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Professional Perspectives: Views of Service Needs for Individuals Diagnosed With Frontotemporal Dementia and Their Families

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Professional Perspectives:

Views of Service Needs for Individuals Diagnosed With Frontotemporal Dementia and

Their Families

by
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Abstract

The purpose of this study was to explore professional's perspectives on the service needs for people with Frontotemporal Dementia (FTD) and their families. A qualitative research design was used to obtain data from (n=4) four professionals from a variety of work settings. The results of this study supported previous literature in identifying the challenges in supporting and lack of services for people with FTD and their caregivers. The major theme which emerged in this research was that there is a need for FTD specific services. The subthemes which emerged to support this theme included: physical activities, more staffing, individualization, collaboration, financial barriers, and education. Implications for future include the need for social workers to provide education and advocate for service needs for people with FTD and their caregiver in multiple levels. In additional to exploring professional perspectives is imperative that future research explore the service and support needs from the perspective of those providing care for individuals diagnosed with FTD.

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INTRODUCTION

Not long ago, a conversation was held between colleagues regarding a concern for a number of clients the program had difficulty supporting currently and in the past; these clients had Frontotemporal Dementia (FTD). Although this population and their caregivers were in great need of the adult day program, the participant's level of energy and presentation of behaviors were difficult for the program to support. These clients often agitated and upset other members of the program (many of whom were older adults with dementia) through inappropriate or rude remarks or gestures and at times aggression. It was decided time and again after many attempts to support the individual that these clients were not appropriate for the services offered at the program. This theme continued into my next internship as caregivers continually shared their stories of desperation and frustration surrounding a lack of services which could appropriately support their loved one as they were continually turned away. These experiences and the stories of clients have fueled my interest in exploring professional's perceptions of the service needs for people with FTD and their families.

Currently, the fastest growing segment of the global population is 60 years of age, or older. This population is expected to grow from 274 million in 2011 to 418 million in 2050, and to 433 million in 2100 in more developed regions of the globe (United Nations, 2013). According to the United States Census Bureau, as of 2010, older adults accounted for 13 percent of the total U.S. population (Vincent & Velkoff, 2010). This percentage of older adults is larger than any prior U.S. census reported, indicating a growing need for professionals to better understand the older adult population (United States Census Bureau, 2012).

To better understand this population, it is necessary to understand that there is enormous diversity in age, race, ethnicity, gender, abilities, and socioeconomic status amongst older adults.

All of which can affect a person's experience and perception of life transitions - behaviors, family interactions, physical and mental health issues, and the utilization and availability of health care services. The older adult population is not only diverse, but also complex, and at times, accompanied by other variables such as chronic disease, psychosocial issues, physical disability, and decreased independence. For example, it is estimated that 87% of adults, age 65 and older, have at least one chronic condition (Volland, 2010). Moreover, Fowels and Greenberg (2011) report that 37% of older adults in 2010 reported some form of disability.

One debilitating condition experienced by older adults that requires a great deal of assistance and care, is dementia. The World Health Organization (2014) reported that 35.6 million older adults have dementia, which is described as "one of the major causes of disability and dependency among older people worldwide" (para. 1). According to the Alzheimer's Association (2014), Alzheimer's disease accounts for 60-80% of dementia cases and it is the most common form of dementia. Other forms of dementia include vascular dementia, dementia with Lewy Bodies and Frontotemporal dementia. Although a diagnosis of any form of dementia can be difficult and challenging for both the person with the diagnosis and their caregiver, a diagnosis of Frontotemporal Dementia or Frontotemporal Degeneration, or FTD as it is commonly referred to, can present an extra layer of challenges for caregivers and service providers.

Frontotemporal Lobar Degeneration (FTLD), or Pick's Disease, is another form of dementia, which primarily affects the frontal and temporal lobes of the brain. According to The Association for Frontotemporal Degeneration (2011), FTD represents 10-20% of all dementia cases. FTD is also one of the most common forms of early onset dementia meaning its onset is generally prior to age 65, with a mean prognosis of 8 years. Unfortunately, it occurs most

commonly in people who are in their 50's and 60's, with an average diagnosis at the age of 60. According to Knopman (2011) as cited by The Association for Frontotemporal Degeneration (2011), this type of dementia affects between 50,000 and 60,000 Americans.

Due to the extent of care needed throughout the progression of these diseases, it is reported that around 15 million Americans provide unpaid care for people with Alzheimer's disease and other dementias. It is estimated that these unpaid or informal caregivers, who are often family members, provided 17.7 billion hours of care in 2013. The value of time and effort expended by these caregivers is valued at approximately $220.2 billion, according to the Alzheimer's Association (Facts and Figures, 2014, p. 30). Although many services are now available to support caregivers of people with Alzheimer's and most other types of dementia, many service providers lack the knowledge and skills needed to provide support to persons with FTD and their caregivers (Chemali, Withall, & Daffner, 2010; Morhardt, 2011; Rosness, Haugen, & Engedal, 2008; Schnall, n.d.).

Oftentimes, caregivers of a person with FTD face a unique set of challenges such as rapid decline, early age of onset, cognitive and behavioral challenges, and severity of impairment (The Association for Frototemporal Degeneration, 2011). Consequently, in order to deliver the best care for the large population of older adults diagnosed with FTD and their caregivers, it is necessary that social workers increase their knowledge and understanding of the impact a diagnosis can have on the person diagnosed with FTD, how to support caregivers who bear the responsibility of caring for this population, and the types of services needed to meet the unique needs of this population. To that end, this study will explore social workers' and other professional's perspectives on the services needed to provide the best care for people diagnosed with FTD, and how to best support the individuals who provide their care.

LITERATURE REVIEW

Historical Perspective of Frontotemporal Dementia

According to Yeahworth and Burke (2000), Dr. Arnold Pick first described Picks disease in 1892. Congruent with current descriptions, Dr. Pick believed the disease was progressive, with no known cause, and an average age of onset of 65. Dr. Pick also reported that the youngest person listed was 34, and the oldest at age 77. Because Pick's Disease presents in the frontal and anterior temporal lobes, it is currently classified as a type of FTD, which accounts for 1% to 5% of dementia cases. Although most classic cases of Picks disease would now be classified as a subtype of FTD, it is important to note that historically, this was one of the first cases in which a type of FTD was classified.

It was reported by Brun (2007) that further classification and distinction of FTD as its own diagnosis, separate from Pick's Disease, began in the 1960's. FTD was often overshadowed or misdiagnosed as Alzheimer's disease, due to the lack of knowledge regarding FTD. Further separation between Alzheimer's disease became apparent as the presentation of symptoms was markedly different in FTD, compared to Alzheimer's disease (AD), although it was often described as frontal AD. The first publication which described the pathology of FTD was penned in 1987. Subsequently, in the 1970's, FTD cases were present in the literature. In 1994, a consensus on the disease criteria was determined, according to Brun (2007).

Frontotemporal Dementia: A Neurodegenerative Disorder

According to the Joint Programme Neurodegenerative Disease Research (JPNDR), neurodegenerative disorders refer to diseases that cause the death or degeneration of the neurons or nerve cells in the brain. These diseases often affect movement (ataxias), or mental functioning (dementias). Furthermore, these diseases are incurable conditions because once damaged, the

neurons do not reproduce or regrow. Some commonly known neurodegenerative disorders include Parkinson's disease, Huntington's disease, and Alzheimer's disease (JPND Research, 2014).

Frontotemporal Dementia is a term used to describe a group of neurodegenerative disorders which affect the prefrontal and anterior temporal lobes of the brain (Neary, Snowden, & Mann, 2005). The prefrontal and anterior temporal lobes of the brain, which are affected in FTD, are associated with executive control functions such as reasoning, decision making and planning, as well as personality, social behavior, and speech and language comprehension (Association for Frontotemporal Degeneration [AFTD], 2011; Mikesell, 2009; Neary, Snowden, & Mann, 2005). According to the Alzheimer's Association (2014), when these areas of the brain are damaged, social and cognitive function are affected. The areas of degeneration in FTD are different from that of Alzheimer's disease. In Alzheimer's disease, degeneration begins in a part of the brain called the cerebral cortex, which interprets sensations, sounds, smells, generates thoughts, solves problems, makes plans, forms and stores memories, and controls voluntary movement. In addition, the hippocampus, which is responsible for memory, is also greatly affected in AD. These changes in the cortex and hippocampus generally affect a person's thinking, planning, and memory (Alzheimer's Association, 2014).

Cause of Frontotemporal Dementia

Unfortunately, the cause of the disease is unknown, often developing in isolated cases with no direct ties to genetics or lifestyle. However, it is important to note that there may be some cases in which family history may suggest a hereditary connection, although most cases are not linked with genetics (AFTD, 2014). Currently, there is also no treatment; symptom

management is often utilized. To that end, different medications are often used in combination with environmental controls, monitoring, and supervision (Yeaworth and Burke, 2000).

Types of Frontotemporal Dementia

<u>Behavioral Variant FTD</u>

According to the AFTD (2014), there are many subtypes of FTD, which are identified according to the signs and symptoms presented. Pick Disease (as FTD was formerly called) is a form of FTD that presents with similar symptoms of Behavioral Variant FTD. However, individuals diagnosed with Picks Disease may also experience language and cognitive difficulties, although it is primarily differentiated from other forms of FTD by abnormal collections of protein in the brain known as Pick bodies. Behavioral Variant FTD (bvFTD) is a form of FTD which is primarily marked by a person's inability to control and adjust their behavior in social settings, changes in personality, and loss of empathy. Some symptoms include impulsive acts, hypersexual behavior, mood changes, apathy, repetitive behaviors, and hyper oral activity such as over eating. When thinking about FTD, the presentation of symptoms in bvFTD appear to be the most well-known in comparison to other symptom presentations in other forms of FTD; therefore, this will be the form of FTD discussed in this study.

<u>Nonfluent and Semantic Primary Progressive Aphasia</u>

Nonfluent and Semantic Primary Progressive Aphasia's (nPPA and sPPA) are marked by changes in ability to speak, read, write, and understand what others are saying (AFTD, 2014). Nonfluent Primary Progressive Aphasia generally presents as a deterioration of a person's ability to produce speech until they eventually become mute. Other challenges people may face with nPPA include difficulty swallowing, and reading and writing deterioration. Semantic Primary Progressive Aphasia generally presents as a person's inability to understand words. In this type

of nPPA, the person is still capable of speaking; however, as the disease progresses, their speech becomes more difficult to understand and they may become unable to recognize familiar objects and faces. These forms of FTD do not generally encompass the behavior or personality changes as shown in bvFTD until the later stages of the disease.

Progressive Supranulear Palsy

The AFTD (2014) describes Progressive Supranulear Palsy as a form of FTD that generally presents as issues with gait and balance. It is recognized through a progressive inability to coordinate eye movement, which affects vision. Other common symptoms include difficulty swallowing, difficulty with speech, immobility of the face, and forced laughing or crying. Similar to PPA, symptoms and behaviors as seen in bvFTD may begin to present as the disease progresses, although symptoms similar to bvFTD generally remain milder (AFTD, 2014).

Cortocobasal Syndrome

Although the hallmark behaviors of FTD are most present in bvFTD, PPA, and PSP, another type of FTD, Cortocobasal Syndrome (CBS), is most commonly recognized as a movement disorder, although individuals may present and develop cognitive deficits. Individuals diagnosed with CBS may experience a number of movement symptoms such as tremors, rigidity, akinesia - slowness or absence of movement, and limb dystonia – and abnormal posture of limbs (AFTD, 2014). Some cognitive symptoms that may present are apraxia - inability to complete purposeful movements such as using utensils, acalculia - difficulty completing simple calculations, and visual special impairment.

<u>FTD with Motor Neuron Disease</u>

The AFTD (2014) also identified another form of FTD; FTD with Motor Neuron Disease (FTD/MND). A person with this type of FTD may present behavior and language changes as described by the other types of FTD; however, changes in muscles and the ability to move also occur. Some common symptoms include muscle weakness, twitches, cramps, stiffness, shrinkage, and exaggerated reflexes (AFTD, 2014).

Frontotemporal Dementia Versus Alzheimer's Disease

As previously stated, FTD results in changes of a person's behavior, personality, language, and motor skills, as well as a person's ability to function. In a study by Lough et al. (2006), individuals with FTD showed a great deal of impairment in their ability to show empathy, as well as an inability to recognize and process the emotions of others. The same inability to socially connect was also observed in people with FTD in a study by Mendez et al. (2014). In this study, people with bvFTD, Alzheimer's disease (AD), and their caregivers were clinically observed in their home setting. Patients with bvFTD were easily distinguishable by researchers from their caregivers and people with AD. In comparison, people with AD were not distinguishable from their caregivers. Those with FTD showed marked differences from those with AD. The most observable differences reported were their inability to socially engage with the caregiver through a lack of either "you statements or emotionally experiencing the presence of another person" (p. 218), lack of manners, rate, and manner of eating. These deficits in recognition and processing of emotion and social norms may play a large part in their inability to function in a social context. Because of this inability to function in a social setting, it can be difficult for the caregivers to engage and communicate with the person with FTD, utilize community resources, as well as form a support system.

Caregiving for Individuals Diagnosed with FTD

As illustrated by the literature, dementia causes a decline in mental ability severe enough to interfere with daily life (Alzheimer's Association, 2014). Bertrand, Fredman, and Saczynski (2006) found that being a caregiver for a family member with dementia can be more difficult and time consuming compared to caring for an older family member without dementia. In addition, Fisher, et al. (2011) found that caregivers of older adults with dementia spend more hours providing care, and showed more depressive symptoms than informal caregivers of older adults with cognitive impairments that are not dementia related. This burden can be most challenging for family members living with the older adult. Many times the person providing care for the person with dementia may be an older adult themselves, e.g., spouses or older adult children.

As previously stated, of the many people caring for a person with dementia, many of them are faced with unique challenges of providing care for a person with FTD. For example, a case presented in an article by Kumamoto et al. (2004) demonstrates the challenges presented to the caregivers of two clients with FTD:

> These FTD patients had abnormal eating behaviors such as cramming of food into
> one's mouth and the abnormal manner of eating. They had to be fed bit by bit
> with total caregiver assistance. They were also overactive, restless and
> distractible, which subsequently caused problems with ADL assistance including
> extreme uncooperativeness toward their caregivers. Other behavioral symptoms
> associated with FTD, e.g., stereotypic behavior, distractibility and high
> impulsivity, were also considerably burdening to the caregivers. (p. 33)

Although this short description does not go into the details of each case, one begins to get a glimpse of the level of difficulty some caregivers may experience in their efforts to care for

individuals diagnosed with FTD.   Consequently, a study conducted by Mioshi, Bristow, Cook, and Hoges (2009) found that depression is a primary feature experienced by caregivers of persons with FTD, and it accounted for 58% of their stress related scores. Moreover, depression and stress in caregivers who cared for individuals diagnosed with FTD were significantly higher than they were for caregivers individuals diagnosed with Alzheimer's.

Consistent with the findings in Mioshi et. al. (2009), in their study, Diel- Schmid et al. (2013) found that 60% of FTD caregivers reported a great deal of strain, and 50% of them showed clinically significant levels of depression. In addition, this study found that 72% of caregivers were living with the person diagnosed with FTD, and 31% of the caregivers were also caring for another person - most often a child - in addition to the care they provided to the person diagnosed with FTD. In the final analysis, this study pointed out that the symptoms of FTD that created the greatest burden for the caregivers were aggression, lack of manners, occurrence of misdemeanors, and egocentric behavior, although physical impairment and amount of care needed were also prominent factors.

When comparing the experiences of caregivers who cared for individuals diagnosed with AD with the experiences of caregivers of individuals diagnosed with FTD, a difference in caregiver burdens was reflected in the literature. According to Riedijk, et al. (2006), caregivers for both AD and FTD were equally burdened with different types of emotional experiences. However, caregivers of a person with FTD reported more burden from the caring process. Riedijk, et al. suggested that this discrepancy may be due to external factors such as lack of support and services for this type of dementia, as well as the speed and age of decline in comparison to caregivers of individuals diagnosed with AD.

Difficulty Accessing FTD Services

As stated previously, there is a need for services specific to people with Frontotemporal dementia. Schnall (n.d.), an experienced service provider for caregivers and persons with FTD reports that because this disease is not well known, it can be difficult to obtain a diagnosis, receive understanding from friends and family, and utilize the available services and memory care for older adults or adults. The difficulty in utilization of services is often due to the difficult behaviors presented and early age of onset, which are often not accommodated because of facility restrictions. Similarly, Morhardt (2011) reported that common issues faced by the person with FTD and their caregivers include difficulty obtaining a diagnosis, financial stress often due to loss of employment or income difficulty accessing social security disability insurance, and finding community or long –term care facilities that are trained to care for FTD patients.

Rosness, Haugen, and Engedal (2008) found that more people with FTD were admitted to nursing homes for short or long-term care, compared to early onset AD. It was also reported that family caregivers of persons diagnosed with FTD were significantly less satisfied with counseling and follow-up provided by health care workers in an agency, as well as dissatisfaction with the information regarding the disease they received in these settings, as compared to caregivers of persons diagnosed with early onset dementia. Another common issue that arises for this population is that the State- Department on Aging Services for individuals diagnosed with dementia, under the age of 60, do not have similar options as individuals diagnosed with dementia over the age of 60. For the most part, the State Department of Rehabilitation Services typically focuses on mental disabilities, not dementia related diagnoses, although they serve individuals between the ages of 18-59 (Morhardt, 2011).

In another case study conducted by Chemali, Withall, and Daffner (2010) of a young patient with FTD, the behaviors of the reported client made her unable to care for her children, and she distanced herself from her caregivers. Her young age and presentation of symptoms made it difficult to diagnose in an outpatient setting, as many individuals with FTD are misdiagnosed for psychiatric issues, due to a lack of knowledge in the clinical community. Moreover, Chemali, Withall, and Daffern found that it was difficult to find a facility that would accept a person with younger onset of the disease, behavioral presentations, physical strength, and mobility, as medical challenges were often outside of the scope of care provided by most residential and acute facilities.

These issues in accessing services were also found in two case studies reported by Morhardt (2011), who discussed some common service issues faced by people with FTD and their families. Morhardt stated,

…an adult day center was able to manage her father's care very well until her
father started to display increasing bouts of agitation which would quickly
escalate to violence, due to behavioral outbursts, he was psychiatrically
hospitalized, and then the searched for the long-term care facility began.
 After several rejections, and based on his history and the diagnosis of bvFTD, unfamiliar
 to most facilities, one long term community finally agreed to accept him. He was there
for less than three months when the nursing home concluded they could no longer
manage his care due to his challenging behavior, and he was re-admitted to the
hospital and placed on another psychiatric unit. Ultimately, he had been
hospitalized at four psychiatric units and resided in three different nursing
facilities before he passed away…. After Over 50 rejections, the family remains

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convinced that no facility was really equipped to care for their father's behavioral

challenges and agitation. (pg. 739).

Although it is important that facilities recognize their limits and capabilities, it may also

be important for service networks to create options that are appropriate and meet the needs of the

underserved. Chemali, Withall, and Daffner (2010) suggested that there needs to be more global

education and awareness in both communities, and more important, in health care settings

because many physicians are unfamiliar with the diagnosis. Consequently, they often cannot

offer proper resources and knowledge regarding prognosis and diagnosis. Chemali, Withall, and

Daffner further opined that there needs to be more training in high levels of care, and facility

resources for younger individuals diagnosed with early onset dementia.

Models of Professional Caregiving for FTD Patients

<u>ABC Model</u>

Although there is still a great deficit of service providers and facility options for people

who have FTD, some facilities and professionals are working to develop programs and models of

care for those with FTD. Merrilees (2007) described an educational model for professional and

informal caregivers who work with individuals diagnosed with FTD. The model Merrilees

described can be used in the assessment of, and interventions for, symptoms experienced by

individuals diagnosed with FTD. The model is described as an ABC model or "antecedent-

behavior-consequence" (p.66) model in which the antecedent is the illness of the brain, the

behavior is the embarrassing or stressful behavior, and the consequence is the family's response

to the behavior. This appears to be helpful for family members or staff at a facility when

working with and processing frustrating behaviors. The model also suggested distraction and

redirection, as well as medication for symptom management, in order for informal and professional caregivers to better care for persons diagnosed with FTD.

Interdisciplinary Team Model

Grinberg, et al. (2008) described an interdisciplinary team model which integrated specialized FTD care into a preexisting day program in Toronto Canada, based on a needs assessment for family members who care for a person diagnosed with FTD. This program utilizes an interdisciplinary approach in which participants are cared for by additional, specifically trained staff, who are familiar with behavioral management techniques specific to those diagnosed with FTD, and who receive continuing education specific to FTD. For example, clients are placed in small groups in a safe setting, and they participate in active and meaningful activities that are altered by program staff to meet the needs of these clients. The staff of the clinic also works closely with an interdisciplinary team from a memory disorder clinic, and staff from both facilities meet to coordinate care and problem solve issues in monthly rounds, in order to strengthen the provision of care. Grinberg found that this model allowed FTD patients to utilize a service that met their unique needs, while also providing support, education, and respite to families.

Informal Caregivers

Informal caregivers provide unpaid assistance to others in need of care. They generally consist of immediate family members; however, they can include other relatives or friends (Alzheimers Association, 2014). Being an informal caregiver to a family member or friend has shown to have a positive influence on the care recipient; however, it can be emotionally, psychologically, and physically taxing on the person providing the care (Navaie-Waliser, Feldman, Gould, Levine, Kuerbis, & Donela, 2002).

For example, some mental health issues associated with informal caregiving include added stress (Aranda, 1997; Croog, Burleson, Sudilovsky & Baume, 2006), depression (Gallagher, Rose, Rivera, Lovett & Thompson, 1989; Croog, Burleson, Sudilovsky & Baume, 2006), and anxiety (Croog, Burleson, Sudilovsky & Baume, 2006). A study conducted by Straight and Harvey (1990) found that both primary and secondary informal caregivers are at risk for loneliness, mild depression, and low life satisfaction. The U.S. Department of Health and Human Services (2012) also reported that informal caregivers are more likely to have long-term medical problems, have a weaker immune response, higher levels of stress hormones, spend more days sick, and have higher levels of obesity.

Older Adults as Caregivers

Of the many people providing informal care, 13% of the caregivers are age 65 and older (U.S. Department of Health and Human Services [USDHHS], 2012). In a study conducted by Navaie-Waliser, et al. (2002), which examined the level of vulnerability of caregivers, found that informal caregivers age 65 and older tended to be more vulnerable to physical and mental health issues than other informal care providers. It has also been reported that elderly informal caregivers were 65% more likely to die within four years after taking care of their spouse or loved one if they experienced high levels of stress, compared to those who did not report as much stress (USDHHS, 2012). This is important to note as the caregivers of a person diagnosed with FTD may be older adult parents or spouses, or other older adult family members.

Summary

To summarize, the literature provides an understanding of the evolution of FTD. It reveals the severity of the symptoms experienced by individuals diagnosed with this debilitating disease. Moreover, those who are charged with caring for the FTD population need not only have

knowledge and skills, but they also need support. Research has begun to look at different ways to improve professional caregiving for the FTD population, as caregiving provided by family members and friends, although positive, has proven to be personally devastating.

CONCEPTUAL FRAMEWORK

The ecosystems theory describes the influence the environment and systems have on a person's life and behavior. It also describes how people in turn influence the environment. Specifically, this theory suggests that there is a flow of influence between the micro, mezzo, and macro levels (Miley, O'Melia, & DuBois, 2011) of social work practice. Therefore, the ecosystem theory is the most appropriate lens to use to explore ways of improving the services required to effectively care for individuals diagnosed with FTD,

According to von Bertalanffy (as cited in Miley, 2011), "a fundamental principle of ecosystems theory states that change in one part of the system creates change in another part of the system which, in turn, changes the functioning of the entire system" (p. 35). Moreover, Miley suggested that changes can be made on the micro level (individuals, families or small systems), mezzo level (organizations or formal groups), and macro (community, institutional, and societal systems). For example, the literature review revealed that the current lack of knowledge and skills required to serve individuals diagnosed with FTD (macro level) can a have a negative impact on caregivers. In turn, the negative impact experienced by the caregiver, such as stress or depression, could also impact the caregiver's work setting (mezzo level), or the quality of care they provide to individuals diagnosed with FTD (micro level). Similarly, if change takes place through education and the creation of better services for individuals with FTD (macro level), the influence of this change could positively impact caregivers and the individual diagnosed with FTD(micro level).

Therefore, when thinking about the challenges faced by persons with FTD, it is important to look at how the issues faced by this population interact with the other systems, and how changes at one level can influence change on others. According to the ecosystems framework,

the ability for humans to succeed in their environment depends upon the quality of interaction between the person and their environmental system (Miley at. al, 2011). This is an important perspective when considering how available services in a caregiver's environment could either positively, or negatively influence their quality of life, and how social workers can impact this system and available services. "Social workers target changes within an environmental system to benefit their client" (Miley et.al., p. 43). Therefore, this study seeks to explore what kinds of changes clinical social workers and other professionals believe are needed in the larger service system, in order to positively impact the individuals diagnosed with FTD, and their caregivers.

METHODOLOGY

Research design

The purpose of this study is to explore social worker's and other professional's perspectives of the services needed to best support persons with FTD, and their caregivers. To explore the service needs for people with FTD and their families, a qualitative method was used. This method was used because of the exploratory nature of this research. According to Monette, Sullivan, and DeJong (2010), this exploratory nature refers to projects in which the existing literature or knowledge is sparse; therefore, meaning, concepts, and theory are "grounded in the data" (p.225) or developed from the data. Although this method is inductive by nature, this approach still utilizes existing theories to understand and describe the data which emerges. The qualitative method also allows the researcher to observe and interact with the respondent in a way which allows for further questions and clarification (Monette, Sullivan, & DeJong, 2010).

Sample

Purposive sampling was used to conduct the study. Purposive sampling allows for the selection of participants with relative knowledge and experience in the area under review, while excluding others who may not be able to contribute or inform the data (Monette, Sullivan, and DeJong, 2010). To that end, social workers and other professionals who have experience working in geriatric care settings such as day programs, home care, hospitals, housing assistance agencies, and long-term care settings in the twin cities metropolitan area in Minnesota were be selected to participate in the study. Participants were contacted via an e-mail containing background information on the study, along with a brief expectation for participation.

Data Collection

The researcher used a snowball sampling method to identify potential participants. Data collection was completed using the following steps:

1) The researcher used her connection with a licensed clinical social worker (LICSW) who works specifically with individuals with FTD as well the researcher's committee members to help identify social workers and other professionals who have experience working with individuals with FTD and their caregivers in the Twin Cities metropolitan area.

2) Once a list of potential participants was collected. This researcher sent out and e-mail to potential participants describing the study and inviting them to participate.

3) Potential participants who responded to the initial recruitment e-mail were then contacted to set up an interview. Participants who did not respond to the initial e-mail, were e-mailed again two weeks later.

4) Four interviews were conducted which were each approximately 45 minutes in length

5) The researcher then transcribed and coded the interviews.

Instrument

According to Monette at. al. (2010), ethnographic interviews allow the researcher to explore the perceptions and thoughts of the participant on a specified topic without imposing structure or constraining the participant's views and forms of expression. Therefore, to best explore social workers and other professionals perceptions on service needs, the research instrument for this study consisted of a semi structured interview schedule to obtain qualitative data; see Appendix A. The interview's lasted approximately 45 minutes, and were tape recorded for transcription purposes. The audio recordings were transcribed by this researcher. This

instrument assisted the researcher in analyzing the demographic information of the participant such as age, race, gender, level of education, type of accreditation, and years of experience working with the FTD population. The instrument consisted of 13 open ended question which address the current services available, the service needs for people, and ways to support and advocate for the service needs of people with FTD and their caregivers. The questions were constructed by using the information gathered from the literature review and input from committee members and research chair. The committee members and research chair increased the validity of the study by helping in the creation of the questions.

Data Analysis

The data collected was analyzed using the grounded theory approach in which themes will be inductively created from the transcript (Monette, Sullivan, and DeJong, 2010). According to Toft, 2012, the first step in this process is open coding which is a technique in which a few words are used to summarize the main points of each sentence or line in the transcript. Next, similar codes which occurred at least three times in the transcript will be made into overarching themes in a process called Axial coding. The themes as well as important coding notations are then categorized into larger groups (Toft, 2012).

Protection of human subjects

Prior to the interview, the respondent were given a copy of the research questions as well as the consent form which was approved by the IRB in order to ensure participant protection. The consent form discussed the steps that were be taken to protect the participants from harm, including issues of confidentiality, and contact information for the responsible parties at the University of St. Thomas School of Social Work. The researcher encouraged participants to ask questions before and after the interview to ensure participant understanding about the current

research project. The researcher informed participants that the study is voluntary and they were allowed to withdraw participation prior to May 1ST 2015. All names were removed from the data and a number was administered to each participant. Data collected was held in a password protected computer. The audio recordings of the interview were deleted after May 1st, 2015, after the completion of the transcription and coding processes.

Research Setting

Research interviews took place in a number of different locations. Two interviews were held in a private meeting room at the participant's agency. One interview was held in the meeting room of a coffee shop, and another interview was held in a study room on the St. Thomas Campus. All interviews were with local professionals in the Twin Cities Metro Area. Two participants were from an adult day program, one participant was from a senior advisory housing agency, and another was from a residential living facility for young onset dementia.

Researcher Bias

As mentioned above, this researcher has theorized that there may be a need for more services for people diagnosed with FTD and their caregivers from former and current work experiences. This researcher has worked with colleagues who have had concerns regarding their ability to provide support and services to this population through their agency. This researcher also has personal work experience working with caregivers of people diagnosed with FTD and experience working within the dementia care services available to people diagnosed with different types of dementia. The age, race, socio-economic, religious, and gender background of this researcher may also influence the findings and conclusions. This researcher's past experiences, along with information gathered during the literature review phase of research, could potentially influence the conclusions formed. To reduce researcher bias Committee

members reviewed research interview questions in advance of interviews to scrutinize the

content for leading questions (Monette et. al, 2010).

FINDINGS

Sample

      Of the thirteen individuals that were invited to be interviewed for this study, only four individuals were able to participate. The researcher interviewed participants during the month of March 2015. Table 1 as shown below reveals the demographic information of the four participants. Each participant is from the twin cities metro area.

      *Table1.*Participant Demographics

Age	Ethnicity	Gender	Setting	Role	Experience
50	Caucasian	Female	Adult Day Program	RN	10 years
54	Caucasian	Female	Senior Housing Advisor Agency	Senior Advisor	7 years
34	Caucasian	Female	Adult Day Program	Primary Worker	17 years
41	Caucasian	Male	Residential Home for Dementia	Program Director	2 years

Themes

      This research sought to answer the question: "what are the services needed to best support people diagnosed with FTD and their caregivers?" Each participant brought their unique experience and perspectives to the interviews. Themes were identified if three or more participants described the same idea. Comments from the participants will be italicized.

To provide a context for the research findings, it is important to note that all four participants mentioned a lack of current services due to differences in disease presentation compared to other dementias. This will be further addressed in the discussion section. These lack of services, as influenced by the disease presentation, appeared to shape the participants views of services which are needed to best support people with Frontoteporal dementia and their caregivers.

The overarching theme that arose from the data was the need for FTD specific services. Sub themes that supported this overarching theme include: physical activities, more staffing, individualization, collaboration, financial barriers, and education. All subthemes were mentioned as service needs by all four participants, although the perspectives on each identified topic varied.

Physical Activity

The prominent theme that arose from the data was the need for a program that provides a safe, physically open, engaging, and interactive environment for FTD clients. All four participants equally emphasized that this was a great need as it was mentioned consistently throughout all four interviews.
Participant one described the need for a service which allows people with FTD to be physically active and engaged, specifically in the community:

> *And because they are so active, they want to still be out in the community. They want and need someone to drive with them and go to them. They need someone… basically, they make the call and they just need someone to go with them, and the person caring for them adjusts (Participant 1, Page 4, Lines 7-10).*

In addition to being active and engaged in the community, participant one also envisioned a specific location that also allowed the person with FTD to be involved in activities: *I tried to envision a large warehouse type area, like a really neat one, but not a bad place…there are windows, high ceilings, outside area, where it's many folks with FTD, with many stations to do things (Participant 1, Page 4, Lines 29-32)*

Similarly, participant two also describes the need for more active and physically engaging care: "*It would have to be more open and give them more freedom to an extent… a lot of freedom and a lot of space. They need a lot of movement. They just need to pace the energy level is…very overwhelming*" *(Participant 2, Page 4, Line 21-22).* Again, participant two emphasizes the idea and importance of physical activity: "*Yeah, some kind of physical activity for them to engage in*" *(Participant 2, Page 4, Line 28-29).*

In addition to identifying the general need for more physical activity, participant three described what an ideal long-term care facility would look like for people with FTD. Participant three offers the idea of additional staff in addition to a more active environment. Participant 3 reported:

> *Yes, so often it is a place where they can offer them, where they can do more walking, especially if they are somewhat more anxious, so somewhere they can physically more active, so you don't want a really small place. The best place would be a residential home with a lot of staff so they can take them on a walk. To be able to take one person on a walk with them, with FTD it is when they want it, when they need it, they will need someone right now (Participant 3, Page 3, Lines 33-38).*

Participant three also stated:

It would be cool if there was an adult day focused on FTD, because that would help the caregiver to give them a break because it is so exhausting… and it would be cheaper…Like a lifetime fitness, or something, more like a club. More active, more physical, I mean, most of these people seem to be more active, more physical. Or, yeah a lifetime fitness and a children museum combined. I think there are still behaviors that wouldn't work in that kind of environment, so I think we would still need to those well-educated types of home and funding available for people because of those types of challenges (Participant 3, Page 5 Lines 38-40 and Page 6 Lines1-5)

In addition, participant four felt that establishing more active environments could be created across settings. Participant four stated:

Yeah, so if there is a lot of room to walk, like in the house that we built for men, it is rather large and there is some exercise equipment, that can help too just to expend some of that energy. And a lot of the people with FTD, they are used to going out to the gym or running, just a lot of physical activity is good. And a larger courtyard, and outside courtyard that is secured, or someone out there with them (Participant 4, Page 2, Lines 26-29).

Similar to the suggestions made by participant three, participant four continues to expand on the need for a gym-like service:

Creating for long term, or even respite or day programs, a home setting, and for day programs, it could kind of be more of like a YMCA type feel place where there is exercise and different activities, but yeah, something that caters (Participant 4, Page 6, and Lines 21-25).

More Staffing

The need for a location or a means by which to be more active was a practical service need for the FTD population identified by the participants. Similarly, the practical need for staff or someone in a service environment to work closely with the individual with FTD is also necessary. This need for current services to bring in additional staff, or for a new service environment to offer such increased support was a need expressed by all four participants.

When asked to describe a challenges or barriers people with FTD face in terms of finding a facility or services, participant one reported:

> *Um, I would say confinement, you would need more staff. If they want to go for a walk or a drive. Or you know, do something, they need someone to go with them and not hover but protect, be far away enough to not interfere with their whole life, but make sure you are watching them (Participant 1, Page 2, Lines16-18).*

Participant one also describes the barriers she has seen throughout her work regarding the need for more staff in current settings:

> *We try for as long as we can. It becomes vary individualized. Then we start having to pull staff 1:1, due to the fact that they want to get out. There is a lot of commotion. It is very frightening, so it may last a few months, maybe 3-4 but that is really pushing it (Participant 1, Page 1, Lines 13-15).*

Participant four also described the need for more staff as a way to engage people with FTD and why there is a need for such staff. Participant four stated:

> *If there is a ratio, a staff to caregiver ratio that allows a little more 1:1 care to keep them engaged in more meaningful activities that can help because they are just from one thing*

to another, so they just really need a lot of attention and redirection (Participant 4 Page2

Lines 14-17).

Participant 3 also explained the need for more staff:

I would say that the staff is really the most important. They get so obsessed with certain

things and just need staff attention. And that is why if they go to a bigger place, they will

need to hire more staff, and it can get very expensive (Participant 3, Page 4, Lines 1-3).

It appeared as though all participants felt the need for more staff was a barrier to

receiving the current services available. However, it was also posed as a strategy to support the

client. This is something that was suggested to include into new services, or modify in existing

ones. These were contradicting statements posed by the participants.

Individualization

When describing how to best support the individual with FTD, all four participants

reported individualization as a key factor. Individualization was seen as a way to currently

support someone with FTD and to identify the need for more individually tailored services that

are meant to fit a broad range of needs.

Participant one reported individualizing a client's care as a way to best support a person

with FTD. By doing this, participant one reported that this allowed others to view the clients as

more than just the presentation of their disease:

I like to believe people with FTD are individualized in how it comes out with them and

their history, but often as a professional, you hear the word FTD, especially of the

behavioral variety and you think 'nope, not in the community setting, we've tried it, we

can't do it' is usually the first response. Because of the clientele, we know how

frustrating it is, but we have to look at the individual and where they are at….So,

individualize it(Participant 1, Page 6, Line 27- 33).

Similarly, when asked how to best support and care for an individual with FTD, Participant 2 reported about supporting them and engaging them based on their individual preferences:

Uh, it is very individual… You know, it was probably just a couple of months ago

that they were still doing it [activities they enjoyed] you know? Like whether it be

gardening, or someone who liked to walk... Oh man, it is just so individual (Participant 2,

Page4, Line 26-29).

In addition, participant three felt that when working with a person with FTD and their caregivers, it was important to understand the individual person. This facilitated meeting their needs through resources and services which were already in place:

I will try to ask more about what their day is like, because that might be different from

person to person with FTD. How they spend their day, what they like to do, what engage

them. It is always a discussion about their financial situation, and their disease. So once I

really get to know them and their situation really well, then it comes down to where they

are living and what is convenient, so then I start mentally picking over what places I

would call, and it comes down to if they can handle what this clients' needs are, and what

is in their budget (Participant 3, Page 4, Line 35-40).

To individualize care in a residential setting, participant four reported the benefit of using a life legacy approach:

Something that does help though, that we do is know their life. We call it a life legacy,

know their life their occupation, their hobbies and interests…We gather that [person's

personal information] before they arrive, and so our staff studies that and they know

them before they even arrive. As they are arriving, and it is amazing how that really

works. If they bring up things about their past, something might click and they can even

talk about that a little bit if they are verbal, or if they need a shower or personal type

care it can make it easier(Participant 4, Page2, Line 17-24)

The above data demonstrates the need for services to approach the support and all aspects

of care for the individual with FTD by seeing them as an individual with unique needs, interests,

and presentation of the illness.

Collaboration

Again, the theme of collaboration was consistent across all four participants. The

participants felt that both professional and family collaboration was needed across any type of

service, in addition to interprofessional collaboration. Participants described these types of

collaboration as useful tools to support the individual with FTD and their caregiver in the context

of present services, as well as an important aspect to include in any new services for this

population.

Participant one reported the need for all levels of staff to communicate together with the

family to best support them and the individual with the diagnosis. Although this particular adult

day service was reported as not always successful at supporting this population, or at least for

long term care of clients with FTD, this participant felt that this type of program was needed and

presently supported this population:

Well I think it starts with the "frontline staff" to communicate with the nurse and the

social worker, and journaling and communication and passing things on about what

worked and what didn't work. Very intricate behavioral logging. And the social worker

can work with case managers to decide if this is going to continue to see if there is a

backup plan, I can work with staff and physicians, just watching. Calling also the other

social work case managers myself we both do that depending on relationships so the

social worker and I just work together and say you talk to this person and I just talk to

that person. (Participant 1, Page4, Lines 34-41).

Participant Four described how the agency he is a part of tries to collaborate with both professionals and the family to provide the best support for the caregiver:

We have chaplains on staff and our nurse, just a lot of people involved to help support

them. And you know, just being in constant communication with the family too, you

know? That things are okay and here is kind of what to expect you know? Um and just

sharing little stories about "here is what happened today" or just reassuring them. And

keeping them involved in the clinic side of it too with the doctor and the nurse and the

care staff so they feel involved so they can make decisions (Participant 4, Page 4

Lines,35-37and Page 5, Lines1-2).

Financial Barriers

Unfortunately, all four participants identified finances as a barrier to creating and receiving the appropriate services for the FTD population. This barrier was describes in terms of a lack of finances for the families, as well as a lack of funding on a larger government and agency level. For example, this barrier was identified on an individual basis by Participant three who states: *spouse is trying to figure it out, and the spouse is very concerned about the financial part of it, because it is so expensive (Participant three, Page 2, Line28-29).* In addition, participant comments on the lack of available government services and funding assistance:

Yeah so just government funding or programs that is tough. Because it is typically with

them being younger and having a career, now the one has no career anymore, no income,

and the one is trying to work but –swamped?- yeah, there just aren't the dollars there to

help(Participant 4 Page 6, Lines 7-10).

In response to this need for more funding. Participant four also suggested the need

for the creation of foundations as a way to address this barrier:

Yeah, I think our owners are working on establishing a foundation. Because the

money is just not going to be there for long term care, and government subsidies, it's a

little though, they are so complex and the rules keep changing. So I think with private pay

is still the best care (Participant 4, Page 6, Lines20-23).

Education

The final, but no less important theme that emerged from the data was education. Four

out of four participants reported a need for education on multiple levels: first, among agency

staff, second for family members, and third, for the wider population. Education was again used

as a way to both describe a need―such as necessity for more educated and trained staff in

agencies, as well as a way to support and advocate for the FTD population through raising

awareness and assisting family members

On a broad level, many of the participants felt education on more expansive level would

be important, whether they said it directly or by describing how little is known about the disease

in the greater public. Participant one thought that bringing a broader awareness to the general

public would be a means by which to support this population and create more services:

And yeah, how do you get the word out... How can we communicate with them, help them

find a buffer in the community who at least support them, could learn about it, look into it

a little bit more. Get to know this FTD and be able to identify people to get together, we

just need that one person to get informed. I think that is what it takes to spread it out.

They just need someone to learn, help that family, and grow the connections from there.

It would be totally individualized. It is so unique (Participant 1, Page 6, Lines 15-22)

Participant two also spoke to the need for the greater population to be more informed

about FTD.

Hmm, well, I don't know, I guess what social workers do now, just talking to people, and

maybe when they have those Alzheimer's booths, and awareness, just kind of getting

that[information on FTD] in there. And maybe reaching out to other people or maybe

reach out to the doctors who do the diagnosing, and working to better, collaboratively to

develop something (Participant 2, Page6 Lines 4-7).

Participant two expanded on the need for education while also discussing how education

should be done through inter-professional collaboration and the importance of having an

educated trained staff specifically for FTD.

Well, I guess it could be similar to the facility here at (NAME), but it would have to be

only for FTD, and we would need a lot of highly trained staff. And you would have to

know a lot about the client (Participant 2, Page 4, Lines 14-15).

In addition to trained staff and raising greater awareness, participant four felt it was also

important to provide the caregivers of people with FTD with more specific training and

education.

I think it would help if they [caregivers] could get tangibles ways to go back home and

for what every struggle they are having that day or that week how can I do this

differently, because they feel helpless, they don't know, they are not trained like a

caregiver at a facility, so I think it would help if they had more formal, or practical

training I guess. Just day to day. How I can work through this?(Participant 4, Page 5,

Lines 14-18)

Participant three also mentioned the need for greater awareness on a broad level and the

need for trained staff. In addition, participant three was similar to participant four in the

description of the need for educating the caregivers and others, but specifically law makers.

I think it is just educating them [caregivers] for the future and educating them for the

now, to get support for themselves…Staying up- to -date on what is out there too…. I

don't think there are any simple answers, I think the more we can do with education at

the government level about it… which I think is what is needed for a lot of diagnosis with

a stigma about it, any dementia or mental illness, um, and just helping them get educated

and the caregivers I work with, they just want people to know about it (Participant 3,

Page 6, Lines 8-18).

DISCUSSION

Sample

This study did not have a strong response rate. Of the thirteen invited participants, the researcher was able to interview four different professionals: a nurse, a professional caregiver, a senior housing advisor, and a program director. Two of the participants were from and adult day program, one participant was from a senior housing advisor agency, and the other was from a residential home for dementia. The participants ranged in experience from 2 to 17 years. All participants were from the Minneapolis, St. Paul metro area. Unfortunately, no social workers were able to participate in this study; however, themes and similarities were found across all four respondents from different discipline's and agencies. Therefore, the researcher would conclude that that the results are still generalizable across discipline's and work settings with the FTD population.

Summary

The literature reviewed above demonstrated the unique challenges face by individuals diagnosed with FTD and their caregivers due to the unique presentation of the illness, early age of onset, and difficulty utilizing available services. These challenges as mentioned in the literature were also reinforced and reported by all four participants. For example, participant four reported:

> *Well, many of them are younger, maybe 50's or 60's, so it is not a good fit for them in a*
> *place in a long-term care facility with 80 some year olds, and they are very ambulatory*
> *and active, so it is not a good mix with older residents with that type of energy. And the*
> *caregivers, at these facilities, they don't understand FTD, they aren't trained, so they*

may be used to a pleasantly confused 80 or 90 year old lady, who typically can be polite,

or maybe a little resistant, but FTD is so different. (Participant4. Page 1, Line 16-21).

When further pressed regarding differences, participant four also stated:

Oh, being loud, just the way they talk, saying inappropriate things, socially inappropriate

things, or inappropriate actions or words, or maybe being a little ruff with the residents

or caregivers, so they place will say that it is not working, so then they are left, just

basically caregiving from home.(Participant 4, Page 1, line 23-26).

This segment reported by participant four was just one example of the similar concerns

reported by all participants which reinforced the concerns mentioned in the literature reviewed

above (Chemali, Withall, & Daffner, 2010; Grinberg, et al., 2008;Lough et al.,2006; Mendez et

al.,2014; Merrilees, 2007; Morhardt, 2011; Rosness, Haugen, & Engedal, 2008; Schnall, n.d.).

In addition, the researcher asked participants "To your knowledge, what services are

available to people with FTD and their caregivers?" As suggested by pervious research Chemali,

Withall, & Daffner, 2010; Merrilees, 2007; Morhardt, 2011; Rosness, Haugen, & Engedal, 2008;

Schnall, n.d.) it was reported by all participants that there are a lack of services available to this

population. All four participants reported that to their knowledge, the most appropriate service

currently available to this population was one-to- one home care. Although this service was

described as most appropriate, the participants also addressed that an in home services are often

costly. Although it may provide an adequate match for this populations needs, it is not always

accessible financially. A second concern for this type of care reported by both participants and in

the research conducted by Morhardt (2011), is that there are limited home care agencies which

have experience and education working with people diagnosed with FTD.

A second program which was reported to be available to this population per all four participants was an adult day program; however, they were reported to not always successful, as the services which are available do not always match the unique needs of the FTD population and often include participants with different care needs. Again, this was a concern identified in the literature and addressed by one day program as described in the study by Chemali, Withall, & Daffner (2010).

Finally, a second program which was reported to be available to this population was a young onset residential home for dementia by one of the participants. This is residential home for males which serves 6 clientele, including men with FTD. This is a new home which opened during the process of this research. No home in this manner was found in the literature review, but it does address the need or FTD specific programing. Although this service is a wonderful opportunity for some, the participant involved in this program reported that there are still further program and service needs to assist this population.

As a result of the concerns mentioned in the literature review as reinforce by participants, this study sought to explore the professional perspectives of the services needs and how to best support people diagnosed with FTD and their caregivers. Again, the overarching theme that arose from the data was that there is a need for FTD specific services. Sub themes that supported this overarching theme include: physical activities, more staffing, individualization, collaboration, financial barriers, and education. All participants discussed each theme as a positive and important component to create better services for the FTD population and their caregivers.

Themes

 Physical Activity All four participants reported a need for a program or service which allows for more physical activity as both participants and previous literature described the energetic and busy nature often associated with persons with FTD. Although an exercise specific program was not mentioned in previous literature, the nature of people diagnosed with FTD; specifically behavioral variant FTD, as being active and mobile was described in a number of studies. Chemali, Withall, and Daffern (2010) specifically found that the physical strength and mobility were difficult for programs to manage in a residential or acute care facility for older adults with other types of dementia. All participants mentioned this need but described it in different ways. Some felt a program similar to an athletic gym was appropriate, while others emphasized that in the least, a safe place for pacing and walking would be of great benefit to this population.

 More Staffing The four participants also identified the need for more staff as both a barrier to supporting a person with FTD in current service settings as well as a solution. This was a barrier in serving this population as it was reported to be more costly to have higher amounts of staffing in a program, or to hire a companion. However, if possible, having enough staff in a service or program, whether it be an adult day program or residential setting allows for more individualized care as discussed below. According to previous research and the participants interviewed, more staffing is key in supporting persons diagnosed with FTD. Again, Grinberg, et al. (2008), discussed that in order to successfully create the day program as discussed in the study, one key change made was hiring additional staff.

 Individualization. When asked how to best support individuals with FTD within the current services available, and through any new programs or services created, the need for

individualization of care and services emerged as a strong theme. This need for individualization has multiple facets. One participant looked at the practical need for a program to have enough staff to work with and monitor a person with FTD as needed, or to redirect and engage them in individualized activities. In a day program created in Ontario as studied by Grinberg, et al. (2008), it was mentioned that the FTD specific day program offered "tailor –made individual, small group, and specialized activities" (p. 501). The ability to offer such individualized activities was reported by one participant to be a current barrier to providing service for a person with FTD in a non-FTD specific day program, as they are designed for larger group activities.

Participants also emphasized the importance for service providers to learn about the person diagnosed with FTD as an individual. This included learning about their unique history, needs, and interests in order to connect and provided services that match the individual as they are, rather than viewing the person seeing them as a part of a lump- sum of a disease. In the study conducted by Grinberg, et al. (2008), continual learning and information must be gathered by program participants in order to learn about their unique needs. This appears to be similar to the life legacy approach mentioned by one of the participants. This participant described how the program he is a part of uses the information gathered as a way to build trust, rapport between participant and staff, as well as and engage program participants in daily tasks and meaning activities.

Collaboration. Merrilees (2007) states that "Basic ingredients of family support include locating a supportive and knowledgeable health care team that will assist in the management of the patient with FTLD (Frontotemporal Lobar Degeneration)." Participants in this study appeared to value the importance of collaboration across interdisciplinary staff, as well as with the family/caregiver of the person with FTD. To be able to work openly, continually, and closely

on an interdisciplinary team was described by participants as an approach which has been utilized to support clients within the services available today, as well as a need for services in the future.

For example, one participant reported that the first step in attempting to support a person with FTD in their program is to meet and discuss care needs with the family prior to the time the participant enters the program. From this point, different staff are in continual communication with the client's family, updating them, and supporting them. Team meetings with staff from different professions such as social workers, professional caregiver, nurses, and occupational therapist are had on a regular basis to problem solve, and support one another. Similarly, Grinberg, et al. (2008) described the interdisciplinary team model used in a successful FTD specific adult pay program. In this model, social workers, nurses, program director, neurologists etc. come together to create, adjust, and adapt programing to the needs of the participants in the program.

Financial Barriers. Morhardt (2011) reported that common issues faced by the person with FTD and their caregivers include difficulty obtaining a diagnosis, financial stress often due to loss of employment or income difficulty accessing social security disability insurance, and finding community or long- term care facilities that are trained to care for FTD patients. Participants of the present study also expressed these individual financial concerns as well as concerns regarding public funding and government assistance. Four of the participants believed that receiving funding assistance for programs for individuals with FTD would be challenging as this is a small population whose disease is not widely known to the greater public.

To address these barriers, it was suggest by one participant that organizations and service provider's begin to establish foundations in order to financially support the person with FTD.

This was an action being taken by this participant's place of employment in attempts to provide a more accessible service to this group. This suggestion was not found in the research; to fund the FTD specific day program as described by Grinberg, et al. (2008), proposals for funding were made to Ontario Ministry of Health and Long Term Care which awarded funding for the program, showing that with more education, effort, and representation, funding for services such as this may be attainable.

  Education. Chemali, Withall, and Daffner (2010), Riedijk, et al. (2006), and Rosness, Haugen, and Engedal (2008) suggested that there is a need for more global education and awareness in both communities and in health care settings. This need for additional education across multiple settings was mentioned by all participants. One participant specifically felt as though education is needed within communities as a mechanism to reduce stigma of people with dementia, and specifically with FTD. She believed that many of the difficulties faced by persons with FTD and their caregivers was stigma produced by a lack of knowledge and understanding of the disease presentation. This participant felt that to address this through education, was a great step towards providing adequate support and services to this population.

  Similar to Chemali, Withall, and Daffner (2010), participants of this research felt as though it is of importance for services now, and in the future to include more FTD specific training to employers. This need for trained and educated staff was reported amongst participants. It was mentioned by one participantthat in order for this new residential facility to support the FTD population, lengthy training programs and continual education opportunities are necessary to keep staff informed, and engaged about the disease.

  Similarly, Merrilees (2007) described an educational model for professional and informal caregivers who work with individuals diagnosed with FTD. The model Merrilees described can

be used in the assessment of, and interventions for, symptoms experienced by individuals diagnosed with FTD. Although this specific model was not addressed by participants, one participant spoke to the need for practical hands-on education to caregivers who felt needed more concrete tools to address different behavior and learn approaches to support them in their caregiving journey.

Limitations and Recommendations for Future Research

A number of limitations to this study were identified. One limitation to the study was limited number of participants. The data presented in the paper would be more generalizable with a larger and more diverse sample. As mentioned above, the FTD population is rather small, leaving few professionals with experience working with this population. The sample of participant was also not diverse, making the results less generalizable to the greater public. This lack of participants may also speak to the need for more education and services to people with FTD, as the pool of possible participants with knowledge and experience working with people with FTD was rather small and difficulty to compile.

In addition to a limited sample size, no social workers were able to participate in the present research study. Therefore, the unique perspective social workers could offer was not captured, nor was specific suggestions for clinical social work support for this population and their caregivers. However, although no social workers were interviewed, the themes and ideas generated across multiple disciplines remained similar which may indicate that social workers may have also shared similar views as many of these professionals interviewed worked with, or were in contact with social workers. Addition, all of the participants emphasized the importance of working on interdisciplinary teams; many of which specifically mentioned working with social workers.

Lastly, a limitation to this study is the potential for researcher bias which could arise and only one researcher gathered data, coded the data, and interpreted the findings. This research had previous concerns regarding the need for more services for the FTD population which could have biased the researcher's results. However, although there is potential for research bias, colleagues and committee members were involved in the review and crosschecking of the reported findings.

For future research, one manner in which the number of participants and number of social workers could be increase in would be to seek participants across the nation and not limit participants to the surrounding area. This is because the FTD population is rather small, leaving few professionals with experience working with this population. This lack of participants may also speak to the need for more education and services to people with FTD, as the pool of possible participants with knowledge and experience working with people with FTD was rather small and difficult to attain.

It may also be of importance for future researchers to study the specific perspectives of clinical social workers, as well as other professionals from services and programs not included in the sample in order to make the findings more diverse and generalizable across professions and services. In addition to seeking professional perspectives, the service needs as expressed directly from the individuals who formerly, or currently provide care to a person with FTD should also be examined. This may yield to an entirely new perspective for service providers and social workers to consider when attempting to meet the needs of this population, as they are the experts regarding their needs.

Implications and Recommendations for Social Work Practice

Although no social workers were able to participate in the present study, the results gathered from this interdisciplinary pool of participants yielded a great deal of implications and

recommendations for social work practice on a number of levels. As Miley et.al., (2011, p. 43) states, " social workers target changes within an environmental system to benefit their client". Social workers can begin to target the necessary changes needed to best support and assist people with FTD and their caregivers through micro, mezzo, and macro practice.

Social workers can target change in their direct practice by working to educate themselves, colleagues, and their clients on FTD. As social workers become more in contact with the growing older adult population, and the distinction between FTD and other dementias becomes more well-known; social workers will likely grow in their encounters of people with FTD and or their caregivers. Therefore, it is imperative that social workers in these service systems educate themselves on FTD and the services currently available to this population in order to best provide education, support, counseling, and the appropriate resource referrals. This can also include educating other colleagues or agency workers on the nature of FTD and how to work with and support a person with FTD within a service system such as an adult day program or living facility. For example, social workers often serve as a vehicle for which agencies are able to individualize care through their assessments of the individual. Work with the social workers often serve as a vehicle for which agencies are able to individualize care through their assessments and support of the caregivers and families which was described as an important aspect of providing care to an individual with FTD.

It is also important that social workers are knowledgeable and able to advocate for their clients and provide education at the community (mezzo) and government/ agency (macro) level as well. By educating communities and the greater population on FTD through awareness campaigns, conferences, or other means, social workers can work to reduce stigma to assist their clients in feeling supported by their community. Social workers can also educate and advocate

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for this population's needs through the support and education of service providers through conferences, trainings, or other speaking engagements. As stated by one of the participants, "We just need that one person to get informed. I think that is what it takes to spread it out. They just need someone to learn, help that family, and grow the connections from there."(Participant 1 page 4, lines20 -23)

Lastly, social workers can advocate on behalf of this population for funding at the government and community level. Social workers are in the position to conduct future research regarding how to best support and serve this population. Social workers can also work to advocate and push for the necessary service changes implied by the participants on both the agency level, as well as the government level to receive grants, funding, and policy to best support people with FTD and their caregivers.

Conclusion

The current literature suggests that because of age of onset, cognitive and behavioral challenges, and severity of impairment caregivers of a person with FTD face a unique set of challenges. These challenges are exacerbated by the lack of services available to this population as individuals with FTD do not fit well into the already established services for individuals with other types of dementia. Although two existing approaches and services specific to this population were identified and described, the literature was conclusive on the need for more support and services for this population. Therefore, this study sought to explore the service needs for individuals diagnosed with frontotemporal dementia and their families.

Findings from the interviews reinforced the concern as expressed by previous literature regarding the difficulty of caring for a person with FTD and the lack of service available to both the person diagnosed with FTD and their caregivers. The overall themes which emerged from the

interviews were that there is a need for FTD specific services. Sub themes included physical

activities, more staffing, individualization, collaboration, financial barriers, and education.

Previous research aligned ad supported these themes. Future research to support this population

should include the perspectives of social workers as well as the perspectives of caregiver of a

person with FTD.

REFERENCES

Alzheimer's Association. (2014). Alzheimer's disease: Facts and figures. *Alzheimer's and Dementia*, *10*(2), Retrieved from:https://www.alz.org/downloads/Facts_Figures_2014.pdf

Alzheimer's Association. (2014) Inside the brain: An interactive brain tool. Retrieved from http://www.alz.org/alzheimers_disease_4719.asp

Alzheimer's Association (2014).Type of Dementia. *Alzheimer's and Dementia*, Retrieved from http://www.alz.org/dementia/types-of-dementia.asp

Aranda M.P. (1997) The influence of ethnicity and culture on the caregiver stress and coping process: A sociocultural review and analysis. *Gerontologist*, 37, 342–354.

Berkman, B. J., Gardner, D. S., Zodikoff, B. D., & Harootyan, L. K. (2005). Social work in health care with older adults: Future challenges. *Families in Society: The Journal of Contemporary Social Services*, *86*(3), 329-337.

Bertrand, R.M., Fredman, L., & Saczynski, J. (2006). Are all caregivers created equal? Stress in caregivers to adults with and without dementia. *Journal of Ageing and Health*, *18*(4), 534-551.

Brun, A. (2007). Identification and characterization of frontal lobe degeneration. *Alzheimer's Dis Assoc Disorder, 21*(4), S3-S4.

Chemali, Z., Withall, A., & Daffner, K.R. (2010). The plight of caring for young patients with Frontotemporal dementia. *American Journal of Alzheimer's Disease and Other Dementia's, 22*(2), 109-115.

Croog, S. H., Burleson, J. A., Sudilovsky, A., & Baume, R. M. (2006). Spouse caregivers of Alzheimer patients: Problem responses to caregiver burden. *Aging and Mental Health*, *10*(2), 87-100.

Diel-Schmid, J., Schmidt, E., Nunnemann, S., Riedl, L., Kurz, A., Forstl, H., Wagenpfeil, S., &

     Cramer, B. (2013). Caregiver burden and needs in Frontotemporal Dementia. *Journal of*

     Geriatric Psychiatry and Neurology, 26(4), 221-229

Fisher, G. G., Franks, M. M., Plassman, B. L., Brown, S. L., Potter, G. G., Llewellyn, D.,

     Rogers, M. M., & Langa, M. (2011). Caring for individuals with dementia and cognitive

     impairment, not dementia: Findings from ageing, demographics, and memory

     study. *Journal of the American Geriatric Society*, *59*(3), 488-494.

Fowles, D. G., & Greenberg, G. S.(2011) A profile of older Americans: 2011. U.S. *Department*

     of Health and Human Services,,Administration on Aging.

Gallagher D, Rose J, Rivera P, Lovett S, Thompson L.W. (1989). Prevalence of depression in

     family caregivers. *Gerontologist*, *29*,449–456.

Grinberg, A., Langunoff, J., Phillips, D., Stern, B., Goodman, M., and Chow, T. (2008).

     Multidisciplinary design and implementation of a day program specialized for the

     Frontotempral dementias. *American Journal of Alzheimer's Disease & Other Dementia's,*

     22(6), 499-506.

JPND Research (2014). What is Neurodegenerative Disease? *Joint Programme-*

     Neurodegenerative Disease Research. Retrieved from

     http://www.neurodegenerationresearch.eu/about/what/

Kumamoto, K., Arai, Y., Hashimoto, N., Ikeda, M., & Mizuno, Y. (2004). Problems family

     caregivers encounter in home care of patients with Fronttemporal lobar degeneration.

     Psychogeriatric, 4, 33-339.

Lough, S., Kipps, C.M., Treise, C., Watson, P., Blair, J.R., & Hodges, J.R. (2006). Social

    Reasoning, emotion, and empathy in Frontotemporal dementia. *Neuropsychologia, 44,*

    950-958.

Mendez, M.F., Fong, S. S., Shapira, J.S., Jimenez, E.E., Kaiser, N.C., Kremen, S.A., and Tsai, P.

    (2014). Observation of social behavior in Frontotemporal dementia. *American Journal of*

    Alzheimer's Disease and Other Dementias, 29(3), 215-221.

Merrilees, J. (2007). A model for behavioral symptoms in Frontotemporal lobar degeneration.

    Alzheimer Dis Assoc Disord, 21(4), s64-s69.

Mikesell, L.(2009). Conversational practices of a Frontotemporal dementia patient and his

    interlocutors. *Research on Language and Social Interaction, 42*(2), 135- 162.

Miley, K.K., O'Melia, M.O., & DuBoise, B. (2011). *Generalist social work practice: An*

    empowering approach (7ᵗʰ Ed.). Boston: Allyn & Bacon.

Mioshi, E., Bristow, M., Cook. R., Hodges, J.R.(2009). Factors underlying caregiver stress in

    Frontotemporal dementia and Alzheimer's disease. *Dementia and Geriatric Cognitive*

    Disorders, 27, 76-81

Monette, D. R., Sullivan, T. J., & DeJong, C. R. (2010). *Applied social research: Tool for the*

    human services (9th ed.). Belmont, CA: Brooks/Cole.

Morhardt, D. (2011). Accessing community-based and long-term care services: Challenges

    facing person's with Frontotemporal dementia and their families. *Journal of Molecular*

    Neuroscience, 45, 737-741.

Navaie-Waliser, M., Feldman, P.H., Gould, D.A., Levine, C., Kuerbis, A.N., and Donelan

    K. (2002).When the caregiver needs care: The plight of vulnerable caregivers. *American*

    Journal of Public Health, 92(3), 409-413.

Neary, D., Snowden, J., & Mann, D. (2005). Frontotemporal Dimentia. *Neurology, 4*, 771-780.

Riedijk, S.R., Vugt, M.E., Duivenvoorden H.J.,Niermeiher, M.F.,Van Swieten, J.C., Verhey,

     F.R.J., & Tibben, A.(2006). Caregiver burden, health-related quality of life and coping in

     dementia caregivers: A comparison of Frontotemporal dementia and Alzheimer's

     disease. *Dementia and Geriatric Cognitive Disorders, 22*, 405-412.

Rosness T.A., Haugen, P.K., and Engedal, K. (2008). Support to family careers of patients with

     frontotemporal dementia. *Aging and Mental Health*, *12*(4), 462-466.

Schnall, A. (n.d.) Supporting family caregivers of people with Frontotemporal Dementia. *The*

     Canadian Review of Alzheimer's Disease and Other Dementia's. 14-17

Straight, P. R., & Harvey, M. S. (1990). Caregiver burden: a comparison between elderly women

     as primary and secondary caregivers for their spouses. *Journal of Gerontological Social*

     Work, *15*(12), 89-103.

The Association for Frontotemporal Degeneration (2011). *Fast Facts About Frontotemporal*

     Degeneration.

The Association for Frontotempora Dementia's (2014). *FTD Disorders.* Retrieved from

     http://www.theaftd.org/understandingftd/disorders

Toft J. (2012).Grounded theory approach. *University of St. Thomas/St. Catherine's University*

Vincent, G.K., Velkoff, V.A. (2010). The next four decades: The older population in the

     United States: 2010 to 2050. *United States Census Bureau,* 25-1138.

Volland, P. J. (2010). *Social work and aging: Obstacles or opportunities?* In *2010 NCOA-ASA*

     Conference.

United Nations, Department of Economic and Social Affairs, Population Division (2013). *World*

    Population prospects: the 2012 revision highlights and advanced tables. NewYork, 17-

    18.

Unites States Census Bureau (2012, March 1). *Facts for Features: Older Americans Month: May*

    2012.

U.S. Department of Health and Human Services. (2012, July 16). *Caregiver stress fact sheet*.

World Health Organization. (2014). *Dementia: fact sheet*. Retrieved from

    http://www.who.int/mediacentre/factsheets/fs362/en/

Yeaworth, R.C., & Burke, W.J. (2000). Frontotemporal dementia: A different kind of dementia.

    Archives of Psychiatric Nursing, 14(5), 249-253.

Interview Schedule

1.   What us your race, gender, and age?

2.   What is your level of education/ accreditation?

3.   What is your experience working with individuals with dementia?
   - ➢ Do you have experience working with their caregivers?

4.   What times of services are available to individuals with dementia?
   - ➢ What services are available to their caregivers?

5.   What is your experience working with individuals diagnosed with FTD?
   - ➢ Do you have experience working with their caregivers?

6.   To your knowledge, what services are available to individuals with FTD and their caregivers?
   - ➢ Would these be the same or different than people diagnosed with other types of dementia?

7.   What would you say are challenges or barriers faced by individuals with FTD and their families?

8.   What would you say are the greatest services needs for people with FTD and their families?

9.   What, if any, services would you like to see available to this population?
   - ➢ Would they be different the services available to people with dementia? If so, how?

10.   In what ways would these services be beneficial?

11.   What do you see as barriers or challenges to creating or obtaining these services?

12.   What would you say is a social workers role in supporting people with FTD and their caregivers?

13.   How could people begin to advocate for these services?

Consent Form

UNIVERSITY OF ST. THOMAS

Social Worker Perspectives Regarding Service Needs for Individuals Diagnosed With
Frontotemporal Dementia

I am conducting a study which seeks to explore professional's perspectives on the service needs for people with Frontotemporal Dementia (FTD) and their caregivers. I invite you to participate in this research. You were selected as a possible participant because of your professional experience working with people who have been diagnosed with FTD. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Karina Krosbakken, a graduate student at the School of Social Work, St. Catherine University/University of St. Thomas as supervised by Dr. Rosella Collins-Puoch.

Background Information: The purpose of this study is to explore professional's perspectives on the service needs of people with FTD and their families through a qualitative method. This research seeks to explore what services are currently available for people with FTD and their caregivers; but more importantly, what services are needed in order to best support and care for people diagnosed with FTD and their caregivers.

Procedures: If you agree to be in this study, I will ask you to do the following things: You will be interviewed for 45-60 minutes. This interview will be audio taped and parts of the interview will be transcribed and coded. The researcher's interpretation of the data will then be presented to a graduate research class.

Risks and Benefits of Being in the Study: There will be minimal risks to respondents. There is a risk that discussing pervious experiences working with clients with FTD and their families, as well as discussing the areas of service need could trigger reactions which may be uncomfortable for the respondents. To minimize the risk to the respondents, this study will be approved by the University of St. Thomas /St. Catherine University Institutional Review Board (IRB) prior to participation. As a participant, you will also be de-identified, and the data will destroyed following its use for the research assignment. To further protect you as a participant, the audio-recording of the interviews will be coded with a number for each participant (i.e. Participant 1) and will be stored electronically on the researcher's computer which is password protected. The study has no direct benefits.

Confidentiality: The records of this study will be kept confidential. In any sort of report I publish, I will not include information that will make it possible to identify you in any way. The interviews will be coded with a number for each participant (i.e. Participant 1) and will be stored electronically on the researcher's computer which is password protected. A 15-minute segment of the interview

will be transcribed and coded but will not know who you are. I will delete any identifying information from the transcript before they see it. Findings from 15 minutes of the transcript will be presented to my research class. The audiotape will be destroyed immediately after transcription is compete.

Voluntary Nature of the Study: Your participation in this study is entirely voluntary. You may skip any questions you do not wish to answer and may stop the interview at any time. Your decision whether or not to participate will not affect your current or future relations with St. Catherine University, the University of St. Thomas, or the School of Social Work. If you decide to participate, you are free to withdraw at any time without penalty. Should you decide to withdraw, data collected about you will not be used.

Contacts and Questions: My name is Karina Krosbakken. You may ask any questions you have now. If you have questions later, you may contact me at (701) 212-6037. You may also contact my research supervisor, Dr. Rosella Collins-Pouch, at **ADD**. You may also contact the University of St. Thomas Institutional Review Board at 651-962-5341 with any questions or concerns.

You will be given a copy of this form to keep for your records.

Statement of Consent:

I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study. I am at least 18 years of age. *[If additional permissions are needed (e.g. audio or video recording, accessing private student or medical records), include these here.]*

_____   _____

Signature of Study Participant   **Date**

_____

Print Name of Study Participant

_____   _____

Signature of Parent or Guardian   **Date**
      (If applicable)

_____

Print Name of Parent or Guardian
      (If Applicable)

_____   _____

Signature of Researcher   **Date**