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BRAD: A Model of Caring for Persons with Frontotemporal Dementia

Jennifer McGuire
Augsburg College

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Running head: BRAD: A MODEL OF CARING FOR PERSONS WITH FRONTOTEMPORAL
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BRAD: A model of caring for persons with Frontotemporal Dementia

Jennifer McGuire

**Augsburg College
Lindell Library
Minneapolis, MN 55454**

Submitted in partial fulfillment of
the requirement for the degree of
Master of Arts in Nursing

AUGSBURG COLLEGE
MINNEAPOLIS, MINNESOTA
2009

**Augsburg College
Department of Nursing
Master of Arts in Nursing Program
Thesis or Graduate Project Approval Form**

This is to certify that **Jennifer McGuire** has successfully defended her Graduate Project entitled **“B.R.A.D.: A Model of Caring for Persons With Frontotemporal Dementia.”** and fulfilled the requirements for the Master of Arts in Nursing degree.

Date of Oral defense December 11, 2009.

Committee member signatures:

Advisor: Susan K. Nash Date 12-11-09

Reader 1: Joyce B. Perkins PhD RN Date 12-11-09

Reader 2: Katherine L. Chick, RN, MSN Date 12-11-09

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**There's no other love like the love for a brother.
There's no other love like the love from a brother.
~Astrid Alauda**

To my wonderful brother Brad, this model was developed in your honor. I love you.

**With love and patience, nothing is impossible.
~Daisaku Ikeda**

To my incredible husband Greg, your love and patience made this journey possible. I would have never been able to do this without you. All of my love to you!

**If you've had wonderful family relationships, you will be able to call yourself a true success
in life no matter what else you've achieved.
~Vic Conant**

To my amazing parents, Bill and Sue, thank you for your support during this journey. My successes throughout my life are due to your commitment and love for me. This model was developed to give recognition to you both for your amazing dedication and love for Brad. Brad and I are privileged to have you as parents. I love you Mom. I love you Dad.

**A teacher affects eternity; he can never tell, where his influence stops.
~Henry B. Adams**

To my advisor Sue Nash, thank you for years of support and encouragement.

**Coming together, sharing together, working together, succeeding together.
~Unknown**

To my friends Emily and Chris, thank you for your support. We made it!

Abstract

BRAD: A model of caring for persons with Frontotemporal Dementia

Jennifer McGuire

December 2009

Field Project

Frontotemporal dementia (FTD) is caused by a progressive degeneration of the frontal and temporal lobes of the brain (Boxer & Miller, 2005). This degeneration causes profound alterations in personality, social behavior, and language skills. FTD is particularly devastating due to the fact that it commonly affects people during mid-life or earlier. Evidence has shown that caregivers face higher rates of burden, distress and isolation when providing care for someone with FTD than other forms of dementia (de Vugt, Riedijk, Aalten, Tibben, van Swieten, & Verhey, 2006; Kumamoto, Arai, Hashimoto, Ikeda, Mizuno, & Washio, 2004). The Behavioral Recognition, Assessment and Delivery (BRAD) model of care was developed for caregivers to better manage the unique challenging behaviors of persons with frontotemporal dementia. The BRAD model of care is grounded in the work of Margaret Newman and her theory of Health as Expanding Consciousness (HEC).

Table of Contents

Acknowledgements	page iii
Abstract	page iv
Table of Contents	page v
Chapter 1 Introduction	page 1
Background	page 2
Purpose	page 3
Chapter 2 Literature Review	page 6
Background on frontotemporal dementia	page 6
Diagnosing frontotemporal dementia	page 8
Misdiagnoses of frontotemporal dementia	page 11
Caregiver burden	page 14
Nursing theoretical background	page 17
Treatment Routes for Exploring Agitation model background	page 20
Antecedent-Behavior-Consequence model background	page 21
Chapter 3 Development of the BRAD model	page 23
Purpose of the BRAD model	page 24
The BRAD model	page 25
Behavioral Recognition	page 25
Assessment	page 26
Delivery	page 27
Brad's story	page 29
Examples of the BRAD model	page 31
Example one	page 32
Example two	page 34

BRAD: A MODEL OF CARE

Example three	page 35
Chapter 4 Discussion	page 39
Implications for education and research	page 39
Education	page 39
Research	page 40
Health Inequities	page 41
Chapter 5 Conclusion	page 45
Recommendation	page 45
Reflection	page 46
References	page 47
Figures	
Figure A: Comparison of brain PET scans of normal elderly brain, Alzheimer’s disease, and frontotemporal dementia	page 10
Figure B: An illustrated model of Prigogine’s theory of dissipative structures	page 18
Figure C: An illustration of the BRAD model of care	page 24
Figure D: An illustration of example one of the BRAD model of care	page 32
Figure E: An illustration of example two of the BRAD model of care	page 34
Figure F: An illustration of example three of the BRAD model of care	page 35
Tables	
Table 1: Common range of symptoms associated with frontotemporal dementia	page 7
Table 2: The clinical diagnostic features of frontotemporal dementia	page 9
Table 3: Comparing characteristic differences of frontotemporal dementia and Alzheimer’s disease	page 12

Chapter 1: Introduction

Introduction

Every illness has its own distinctive characteristics and challenges. When the illness is frontotemporal dementia (FTD), the caregiver is the one who experiences the burden of these unique behavioral challenges. This dementia is particularly devastating to caregivers due to the apathy, personality changes and unusual behavioral changes that are unique to those afflicted with frontotemporal dementia. Caregivers will find themselves caring for someone who is profoundly different from the person they once knew.

Challenging behaviors caused by FTD can be difficult and stressful. The disease is often misdiagnosed and once recognized, it is difficult to manage (Mendez, Shapira, McMurtray, Licht, & Miller, 2007; Viskontas & Miller, 2009; Yeaworth & Burke, 2000). Evidence has shown that caregivers face higher rates of burden, distress, and isolation when providing care for someone with FTD than other forms of dementia (de Vugt, Riedijk, Aalten, Tibben, van Swieten, & Verhey, 2006; Kumamoto, Arai, Hashimoto, Ikeda, Mizuno, & Washio, 2004).

Frontotemporal dementia is one type of disease of the frontotemporal lobar degeneration (FTLD) group of related conditions that are caused by a progressive degeneration of the frontal and temporal lobes of the brain (Boxer & Miller, 2005). This degeneration causes profound alterations in personality, social behavior, and language skills. Psychiatrist Agronin (2008) explains that the early cardinal symptoms of FTLD are language and behavioral disturbances, appearing most often before obvious cognitive impairments present themselves. This disease is particularly devastating due to the fact that it commonly affects people during mid-life or earlier.

There are three subtypes of FTLD: behavioral or frontal-variant frontotemporal dementia (bvFTD or simply FTD) representing approximately 56 percent of the cases; temporal variant

(tvFTD) or semantic dementia (SD) reflected in approximately 20 percent of those diagnosed; and left frontal and insular predominant degeneration called progressive non-fluent aphasia (PNFA) which is apparent in approximately 25 percent of the cases (Viskontas & Miller, 2009). Behavioral variant FTD has also been described in research as frontal variant (fvFTD) and Picks Disease (PiD). For this project behavioral variant or FTD which accounts for a large percent of all FTLD will be the focus. Throughout the remainder of the project the term FTD will be used to identify the phenomena being explored.

Background

According to physicians, Viskontas and Miller (2009), FTD is more common in people less than 60 years of age than Alzheimer's disease (AD), and accounts for as much as 20 percent of people with degenerative dementias. This disease places increased burden on caregivers and society, due to the young age of onset. People diagnosed with FTD are under researched and disenfranchised due to the competing attention that is given to AD, the early onset of the disease, misdiagnoses that happens at each stage of the disease, and the fact that it has been largely ignored in the literature during most of the twentieth century (Viskontas & Miller, 2009; Yeaworth & Burke, 2000). Rosalee Yeaworth, a professor of nursing, describes how many services for people with dementia are designed for older adults who have Alzheimer's (Yeaworth & Burke, 2000). Due to the age of onset of this disease many caregivers are often younger, in the work force, and caring for children still in the home. Long term care facilities and community services are unwilling to admit younger healthy looking people into their programs (Yeaworth & Burke, 2000).

The person with FTD presents with numerous self-care deficits and relies on the assistance of caregivers to meet their needs and keep them safe. Behaviors present unique

challenges and often become the primary form of communication. According to Yeaworth and Burke (2000) family caregivers of persons with FTD find the care problematic due to the younger age of the person, unpredictable behavioral problems, and the fact that many services are designed for persons with AD, who in essence are much older. Both stressful and dangerous, these professors of nursing find that the three most common challenging behaviors for caregivers are aggression, disinhibition, and exploratory behavior (Talerico & Evans, 2001). One only needs to search the literature to know that there is no model or tool designed especially for management of FTD. There are tools designed for dementia in general or Alzheimer's disease, but none specifically designed for the challenging behaviors of FTD.

Purpose

The purpose of this project is to create a model for caregivers to better manage the unique challenging behaviors of persons with frontotemporal dementia. The differentiation of FTD from AD will be explored. A model of care for FTD will be developed that is grounded in the work of Margaret Newman and her theory of Health as Expanding Consciousness (HEC).

Margaret Newman's theory of HEC is a base for an ethical and holistic approach to caring for someone with dementia (Picard & Jones, 2005). Newman's nursing paradigm concept of health is pattern recognition. This concept is a base for providing holistic care for persons with frontotemporal dementia. Pattern recognition is the key component in managing challenging behaviors. Everyone suffering from FTD is unique, and as language skills and the ability to communicate decline, challenging behaviors will increase and become the person's new pattern. By understanding the pattern of the whole the caregiver can recognize the importance of being with the person instead of just doing something for the person.

The **B**ehavioral **R**ecognition, **A**ssessment and **D**elivery (**BRAD**) model is created for caregivers to better manage the unique challenging behaviors of persons with frontotemporal dementia. It is named for my wonderful younger brother Brad who was diagnosed in January of 2007 with FTD at the age of 25. He received the diagnosis after a long painful journey of misdiagnosis and misinterpretations of his personality, cognitive, and behavioral changes. The model is created to honor him in hope that other families can use it to deliver care during their journey with FTD. This disease has profoundly affected my family. The personal experience with my brother has contributed to the development of the BRAD model. As a family caregiver of someone with FTD, I know the importance of recognizing behaviors, assessing the person-environment connection and delivering individualized care.

Two behavioral models were reviewed in the process of designing the BRAD model. The Antecedent-Behavior-Consequence (ABC) model was designed for caregivers to observe the antecedent (trigger) that contributes to a behavior and consider the consequence (response) to that behavior by a person with dementia (Merriless, 2007). The Treatment Routes for Exploring Agitation (TREA) model was designed for use with older persons with dementia, particularly Alzheimer's disease, who are experiencing agitation (Cohen-Mansfield, 2000). There are elements from each model that are useful for caregivers of persons with FTD, but these models do not address the management of the unique challenging behaviors of FTD. Symptoms and behavioral problems experienced by a person with FTD are unique and quite different than those experienced by a person with Alzheimer's disease (Banks, Rogalski, Medina, Skoglund, & Morhardt, 2006; de Vugt et al., 2006; Kumamoto et al., 2004).

Behavioral changes are prominent features of this disease and a model of care is urgently needed for everyday application by this group of caregivers. Implementing a model of care that

focuses on behavioral recognition and assessment of the person-environment connection are key components in delivering individualized care. Caregivers can provide such care to persons with FTD by using the BRAD model when experiencing unique challenging behaviors. The following chapter examines the literature and nursing theoretical foundation for the design of this care model.

Chapter 2: Literature Review

An in-depth analysis of FTD shows the need for a model of care that addresses the unique behavioral challenges. The BRAD model of care incorporates Margaret Newman's theory of Health as Expanding Consciousness to create a paradigm shift and approach of care to persons with FTD. Other tools and models of care for persons with dementia are explored. The differences of frontotemporal dementia and Alzheimer's disease are compared and distinct caregiving needs are revealed.

Background on frontotemporal dementia

Frontotemporal dementia is characterized by profound changes in behavior, personality, and language ability. According to the Association for Frontotemporal Dementias, personality changes caused by the disease will be characterized by inappropriate social behaviors which include "swearing, overeating or drinking, impulsivity, shoplifting, hypersexual behavior, and deterioration in personal hygiene habits" (para. 7). Other common behaviors experienced by someone with FTD are decline of interpersonal connections, apathy, disinhibition, inflexibility, distractibility, ritualistic behaviors, emotional bluntness, and social misconduct (Kipps, Knibb, & Hodges, 2007). Language deficits are characterized by "slowed simpler speech with word finding difficulty" (Agronin, 2008, p. 155) and associated with "impairment in semantic memory or of the knowledge of particular words and objects and their meaning" (Agronin, 2008, p. 155).

The frontal lobes of the brain have a vast anatomic and functional array. When damage and atrophy occur to these structures the person can experience effects to their executive function, behavioral control, and language (Agronin, 2008). According to Viskontas and Miller (2009) "dysfunction in these critical frontal and anterior temporal regions seems to be driving the

disinhibition, apathy and eating disorders” (p. 48). Table 1 lists the common range of symptoms experienced by a person with FTD. Each person affected by FTD will experience their own unique course of this disease. There is no way to predict which symptoms will develop or in which order they will appear.

Table 1		
<i>Common range of symptoms associated with frontotemporal dementia</i>		
BEHAVIORAL SYMPTOMS		
Hyperoral	Agitation	Aggression
Decline in personal hygiene	Hyperactivity	Impulsive
Hypersexual	Swearing	Disinhibition
Repetitive behavior		
LANGUAGE SYMPTOMS		
Impaired semantic memory	Dysarthria	Esholalia
Word finding difficulty	Perseveration	Mutism
Decrease reading comprehension	Decreased writing comprehension	Aphasia
COGNITIVE SYMPTOMS		
Inflexibility	Distractibility	Mental rigidity
Ritualistic behaviors	Lack of insight	Poor judgment
Difficulty with problem solving		
EMOTIONAL SYMPTOMS		
Apathy	Emotional bluntness	Mood changes
NEUROLOGICAL SYMPTOMS		
Movement dysfunction	Muscle dysfunction	
PSYCHIARTIC SYMPTOMS		
Depression	Mania	Delusions
Auditory Hallucinations	Visual Hallucinations	Paranoia

Note. Adapted from The Association for Frontotemporal Dementias. Copyright 2009 by www.ftd-picks.org

Diagnosing frontotemporal dementia

Nursing program director and professor Cotter (2007) reports that there are more than 55 illnesses that can cause dementia. The National Institutes of Health (2009) reported that researchers estimate that FTD accounts for as many as 10 percent of all dementias. While Alzheimer's disease is the leading cause of dementia, FTD is the third leading cause of dementia (Cotter, 2007).

Diagnosing FTD is an evolving and challenging process. "Frequent misdiagnosis of FTD occurs because of the variable behavioral presentations of this disease" (Mendez et al., 2007, p. 833). No one specific medical exam, test, or neuropsychological measurement will confirm a diagnosis of FTD. Researchers Cocyk and Wright (2008) found that the diagnosis of FTD is made based on diagnostic tests used to rule out other diseases and brain injuries that have similar symptoms. According to Hodges (2007), a professor of cognitive neurology, careful attention needs to be given to the initial complaints, the length of time experienced, and the order in which the symptoms presented. Symptoms experienced are rarely elicited from the person due to the lack of awareness and apathy, which makes it vitally important to involve the spouse and/or family when gathering a history and completing an assessment. Diagnosing FTD depends almost entirely upon the family's reports of changes in personality and social comportment. People with FTD are generally unaware of their deficits and will not be concerned about the diagnosis (Boxer & Miller, 2005). Table 2 shows the clinical diagnostic criteria for frontotemporal dementia.

Table 2

The clinical diagnostic features of frontotemporal dementia

Character change and disordered social conduct are the dominant features initially and throughout the disease course. Instrumental functions of perception, spatial skills, praxis and memory are intact or relatively well preserved.

Core diagnostic features

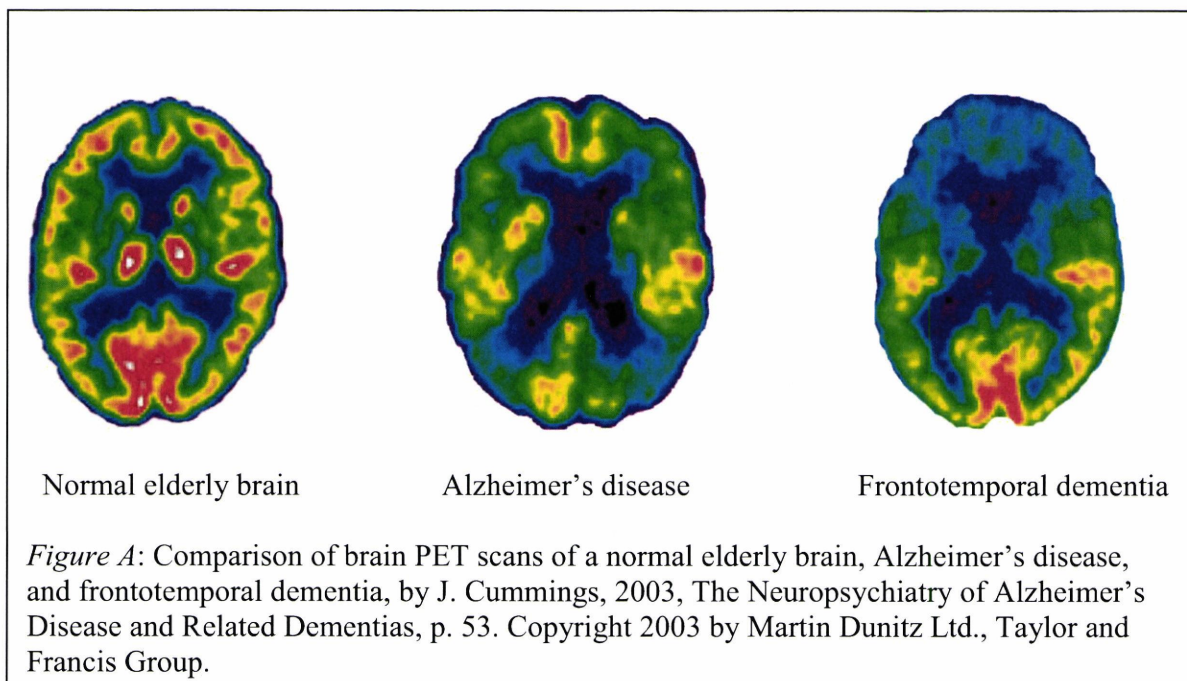
- Insidious onset and gradual progression
- Early decline in social interpersonal conduct
- Early impairment in regulation of personal conduct
- Early emotional blunting
- Early loss of insight

Supportive diagnostic features

- Behavioral disorder
 - Decline in personal hygiene
 - Mental rigidity and inflexibility
 - Distractibility and impersistence
 - Hyperorality and dietary changes
 - Perseverative and stereotyped behavior
 - Utilization behavior
- Speech and language
 - Altered speech output
 - Stereotypy of speech
 - Echolalia
 - Perseveration
 - Mutism
- Physical signs
 - Primitive reflexes
 - Incontinence
 - Akinesia, rigidity, and tremor
 - Low and labile blood pressure
- Investigations
 - Neuropsychology: significant impairment on frontal lobe tests in the absence of severe amnesia, aphasia, or perceptuospatial disorder
 - Electroencephalography: normal on conventional EEG despite clinically evident dementia
 - Brain imaging (structural and/or functional): predominant frontal and/or temporal abnormality
- Clinical features
 - Onset before 65 years: positive family history of similar disorder in first-degree relative
 - Bulbar palsy, muscular weakness and wasting, fasciculations (associated motor neuron disease present in a minority of patients)

Note. By J. Cummings, 2003, *The Neuropsychiatry of Alzheimer's Disease and Related Dementias*, pp. 219-220, Copyright 2003 by Martin Dunitz Ltd., Taylor and Francis Group.

Along with physical exam, history, and psychological testing, “imaging techniques are a key factor in the diagnosis, and improved techniques probably account for the increased frequency of the diagnosis” (Yeaworth & Burke, 2000, p. 251). FTD is a progressive dementia which can be diagnosed by combining clinical features that correlate with patterns of brain atrophy shown using neuroimaging (Boxer & Miller, 2005). The use of Magnetic Resonance Imaging (MRI), Single Photon Emission Computed Tomography (SPECT), and Positron Emission Tomography (PET) can reveal the characteristic atrophy in the frontal and temporal lobes of the brain. The SPECT measures cerebral blood flow and the PET will measure the brain-glucose metabolism (Cummings, 2003).



The three images shown in Figure A represent PET scans of the brain. The frontal lobes, found in the front of the head, are located on the top of the PET scan images. The occipital lobes, found in the back of the head, are located on the bottom of the PET scan images. The temporal lobes are located on either side of the head behind the ears with the parietal lobes above

the temporal lobes and between the frontal and occipital lobes. The normal brain shows multiple colors indicating normal blood flow and metabolic patterns throughout each lobe. The purple and blue colors on the PET scan indicate a diminished blood flow and hypometabolism. The brain with Alzheimer's disease shows colors of purple and blue in the bilateral parietal lobes. The brain with FTD shows colors of purple and blue in the bilateral frontal and temporal lobes. The neuroimages found on a PET scan show the distinct patterns of atrophy found in both FTD and Alzheimer's disease.

Researchers Mendez et al. (2007) conducted a retrospective assessment of diagnostic criteria for diagnosing FTD. The study involved 134 people suspected of having FTD that were referred for clinical evaluation. Their study found that consensus criteria and neuropsychological measures lacked the sensitivity for detecting FTD, but functional neuroimaging scans increased the probability for detecting FTD. The results showed that the use of functional imaging such as SPECT or PET scan achieved more than 90 percent sensitivity for detecting FTD. The researchers came to the conclusion that clinical diagnosis of FTD needs to include functional neuroimaging.

Misdiagnoses of frontotemporal dementia

FTD is a disease that devastates the lives of not only the person with the disease but also their family and friends. The person will not recognize or have little to no insight of the affects of their behaviors, and have little or no concern about the effects of those behaviors on family, friends, and colleagues. "The presentation of FTD as a change in personality or conduct is often profoundly disturbing to all who know the individual and may cause considerable disruption at home and in the workplace" (Yeaworth & Burke, 2000, p. 250). Unlike AD where social respectability is unaffected, people that suffer from FTD present as apathetic, rude, and self

centered to their colleagues, friends and family (Viskontas & Miller, 2009). Table 3 combines clinical features and symptoms of both AD and FTD to compare.

Features & Symptoms	Frontotemporal Dementia	Alzheimer's Disease
Onset	Usually 40-60 years of age	Usually >65 years of age
Memory	Later impairment	Early impairment
Language	Early impairment	Evolving Aphasia
Visuospatial skills	Later impairment	Early impairment
Executive functions	Early impairment	Later impairment
Behavior	Early changes	Later changes
Key Deficit Pattern	Executive functions	Memory
Cardinal behavior	Disinhibition	Wandering
Initial Symptom	Personality changes	Memory dysfunction
Attention	More distractable	Less distractable
Loss of personal awareness	Common early	Common later
Eating pattern	Hyperorality	Anorexia
Disinhibition	Common	Common, but less severe
Apathy	Common and severe	Common and less severe

Note. Adapted from M. Agronin, 2008, *Alzheimer Disease and other Dementias*, p. 158. Copyright 2008 by Lippincott Williams & Wilkins; J. Cummings, 2003, *The Neuropsychiatry of Alzheimer's Disease and Related Dementias*, p. 222 & p.231. Copyright 2003 by Martin Dunitz Ltd., Taylor and Francis Group; L. Cycyk & H. Wright, 2008, *Aphasiology* 22(4), p. 435. Copyright 2008 by Psychology Press.

According to the National Institutes of Health (2009) FTD was recognized as a clinical entity separate from AD in the 1980's. Even with the clinical recognition, FTD continues to be difficult to diagnosis at all stages of the disease. People with early symptoms, "lack all the necessary core features for the clinical diagnosis of FTD and fail to meet diagnostic criteria on initial assessment" (Mendez et al., 2007, p. 830). FTD is frequently diagnosed in the early stages as a psychiatric disorder due to the changes in personality and behavioral changes, and in the later stages it is often confused with AD (Agronin, 2008). The symptoms of disinhibition and impulsivity can resemble an anxiety or personality disorder. FTD in the early stages is often mistaken for a mid-life crisis given the age of the person and personality changes that are happening (Viskontas & Miller, 2009). These changes are often thought to be stress induced or misdiagnosed as atypical depression (Hardin & Schooley, 2002).

Researchers Gregory and Hodges (1996) performed a retrospective investigation of twelve people who were clinically diagnosed with FTD. The people investigated were all evaluated by consulting psychiatrists. The results of the study found that seven out of twelve people diagnosed with FTD first saw psychiatrists for what was thought to be a psychiatric disorder. The other five people were referred to a neurologist. Of the seven who did see a psychiatrist, one third (four people) received an initial psychiatric misdiagnosis. The four initial psychiatric misdiagnoses were: schizophreniform psychosis, psychogenic memory impairment and depression, recurrence of a depressive illness with obsessional-compulsive features, and alcohol dependency with hypomanic features. This retrospective study shows that misdiagnosis of FTD can occur due to numerous insidious symptoms.

The misdiagnosis tends to categorize or mislabel these persons with behaviors that are stigmatized in our society. Physicians Lipton and Boxer (2009) found that the hallmark feature

of FTD is lack of insight and the person is “often impulsive and oblivious to societal or other limitations on their actions” (p. 220). For instance, the concept of payment for goods is lost which can result in shoplifting. Physicians Boxer and Miller (2005) have found that frontal lobe dysfunction found in FTD leads to disinhibition, poor impulse control, antisocial behavior, decrease in compliance, lack of modesty, lack of empathy, and self centeredness. This dysfunction or atrophy of the frontal lobes can cause persons with FTD to exhibit behaviors of impulsive hoarding, gambling, obsessive counting, theft, assault, public masturbation or urination, and inappropriate or offensive speech.

Once FTD is correctly diagnosed the caregivers must learn how to manage the unique challenging behaviors caused by this disease. Perry and Miller (2001) find that behavioral management approaches to FTD need to be developed differently from Alzheimer’s disease due to the behavioral, cognitive, and neurochemical differences. Persons with FTD have behavioral symptoms that are quite different from those of AD and pose a higher rate of caregiver burden and distress (de Vugt et al., 2006; Kumamoto et al., 2004). FTD caregivers have different needs compared to AD caregivers and that challenging behaviors are a common concern among family caregivers (Banks et al., 2006). The amount of care provided by caregivers to a person with FTD is greater than a person with AD (Mioshi, Kipps, Dawson, Mitchell, Graham, & Hodges, 2007).

Caregiver burden

Caregiver burden is a term used to describe the effects of the physical, emotional, and financial toll of providing care (Gallagher-Thompson, Lonergan, Holland, China, & Wesson Ashford, 2009). Dementia care is time-consuming and has a high economic cost for caregivers. Cotter (2007) reports that as the prevalence of dementia increases, so does the economic, medical and societal impact. A study conducted in 2005 estimated that the global cost of dementia

including both medical expenditures and informal care costs was \$315 billion U.S. dollars. Of the \$315 billion, the direct cost of healthcare was \$210 billion (Savva & Brayne, 2009). Savva and Brayne (2009) reported on a National Longitudinal Caregiver Study that was conducted on caregiving in the United States. This study estimated the costs in terms of value of the caregiving, loss of earnings, expenses to caregivers with formal services, and their own healthcare costs. The study discovered that caregivers spent an average of \$4500 annually out of pocket for a multitude of formal health services.

Researchers from the Netherlands, de Vugt et al. (2006) conducted a study of 47 spousal caregivers of persons that suffered from either FTD or AD to measure the effects of behavioral problems. The results of the study found that spousal caregivers of persons with FTD reported higher levels of general burden and felt less competent than spousal caregivers of persons with AD. The finding showed a significantly higher level of agitation, apathy, disinhibition, and aberrant motor behaviors in persons with FTD versus persons with AD. The potential limitations of this study include the small sample size and that the impact of the caregiver's coping styles, social support and relationship with their spouse was not explored. The conclusion from the study suggests that spousal caregivers of persons with FTD experienced more caregiver distress related to the specific behaviors caused by FTD. The researchers speculate that some causes for the increase of caregiver distress is frustration with possible misdiagnoses which may have delayed needed care, disruption to an active independent lifestyle, and additional care responsibilities when children may still be at home. The researchers suggest that more focus should be given to problem behaviors caused by FTD and specific interventions developed to reduce caregiver distress. This study also shows the importance of identifying the behavioral

differences between FTD and AD when developing specific interventions that cause caregiver distress.

Nursing researchers from Tokyo, Kumamoto et al. (2004) conducted a qualitative study of two families that were caring for a family member who was diagnosed with FTD. Semi-structured interviews were conducted with caregivers in their home settings to discover the burden and problems associated with caring for a person with FTD. The researchers concluded that the behavioral symptoms of persons with FTD are quite different than AD and other forms of dementia. This study provided specific details of both the behaviors associated with FTD and those that cause a great deal of family caregiver distress. The results of this study clearly show that behaviors such as abnormal eating patterns, difficulty performing activities of daily living, and impulsivity create a significant problem which results in burden among family caregivers. They suggest that specific measures and resources should be developed to meet the needs of caregivers for persons with FTD who have unique challenging behaviors.

Three doctoral candidates in psychology and neuroscience and two social workers specialized in cognitive neurology and Alzheimer's disease in Chicago Illinois, organized a series of three educational and support conferences for caregivers of persons with FTD and primary progressive aphasia (Banks et al., 2006). While performing a needs assessment, it was discovered that these family caregivers have different needs compared to other forms of dementia. They determined that support should be provided to reflect these unique needs. Each conference was attended by approximately 50 people from across the United States and as far away as the country of Ireland. It revealed that challenging behaviors was one of the emerging topics discussed by caregivers at each conference during the breakout sessions. The group

determined through feedback questionnaires that the conference was a success and plan to continue the educational and support conferences in the future.

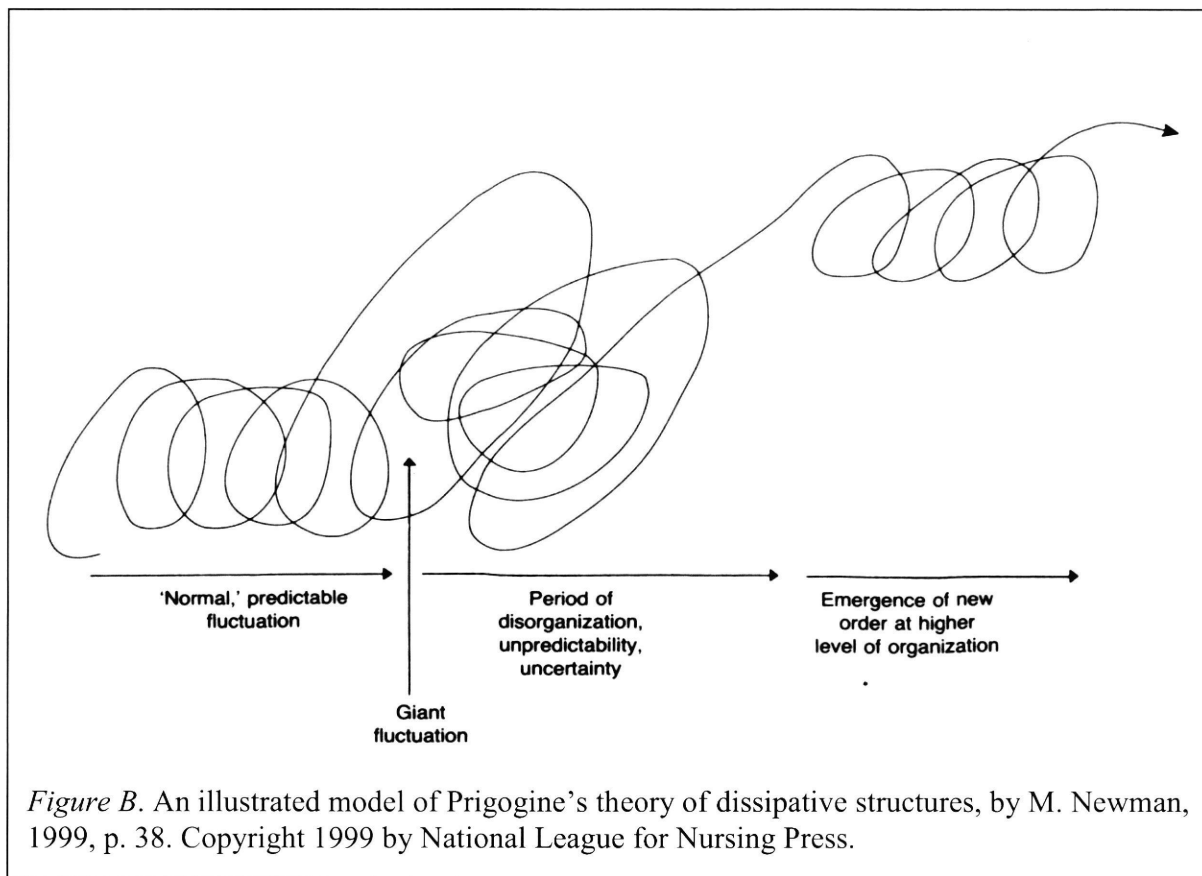
Researchers Mioshi et al. (2007) conducted a study that involved evaluations and measurements of activities of daily living (ADL) in three clinical variants of FTD (behavioral variant frontotemporal dementia, progressive nonfluent aphasia, and semantic dementia) along with Alzheimer's disease. This cross-sectional study involved 95 patients and family caregivers. The purpose of the study was to describe the severity of impairment of ADL's and compare performances of ADL's between people with FTD and AD. The researchers concluded that behavioral variant FTD (bvFTD) has devastating effects on ADL's and the greatest degree of impairment in both the basic activities of daily living (BADL) and instrumental activities of daily living (IADL). The data showed that bvFTD had the greatest impairment compared to the other groups in the BADL's of dressing, eating, and hygiene and IDAL's of telephone use, leisure/house chores, managing medication, and meal preparation. This study clearly shows that the behavioral and cognitive changes associated with FTD are profound.

Nursing theoretical background

Margaret Newman's concept of health was conceived during her experience as a caregiver for her mother who suffered from Amyotrophic Lateral Sclerosis (ALS) (Newman, 2008). Newman's theory of HEC has three basic assumptions and the premise that health is an expansion of consciousness. Newman (2008) summarizes the three basic assumptions of HEC.

The basic assumptions of the theory have been synthesized as follows: health is an evolving unitary pattern of the whole, including patterns of disease. Consciousness is the informational capacity of the whole and is revealed in the evolving pattern. Pattern identifies the human-environmental process and is characterized by meaning (p. 6).

Newman (2008) uses Prigogine's theory of dissipative structures to further demonstrate the concept of health as expanding consciousness. Figure B shows an illustration of Prigogine's theory of dissipative structures. Prigogine's concept of uncertainty that happens during times of turmoil is significant in Newman's theory of HEC. The theory of dissipative structures supports Newman's concept that even negative events that cause turmoil are opportunities for growth and part of the process of expanding consciousness (Newman, 2008).



Newman uses the theory of dissipative structures to show the process of the continual pattern of movement towards a higher level of consciousness. The process starts out in a routine way with predictable movement within the system until it is disrupted by a significant event that results in a large fluctuation (Newman, 2008). The large fluctuation is created by turmoil and

system reorganization can occur to a higher level of consciousness during this tumultuous period (Newman, 2008). Eventually, the turmoil will be balanced by the interaction with the environment which will result in a leveling off and balance will be restored but at a higher level of consciousness.

Research guided by HEC has uncovered that “pattern recognition and times of turbulence are opportunities for growth, healing and transformation” (Picard & Jones, 2005, p. 22). According to Newman (2008) when turmoil is viewed within the entire context (environment), then higher consciousness will be achieved. “Pattern recognition is an essential element in the life process. It is crucial to survival” (Picard & Jones, 2005, p. 4). Identifying patterns is the essence of caregiving. Pattern recognition represents the relationship of things past, present and future. The caregiver and the person being cared for reflect the whole. Wholeness and connectiveness give opportunities for family caregivers to see patterns and their meanings (Picard & Jones, 2005). Achieving a higher level of consciousness for caregivers involves seeing patterns instead of seeing problems. Change can be viewed as disruptive and disorganized as one moves to a higher level of consciousness (Picard & Jones, 2005). According to Newman (2008) pattern and health should be viewed as:

The shift is from treatment of symptoms of disease to search for patterns; from viewing pain and disease as wholly negative to viewing them as information about the pattern of the whole; from seeing the body as a machine in good or bad repair to seeing the person as a dynamic field continuous with the larger environmental field; from seeing disease as an separate entity to seeing it as a unitary process (pp. 11-12).

While healing of the person with FTD is not possible, pattern recognition offers hope in management and can guide and improve caregiving of persons with FTD.

When the caregiver can recognize both the individual patterns of the person along with the patterns of the disease, managing challenging behavior is possible. Recognition of patterns involves what is important to the person with FTD; their needs and wants. It starts with the caregiver who observes challenging behaviors, finds meaning in the behaviors, and recognizes the numerous patterns that can occur (Newman, 2008). All challenging behavior has meaning.

According to Newman, the environment is viewed as a universe of open systems in which the person interacts with the environment through energy fields (Marchione, 1993). If health is defined as the interaction between the person and their environment, and health is expansion of consciousness, then the person with FTD is unable to achieve a higher level of consciousness due to the progressive cognitive degeneration of this disease. It is essential that caregivers who engage and interact with the person with FTD recognize patterns of behavior as the new means of communication.

According to Ruka (2005) a nursing home administrator, “there is a pressing need to create care environments that emphasize an understanding of behavior so as to maximize quality of life” (p. 95). Due to the damage caused by FTD, behavior becomes the new language and is a way to communicate needs, wants, emotions and concerns. Psychiatrists Sutor and Rummans, along with Psychologist Smith, healthcare professionals who work for Mayo Clinic’s Department of Psychiatry and Psychology, state that:

Behavior should be recognized as a form of communication, rather than as random, unpredictable, or meaningless events. Caregivers who learn what to expect as the disease progresses can anticipate cognitive and functional limitations and the expected behavioral effects as the dementia progresses (Sutor, Smith, & Rummans, 2002, p. 35).

Treatment Routes for Exploring Agitation model background

Two complimentary models used for treating behaviors caused by dementia were reviewed in the development of the BRAD model. The first model is the Treatment Routes for Exploring Agitation (TREA) model. This was designed for caregivers to address individualized treatment for behavioral problems caused by dementia. It is primarily used for managing agitation in elderly people who suffer from Alzheimer's disease. Researcher Cohen-Mansfield (2000) describes the five assumptions of the TREA model as the following: First is that different problem behaviors have different etiologies, different meanings that require different approaches to treatment. The second is appropriate caregiving starts with a methodology for detecting the needs of the person with dementia. Third is every attempt must be made to understand the etiology of the behavior in order to develop a specific treatment plan. Fourth is non-pharmacologic approaches should be tried before pharmacologic treatments. And finally, treatment of behaviors needs to be individualized.

The goal is to reduce caregiver burden while improving the quality of life for the person with dementia (Cohen-Mansfield, 2000). The theoretical framework behind the model is that unmet needs are the source of behavioral problems. The key elements of the model are individualized treatment plans, a detective approach to care, involvement of family, and providing interventions that are focused on prevention, accommodation, and flexibility.

Antecedent-Behavior-Consequence model background

The second model reviewed is the Antecedent-Behavior-Consequence (ABC) model. The antecedent is considered the trigger of the behavior, and the consequence is the response or reaction to the behavior (Merrilees, 2007). According to nursing researcher Merrilees (2007) dementia caregivers often receive education on how to use the ABC model. The premise of the model is that behaviors are a result of the disease and not caused intentionally by the person with

dementia. The most effective use of the model involves recording the ABC's in a log to evaluate each antecedent and consequence for each behavior. This provides the caregiver with a way to analyze the antecedent (trigger) that caused the behavior and learn how to modify the trigger and/or the consequences in order to reduce and/or prevent the behaviors (Merriless, 2007).

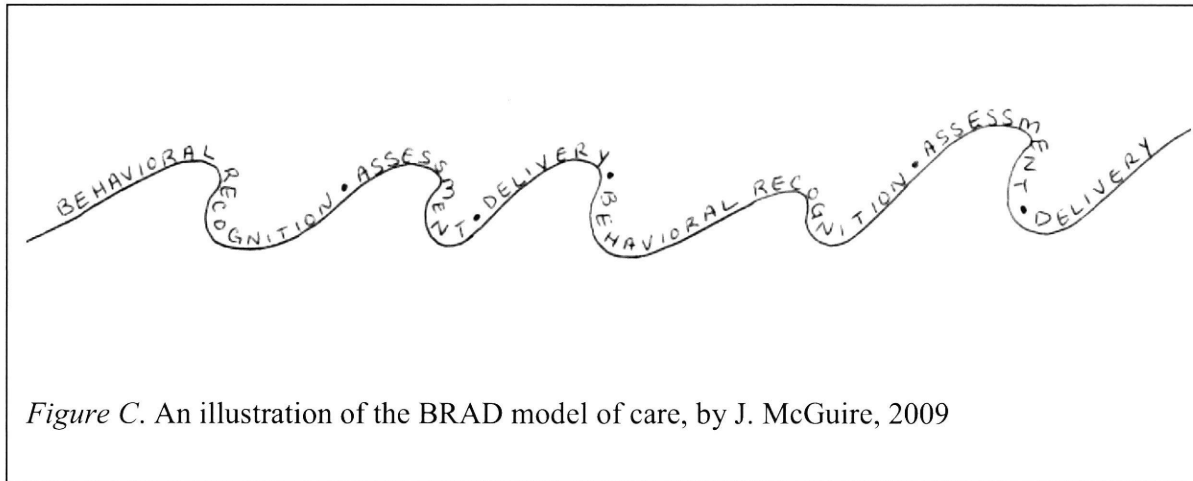
The BRAD model is grounded in Margaret Newman's Health as Expanding Consciousness theory along with elements from the TREA and ABC models. Researchers have shown that caregiver burden is high when caring for someone with FTD (de Vugt et al., 2006; Kumamoto et al., 2004). When behaviors caused by FTD are unmanaged, the caregiver is in a pattern of caring that is burdensome, isolating, and frustrating. The BRAD model is designed to give the caregiver a simple model to deliver care that manages the unique challenging behaviors caused by FTD. The following chapter will discuss the development of the BRAD model.

Chapter 3: Development of the BRAD model

This chapter describes the development of the model along with examples of its application. The Behavioral Recognition, Assessment and Delivery (BRAD) model of care is designed for caregivers to manage the unique challenging behaviors caused by FTD. The purpose of the model is to reduce caregiver burden while increasing quality of life for the person with FTD and the caregiver. The three assumptions of the BRAD model are:

1. Behavioral Recognition is essential in detecting patterns.
2. Assessment of the person-environment connection is needed in order to deliver appropriate care.
3. Delivery of care is based on behavioral patterns, assessment of the person-environment connection, and individual needs of the person and caregiver.

When the family first hears that their loved one has frontotemporal dementia, it feels like being hit by a tsunami. A diagnosis of FTD, like a tsunami, forces a family into the unknown accompanied by an eruption of emotions and fears. The waves produced after the tsunami represents the visual image for the BRAD model. Figure C. shows an illustration of the variable pattern of waves that follow the tsunami. Each wave represents the numerous and unique challenging behaviors caused by FTD. Each wave shown is different, just like each challenging behavior caused by FTD will be different. The model is designed to identify each person's unique behavioral pattern. Caregivers can apply the BRAD model of care to each behavioral wave pattern that is experienced. This model can be the life line that keeps caregivers a float as they ride the waves of challenging behaviors experienced after the tsunami.



Purpose of the BRAD model

As explained in the previous chapter, researchers de Vugt et al. (2006) and Kumamoto et al. (2004) found that burden is high among caregivers of FTD as a result of the unique behavioral challenges. When a person is diagnosed with FTD their family members become caregivers. Savva and Brayne (2009) explain that family in most cases have no prior training or experience in providing care to someone with dementia, and that the primary stress is the enormous demand of care itself. In most cases due to the young age of onset, the initial impact of caring for someone with FTD falls solely on the family. The lag between onset of symptoms and accurate diagnosis can be a lengthy process (Mendez et al., 2007; Viskontas & Miller, 2009). This period of being adrift with no answers adds to caregiver frustration and stress. The purpose of developing the BRAD model is to give caregivers a tool to reduce burden while increasing quality of life. It is grounded in Newman's HEC theory guided research on pattern recognition. The model was also influenced by the ABC model assumption that modification to the

antecedent (trigger) can influence behavior and the TREA model assumptions that behaviors have different meanings and treatment needs to be individualized.

The BRAD model

Behavioral Recognition. The first assumption of the BRAD model of care is that behavioral recognition is essential in detecting patterns. According to Newman (2008) identifying patterns is the essence of caregiving. As unique challenging behaviors occur it is vital for the caregiver to identify the patterns and give them meaning. The first step towards behavioral recognition is receiving education about FTD. “Instilling a sense of control through educating the caregiver about the nature of FTD is necessary prior to the commencement of any intervention” (Lough & Garfoot, 2007, p. 302).

Behavioral recognition starts with caregivers receiving education on the unique behavior changes that can occur with FTD. “Caregivers who learn what to expect as the disease progresses can anticipate cognitive and functional limitations and the expected behavioral effects as the dementia progresses” (Sutor, Smith, & Rummans, 2002, p. 35). The education needs to focus on the clinical presentations, symptoms, and function of the frontal and temporal lobes of the brain in order to understand why challenging behaviors are occurring. Through education, caregivers will learn the multiple behavioral, language, social, and personality changes that cause challenging behaviors in persons with FTD. Once caregivers are aware of the behaviors that can occur due to FTD and their meanings, patterns can be identified by behavioral recognition.

Newman’s concept of pattern describes the interconnectedness of the person with their environment and pattern recognition as the means in which to interpret the behavior as a form of communication. The caregiver’s movement towards expanding consciousness is developed, as patterns are seen as the wholeness of the person and behaviors are recognized as new ways of

communication. “The evolving pattern of the person is best portrayed as sequential patterns over time” (Marchione, 1993, p. 21) and “illustrates a person’s pattern of the whole” (Marchione, 1993, p. 21). When peaks and lulls are seen in succession the unique pattern of the whole wave is revealed.

To see health as the pattern of the whole, caregivers need to see that FTD is not a separate entity but a manifestation of the evolving pattern of the person-environment interaction (Newman, 2008). Pattern recognition can be achieved by connecting with the person and understanding new patterns of behavior as forms of communication. “Part of pattern recognition is being able to look at things from a different point of view, a reframing of the situation by shifting the angle of viewing” (Newman, 2008, p. 77). By seeing the pattern of the whole one can recognize the importance of being with the person instead of just doing something for the person. Caregivers who use the BRAD model of care, which incorporates the HEC theory of pattern recognition, will begin to see new patterns of the person with FTD.

Assessment. The second assumption of the BRAD model of care is that assessment of the person-environment connection is needed in order to deliver appropriate care. Through behavioral recognition and assessment, patterns will be discovered. Caregivers must be present in order to see the interconnectedness between the person and their environment. To a person with FTD there is only the present, there is no past or future. Newman (2008) states that caregivers who are “in the moment” during times of uncertainties will be able to assess the situation and respond to the uniqueness of the person and their pattern (p. 77).

Merrilees and Miller (2003) find that attention to body language and behavioral cues are necessary due to the language and communication deficits in persons with FTD. Ideally, strategies to manage FTD should focus on environmental changes (Merrilees & Miller, 2003).

The ABC model focuses on antecedents (triggers) to a behavior. According to Sutor, Nykamp, and Smith (2006) environmental factors and how a caregiver approaches care is often the antecedent. Assessment of the environment is needed to understand the meaning behind the pattern that is identified through behavioral recognition. According to Talerico and Evans (2001) it is important to alter the physical environment that can cue unwanted behaviors. A stressful and dangerous situation is when the person with FTD wanders out of the house. When a person with FTD sees shoes and outerwear it represents things you put on to leave the house. One example of altering the physical environment to remove environmental cues would be to remove shoes and outerwear from sight, which can reduce the unwanted behavior of the person with FTD wandering out of the house.

Ruka (2005) explains that “people with dementia characteristically exhibit variability in their behaviors, emotions, and patterns. Although this variability may appear chaotic, it is a form of expression indicative of the rhythm and interaction of the person with his or her environment” (pp. 102-103). It is important to remember that all behavior has meaning when delivering care based on behavioral patterns. Caregivers need to focus on assessing the cause of the behavior instead of trying to change the person with dementia (Sutor, Nykamp, & Smith, 2006).

Delivery. The third assumption of the BRAD model of care is delivery based on behavioral patterns, assessment of the person-environment connection, and individual needs of the person and caregiver. According to Mayo Clinic dementia education specialist Angela Lunde, “When you meet a person with FTD, you have met one person with FTD” (personal communication, March 12, 2009). This statement reflects the importance to remember that every person with FTD is different. Each swelling wave pattern will have its own individual patterns of peaks and lulls.

According to the TREA model, delivery of care needs to be individualized. Behaviors will have different meanings which will require a particular delivery of care. “Individualization is important for the effective maintenance of safety as well as enhanced quality of life for both the person and their caregivers” (Talerico & Evans, 2001, p. S54). It is important to embrace the meaning of the patterns and be present for each situation. Delivery of care will need to be individualized due to the distractibility and high impulsivity in persons with FTD. Delivery of care that is being provided today might not be the care that is needed tomorrow.

The TREA model focuses on prevention, accommodation and flexibility as essential elements to individualized care. The TREA model is centered on environmental changes that will prevent the development of unmet needs. These unmet needs may develop into challenging behaviors. When a person with AD forgets to eat, behaviors could result due to the unmet need of being hungry. Caregivers can prevent the behavior by assisting the person to remember to eat and by providing or offering food regularly. Prevention of behaviors by controlling unmet needs is possible when caring for someone with AD, but not with FTD. Clinical psychologists Lough and Garfoot (2007) have found that behaviors that present in persons with FTD result from the loss of executive control and loss of insight. Persons with FTD will always have challenging behaviors even if their needs are being met. Many tools and models to control challenging behaviors were developed for Alzheimer’s disease and were based on management of unmet needs (Lough & Garfoot, 2007).

Wave after wave crashing on the shoreline causes erosion, but by using riprap on the shoreline erosion caused by waves can be prevented. Caregivers, like the shoreline, can use the BRAD model of care to minimize the erosion caused by challenging behaviors. The BRAD model focuses on delivery of care that is proactive versus reactive. Delivery of care that is

proactive must be based on patterns identified through behavioral recognition and the assessment of the person-environment connection. If care is being delivered in a reactive way then the person's behavioral pattern and person-environment connection has not been identified.

Behavioral recognition and assessment will allow caregivers to see patterns and achieve a higher level of consciousness which will allow for a more meaningful delivery of care.

Brad's story

Brad, a 24 year-old college educated man, spent eleven days in a neurological intensive care unit in February 2005 due to encephalitis. During the next eight months there were changes in personality that culminated in Brad having to move home with his parents. His functional ability to manage activities of daily living declined and his personality changes became more pronounced which prevented him from being able to live independently.

Between October of 2005 and January of 2006, Brad underwent numerous medical tests and procedures to determine the cause of these changes. The neuropsychological testing suggested that Brad had significant cognitive deficits and severe behavioral changes. According to the Neurologist the MRI showed "slight gray matter changes" and the family was told he had an acquired brain injury due to the encephalitis. Brad's family was concerned, even though Brad did not acknowledge or recognize any of the changes in personality or behaviors witnessed by his family. Brad and his family endured multiple questioning about his potential drug and alcohol abuse, as well as accusations and erroneous conclusions about what he might have done to have contributed or caused the changes that were happening.

The family experienced generalized frustration and foundational distrust with the healthcare professionals throughout this journey. Months after leaving the hospital due to encephalitis, Brad's parents were concerned about him being unable to function or manage the

activities of daily living. These concerns were discussed with the physician during a follow-up appointment. The physician listened to the multiple concerns and then, with a look of irritation on his face, told Brad's parents, "You need to cut the apron strings and let this young man live his life". Another example of misunderstandings and adversarial positioning was reflected when a psychologist told the family that he had the most "enlightening conversation" with Brad. He was being sarcastic as he said he had some concerns about Brad's care. The psychologist questioned the family since Brad said he was being locked in the basement and not allowed to see his friends. This untrue statement to the psychologist further exemplified the family's concerns about his behavior changes. These healthcare professionals were unconcerned about Brad's personality and behavior changes.

Brad was referred to a major tertiary medical center in January of 2006. In February, Brad underwent another MRI and was found to have moderate to severe brain damage from a presumed acquired brain injury due to the encephalitis. The family was concerned about the dramatic changes from the previous MRI images and the personality changes that were being witnessed. At the much anticipated appointment the family discussed their concerns and urged comparison with the previous MRI scans, but the Neurologist refused to look at the previous MRI scans. The Neurologist told the family that "you wanted a referral to the brain injury rehabilitation program, so I will do that".

Brad attended a brain injury rehabilitation program for five months. During that time, the family waited and hoped, but saw no improvement and noted further deterioration. The family repeatedly urged for another MRI to be performed. In September 2006, when it was clear that the brain injury rehabilitation program was failing to meet Brad's needs, the medical consultants

finally agreed to perform the MRI. The MRI showed a rapid progressive degeneration of the brain, which was most profound in the frontal and temporal lobes.

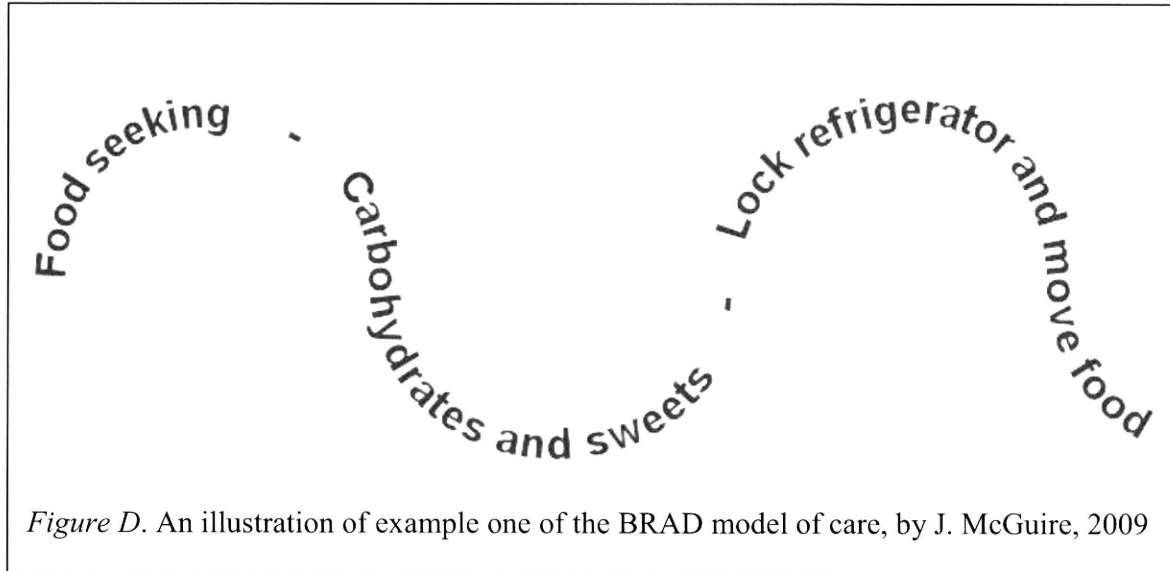
Due to the profound changes on this MRI, Brad was immediately referred to a Behavioral Neurologist. The following tests were done in the month of October: blood work (17 vials of blood taken on just the first day), 24 hour urine sample, electroencephalogram (EEG), lumbar puncture, ultrasound, skin biopsies, and a PET scan. In November 2006, it was suggested that Brad undergo a brain biopsy to assist in a diagnosis. After almost two years, Brad and his family received the devastating diagnosis of frontotemporal dementia in January 2007 just weeks before his 26th birthday. The tsunami the family had been experiencing finally had a name.

Brad was cared for and financially supported by his parents in their home from October 2005 to October 2007. It was not easy for Brad's family to find a facility that was willing to care for a young adult with FTD. In October 2007, Brad moved to a small residential facility designed for young people with brain injuries and cognitive impairments that require 24 hour care. They were willing to care for Brad even though the caregivers had never cared for someone with FTD. His family continues to be highly involved in his care and financially provides for everyday expenses not covered by federal and state assistance. Brad continues to live in the residential facility with hospice involvement in his care.

Examples of the BRAD model

Caregiver burden was experienced by the family while providing care to my brother, due to the numerous unique challenging behaviors caused by FTD. The behaviors experienced were both difficult to manage, but also rewarding when we were able to provide the best care possible by using the BRAD model. The following examples will show how my family applied the

BRAD model when experiencing three specific behavior patterns: constant food seeking, agitation with showering, and paranoia when the telephone rang.



Example one. Food seeking is a unique challenging behavior experienced by caregivers of persons with FTD. **Behavioral Recognition** is used to identify the pattern of food seeking. The act of food seeking is daunting for caregivers. Brad would roam around in the kitchen throughout the day, opening the refrigerator and cabinets in search of food. For my brother, food seeking involved the pattern of craving carbohydrates and sweets, overeating, cramming food in his mouth and eating too fast. This pattern of behavior presented with numerous safety concerns. Caregiving involved the overwhelming task of being hyper-vigilant when he was food seeking and eating. Brad would seek food at anytime during the day. He would be finished with a meal and be back in the kitchen seeking more food. He has eaten a whole large bag of dinner rolls within minutes. He has eaten raw uncooked meat that was taken from the refrigerator without being noticed. He has crammed cookies into his mouth so fast that he has choked. He has

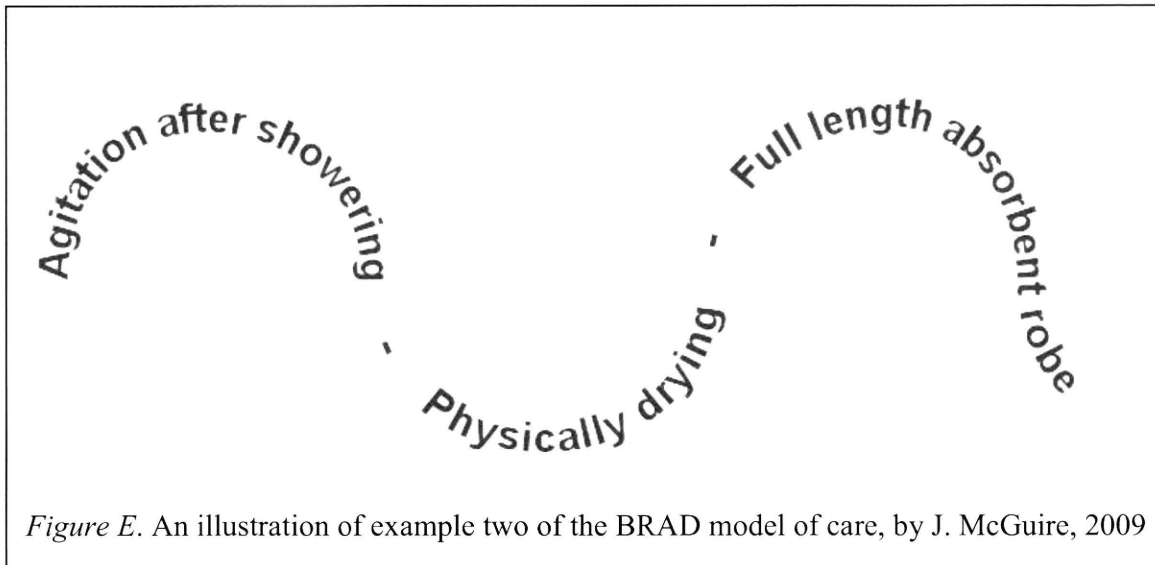
attempted and was almost successful in putting his hand into rapidly boiling water to retrieve pasta.

Brad became aggressive when trying to seek food. He would push, hit and tackle someone to swipe the food he wanted from your hands. His food seeking pattern has even caused him to rip the door off of a kitchen cabinet in order to get crackers. It was discovered when caregivers use the words “no”, “stop” or “don’t eat that” in a loud voice, it would intensify the food seeking or cause aggression. We discovered by remaining calm and using the phrases: “Let me get it ready”, “Let me give it to you”, “Let me help you”, or “Let me put it into a bowl” would result in Brad handing over the food to his caregiver.

We also discovered certain food items could be used to gain his attention and cooperation with activities of daily living that needed to be done. Skittles candy was the most successful food item used. All Brad would need to hear was the word or the sound of the wrapper, or the sight of the red bag to get his attention.

Once the pattern was identified, we as caregivers needed to assess the person-environment connection to find new ways to reduce the food seeking. Through **Assessment** it was discovered that locking the refrigerator and removing carbohydrates and sweets from the kitchen reduced the amount of time spent in the kitchen seeking food. The **Delivery** of care involved moving all food that caused the food seeking in the kitchen to other places in the house and putting a lock on the refrigerator. The lock on the refrigerator needed to be accessed by the caregivers without having to use a key or trying to remember a combination. A cable wire was wrapped around the refrigerator and secured with a carabineer. The carabineer allowed easy access for caregivers, but was enough of a deterrent to keep Brad out of the refrigerator. Fruit and low fat snacks were left out in plain sight as a distraction and to encourage eating them

instead of seeking carbohydrates and sweets. Food seeking was not eliminated, but was reduced by using the BRAD model of care, which resulted in less caregiver burden.

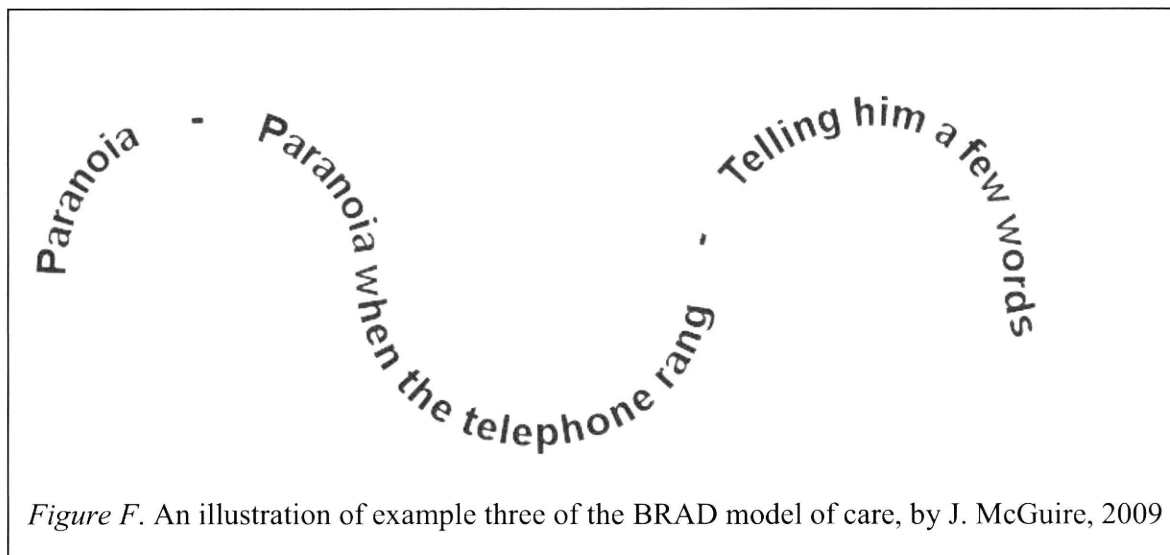


Example two. Agitation while showering is a common challenging behavior experienced by caregivers of persons with FTD. **Behavioral Recognition** was used to identify the pattern of agitation during showering. The shower itself did not cause agitation. For my brother it was the pattern of drying him off with a towel that caused the agitation. Providing assistance with showering in a bathroom that is designed for one person is complicated. Brad would be soaking wet and would want to leave the bathroom immediately after getting out of the shower. The agitation started when trying to dry and clothe him before leaving the bathroom. When drying him off, Brad would hit and shove the caregiver who was also soaked with water and standing on a wet slippery floor. It was not easy for his parents and sister as caregivers to provide a shower while maintaining his sense of dignity and privacy.

Once the pattern was identified we as caregivers needed to assess the person-environment connection to find new ways to dry him off after showering. Through **Assessment** it was discovered that he was less agitated when allowed to leave the bathroom wet. As caregivers we

discovered one day that getting him to put on a robe solved the problem of drying him off and allowed him to leave the bathroom immediately after the shower. Due to the restlessness and agitation after the shower using a fan or hair dryer was not successful.

Delivery of care involved getting a full length absorbent robe to be used after showers to dry off instead of towels. Agitation was decreased by using the robe and allowing him to leave the bathroom. The agitation after showering was reduced by using the BRAD model of care, which resulted in less caregiver burden.



Example three. Paranoia is a common challenging behavior that is experienced by caregivers of persons with FTD. **Behavioral Recognition** was used to identify the pattern of paranoia. My brother experienced paranoia every time the telephone rang. The pattern identified when the telephone rang, was Brad repeatedly saying, in a very apprehensive voice, and with a look of suspicion on his face, “Who is it”. For caregivers the phrase “Who is it” repeated over and over again causes a great deal of irritation. It was difficult answering the phone with Brad yelling “Who is it” until you gave him an answer. It was exasperating trying to

give him a detailed explanation of who was calling and realizing the explanation would not relieve his paranoia.

Once the pattern was identified we as caregivers needed to assess the person-environment connection to find new ways to decrease the paranoia when the telephone rang. Through **Assessment** it was discovered that his paranoia would quickly be relieved when the person calling was someone he knew. Out of sheer frustration one day Brad's parents discovered that if they said "it's Jennifer", even when it was not Jennifer calling, he would become calm and stop saying "Who is it". The same calming effect worked when Dad would say "it's Mom" or Mom would say "it's Dad" even though it was not them calling when the phone rang.

Delivery of care involved telling him "it's Jennifer", "it's Mom", or "it's Dad" every time the telephone rang, even though that person was not the one calling. This worked even if it was Jennifer herself who told Brad "it's Jennifer". This discovery was made one day by accident when the telephone rang, while sitting right next to him. Through using the BRAD model of care paranoia when the telephone rang was quickly minimized by simply saying a few words, which decreased caregiver burden.

These examples show how using the BRAD model of care during waves of challenging behaviors can reduce caregiver burden while increasing the quality of life for the person with FTD and the caregivers. The behaviors that were experienced while caring for my brother were perceived differently after applying the BRAD model of care. Before the behavioral recognition and identifying patterns of food seeking, agitation with showering, and paranoia when the telephone rang was discovered; my family would struggle with frustrating situations of trying to stop his behaviors. We thought the food seeking was a lack of self control and if we challenged him with food or reasoned with him about the food seeking we would be able to change the

behavior. We also could not understand him being agitated after showers, because drying off after a shower was a necessary task that needed to be done. The paranoia when the telephone rang caused extreme irritation when we could not relieve the paranoia by giving a detailed explanation of who was really on the telephone. Because we did not have a model of care that focused on behavioral recognition, we were being hit with wave after wave of behaviors that we could not understand or manage.

Newman (2008) states that identifying pattern is one use of consciousness and the caregivers, the environment, and the person being cared for reflect the whole in this situation. Wholeness and connectiveness give opportunities for family caregivers to see patterns and their meanings (Picard & Jones, 2005). Connectiveness involves the caregiver being present to detect challenging behaviors, give them meaning, and recognize the various patterns. Newman's theory of HEC would determine that a higher level of consciousness was achieved by Brad's caregiver when we used the BRAD model of care to manage the unique challenging behaviors of food seeking, agitation with showering, and paranoia when the telephone rang. Achieving a higher level of consciousness for caregivers involves seeing patterns instead of seeing problems. "The process of pattern recognition focuses on what is meaningful in the lives of the participants" (Picard & Jones, 2005, p. 6).

Newman's HEC theory and research on pattern recognition led to the development of the BRAD model of care. When waves of challenging behaviors occur families can use behavioral recognition to identify patterns. Assessment of the person-environment connection will help caregivers find meaning of patterns, which will lead caregivers to appreciate the wholeness of the situation in order to deliver care. Individualized appropriate care can be given once pattern

and connection is found. Behaviors caused by FTD will always be present. Caregivers are able to ride the waves and stay afloat by using the BRAD model of care.

Each person with FTD is different and will have distinctive challenging behaviors. The previous examples illustrate how using the BRAD model of care reduced caregiver burden, which increased quality of life for Brad and his caregivers. The Behavioral Recognition, Assessment and Delivery (BRAD) model of care is designed with the purpose of giving caregivers a tool to manage unique challenging behaviors experienced when caring for someone with FTD.

Chapter 4: Discussion

Implications for education and research

Education. Mendez et al. (2007) reports that an accurate diagnosis has become progressively more important for the development of new therapeutic therapies. The large number of misdiagnoses of FTD results in delay of adequate care, caregiver mistrust, and frustration (de Vugt et al., 2006). “The high misdiagnoses rate is particularly troublesome since around 20% of all persons with presenile forms of degenerative dementia suffer from FTD” (Lindau, Almkvist, Kushi, Boone, Johansson, Wahlund, Cummings, & Miller, 2000, pp. 286-287). Education and increased awareness of FTD needs to start with healthcare professionals.

Awareness and comprehension of FTD should be directed at healthcare professionals in order to provide an accurate diagnosis and the best care possible. Personality and behavioral changes are the hallmark characteristics of this form of dementia. It is important to provide education and to raise awareness of FTD among primary care physicians as well as psychologists and psychiatrists. These professionals are the ones from whom family members will be seeking advice related to concerns about a loved one’s behavioral and personality changes.

The Alzheimer’s Disease Research Center at the Mayo Clinic is currently one of 30 National Institute of Aging (NIA) funded centers in the United States. Through this funding Mayo has made great improvements in providing support and education to families caring for someone with FTD. The research center offers programs and information for persons and families who are impacted by mild cognitive impairment, Alzheimer’s disease, Lewy Body dementia, and frontotemporal dementia. A program offered to families is the family seminars on Lewy Body and frontotemporal dementias. The family seminars provide families with information, resources, and problem solving skills related to FTD in a supportive setting with

other families who are dealing with a similar diagnosis. There is also a series of educational classes intended for those caring for someone with dementia or who are seeking more information about these diseases.

This format, the family seminars, would be a great setting to discuss and educate about the BRAD model of care. The seminars provide a general overview of the disease, information about what to expect as the disease progresses, family support time, plans for providing care, how to deal with difficult decisions, and medical issues encountered during the later stages. The one area that is not covered during the seminars is how to manage unique challenging behaviors. The BRAD model of care would provide families who attend the seminars with a useful tool to manage behaviors caused by FTD. Family caregivers, who receive education and become knowledgeable in the clinical presentations and symptoms, would be able to use the BRAD model of care.

Research. Merrilees (2007) suggests future research that focuses on the caregiver experiences would help identify types of strategies and services needed. “Qualitative research offers the opportunity to focus on finding answers to questions centered on social experience, how it is created, and how it gives meaning to human life” (Speziale & Carpenter, 2003, p. 2). Qualitative research studies would provide insight into the challenges being experienced by caregivers of persons with FTD. This research should be done in order to hear caregivers’ stories and learn from their successes and mistakes.

Nursing professors Speziale and Carpenter (2003) write that the aesthetic view of qualitative research would provide a framework that is based on recognition of patterns instead of an explanation of facts that can be generalized. This type of research would help identify the unique challenges of families caring for persons with FTD. “There is a dire need for further

research that specifically targets efficacious interventions for behavioral symptoms in this underserved population of dementia sufferers” (Talerico & Evans, 2001, p. S54). Lough and Garfoot (2007) explain that a broad theoretical framework is needed to be successful in reducing challenging behaviors experienced by persons with FTD. The theoretical framework of Margaret Newman’s Health as Expanding Consciousness provides the necessary ground work for the BRAD model of care. Newman (2008) explains that identification of patterns is the essence of caregiving. Qualitative research with an aesthetic view needs to be done on the BRAD model of care.

Health Inequities

Talerico and Evans (2001) report that there are limited biomedical treatment options to manage behavioral symptoms related with FTD. Much of the medical understanding of this disease is based on a limited number of observations of persons with FTD. Treatment of FTD is not well known due to the small number of recognized cohorts (Agronin, 2008). Lipton and Boxer (2009) report that no treatment for FTD is approved by the Food and Drug Administration (FDA), and more randomized controlled trials need to be done. Cycyk and Wright (2008) discovered in their literature review that only a few single-case studies address the appropriate treatments for persons with FTD and that much of the evidence based research studies that investigate management of dementia are based on Alzheimer’s disease.

Strong bias against people with dementia is prevalent in our society. Daniel Kuhn, a licensed social worker and director of the Professional Training Institute for the Alzheimer’s Association in Chicago, and Jane Verity, a founder and director of Dementia Care Australia wrote a book on the art of dementia care. Kuhn and Verity (2008) state that “society places a high value on thinking, memory, and productivity” (p. 8). People with dementia are

disenfranchised because they are unable to contribute to society in the usual way and in most cases they cannot speak for themselves (Kuhn & Verity, 2008).

Merrilees (2007) finds that dementia symptoms experienced will have a vast impact and add substantial cost for families. Frontotemporal dementia causes profound lapses in financial and interpersonal judgment. Persons with FTD may find they are unable to control their spending on purchases, compulsively gamble, or even shoplift. These outlandish behaviors seem logical to the person with FTD. Due to the damage caused by this dementia the person will have little to no insight into the financial problems caused by their unusual behaviors. Financial and personal assets have been lost due to the person's poor decision-making and judgment (Merrilees, 2007). When a person with FTD is unable to continue working, they along with their family, experience the loss of income, benefits, and possible retirement.

Agronin (2008) reports that caregivers spend on average \$10,000 annually for unreimbursable services and supplies for a person with dementia. Financial expenses related to the care of a person with FTD contributes to caregiver burden. Savva and Brayne (2009) report that there is considerable cost to the economy due to caregivers and persons with FTD leaving the workforce. As mentioned earlier, the National Longitudinal Caregiver Study reported in Savva and Brayne (2009)

estimated that 60% of caregivers reduce working hours because of caregiving, 42% reported being later for work because of caregiving, and 39% had taken sick leave. Half of the persons who had retired reported that caregiving responsibilities were the main reason for their retirement (p. 29).

“Dementia has an economic impact on individuals, healthcare services, and the wider economy” (Savva & Brayne, 2009, p. 32). Informal family caregivers play a significant role without financial compensation which is estimated at \$196 billion United States dollars in healthcare costs (Cycyk & Wright, 2008). United States businesses were informed by the Alzheimer’s Association in 2002 that the total indirect economic cost of dementia was estimated at \$61 billion (Savva & Brayne, 2009).

Argonin (2008) finds one estimate that 70-80% of persons with dementia are cared for in their homes with the majority of care being provided by family members. Deciding to move a loved one to a long term care facility is a major decision for families to face (Merrilees, 2007). It is vital to match the needs of the person with FTD to the long term care facility. “Many community dementia services are reluctant to accept young healthy looking persons in their programs, particularly if that person is a man and is exhibiting problematic behaviors” (Yeaworth & Burke, 2000, p. 252). Due to this situation caregivers are forced to choose facilities and services that are more age appropriate but are not designed for persons with FTD. Merrilees (2007) states that finding placement in a facility for a younger person with behavioral disturbances is extremely difficult.

My brother’s situation is a great example of this inequity. There were many barriers when my parents made the difficult decision to start looking for a facility to care for my brother. Numerous local nursing homes would not even consider taking him due to his young age. Even if these facilities would consider caring for him, my family would be uncomfortable having him there. Given my brother’s age we needed to find a facility that fit his age not necessarily his disease. He is being cared for in a four bedroom residential care facility that specializes in

traumatic brain injuries. The age of the population was a good fit for my brother but the facility was not designed to care for persons with dementia.

When waves of challenging behaviors are causing caregiver burden, families will turn to healthcare professionals for guidance and help with management. Behaviors caused by frontotemporal dementia will always be there, so a simple model of care is needed to provide families with a way to manage behaviors, decrease caregiver burden, and increase quality of life. There are many health inequities faced by persons with FTD and their families. Specific education and research on FTD is needed in order to provide them with the best information, resources, and tools to manage this unique form of dementia.

Chapter 5: Conclusion

In summary, persons with frontotemporal dementia experience profound changes to their behavior, language, and personality. FTD is particularly devastating to caregivers due to the personality and unusual behavioral changes that are unique to this disease. Caregivers will find themselves caring for someone that is profoundly different from the person they once knew. Challenging behaviors caused by FTD can be difficult and stressful.

The purpose of the BRAD model of care is to reduce caregiver burden while increasing quality of life for the person with FTD and their caregivers. Viskontas and Miller (2009) report that research in recent years has accelerated now that FTD has finally been recognized as a significant, relatively common disease that is distinctive from Alzheimer's disease. Future research should be done to identify specific needs, concerns, and experiences of caregivers of persons with FTD in order to discover useful management strategies (Cycyk & Wright, 2008; Merrilees, 2007). The BRAD model of care could provide a blueprint for future research studies.

Recommendation

The goal at the beginning of this project was to get the BRAD model of care published in major nursing and medical journals. Banks et al. (2006) report that public awareness is needed on FTD in order to draw attention to the extraordinary needs that are faced by families that are coping with this unfamiliar disease. Quality care can be provided to persons with FTD, by increasing awareness and improving diagnostic accuracy (Merrilees, 2007). In order to reach a large number and a variety of healthcare professionals, I would like to submit an article for publication using this project as the foundation to one of the following nursing and medical journals: Nursing Science Quarterly, Journal of Neuroscience Nursing, Journal of Psychiatric

and Mental Health Nursing, American Journal of Nursing, Journal of the American Medical Association, Neurology, and American Journal of Psychiatry. The key is finding the best forum to reach the broadest audience.

Reflection

My hope is that through awareness, research, and education, persons with FTD and their families will find support, resources, and hope for a treatment. Developing the BRAD model of care was an enlightening journey for me. My roles have changed throughout the years since my brother became ill and then diagnosed with FTD. I am no longer a direct care provider, since his move to a residential care facility. My role now is being an advocate for my brother and helping raise awareness of FTD. This model of care shows my family's dedication, struggles and accomplishments while providing care for my brother Brad. The BRAD model of care was developed to honor my brother and give recognition to my family for their dedication to his care.

To learn more about FTD please visit The Association for Frontotemporal Dementias (AFTD) at

www.ftd-picks.org

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