6-year history of symptoms. Her husband Rob recounts a complex of symptoms including behavioral and personality change and short-term memory loss. Pre-morbidly, the patient was noted to be patient, energetic, and fastidious. The symptoms began when Jackie developed anxiety about being left alone. She had several episodes in stores in which she was verbally confrontational with the staff. In another incident her credit card was declined but she took the items out of the store anyway. Jackie exhibited other problems in judgment. In one year, $40,000 disappeared from her saving account, yet she was unable to tell family what had happened to the money. These behaviors were initially interpreted as being related to menopause. Her family sought an evaluation for the changes. Her history, examination, cognitive testing, and brain imaging (bilateral frontal atrophy, worse on the right side) were consistent with bvFTD dementia. Jackie continued to reside at home with Rob. There were several sons, daughters, and grandchildren residing nearby.

Three years after the onset of symptoms Jackie began to uncharacteristically drink alcohol to excess including drinking shots at a bar while on vacation. On another occasion she drank an entire bottle of wine. She was belligerent with family members, often arguing with young children in the family about the rules of games or who could choose television programs to watch. Jackie developed rigid and compulsive behaviors. She drove up and down her street repeatedly, at one time logging 246 miles on the odometer of her car. She had episodes of pacing the length of the house that lasted for hours. During one episode lasting 14 hours she did not eat or sleep and soiled herself. She eventually collapsed, hit her head, and was taken to the emergency room. She was eating excessively at this time, filling her mouth with food and eating until the food was taken away. She had a 40–50 pound weight gain during this time. She had several episodes of choking during this period. At this time, her husband also began to notice short-term memory problems. Most notably she forgot an incident in which the paramedics had to be called because she was choking on food. During this time, she developed urinary incontinence that seemed to be a function of lack of concern about making it to the bathroom in time to use the toilet. She spent many hours in bed, or sitting and watching television. When incontinence was pointed out to her, she would express lack of concern and was unable to bathe or dress herself without reminders and assistance.

Later in the illness, Jackie had a decrease in appetite and lost interest in food. She had a 30-pound weight loss in the course of 18 months. She exhibited profound apathy and spent her time primarily sitting in one place and watching television. Over time, Jackie appeared to be less interested in matters relating to her family. She had brief episodes of pacing and periods of agitation that lasted a few seconds. Although she spoke very little, she was able to speak in entire sentences and followed conversations. She was unable to participate in any daily chores or tasks around the house. She preferred to watch musicals and grew restless when the content of the program was too complex. Jackie required one-to-one assistance with hygiene and feeding.

Issues for the FTD caregiver

Obtaining a diagnosis

Families often relate the difficulties in obtaining a correct diagnosis for patients exhibiting changes in behavior and personality. These symptoms are often mistakenly attributed to depression, mid-life concerns, marital conflict, and other psychiatric conditions (often bipolar disease or schizophrenia). In Jackie's case, the family attributed problems to menopause. It can take years before families are able to get the patient diagnosed correctly. Patients with bvFTD often perform very well on standard tests of cognitive function, exhibiting good memory and language. Practitioners who are more familiar with deficits seen in AD (poor memory, getting lost, word-finding deficits) may be reluctant to view the personality and behavioral changes as the result of a neurodegenerative condition. An APN familiar with atypical dementias can be a valuable resource to families in finding the providers and centers more familiar with these conditions. A referral to a specialty clinic or center can reap benefits to the patients and families in clarifying the clinical symptoms and providing a framework for future planning and decision-making.

Managing socially unacceptable behaviors

Initially, Jackie exhibited several social behaviors that created frustration and embarrassment for her family. She repeatedly had negative interactions in public and with storeowners, yet had no insight that her behavior was negative or problematic. She repeatedly told her husband "What are you worried about? I'm fine." The APN provided a letter from the doctor that briefly explained how the medical condition affected Jackie's judgment. Rob gave the letter to several storeowners and also set up store accounts so that items could be charged in the event Jackie did not pay. She was given a small amount of cash to carry, but was not given access to credit cards or the checking account. Family members carried small business-type cards that briefly explained that Jackie had problems with behavior due to a medical condition. They used the cards during difficult encounters to facilitate understanding with the public.

Another distressing behavior for Jackie's family was her progressive apathy. Rob was especially distraught to see his formerly active wife become so content to sit and do nothing. He tried repeatedly to engage her interest in activities and was frequently worried that she was depressed. Jackie failed to respond to requests, often telling him "I'll do that later." With coaching by the APN, Rob eventually found a level of acceptance for the apathy and some success by offering limited choices to Jackie. For example, rather than asking if she wanted to go for a walk around the block, he would take her hand and request she come with him.

As a result of disinhibition, changes in serotonin levels, and/or anatomic effects of disease, many patients with bvFTD exhibit compulsive eating or hyperorality. Jackie's family had to supervise her food and alcohol intake. They locked cabinets in the kitchen and provided supervision in public to prevent her from taking food from others' plates. Over time, Jackie required 1:1 supervision during mealtimes due to her high risk for choking.

Managing functional changes

Dementia leads to deficits in functional abilities. These functions are classically divided into two categories. The first are called instrumental activities and refer to complex tasks such as bill paying, working, shopping, driving, managing appointments, and packing for a trip, etc. The second category refers to basic activities such as eating, bathing, dressing, and using the bathroom. The ability to engage in complex activities is typically affected earliest in dementia. In Jackie's case, she had early impairment in her abilities to manage money appropriately, a typical finding in patients with bvFTD. Her poor judgment and impulsivity had placed her, and her family, at financial risk. Due to the early and severe loss of judgment in patients with bvFTD, caregivers must intervene earlier in the areas of legal and financial planning. This intervention is essential to prevent overspending and other fiscal vulnerabilities and to ensure the safety of financial resources. Therefore, at the recommendation of the APN, one of the first steps for Rob was to obtain Durable Power of Attorney for Legal and Finances and to establish conservatorship.

Communication

The decreased empathy, distractibility, and poor working memory found in bvFTD can make communication with the patient very difficult. While the ability to speak may not be as affected in some patients, caregivers often report a lack of emotional connectedness and awareness in patients with bvFTD. These patients may only want to talk about the issues that they are interested in or obsessed by at the expense of others' interest in the conversation. An APN familiar with FTD can assist family members to develop communication styles with their loved one that emphasize matter of fact responses, distraction or non-response to repetitive or obsessive conversation topics.

Long term and terminal care

As apathy increases in the later stages of the illness, the physical care needs often become more intense. Caregivers have described the difficulties in finding placement in long term care (LTC) facilities that are reluctant to accept younger patients exhibiting social and personal misconduct. It can be difficult for families to imagine their loved one in a day program or facility with participants who are much older. The APN can be a liaison between a day program or LTC facility in order to education staff about the illness. An APN knowledgeable about FTD provides valuable assistance to the family to develop realistic goals around placement and end of life care.

Caregiver physical and emotional health

For many caregivers, the demands of the patient make it difficult to pay attention to their own physical and emotional health. Caregivers may forego their own medical appointments and check-ups. Caregivers need practical help and advice regarding caregiving issues as well as emotional support. Rob benefited from attendance at a monthly FTD caregiver support group. Rob had always derived great pleasure from a weekly golf game with several close friends; his children assumed care for Jackie so that he could continue the tradition. The APN was available by telephone or in-person meetings to offer support and advice as Jackie's care needs shifted.

Case 2-Semantic Dementia (SD)

Linda was divorced woman with one daughter. She was retired from her job as a high school English teacher. Linda was first evaluated at the age of 65. Two years prior she was noted to have a shorter temper and difficulty coming up with the names and meanings of certain objects. The example given by the patient's daughter, Sarah was of her mother forgetting both the name "peanut butter" and what peanut butter was used for, although she was able to make a peanut butter sandwich. She could not always come up with the name of familiar people. She appeared to have fairly good recall of recent events, strong visual spatial skills, and intact executive function. Her history, examination, cognitive testing, and brain imaging (bitemporal atrophy, worse on the right than on the left) were consistent with semantic dementia.

Over several months, Linda demonstrated obsessive-compulsive behaviors. She became attracted to children's toys and small animals and would approach young children to pat them on the shoulder. Prior to her illness she was described as dressing stylishly and tastefully, yet began wearing clothes with bright colors and childlike logos. She became fixated on her personal health, developed multiple somatic complaints, often discussing these issues in detail in public. She began playing Solitaire and blackjack several hours a day on her computer. Over time she wore clothing only in shades of purple. Her ability to name objects was markedly diminished. Linda's awareness of her deficits resulted in depression.

At first Linda continued to live independently. She used reminder notes for appointments and chores. She had trouble reading, but was able to comprehend conversations. She prepared her meals, yet had increasing difficulty following recipes, and was unable to recognize many foods and kitchen utensils. She developed a rigid habit of drinking a sip of water from a certain water bottle at 5-minute intervals. Her weight declined which her daughter attributed to a rigid fixation of only 2 small meals per day consisting of shredded wheat for breakfast and chicken for dinner. While she was able to complete mathematic calculations, she experienced some trouble with her finances. When preparing her taxes she phoned her daughter to ask, "What is a savings account?" She continued to drive without getting lost or disoriented.

One year after being diagnosed, Linda's semantic deficits progressed. She no longer recognized familiar people, even family members. She reportedly hit a parked car and drove away from the scene. A bystander recorded her license plate number and when the sheriff came to her home, she denied knowledge of the accident. She often mistook condiments as regular food and would taste them in order to identify what they were. She had a few episodes of shoplifting alcohol. She demonstrated childlike behavior and laughed and cried more readily. Her comprehension abilities declined and she no longer read. She continued to exhibit strong short-term memory and visuospatial skills.

Two years after diagnosis, Linda demonstrated increasing apathy. She spoke only when spoken to. She was unable to follow movies, TV shows, or conversations. She played solitaire on the computer for hours, although there was an overall decrease in obsessive-compulsive behaviors. She was content if able to follow a rigid daily routine.

Issues for the SD caregiver

Obtaining a diagnosis

Changes in language and speech are commonly attributed to stroke or Alzheimer's disease. It can be difficult to distinguish between the loss of word meaning in SD and word finding difficulties common in AD. Like bvFTD, the emotional and behavioral changes are often mistaken for mood and psychiatric disorders, mid-life problems, or marital issues. Clarification and education regarding the anatomical correlates for these symptoms by the APN can help the family gain understanding and acceptance for the changes they are observing in the patient.

Managing socially unacceptable behaviors (disinhibition, hyperorality, apathy)

For Sarah (Linda's daughter), managing and accepting behavioral and personality symptoms were a major component of her caregiving challenges. Initially, Linda exhibited crankiness and irritability above her baseline personality. The behaviors were initially embarrassing, frustrating and annoying. With increasing atrophy of the right temporal lobe of the brain, Linda exhibited rigid and compulsive behaviors as well as other socially questionable behaviors such as increased focus on children and childlike items. These social behaviors became riskier, for instance her attraction to children and children's toys fostered concern and alarm in public and it became increasingly difficult for Sarah to distract her mother. Sarah became worried that parents and others in the public would react negatively to her mother's obsessions. She worked with the APN to develop strategies to minimize negative public situations. The APN provided a brief letter from her mother's neurologist explaining the disease impact on her mother's behavior. Sarah used this letter with several storeowners after shoplifting incidents. Sarah also carried business-type cards that briefly stated her mother suffered from an "Alzheimer's-like disorder" that affected her behavior. She handed these to others if her mother's behavior warranted explanation. Sarah also obtained a Medic Alert bracelet for her mother through the Safe Return program of the Alzheimer's Association. The bracelet provided the diagnosis and family contact information. Selective serotonin reuptake inhibitors (SSRIs) are used in management of behavioral problems in FTD (19,20), and Linda was started on medication. The APN provided education about common side-effects and expected outcomes from the treatment.

When it became impossible to overcome her mother's obsession with playing solitaire for hours on the computer, Sarah resorted to scheduling necessary appointments for her mother around her computer time. In Linda's case, she spent time on the computer in the morning and by late afternoon, could be cajoled to leave the house. Therefore, the early afternoon was the better time to complete appointments (medical, hair dresser, etc).

Linda's compulsive food habits led to weight loss. Sarah tried providing an array of food choices during the day, but it was typically impossible to get her mother to eat more. With the urging of the APN, Sarah then focused on offering those foods her mother preferred multiple times during the day.

Managing functional changes

Ensuring safety of the patient given their poor judgment and comprehension deficits (speech, reading) is a challenging task. Sarah found it necessary to eliminate hazards in the house for her mother. Items such as kitchen knives had to be removed due to Linda's increasing confusion about what the objects were and how to safely handle them. Toxic chemicals and cleansers were either thrown out or locked up. Linda managed her medications safely and took them by a strict schedule, although her daughter periodically counted the pills to make sure her mother had not made any mistakes. Due to Linda's inability to communicate, Sarah managed prescription refills, scheduled all appointments, and handled correspondence for her mother.

Communication

Communication and comprehension difficulties progressed for Linda due to the loss of semantic knowledge. It became increasingly difficult for Sarah and others to tell whether her mother understood and followed conversations. Cognitive testing helped to identify this progression. The APN used these testing results to identify strengths and weaknesses in Linda's comprehension. For instance, initially Linda lost the meaning of single words but could understand the overall meaning of what was being communicated to her. Over time, it was necessary for those around her to talk in simpler sentences and use visual cues to aid her comprehension. The APN coached Sarah in effective forms of communication. Sarah used pictures from magazines, rather than speaking, to communicate with her mother. Linda's cooking abilities changed in that she gradually gave up preparing many of the dishes she had formerly made. She focused on a few set recipes but eventually lost interest in cooking altogether. For a period of time, Linda remained at home and Sarah hired live-in caretaking for supervision of cooking, medication administration, and safety. At some point, many families choose to move their loved one into a facility such as assisted living, board and care, or nursing home.

Managing care for the long term

Patients with SD will lose capacity to make reasonable and sound decisions, and when this happens, it is necessary to have someone make decisions on their behalf. Ideally, the patient's wishes can be discussed and documented within an Advance Directive while they are still able to show sound judgment. For Sarah, decision-making focused on maintaining her mother's safety and well-being. There were financial hardships in hiring live-in help. Sarah relied on advice from both an attorney and a financial adviser in managing the financial and legal issues involved in her mother's care. When the decision was made to move her mother from the house, Sarah had to confront her mother's unhappiness and resistance to moving out.

Caregiver physical and emotional health

Sarah juggled a variety of complex issues. She was not only the primary caregiver for her mother, but was a mother and wife who worked full-time. The APN worked with her to identify effective coping strategies. Sarah found it helpful to seek counseling and treatment when her anxiety and depression mounted with the caregiving challenges. She also derived benefit in adhering to her gym workouts three days a week. Sarah had several close girlfriends who took her out to lunch once a month.

The FTD Caregiving Experience

The features and behavioral symptoms of FTD suggest that the experience of caregiving, along the course of the disease, is uniquely challenging. Behavioral symptoms in FTD are associated with high levels of caregiver distress and burden (21,22). In our clinical experience, it is the combination of multiple factors (behavioral changes, the patient's lack of insight, the high burden of care in the early disease stages, and early age of disease) that create a profound negative impact on family caregivers. A lack of public awareness and a paucity of resources about FTD often lead to challenges in obtaining the correct diagnosis. FTD symptoms may be attributed to marital problems, stress, and depression. In seeking answers, families often turn to their primary care physicians, psychiatrists, clergy and marriage counselors for guidance. For some families, months or even years may pass before reaching a proper diagnosis. Late disease identification and misdiagnosis reduces the family's ability to find appropriate educational and supportive resources, treatment and management. Further, families are often referred to resources designed for caregivers of persons with AD, although these services often do not adequately address the specific needs faced by caregivers of FTD patients (23).

The social, financial, and occupational impact of the disease may be unique and different than that of an older person affected by AD. The person with FTD may be parenting young children. There may be financial problems due to the affected person's job loss, bad investments, or over- spending (24). Retirement benefits may be unexpectedly affected by the person's inability to stay in the work force. Younger age of disease also creates conflicts for families trying to obtain insurance coverage through state and federal programs.

Relationships with spouses and children may suffer profound disruption. Families may be embarrassed by inappropriate behaviors and relationships in the family often suffer as a result of odd and upsetting behaviors. Although not a common problem, hypersexuality does occur more frequently in FTD than in other dementias (25). Some families have to deal with the police or courts because of trouble caused by the patient’s behavior.

In addition, incorrect diagnoses can result in patients receiving inappropriate treatment. For instance, AD is associated with a decline in the neurotransmitter acetylcholine. Patients with FTD who are incorrectly diagnosed with AD may be put on medications that boost acetylcholine. In clinical experience, this can result in increased agitation and no improvement of cognitive symptoms. Finally, aspects of end-of-life care for patients with FTD are uniquely challenging given shorter mortality, younger age of patients, and other disease characteristics.

Conclusions: The Role of the Advanced Practice Nurse

APN’s, with expert knowledge about FTD and the ability to organize and implement educational, supportive, and management strategies throughout the disease trajectory, are in an excellent position to assist FTD families. Table 1 provides a framework for suggested role implementation of the APN in working with FTD families. Research focused on identification of FTD symptoms and distinguishing between different etiologies for dementia found that experts in FTD were essential to gathering and interpreting data from family caregivers (26). Supportive educational efforts focused specifically on FTD has proved to be beneficial for FTD family caregivers (27). Overall outcomes for the patient with FTD include care that is provided in a manner that meets their functional level and safety needs, and that negative symptoms are well managed. Outcomes for the family caregiver include the expression of effective caregiving skills, and that stress and burden are well managed. The APN holds the ability to positively influence care outcomes for both the patient and the family caregivers.

In a position paper, The National Association of Clinical Nurse Specialists (NACNS) identified fundamental and specialized competencies of the APN. These competencies included skills in leadership, collaboration, and consultation. The NACNS further provided a framework outlining “spheres of influence” for the APN encompassing the patient (client or client group), nursing personnel, and organization (or network) (28,29). The clinical vignettes in this paper have illustrated some of the possible interventions of the APN in caring for patients and families living with FTD. These interventions mirror the competencies of the APN. In teaching families and other professionals about FTD, providing one-to-one counseling to families about behavior management and offering practical solutions to the unique problems that are confronted in FTD, the full spectrum of APN competencies is realized. Expertise and leadership of APN’s are, and will continue to be, essential in the formation and establishment of new models of care designed for the FTD family caregiver and the patients they care for.

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Biographies

Jennifer Merrilees, RN, PhD-C received her Master's Degree in Nursing from the University of California, San Francisco and is certified by the American Nurses Association in Gerontological Nursing. She is a Clinical Nurse Specialist at the Memory and Aging Center and Associate Clinical Professor (volunteer series) for the UCSF School of Nursing. Ms. Merrilees is part of a multidisciplinary team focused on the evaluation and management of people with cognitive and behavioral symptoms. She is one of the primary nurses for the NIH-funded program project grant entitled Frontotemporal Dementia: Genes, Emotions and Imaging. Her work at the Memory and Aging Center focuses on behavioral symptoms in dementia and support and education for family caregivers. She directs a research project exploring the dementia caregiver experience. She was awarded a John A. Hartford pre-doctoral scholarship and is currently pursuing doctoral education at the UCSF School of Nursing with a focus on rest-activity disruption in dementia.

Robin Ketelle, RN, MS received her Bachelor's degree in nursing from UCLA and a Master's degree in gerontological nursing from UCSF. Robin's career has involved work in medical surgical nursing, psychiatric nursing and geriatric nursing. She has held research positions at both the UC Davis and UCSF state funded Alzheimer's Disease Research Centers of California (ARCC). Her work at the ARCCs included expert clinical care as a Clinical Nurse Specialist and as a Clinical Trials Coordinator for patients and families participating in dementia research. Robin returned to the Memory and Aging Center in May 2006 and since that time has been the primary nurse for the NIH funded Alzheimer Disease Research Center (ADRC) program, interviewing caregivers and study partners about participants' everyday functioning, mood and behavior. She also manages the NIH-funded program project grant entitled Frontotemporal Dementia: Genes, Imaging and Emotions and interviews caregivers participating in that study as well. Additionally, Robin facilitates the caregiver support group for families and friends of patients with frontotemporal dementia.

Table 1

Suggested Role Implementation for the APN Working with Patients with FTD and Their Families

Patient/Client	**1**	Participate in the diagnostic evaluation via interviews with family members about symptoms, progression, and challenges.
	2	Problem-solve regarding issues such as obtaining appropriate diagnosis, management of behavioral and language changes, advances in treatment, and strategies to maintain emotional and physical safety for both the patient and family caregiver.
	3	Connect families with appropriate resources, e.g., attorneys, social workers, care providers for FTD patients, and counselors/therapists for family caregivers.
	4	Liaison with assisted living, nursing home, and day programs to aid in smooth transitions for patients and families.
	5	Foster education and support for family caregivers by the facilitation of support groups, educational classes, and conferences.
	6	Create and maintain an up-to-date collection of written, electronic, and video educational resources.
	7	Ensure access to education for long-distance caregivers through the use of web-based information, video, and conference calling.
Nursing Personnel	**1**	Provide lectures and clinical preceptorships in FTD for nursing students in health care.
	2	Provide education and consultation for nurses working in care delivery sites with FTD patients.
Organization/Network	**1**	Design and implement research focused on FTD and caregiving.
	2	Promote clinical and research-driven publications on FTD and caregiving.
	3	Present abstracts, posters, and lectures at dementia-related conferences.
	4	Coordinate an FTD clinical and/or research program.
	5	Collaborate with other clinical and/or research practices with expertise in FTD.
	6	Direct staff training, program development, and quality improvement initiatives.
	7	Raise public awareness through the design and implementation of education on FTD.
	8	Participate in consensus conferences and publications regarding FTD.
	9	Maintain positions on advisory boards and councils focused on FTD.