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THE EFFECTS OF SOCIALIZATION ON THE PROGRESSION OF DEMENTIA

A MASTER'S PROJECT SUBMITTED TO THE GRADUATE FACULTY  
GRADUATE SCHOOL BETHEL UNIVERSITY

BY

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IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF  
MASTERS OF SCIENCE IN PHYSICIAN ASSISTANT

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## ABSTRACT

Dementia is an umbrella term for a group of disorders marked by a decline from baseline in memory, executive function, and other cognitive functions such as reasoning, handling complex tasks, and spatial orientation, all of which interferes with activities of daily living and independence (Larson, 2019). Current pharmaceutical management of dementia and related symptoms is limited (Press & Alexander, 2019b). As dementia progresses, the cognitive skills required to maintain social interactions and familial relationships decline, therefore affecting the perceived loneliness and isolation of the person living with dementia. This research was conducted to understand the role of socialization in the care and management of people who live with dementia in long-term care facilities.

Video interviews were conducted with ten long-term care facility workers who work directly with residents diagnosed with dementia. Participants were asked to describe the socialization opportunities at the facilities they worked at for residents living with dementia as well as their feelings regarding the impact that socialization has on the dementia-related behaviors of the residents.

All participants noted opportunities for organized socialization at their facilities, and all participants felt organized socialization was beneficial for residents with dementia. All participants believed that organized socialization activities decreased dementia-related behaviors.

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## **Chapter One: Introduction**

### **Introduction**

Dementia is one of the leading causes of disability and death worldwide, making the prevention, diagnosis, and treatment of dementia an important area of research in the 21st century (World Health Organization, 2017). Recent research has suggested that loneliness, or the perceived lack of social connections, may be linked to poorer health outcomes including an increased risk of dementia (Sommerlad, Sabia, Singh-Manoux, Lewis, & Livingston, 2019; Taube, Kristensson, Sandberg, Midlöv, & Jakobsson, 2015; & Luo, Hawkey, Waite, & Cacioppo, 2012). The following chapter discusses the current prevalence of dementia, current treatment and management options, and possible impacts that loneliness may have on the development and progression rate of dementia. The chapter will also outline the purpose of the study and its importance within the medical community.

### **Background**

Dementia affects approximately 47 million people worldwide and accrues up to 10 million new cases annually (World Health Organization, 2017). In the United States, approximately 5.8 million adults live with dementia (Alzheimer's Association, 2019). An estimated \$290 billion is spent on dementia care annually in the United States, and this number is expected to rise to nearly \$1.1 trillion in 2050 if a widely available, disease-modifying treatment is not developed (Alzheimer's Association, 2019).

Currently pharmaceutical management of dementia is limited, with cholinesterase inhibitors, memantine, and antioxidants, such as vitamin E and selegiline, being some of the only

medications approved (Press & Alexander, 2019b). These medications are largely for symptomatic management rather than disease modification, although research has suggested that memantine may be neuroprotective (Press & Alexander, 2019b). Due to the nature of this mechanism of medication being largely symptomatic, both pharmacologic and non-pharmacologic therapy, including supportive care, are important aspects of dementia management.

People with dementia experience a level of cognitive decline that may impact their ability to maintain social connections and maintain appropriate self-care, requiring them to move into a long-term care facility (Doyle, de Medeiros, & Sanders, 2012). These life changes may contribute to further feelings of loneliness. Recent research has suggested that feelings of loneliness may contribute to poorer health outcomes. In a longitudinal analysis of 30,000 older adults in the United States, Luo et al. (2012) found that individuals who reported the highest levels of loneliness were 1.96 times more likely to die within the next six years than those who reported the lowest levels of loneliness, irrespective of health behaviors. Another study found significant differences in health care reported quality of life and number of health complaints between those who reported recent feelings of loneliness and those who did not (Taube et al., 2015).

### **Problem Statement**

As dementia progresses, the cognitive skills required to maintain social interactions and familial relationships decline, therefore affecting the perceived loneliness and isolation of the person living with dementia. Also, socialization is well understood as an integral part of

maintaining cognitive function and overall emotional wellbeing (Sommerlad, Sabia, Singh-Manoux, Lewis, & Livingston, 2019; Taube et al., 2015; & Luo, Hawkey, Waite, & Cacioppo, 2012). Currently, over 1,000,000 people living with dementia in the United States live in a long-term care facility (Lepore, Ferrell, & Wiener, 2017). This population is exposed to drastic changes in their surroundings and the people they interact with on a daily basis when they move into long-term care facilities. Research lacks insight into socialization in long-term care facilities and the impact that socialization has on the quality of life of people living with dementia in long-term care facilities. Patient care assistants and nurses must discuss how socialization in long-term care facilities eases the transition from independent living to care facility-based living and impacts the rate of dementia progression to better care for the residents and create a better quality of life. Further, research must discuss ways to assess and improve socialization in long-term care facilities for residents, and specifically residents with dementia, to improve their quality of life, ease transitions into new facilities and living situations, and help minimize the progression of dementia.

### **Purpose**

The purpose of this study was to understand the role of socialization in the care and management of people who live with dementia in long-term care facilities. By interviewing direct care personnel regarding their experiences, the impact of social connections on the behaviors of people who live with dementia was explored. The study aimed to explore the relationship between the amount of socialization activities residents participate in and the frequency of dementia related behaviors.

## **Significance of the Problem**

This study has significance to healthcare practitioners, direct care staff, and long-term care facility directors, as well as families of people living with dementia. The progression of dementia typically requires extensive medical intervention, care, and treatment. Understanding how socialization plays a role in the development and progression of dementia can provide valuable insight into treatment and management plans. The National Institute of Aging approximated that persons with dementia averaged over 35 thousand dollars of Medicare expenditures versus persons without dementia who averaged under five thousand dollars of Medicare expenditures (NIH, 2015). This study may also help to identify the benefits of socialization programs in long-term care facilities in regards to improvements in dementia outcomes, thus reducing the visits and medical intervention needed in patients with dementia. This study will also provide insight into current programs offered by long-term care facilities and the efficacy of these programs in regards to disease progression.

## **Research Question**

To gain insight into the practices of socialization in long-term care facilities and how socialization affects progression and behaviors in residents who live with dementia, the study sought to answer the following question:

1. How do direct care nursing home personnel perceive the impacts that organized group activities have on the dementia-related behaviors of adults with dementia within the long-term care facility?

## **Definitions of Terms**

For clarity and understanding throughout this research paper, the following terms must be defined.

**Alzheimer's Disease:** a type of dementia marked by the presence of beta amyloid plaques and tau tangles within the brain that result in a decline in memory, thinking, and behavior (Alzheimer's Association, n.d.).

**Dementia:** “severe impairment or loss of intellectual capacity and personality integration, due to the loss of or damage to neurons in the brain” (Dictionary.com, para. 1)

**Frontotemporal Dementia:** “refers to a group of disorders caused by progressive nerve cell loss in the brain's frontal lobes (the area posterior to your forehead) or its temporal lobes (the regions medial to your ears)”. (Alzheimer's Association, n.d., para. 1).

**Group Activities:** Any activities organized by the long-term care facility that involve more than one resident.

**Informal Socialization:** The process of being socially engaged with other people outside of organized group activities.

**Lewy Body Dementia:** “a type of progressive dementia that leads to a decline in thinking, reasoning and independent function because of abnormal microscopic deposits that damage brain cells over time” (Alzheimer's Association, n.d., para. 1).

**Long-term care facility:** includes nursing homes, assisted living, or skilled nursing home facilities (CDC, 2019)

**Neurodegenerative:** any pathological condition primarily involving the degeneration of neurons leading to a wide variety of clinical presentations (Przedborski, Miquel, & Jackson-Lewis, 2003)

**Socialization:** The process of being socially engaged with other people. For the purpose of this research project, this includes both organized group activities and information socialization.

**Vascular Dementia:** “a decline in thinking skills caused by conditions that block or reduce blood flow to various regions of the brain, depriving them of oxygen and nutrients” (Alzheimer’s Association, n.d., para. 1).

## **Conclusion**

Dementia is highly variable, yet one of the leading causes of disability worldwide (WHO, 2017). Treatment and management are complex and very specific to the individual, yet little knowledge exists on how socialization activities play a role in the management of dementia, especially in the setting of a long-term care facility. Health care workers and practitioners must increase their knowledge on the impacts of socialization in order to best manage their patients living with dementia. Long-term care facilities must also be aware of those same impacts in order to optimize their activity schedules to help their residents with dementia. This study looked into the effects that socialization has on dementia progression in residents living in long-term care facilities. This study also looked into the types of socialization regimens long-term care facilities currently have in practice and to what extent these activities were being utilized by people who live with dementia. The next chapter will be a summary of the literature currently available on the topics of dementia and socialization. Specifically, the chapter will discuss the various types of dementia, the impact of loneliness on health outcomes, the impact of loneliness

on dementia, and the types of socialization programs currently available for adults with dementia.

## **Chapter 2: Literature Review**

### **Introduction**

Dementia is an umbrella term for a group of disorders marked by a decline from baseline in memory, executive function, and other cognitive functions such as reasoning, handling complex tasks, and spatial orientation, all of which interferes with activities of daily living and independence (Larson, 2019). Worldwide, approximately 47 million people are living with dementia and an estimated 10 million new cases present annually, making dementia one of the leading causes of disability and death worldwide (World Health Organization [WHO], 2017). The major forms of dementia include Alzheimer's disease, frontotemporal dementia, Lewy body dementia, and vascular dementia (WHO, 2017).

The relationship between social contact and presentation of dementia and manifestation of the disease is an important body of research. Research studies have explored the impact of prevalent social networks on disease progression compared to the seemingly more advanced stages of physical and anatomical pathologies associated with dementia (Bennett et al., 2006). This chapter will aim to discuss the clinical signs and symptoms, epidemiology, and diagnosis of various forms of dementia, along with current research and insights into the effect socialization has on the progression of the disease.

### **Alzheimer's Disease**

#### ***Introduction***

Alzheimer's Disease (AD) is a neurodegenerative disease that affects up to 10% of adults 65 years and older, and up to 80% of adults over 85 years of age (Clarfield, 2005). With an

increased life span, the rate of AD is growing (Kene, Montine & Kuller, 2018). The process of AD takes time to surface. Patients will report complaints of memory loss far before their diagnosis of AD. Delayed reports of memory loss is due to a quieter, pre-symptomatic phase of AD that begins with a series of biochemical changes in the brain (Kene et al., 2018). This section will provide current research on risk factors, pathophysiology, diagnosis, pharmacologic and non-pharmacologic treatment options, and complications associated with AD.

### ***Risk Factors***

The most conclusive research has recognized that age, positive family history, and genetic mutations are the most prevalent risk factors for Alzheimer's Disease (Kene et al., 2018). The genetic implications of AD are regarding the presence of the APOE4 gene, or the human apolipoprotein E4 gene, is a risk factor in developing AD. One of the three alleles associated with APOE, epsilon 4 (e4), shows an inherited impairment of the clearance of amyloid beta proteins from the brain (Kene et al., 2018). The presence of APOE4 puts an individual at a 50% risk of development of the disease as compared to those who do not exhibit the gene (Scheltens et al., 2016).

Genetic risk factors for AD include early and late onset, family history, and trisomy 21. Genetic testing can be done to identify these risk factors by testing the individual for the proteins that are associated with early and late onset (Kene et al., 2018). Inherited AD, and therefore by association early-onset dementia, is only found in 1% of the population (Wolk & Dickerson, 2018). Trisomy 21 is an additional risk factor for the development of AD. Adults with trisomy 21 have more production of APP due to an additional APP gene on chromosome 21 upregulating

mRNA production and thus upregulating the production of APP protein products. Onset of AD from Trisomy 21 is around 50 years of age (Kene et al., 2018, Sherva & Kowall, 2018).

Additionally, acquired risk factors in AD include: hypertension, dyslipidemia, cerebrovascular disease, peripheral atherosclerosis, type 2 diabetes and obesity, lifestyle and activity, brain trauma, and medications (Kene et al., 2018). Environmental risk factors include secondhand smoke, air pollution, and pesticides (Kene et al., 2018).

### ***Pathophysiology***

Early onset dementia is characterized by mutations relating to the inhibited clearance, amped up production, or abnormal aggregation of the amyloid beta protein (Kene et al., 2018). Amyloid precursor protein (APP), presenilin-1 gene (PSEN1), and the presenilin-2 gene (PSEN2) are all autosomal dominant and increase the risk of early onset AD by 100% (Kene et al., 2018). These genes encode for their protein products. APP is important for synaptic transmissions and is located on chromosome 21q, PSEN1 in intracellular signaling and cell cycle and death and located on chromosome 14q, and PSEN2 in apoptosis while located on chromosome 1q (Kene et al., 2018; Sherva & Kowall, 2018). Each of these proteins is capable of obtaining an extensive amount of mutations in their genes affecting their respective protein products and therefore roles that these products are supposed to carry out for the cells, all of which show high penetrance into the development of AD (Kene et al., 2018).

Late onset AD is concerned with the APOE e4 protein located on chromosome 19 (Sherva & Kowall, 2018). Late onset is more complex than early onset in that late onset is not simply due to the presence of this protein but related to the genetic factor of this protein

accompanied by the effect of environmental and epigenetics influencing its expression (Kene et al., 2018). Research today still includes unknowns in the discovery of the absolute pathogenesis of Alzheimer's Disease, however researchers readily agree that the pathogenesis involves amyloid beta proteins and tau proteins (Kene et al., 2018).

In persons that develop AD, studies have shown a link between overproduction, decreased clearance, or both, of the amyloid beta protein (Kene et al., 2018). The amyloid precursor protein undergoes mutations that causes the protein to combine into small aggregates called oligomers as opposed to the unmutated gene producing aggregates called fibrils (Kene et al., 2018). The formation of tangles by aggregation of toxic forms of tau protein molecules, a protein associated with microtubules, is a second pathway to AD. The mutated and hyperphosphorylated tau protein that forms these pathologic tangles can then be transmitted from neuron to neuron which corroborates the spread of AD in the brain (Kene et al., 2018). Amyloid beta and tau are the primary proteins of study in research conducted on AD and likely the two proteins that get the most recognition. However, the literature also shows that the development of AD or risk factors leading to AD, are a combination of many different events happening in the brain (Kene et al., 2018).

### ***Diagnosis***

The diagnosis of Alzheimer's disease has come a long way, as the traditional diagnosis of Alzheimer's Disease was once post-mortem during autopsy of the brain. Currently, diagnosis is reliant on MRI and PET scans of the brain with the distinguishing features of two cerebrospinal markers, the abnormal proteins amyloid beta and tau (Kene et al., 2018). Memory problems are

the most common initial sign of AD, with other cardinal symptoms such as executive dysfunction and visuospatial impairment also manifesting early on (Wolk & Dickerson, 2018). Although memory disturbances are characteristic at onset, many individuals are dying from AD without an antemortem diagnosis (Kene et al., 2018). Population-based studies have shown that 33% of persons that died over the age of 85 years old without diagnosis had pathologic findings that were consistent of AD (Kene et al., 2018).

### ***Treatment***

Pharmacologic and non-pharmacologic care options exist for the management of AD and its symptoms. Although no definitive treatments exist in the management of AD, medications are available to help decrease the rate of decline seen in these patients. Current research indicates that cholinesterase inhibitors, mesalamine, and vitamin E are all viable options to stop this progression and address associated symptoms (Epperly, Dunay & Boice, 2017). Cholinesterase inhibitors increase the amount of acetylcholine between adjacent neurons within the brain and thus allow for enhanced transmission of information (Epperly, Dunay & Boice, 2017). Memantine is a partial N-methyl-d-aspartate (NMDA) receptor antagonist. These work to diminish the harmful excitation that occurs at the NMDA receptor (Epperly, Dunay & Boice, 2017). The combination of both the cholinesterase inhibitors and mesalamine have shown increased efficacy in treatment goals in research (Epperly, Dunay & Boice, 2017). Additionally, vitamin E supplementation has protective benefits due to its antioxidant properties amongst the cortical neurons in the central nervous system. Vitamin E can also be used in combination with cholinesterase inhibitors or memantine (Epperly, Dunay & Boice, 2017).

Non-pharmacologic options in the management of AD include: managing behavioral disturbances, nutrition, exercise programs, and occupational therapy (Press & Alexander, 2019b). Nutrition is crucial to managing AD as patients can often suffer from the loss of the sense of smell, leading to decreased appetite and insufficient weight maintenance. Adding nutritional supplements or high calorie foods are options for optimizing weight gain (Press & Alexander, 2019b).

Occupational therapy (OT) is another non-pharmacologic option in the management of AD. A study where persons with AD were enrolled in OT programs to train how to cope with their disease and strategies to perform functional tasks independently showed improved activities of daily living skills along with other motor and processing skills. These programs were designed for both the patient and their caregiver (Press & Alexander, 2019b).

As AD manifests, patients can begin to develop depression as seen in nearly 50% of patients that suffer from AD (Smith, 2015). Rates and severity of depression become more significant throughout the progression of the disease, although the presentation of depression itself is often difficult as it can be difficult to discern from the symptomatology of AD (Smith, 2015). An option in management of depression brought on by dementia, implementation of routine exercise programs have shown a decrease in depression and progression of AD. These studies, however, are based on AD patients and less so on dementia (Press & Alexander, 2019b; Epperly, Dunay & Boice, 2017). These activity programs have been shown to decrease memory loss and also improve the functional capacity of patients with AD (Epperly, Dunay & Boice, 2017).

### ***Complications***

The diagnosis of AD, or dementia as a progressive symptom, does not solely affect the individual this disease is manifesting in. Management for behavioral disturbances is life changing not only for the patient but for the families that care for these patients. Persons with AD can suffer from: delusions, hallucinations, depression, agitation, aggression, and sleep disturbances (Press & Alexander, 2019a). In today's society, individuals with dementia often require outsourced care, such as long-term care facilities. However, the rates of depression in elders within nursing homes are greater than the approximate 16% of individuals in the general population who experience depression (Tsuno & Homma, 2009). Depression rates are an important consideration, as depression in residents living in these nursing homes can increase mortality by 59% (Tsuno & Homma, 2009).

### ***Summary***

Alzheimer's Disease is a complicated and progressive neurodegenerative disease that impacts a large percent of our population due to the increased life span from diagnosis and treatment improvements since its discovery (Clarfield, 2005; Kene, Montine & Kuller, 2018). Diagnostic improvements in using imaging and cerebrospinal fluid for key markers of amyloid beta and tau proteins have led to earlier diagnoses and subsequent earlier initiation of treatment (Kene et al., 2018). Diagnosing and treating AD sooner has improved the quality of life in those suffering from AD while additionally decreasing the rate of cognitive decline (Epperly, Dunay & Boice, 2017). The next section will describe vascular dementia and its defining characteristics.

## **Vascular Dementia**

### ***Introduction***

After Alzheimer's dementia, vascular dementia is the second most common type of dementia (Smith & Wright, 2018). Vascular dementia may also be referred to as vascular cognitive impairment, multi-infarct dementia, subcortical dementia, and poststroke dementia (Rae-Grant, 2019). Vascular dementia is found in combination with other forms of dementia in 30-40% of dementia cases (Smith & Wright, 2018; Rae-Grant, 2019). Pure vascular dementia is less common, making up 10% of dementia cases (Smith & Wright, 2018). Vascular dementia is defined as a syndrome caused by any cerebrovascular disease or impaired cerebral blood flow that leads to cognitive dysfunction, symptoms can range from mild cognitive deficits to frank dementia (Smith & Wright, 2018; Rae-Grant, 2019). This section will discuss the risk factors, pathophysiology, clinical presentation, diagnosis, and treatment options for vascular dementia.

### ***Risk Factors***

Risk factors for vascular dementia include any behaviors or predisposing conditions that increase the risk of vascular disease such as advanced age, hypertension, diabetes, high cholesterol, smoking, atrial fibrillation, low physical activity, and high BMI (Smith & Wright, 2018).

### ***Pathophysiology***

The impaired cerebral flow that causes vascular dementia may be due to chronic hypoperfusion related to progressive atherosclerotic changes, or it may be related to acute embolic or hemorrhagic stroke (Smith & Wright, 2018).

Cerebral small vessel disease, or arteriosclerosis of the smaller vessels in the brain, is the most common cause of vascular dementia (Smith & Wright, 2018). The walls of arteries and arterioles become thickened and sclerotic, impairing blood flow to areas of the brain such as the basal ganglia and corona radiata. Another common underlying cause is cerebral amyloid angiopathy, in which there are deposits of beta amyloid plaques in small arteries and arterioles (Smith & Wright, 2018). Beta amyloid plaques are also present in Alzheimer's disease, however those plaques are found outside of the vasculature within the parenchyma rather than intravascularly (Keene, Montine, & Kuller, 2018). Other underlying causes include acute brain infarctions, cerebral hemorrhage, white matter lesions, small vessel disease, cerebral autosomal dominant arteriopathy, inflammatory conditions, and genetic conditions (Smith & Wright, 2018; Rae-Grant, 2019).

### ***Clinical Presentation***

The clinical presentation of vascular dementia depends on the underlying etiology. The patient or caretaker may report a decline in cognitive function or difficulties with activities of daily living with or without a history of an acute stroke (Rae-Grant, 2019). If related to an acute stroke, vascular dementia will present as the new onset of impaired cognitive and executive functions following the stroke (Smith & Wright, 2018). The specific symptoms a patient presents with depends on the region of the brain damaged in the preceding stroke, with multi-infarct or multi-hemorrhagic strokes leading to the more clinically significant dementias (Smith & Wright, 2018). Vascular dementia may also be related to chronic vascular changes in the brain, in which case symptoms would come on more gradually (Smith & Wright, 2018). The most common

symptoms seen are changes in executive function and processing speed, however changes in memory and other functions may also be seen (Smith & Wright, 2018).

### ***Diagnosis and Treatment***

Diagnosis of vascular dementia is primarily based on three criteria. The first is classifying the cognitive changes the patient is presenting with as either mild cognitive impairment or as dementia (Smith & Wright, 2018). The second criteria is documenting that there is cerebrovascular disease present, this can include a stroke, TIA, or imaging of silent chronic cerebrovascular disease (Smith & Wright, 2018). Thirdly, it must be documented that the amount of cerebrovascular changes present is sufficient to contribute to changes in cognition (Smith & Wright, 2018). For example, the onset of dementia symptoms following a stroke is sufficient to diagnose vascular dementia if cognitive decline was not present prior to the stroke (Smith & Wright, 2018). Vascular dementia may be diagnosed from a significant and thorough clinical history and routine neuroimaging studies (Smith & Wright, 2018). Magnetic resonance imaging (MRI) is the imaging method of choice to evaluate for evidence of cerebrovascular disease in vascular dementia (Rae-Grant, 2019).

Like other forms of dementia, pharmacological management of vascular dementia is limited. Options include donepezil for patients with pure vascular dementia, galantamine for patients with pure vascular dementia or mixed dementia, and nimodipine (Rae-Grant, 2019). There is some evidence available to suggest supplements such as CDP-choline, cerebrolysin, and ginkgo biloba may improve cognition (Rae-Grant, 2019). Patients and their caretakers can also

consider behavioral interventions and caregiver support and counseling to reduce dementia related behaviors and delay moving into a long-term care facility (Rae-Grant, 2019).

### ***Summary***

In summary, vascular dementia is the second most common form of dementia (Rae-Grant, 2019). Though it is typically present along with other forms of dementia such as Alzheimer's disease, it can be present on its own (Rae-Grant, 2019). Diagnosis is made based on the presence of vascular changes within the brain seen on MRI and clinical suspicion that these changes are contributing to the clinical signs of cognitive decline (Smith & Wright, 2018). Treatment is largely limited, with behavioral interventions playing a large part in management (Rae-Grant, 2019).

## **Lewy Body Dementia**

### ***Introduction***

Lewy body dementia (LBD) is the third most common type of dementia, constituting up to 30% of dementia cases (Latimer & Montine, 2018). The average age at presentation is 75 years old, and men are more likely than women to develop LBD (Latimer & Montine, 2018). Genetic risk factors have been found to contribute to up to 36% of LBD (Latimer & Montine, 2018). The environmental and lifestyle risk factors for LBD are not currently well understood, though there is evidence to suggest that a history of loss of consciousness following traumatic brain injury may contribute (Latimer & Montine, 2018). This section will discuss the underlying pathophysiology, clinical presentation, diagnosis, and treatment of Lewy body dementia.

### ***Pathophysiology***

LBD shows regional atrophy in the frontal, temporal, and parietal lobes of the brain as well as more severe atrophy in the cingulate gyrus and amygdala (Latimer & Montine, 2018). The biological hallmark of LBD is the presence of Lewy bodies in the anterior frontal and temporal lobes, cingulate gyrus, substantia nigra, and insula (Farlow, 2017; Latimer & Montine, 2018). Lewy bodies are small alpha-synuclein and eosinophil aggregates within neurons (Farlow, 2017). Alpha-synuclein is a protein that is found at presynaptic terminals throughout the brain and is thought to play a role in neurotransmitter release (Latimer & Montine, 2018). When these proteins become aggregated, they interfere with normal neuron to neuron signaling in the areas of the brain that they affect (Latimer & Montine, 2018).

As mentioned above, genetic factors have been found to contribute to up to 36% of LBD, with some genetic mutations being cited as an underlying cause and others simply contributing to an increased risk for disease development (Latimer & Montine, 2018). The genes that have been found to possibly be linked to LBD have also been linked to other neurodegenerative diseases; there are currently no known genetic markers that are specific to LBD (Latimer & Montine, 2018). Some of the genes that have been implicated in neurodegenerative diseases include SNCA, APP, and PSEN1/PSEN2 (Latimer & Montine, 2018). The SNCA gene codes for the alpha synuclein protein (Latimer & Montine, 2018). Several point mutations in this gene have been linked to LBD, Parkinson disease, and frontotemporal dementia; it has been suggested that these mutations may increase the likelihood of these proteins to aggregate (Latimer & Montine, 2018). Mutations to APP have previously been linked to Alzheimer's dementia, and recently a

link between the APP717 mutation and the presence of Lewy bodies on autopsy has been established (Latimer & Montine, 2018). PSEN1/PSEN2 point mutations lead to mutations of the protein presenilin, which is responsible for processing the protein amyloid (Latimer & Montine, 2018). Mutations may contribute to increased formation of Lewy bodies (Latimer & Montine, 2018).

### ***Clinical Presentation***

LBD is defined as a dementia with at least two of the following features: visual hallucinations, parkinsonism, cognitive fluctuations, dysautonomia, or REM behavior disorder, with visual hallucinations and parkinsonism being the most common defining features (Farlow, 2017, 2019). Though the clinical presentation of LBD is fairly similar to both Alzheimer's dementia and Parkinson disease, the sequence of symptoms is distinct (Farlow, 2017; Latimer & Montine, 2018). Patients with LBD tend to have decline in visuospatial function, attention, and executive decision making prior to having memory loss (Farlow, 2017). In Alzheimer's, memory loss tends to be the first symptom (Farlow, 2017). In comparison to Parkinson's dementia, LBD features dementia followed within one year by the onset of parkinsonism (bradykinesia, akinesia, and/or limb rigidity), whereas Parkinson's dementia begins with the motor symptoms and progresses to dementia after about one year (Connors et al., 2018).

### ***Diagnosis and Treatment***

Diagnosis of LBD is often made clinically, however specific patterns of atrophy and metabolic changes within the brain due to the presence of Lewy bodies are detectable on MRI

and PET scans (Farlow, 2017). Biomarker tests specific to LBD are currently under investigation (Farlow, 2017).

In regards to prognosis, LBD is like other dementias in that it features progressive cognitive decline that inevitably leads to death (Farlow, 2019). There are no disease-course altering treatments currently available for LBD, and treatment is therefore focused on symptom relief. Symptomatic treatment of LBD tends to be more difficult than treatment of some other dementias due to the presence of both psychosis in the form of visual hallucinations and parkinsonism as well as a tendency for antipsychotic sensitivity to be present in LBD (Connors et al., 2018; Farlow, 2019). Overall, medications tend to be poorly tolerated, with antiparkinsonism agents such as levodopa increasing psychiatric symptoms and antipsychotic drugs, antidepressants, and benzodiazepines worsening parkinsonism, confusion, and autonomic dysfunction (Farlow, 2019). The most efficacious drugs seem to be cholinesterase inhibitors including donepezil and rivastigmine (Connors et al., 2018; Farlow, 2019). In small limited studies these medications improved cognition, psychotic symptoms, and parkinsonism symptoms in patients with LBD (Farlow, 2019).

Another key part of symptom management in LBD is the use of non-pharmaceutical treatments. Some options for non-pharmaceutical interventions that have been found to provide mild improvement include honey-thickened liquids and postural adjustments to avoid aspiration, electroconvulsive therapy and transcranial magnetic stimulation to treat depression, psychological interventions to decrease distress during visual hallucinations, exercise and physical therapy to improve gait, environmental modification to reduce distress with delusions,

music therapy to help with agitation, and occupational therapy (Connors et al., 2018). None of these approaches have been studied extensively and may only provide modest improvement in symptoms.

### ***Summary***

In summary, LBD is the third most common cause of dementia (Latimer & Montine, 2018). Though the underlying biology is largely unknown, there are several genetic mutations that have been linked with the presence of Lewy bodies, or alpha synuclein protein aggregates, in the brain (Latimer & Montine, 2018). LBD typically presents as loss of executive decision making capabilities, followed by the onset of dementia, followed by the onset of parkinsonism (Farlow, 2017). There are no disease altering treatments available, and symptomatic management is therefore indicated (Connors et al., 2018; Farlow, 2019).

## **Frontotemporal Dementia**

### ***Introduction***

Frontotemporal dementia (FTD) is an encompassing term that includes neurodegenerative conditions that may affect many different areas of cognitive function, including motor function, language, behavior, speech, and cognitive control (Olney, Spina, & Miller, 2017). FTD onset usually occurs in a person's 60s (Lee, Yaffe, & Wilterdink, 2019). FTD is one of the most common types of dementia, with its prevalence ranging from 3% to almost 27% (Vieira et al., 2013). Diagnosis may take up to several years after onset of symptoms, and the average length of life post diagnosis can range from 8-10 years (Bang, Spina,

& Miller, 2015). This section will serve to describe the history, signs and clinical features, progression, and diagnosis of frontotemporal dementia and its variant disorders.

### *History*

Throughout time, the definition and classifications of FTD have evolved. FTD was first described in 1892 by a neurologist named Arnold Pick, when he reported a patient who had progressive language deficits along with left temporal lobe atrophy (Bang et al., 2015). Alois Alzheimer analyzed Pick's cases and later distinguished them as Pick disease, characterized by the set of symptoms along with cytoplasmic inclusions with an affinity for silver stain (Lee et al., 2019). This definition was altered by Pick's students, who separated general FTD from the specific subtypes in which Pick bodies are present in the brain tissue (Olney et al., 2017).

From the discovery made by Pick until the 1970s, little was researched on dementia (Olney et al., 2017). A team of French researchers, Delay, Brion, and Escourolle, published a paper on the differences between Alzheimer's disease and Pick's disease, which up until that point were regarded as the same condition with a vascular etiology and accepted as one of the main causes of senility (Olney et al., 2017). The paper described differences in the clinical and anatomical findings between the two diseases (Thibodeau & Miller, 2013). Researchers found that Pick's disease showed frontotemporal atrophy with a lack of apraxia and agnosia, whereas Alzheimer's disease showed more distributed atrophy with symptoms of apraxia and agnosia (Olney et al., 2017). In the 1900s, Pick's disease was renamed into frontotemporal dementia, an encompassing term that includes three subsets: behavioral variant, semantic dementia, and progressive nonfluent aphasia (Olney et al., 2017).

### ***Clinical Presentation***

Frontotemporal dementia is currently classified into three subcategories. Behavioral variant FTD is associated with failure to maintain appropriate behaviors, semantic variant is associated with deficits in logic and understanding language and progressive primary progressive aphasia is associated with speech and grammar deterioration (Bang et al., 2015). Initially, a patient can present with specific symptoms for a certain variant of FTD, but overtime, brain atrophy of the frontal and temporal lobes will converge and a more non-specific FTD will progress (Bang et al., 2015). This section will serve to specify the clinical features of FTD variants and differentiate between the subtypes.

**Behavioral variant.** Behavioral variant frontotemporal dementia (bvFTD) is marked by progressive changes in behavior, personality, and emotion (Olney et al., 2017). Symptom onset usually presents in a patient's sixties, but can present anywhere from their twenties to their nineties (Lee et al., 2019). Because of the range of changes a patient can experience, diagnosis of bvFTD can be delayed for years after symptoms onset (Lee et al., 2019). The most common behaviors of bvFTD include personality changes, disinhibition, and apathy (Bang et al., 2015).

Disinhibition during bvFTD progression can include a wide range of symptoms, which may have an impact on familial relationships, and even the patient's safety. Impulsiveness and carelessness increase in bvFTD, leading to behaviors such as reckless spending, public urination, hit-and-run accidents, approaching strangers, a lack of physical and/or sexual boundaries, and taking other people's possessions (Lee et al., 2019). Patients lack of fiscal responsibility may place the patient in a financial crisis (Bang et al., 2015). Although patients may take

inappropriate sexual advances or make sexual remarks toward strangers, patients usually have a decreased sex drive (Bang et al., 2015). Apathy is another hallmark symptom of bvFTD. Patients may experience a wide variety of emotional changes as their disease progresses, and their emotional priorities may shift, resulting in resentment from family and friends and strain on caregiver relationships (Lee et al., 2019). These changes may include a lack of interest in work, decreased social interaction with family and friends, and a decreased awareness of the emotional needs of those around them (Bang et al., 2015). Aside from personality changes, patients can also show an increase in compulsive behaviors. Oftentimes, patients will start to display simple, repetitive movements or compulsive behaviors such as binge eating, compulsive cleaning, repeating certain phrases (Lee et al., 2019). In 15-20% of cases, patients will develop an associated motor neuron disease (Lee et al., 2019).

**Semantic Variant.** Semantic variant frontotemporal dementia is marked by impaired comprehension of language and speech (Lee et al., 2019). With advancing in brain mapping, researchers are noting that atrophy in the left temporal lobe is associated with language impairments and a progressive loss of semantic knowledge (Bang et al., 2015). Patients with semantic variant FTD tend to have a slower progression of the disease and are the least likely variant to have a genetic cause (Bang et al., 2015).

Oftentimes, the first symptom that will be noticed in a person with semantic variant FTD is word-finding difficulty (Lee et al., 2019). Symptoms usually progress from difficulty recognizing uncommon words, such as elephant, to more commonly used words, such as spoon (Bang et al., 2015). Early in disease progression, patients tend to maintain their ability to

recognize complete sentences, while their ability to recognize single words decreases (Lee et al., 2019). Patients may also have a difficult time with words that contain irregular spellings, such as yacht (Lee et al., 2019). Descriptions of words will not make up for a lack of remembrance of what the original word was (Bang et al., 2015). As the disease progresses, words and language comprehension tend to broadly disappear, along with gaining attributes of other FTD variants (Bang et al., 2015). One interesting development in semantic variant FTD is a development of artistic talent (Bang et al., 2015). Often patients will take on a compulsion for painting, drawing, or music (Bang et al., 2015).

**Nonfluent primary progressive aphasia variant.** Nonfluent variant frontotemporal dementia (nvFTD) is marked by progressive speech deficits due to motor control and an inability to speak with proper grammar or speech sounds (Lee et al., 2019). Research has noted a correlation between atrophy of Broca's area and nvFTD (Bang et al., 2015). Early stages of the disease may show only slight errors in grammar or mispronunciation, and often these errors will go unnoticed (Bang et al., 2015). As the disease progresses, patients with nvFTD will eventually become completely non-verbal, as well as gaining attributes and behaviors consistent with other variants of FTD (Bang et al., 2015).

Patients with nvFTD will progress from slight errors in grammar or pronunciation errors in sentence structure, including word or syllable insertions, deletions, or substitutions (Lee et al., 2019). Patients are unable to repeat the same word multiple times without creating new pronunciations each repetition (Bang et al., 2015). Speech becomes slow, slurred, and takes much more effort as the disease progresses (Bang et al., 2015). Initially, patients may have a

difficult time with spoken words, but can communicate effectively with written language (Bang et al., 2015). As time progresses, the ability to communicate in any form of language will decrease and patients will also start to show a decrease in the ability to understand language and complex sentences (Lee et al., 2019).

### ***Diagnosis***

Diagnosis of frontotemporal dementia is a largely clinical process in the initial stages. To gain insight into the specific variant and progression of the disease, extensive imaging is required to analyze brain atrophy, often involving magnetic resonance imaging to determine exact locations where the atrophy is occurring (Marino et al., 2019). Specific criteria have been developed for identifying each variant of FTD, and this section will serve to differentiate between the diagnostic processes of each variant.

The current diagnostic criteria for behavioral variant FTD was developed in 2011 by the International Behavioral Variant FTC Criteria Consortium (Lee et al., 2019). The criteria contains information about clinical presentation, imaging, genetic tests, and neurology testing (Lee et al., 2019). Diagnosis status is broken down into different stages: possible diagnosis, probable diagnosis, and definite diagnosis (Lee et al., 2019). Possible diagnosis requires that at least three of six clinical symptoms (disinhibition, apathy, loss of sympathy, compulsive behaviors, increased oral intake, hyperorality, and a lack of executive control) be present (Bang et al., 2015). Probable diagnosis requires the clinical criteria in addition to a functional decline and imaging showing specific frontal or temporal atrophy (Lee et al., 2019). Definitive diagnosis of bvFTD are obtained by post-mortem biopsy and histological analysis (Lee et al.,

2019). The possible diagnosis criteria has a sensitivity of 85% and the probable diagnosis criteria has a sensitivity of 75%, based on post-mortem confirmation (Lee et al., 2019).

The current diagnostic criteria for the semantic and nonfluent variants of FTD were developed in 2011 by the international expert consensus (Lee et al., 2019). The general criteria include both required features, and a lack of other features. Patients must have all of the required criteria to be considered for a diagnosis of semantic or nonfluent FTD (Bang et al., 2015). The required features are as follows: difficulty with language, impaired activities of daily living due to language deficits, and a prominence of aphasia during symptom onset and initial disease progression (Lee et al., 2019). Patients must also be negative for all four of the following criteria: other medical disorders that account for the symptoms, a psychiatric diagnosis that can account for cognitive impairment, prominent initial memory impairments, and significant initial behavior disturbances (Lee et al., 2019). Once these criteria are satisfied, the FTD is then further specified as a nonfluent or semantic variant using a clinical diagnosis and imaging techniques to observe specific areas of atrophy (Bang et al., 2015).

### ***Summary***

Frontotemporal dementia is a complex, widely variable disorder. FTD is an umbrella term for multiple variants of the disease: behavioral variant, semantic variant, and nonfluent primary progressive aphasia variant. Symptoms can range from mild to severe, and can create significant changes in a patient's quality of life over a short period of time. Specific brain imaging has helped to increase the accuracy of diagnosis, progression, and outcome for patients

with FTD. The next section will serve to describe the definition of socialization and how socialization affects health outcomes and quality of life, especially in patients with dementia.

### **Socialization and Health**

Socialization is the process of being socially engaged with other people, and this process plays an important role in people's wellbeing. Loneliness, on the other hand, is a negative emotion that one experiences when their social network does not meet the needs or desires they have for social connectedness (Luo, Hawkley, Waite, & Cacioppo, 2012; Taube, Kristensson, Sandberg, Midlöv, & Jakobsson, 2015). Recent research has suggested that loneliness is linked to increased risk of morbidity and mortality (Sommerlad, Sabia, Singh-Manoux, Lewis, & Livingston, 2019; Taube et al., 2015; & Luo, Hawkley, Waite, & Cacioppo, 2012; Holt-Lundstad, Smith, & Layton, 2010). In fact, loneliness has been found to negatively impact overall health to a degree that is similar to other established risk factors for morbidity and mortality such as smoking and obesity (Holt-Lundstad et al., 2010). It has also been found to negatively impact mental health as well as quality of life (Wang, Mann, Lloyd-Evans, Ma, & Johnson, 2018; Taube et al., 2015). This section will discuss both the impact loneliness has on health outcomes in general as well as the impact loneliness has on dementia.

### ***Loneliness and Health Outcomes***

A meta-analysis of 148 studies that looked at the effects of loneliness and social isolation on morbidity and mortality found that strong social relationships increased overall likelihood of survival by 50% over an average follow up period of 7.5 years (Holt-Lunstad et al., 2010). Importantly, this effect was seen even when accounting for factors such as age, sex, existing

comorbidities, and cause of death, suggesting that loneliness is an independent risk factor for mortality (Holt-Lunstad, Smith, & Layton, 2010). The type of social interaction significantly impacted likelihood of decreased mortality, with complex social integration having the strongest association with decreased mortality and binary residential status having the weakest association (Holt-Lunstad, Smith, & Layton, 2010).

Similarly, Luo et al. (2012) analyzed data collected from 2,101 adults over the age of 50 years old who had participated in the Health and Retirement Study, a United States longitudinal study looking at the health, economics and demographics of aging. Their analysis found that those who reported the highest level of loneliness were 1.96 times more likely to die within six years than those who reported the lowest levels of loneliness (Luo et al., 2012). Correlations were found between loneliness and each of the following factors: increased depressive symptoms, increased functional limitations, and decreased self-reported health (Luo et al., 2012). Interestingly enough, the link between loneliness and worsened health outcomes was seen even when health behaviors were held constant, suggesting that loneliness impacts morbidity and mortality by impacting physiology at a more fundamental level (Luo et al., 2012).

In addition to having negative effects on physical health, loneliness has also been linked to worsened mental health outcomes. A systematic review of the literature performed by Wang et al. (2018) found substantial evidence supporting the idea that individuals with depression who report lower levels of social support experience poorer outcomes. Specifically, they found these individuals who reported a lack of sufficient social support had more severe depressive symptoms, worse recovery between depressive episodes, and decreased social functioning

(Wang et al., 2018). Some preliminary evidence also suggested the potential for similar findings in people who have other mental health diagnoses such as schizophrenia, bipolar disorder, and anxiety disorders (Wang et al., 2018).

In addition to increasing risk of morbidity and mortality, Taube et al. (2015) found that loneliness impacts health related quality of life and health complaints. Elderly people living at home in Sweden were surveyed regarding their experiences with feelings of loneliness, health related quality of life, and specific health complaints. Sixty percent reported having felt lonely in the past year, and there were significant differences in both health care reported quality of life and number of specific health complaints between those who reported feelings of loneliness and those who did not (Taube et al., 2015). The specific health related quality of life parameters that were used in the survey included mobility, self-care, usual activities, pain, and mood. The specific health complaints that were more commonly reported amongst lonely people included difficulties hearing, memory problems, dizziness, loss of appetite, nervousness, and depressed mood (Taube et al., 2015). Health complaints that were not significantly different between lonely and non-lonely people included difficulties talking, difficulties reading, unsteadiness, pain, difficulties walking, mobility limitations, and difficulties sleeping (Taube et al., 2015). This study also found that lonely participants utilized outpatient healthcare services, including primary care and emergency services, more frequently than their non-lonely counterparts (Taube et al., 2015). These findings show that loneliness does have a significant impact on quality of life.

### ***Loneliness and Dementia***

People who have dementia often experience major life events that result in changes in social networks such as declined cognitive function and moving into long-term care facilities, which may contribute to increased loneliness (Doyle, de Medeiros, & Sanders, 2012). Due to the adverse effects that loneliness may have on overall health and quality of life as well as the possible increased risk for loneliness in dementia, it is important to consider how loneliness specifically impacts people with dementia. Kuiper, Zuidersma, Oude, Zuidema, van den Heuvel, Stolk, & Smidt (2015) performed a meta-analysis of longitudinal cohort studies investigating level of social contact as a potential risk factor for the development of dementia in the general population. Level of social contact in the studies reviewed was measured by looking at six categories: social network size, social participation, frequency of social contact, loneliness, satisfaction with social network, and other social relationship factors (Kuiper et al., 2015). The study concluded that low social participation, less frequent social contact, and more loneliness were each associated with a higher incidence of subsequent dementia with statistically significant relative risks of 1.41, 1.57, and 1.58 respectively (Kuiper et al., 2015). The strength of this association was found to be comparable to other known risk factors for dementia such as being physically inactive and having lower levels of education (Kuiper et al., 2015). Another study by Sommerlad, Sabia, Singh-Manoux, Lewis, and Livingston (2019) found a similar connection between one's level of social interaction and their risk for dementia. Through the use of self-report questionnaires, cognitive testing, and tracking electronic medical records, a link was found between spending more time with friends at the age of 60 years old and having a lower risk of

developing dementia (Sommerlad et al., 2019). The study also found that those who spent more time with friends and family during midlife had higher cognitive performance compared to those who spent less time being socially connected (Sommerlad et al., 2019).

Some possible theories explaining the link between loneliness and increased risk for dementia include the “use it or lose it” theory, the stress theory, and the idea of a “cognitive reserve” (Kuiper et al., 2015; Sommerlad et al., 2019). The “use it or lose it” theory is the idea that, like musculature, the more one uses their muscles, the more the muscles will enlarge. Likewise, the more the brain is functioning, the more neurogenesis that occurs and the more synapses that are created. Adversely, when muscles are not used, they atrophy. This theory relates this to the brain and hypothesizes that lack of social stimulation in the brain can cause decline because the brain is not being used like it should be (Kuiper et al., 2015; Sommerlad et al., 2019). The stress theory comes from studies identifying the impacts of stress on the brain. There may be a correlation between stress and anatomical changes to the hippocampus that increase the risk of persons developing Alzheimer’s Disease (Kuiper et al., 2015).

Sommerlad et al. (2019) hypothesized that increased social connection earlier in life may help one to build up a “cognitive reserve,” which may delay or even help prevent dementia. They also hypothesized that those who were less social may have had early decreased cognition that may have contributed to difficulties maintaining friendships (Sommerlad et al., 2019). Bennett, Schneider, Tang, Arnold, & Wilson (2006) studied the impact of social networks on the neural reserve capacity for someone who anatomically displays the pathologies associated with dementia but does not physically, emotionally, or psychologically display the extent of these

known pathologies (Bennett et al., 2006). The study included 89 participants from the Rush Memory and Aging Project that underwent evaluations during life and autopsies that were performed at the time of death (Bennett et al., 2006). Level of social contact was based on the number of children, family, and friends participants saw on average each month (Bennett et al., 2006). Data analyses of the neural reserve capacity study concluded that with decreased social and cognitive activity based on the number of social contacts in participants' lives, there was an increase in the decline of cognitive function (Bennett et al., 2006). Amyloid beta load was not correlated to social contact, however there was a correlation between social contact and decreased tangle density (Bennett et al., 2006). Social networks impacted the tangle production in episodic, semantic, and working memory, with semantic memory being the most influenced by social networks (Bennett et al., 2006).

Cohen-Mansfield, Marx, & Dakheel-Ali (2011) explored the responses of adults with dementia to seven different categories of stimuli including live social, simulated social, manipulative, task-related, music, reading, and self-identity stimuli. Levels of pleasure and interest were higher in live social interactions, or interactions with a dog, a real baby, or a research assistant, than in any other category studied (Cohen-Mansfield et al., 2011). Simulated social interactions, or interactions with a baby doll, plush animal, robotic animal, or respite video, produced the second highest levels of pleasure (Cohen-Mansfield et al., 2011). Cohen-Mansfield et al. (2011) found that these increases in levels of interest and pleasure occurred in those with both lower and higher cognitive function, although those with higher cognitive function had a greater increase in interest and pleasure than those with lower cognitive function.

This study highlights the importance of socialization for adults who have dementia. Another study by Cohen-Mansfield performed in 2017 looked at engagement levels in group activities and found that cognitive function is the most consistent predictor of engagement in group activities. In this study, engagement was measured by duration of participation, observed engagement, active participation, attitude, and time spent sleeping during activities (Cohen-Mansfield, 2017). The researcher noted, however, that the apparent decrease in engagement as cognitive function decreases does not necessarily indicate that people with more advanced dementia are not benefitting from group activities (Cohen-Mansfield, 2017). The benefits they are experiencing may be easier to measure in more objective ways, such as frequency of dementia related behaviors (Cohen-Mansfield, 2017).

Although cognitive changes in dementia may make it more difficult to maintain friendships, staying socially connected remains important to people who live with dementia. Perion and Steiner (2019) interviewed several adults living with mild to moderate dementia regarding their experiences and perceptions of friendships, and identified several key reasons why friendships are an important part of their lives. Participants reported valuing the trust and loyalty that comes from knowing someone for a long period of time and going through many life changes with someone (Perion & Steiner, 2019). They also discussed the importance of reciprocity and being able to help their friends; this sense of reciprocity made some participants feel more “alive” (Perion & Steiner, 2019). The participants also reported a sense of security in knowing someone will be there for them and knowing they will not be rejected or abandoned because of their dementia diagnosis (Perion & Steiner, 2019). Many of the interviewees reported

a sense of relief and satisfaction after sharing their diagnosis with friends and finding that these friends were committed to staying by their side through the difficulties that come with living with dementia (Perion & Steiner, 2019). These interviews serve as a reminder that although many cognitive abilities that are crucial to maintaining friendships such as memory, conversational skills, and facial recognition are diminished over time in dementia, those living with dementia still participate and benefit from meaningful relationships and in being part of communities (Doyle et al., 2012).

### **Conclusion**

Quantifying dementia progression has been noted, but there is a gap in the research that looks at the level of socialization with progression of dementia in long-term care facilities. This study, we will be aiming to analyze the relationship between socialization status and progression of dementia symptoms in long-term care facilities. This study will also look at the current socialization directives these long-term care facilities use to incorporate socialization in their residents and their efficacy. The next chapter will include a discussion about how to measure socialization and progression of dementia. The methodology, structure of performance of a qualitative study, and method of analysis will also be noted.

## **Chapter Three: Methods**

### **Introduction**

The purpose of this study was to explore the types of socialization activities offered to adults with dementia in long-term care facilities and the extent to which these activities impacted dementia-related behaviors. The research question to be addressed was:

1. How do direct care nursing home personnel perceive the impacts that organized group activities have on the dementia-related behaviors of adults with dementia within the long-term care facility?

The following chapter will outline the study design, population selection, research procedures, and potential limitations and delimitations of the study.

### **Study Design**

Qualitative data was collected to answer this descriptive research question in this study. This cross sectional study interviewed direct care staff who have worked in long-term care facilities and asked them to reflect on experiences that the residents they work with have had with group activities while being prompted by interview questions. The behaviors are categorized into the following: behaviors of agitation or aggression, isolation or apathy, hallucinations or delusions, wandering, disturbed sleep patterns, sexually inappropriate behaviors, and the resident's ability to independently perform their activities of daily living (ADLs) (Press & Alexander, 2019a).

## **Study Population**

The participants were direct care staff who have worked at a long-term care facility caring for adults with dementia on a regular basis. Inclusion criteria include direct care staff who have worked the morning and/or afternoon shifts to account for group activities and resident behaviors that may vary throughout the day. These staff include personal care assistants, certified nursing assistants, direct support professionals, licensed practical nurses, and registered nurses at the long-term care facilities that are interviewed. Staff must be at least 18 years of age or older.

Exclusion criteria include temporary employees, office staff, and activities and janitorial staff. Also excluded are employees that have worked at a facility for less than 2 months, or less than 250 cumulative hours, in order to ensure we obtain information from people who have had the chance to regularly interact with, and learn the daily habits of the residents. Participants were recruited through Facebook.

The sample population were residents living in a long-term care facility that were diagnosed with any form of dementia. Exclusion criteria for the sample population include residents not diagnosed with dementia, residents living at other facilities that are not long-term care, and residents that have been at the facility for less than 2 months.

## **Research Procedures**

The researchers recruited interested participants via Facebook. Due to stay-at-home procedures of COVID-19, the interviews were held over Google Hangout or Zoom video chat. Prior to interviewing participants, 2-3 pilot interviews with direct care workers were conducted through a simulated interview. Once the pilot interviews had been completed and IRB approval

had been obtained from Bethel University, the researchers posted the pre-written recruitment message onto Facebook (Appendix B). The post described the research, contained the researchers' emails, and instructions to email the researchers if individuals were willing to participate (Appendix C). Those interested were asked to not comment or react to the Facebook post to ensure confidentiality, but instead to email the researchers directly. The researchers monitored the post for any participants who directly replied to the post. Through private messages, the participants would have been asked to delete their comment or reaction to the post to ensure confidentiality, and they would instead be asked for an email address to be contacted. The Facebook post was made every week until adequate participation was met.

Upon confirmed interest and established eligibility based on the inclusion criteria, the participant was sent the informed consent document via email or through the Google Hangout or Zoom chat feature (Appendix A). Once consent was obtained by the participant, a meeting time over video chat was established between the participant and the researcher. The participant was made aware that they may choose to have their video turned on or off for the duration of the interview. The participant was also told that their contact information would be deleted after the interview is completed and no other identifying information, such as the name of the facility they have worked at, would be collected. The interviews were recorded on the researcher's password protected computer (Appendix D). The recorded interviews were then transcribed, and the audio recording of the interview was destroyed after completion of transcription. It was anticipated that six to ten direct care personnel would be interviewed.

In addition to the informed consent sent by email, the informed consent document was reviewed again by reading a script aloud to the participants at the beginning of the interview explaining that their participation in the study would in no way impact their employment at their facility, or their relationship with the researchers or Bethel University (Appendix A). Any identifying information would be kept confidential, and they have the right to withdraw from the study at any time during the interview without consequence from Bethel University or the researchers. Additionally, they have the right to remove their interview from this study before February 28, 2021. After verbal consent was received, the interview recording began.

The study was introduced using a script read aloud by the researchers; the researchers verbally asked each participant the scripted questions in Appendix D. To assist in identifying behaviors, a document including the six dementia-related behaviors and examples of each was sent through the chat function of the video chat. This document was used as a reference for the participant while answering the interview questions. This document was also explained and read out loud to the participants by the researchers. Participants were asked questions about the residents with dementia at their care facility and their facility's group activities and social events.

Residents' identities remained anonymous. Any information relating to specific residents were relayed to the researchers through use of initials, allowing staff to differentiate between residents during the interview process. The personal information that was retrieved from the staff being interviewed include length of time of employment at the facility, age, position title, shift, and length of experience working with patients with dementia. This information was attached to their coded number as a point of reference and confirmation of inclusion criteria. Staff was

informed that all interview questions were optional to answer and they were able to stop the interview at any moment. Staff were also informed they were able to revoke the use of the information in the study collected at any time during the collection of data up until February 28, 2021.

After recording the data electronically, the information was stored on a password protected computer owned by the researchers until it was analyzed. The transcribed interviews were then evaluated for common themes and experiences based on the phrases and stories of the direct care personnel that were relayed to the researchers. Important paraphrases and quotes that represent the range of opinions presented were included in the results. After completion of the study, the data was kept on an external storage device locked in the PA program office for a minimum of five years, per securing requirements for Bethel University's Physician Assistant Program.

### **Data Collection**

The researchers performed a pilot interview with 2-3 individuals who currently worked in long-term care facilities. Specifically, these pilot interview participants must have cared for residents with dementia in order to make sure our questions were understandable and answerable. The pilot interviewee represented the direct care professional participants that were interviewed during the study. The mock interview was performed just like the official interviews, only the researchers did not record the responses given and the information was not used for the research. The pilot interviewees were asked to provide the researchers with any feedback about questions that were unclear or difficult to answer. The length of the pilot interview was also

noted so that the researchers were able to know how long the formal process would take. With this information, any alterations needed were made to the survey and approved by the research committee before the researchers conducted formal interviews with the chosen long-term care facility workers.

Data was collected via recording of the interviews. The interview transcripts were then analyzed for commonalities in the responses recalling residents that have been active members in group activities displaying less aggression, isolation, inappropriate behaviors, enhanced mental cognition, or greater independence in performing their activities of daily living (ADL).

This research questionnaire was created because, to the best of the researcher's knowledge, there has been no tool created for a qualitative study looking at residents with dementia and the associated behaviors as mentioned above. This tool helped to guide the conversation and helped to elicit memories from the direct care professionals when answering the interview questions. Any comments or suggestions for change were evaluated for and were implemented into the interview questions for an updated questionnaire.

### **Limitations and Delimitations**

Limitations in the study include sample size and willingness of direct care workers to participate in the interview. Due to the subjective quality of this data collection, a limitation also exists as bias about residents' behaviors and participation from the perceptions of the direct care workers may be introduced. Additionally, due to COVID-19, the ability of the researchers to conduct in-person interviews had been suspended. Therefore, all interviews were conducted and recorded through Google Hangout or Zoom video chat links.

A delimitation existed where the retrieved information is from secondary sources, direct care workers, and not the residents themselves. A second delimitation is that the researchers did not distinguish demographics; residents are not included or excluded based upon type of dementia, age, race, gender, or socioeconomic status. The final delimitation is limiting the collection of data on socialization to include the activities that occur between residents and staff within the long-term care facilities, not the families that may be visiting the residents.

### **Conclusion**

In summary, the research question was answered by collecting qualitative data through interviews with direct staff personnel who worked with adults who have dementia at long-term care facilities. Interviews were conducted via video chat. Questions were asked about the types of socialization activities offered, the frequency of these activities, and the impacts these activities had on dementia-related behaviors. The data was then transcribed and analyzed for common themes and ideas. The next chapter will include the results of the interviews conducted by the methods stated above. Direct quotes will be transcribed from the audio recordings and placed within the results section as testimonials. The following chapter, chapter 5, will be a discussion of the results found in chapter 4. Specifically, it will be discussed what trends were found in the interviews and what indications exist for correlating the extent of socialization with dementia-related behaviors.

## Chapter 4: Results

### Introduction

This chapter reviews the results of the qualitative analysis of data collected while interviewing 10 long-term care facility staff. The interview questions were used to try to understand the role of organized and informal socialization in the care and management of people who live with dementia in long-term care facilities. The interviews were conducted during February 2021. The purpose of this chapter is to present and analyze the data collected from the interviews and identify common themes as well as deviations from the common themes that help to answer the following question:

1. How do direct care nursing home personnel perceive the impacts that organized group activities have on the dementia-related behaviors of adults with dementia within the long-term care facility?

The purpose of this study was to identify patterns of social connections and explore their impacts on the behaviors of individuals who live with dementia. Participants were interviewed over virtual video conferencing websites (Google meet, Zoom) and the interviews were recorded and transcribed onto a password protected computer. The participants were asked to describe the organized socialization opportunities at the facilities they worked at for residents living with dementia and their feelings about the impact that socialization has on the dementia-related behaviors of the residents that both participated and did not participate in the activities. The data collected was then analyzed for common thoughts and ideas of the interview participants. The data analyzed in this chapter only includes the interview material of the study participants and

reflects the participants opinions and interpretations of their experiences working in long-term care facilities.

### **Demographics**

All of the participants were recruited via Facebook postings. There were a total of 10 participants interviewed, all of whom met the specified inclusion criteria. All of the participants were at least 18 years old and had worked at a long-term care facility with residents with dementia for at least six months. All 10 of the participants were certified nursing assistants or personal care assistants, and zero were either licensed practical nurses or registered nurses. Nine of the participants were female, and one was male.

### **Data Analysis**

Interviews of participants were performed until the goal of 10 interviews was reached. Upon completion of the tenth interview, more than adequate saturation of information had been provided. The Research Methods section in Chapter 3 provides more information on interview protocol.

After each interview, data was transcribed into a password-protected document and organized into different sections. The sections include how facilities encouraged socialization, factors affecting participation in social activities, and finally the impact of socialization on dementia-related behaviors.

### **How Facilities Provide Socialization Opportunities**

The participants were asked to describe what forms of socialization, both organized and unstructured, took place in their facility. This was asked to gain a better understanding of the

types, frequency, duration, and setting of group activities offered in long-term care facilities for residents with dementia. A wide variety of activities were offered for residents with dementia, both as a separate group or in combination with other residents in the facility not diagnosed with dementia. A summary of the categories of social activities offered to residents with dementia is found in table 1. In addition to activities taking place at the long-term care facility, there were activities that occurred outside the facility as well. These activities included outdoor chalk drawing, walking around the facility grounds, and shopping trips to stores.

Nine of the ten participants reported that activities in their facility were offered at least daily, with one participant stating that organized activities were offered twice weekly. Of participants who reported daily activities, two reported activities occurred twice daily and three reported activities occurred more than twice daily. Participants clarified that certain types of activities, such as group exercises or listening to music, occurred more regularly, whereas religious services and community outings were more likely to occur weekly or monthly. Time of day that the activities were offered varied. The earliest reported time that an activity was offered was 8:30 AM. The activities were offered throughout the day, including morning, lunch time, afternoon, and the latest reported activity was in the evening.

Personnel responsible for the organization of the activities varied depending on the facility. Seven of the participants specifically mentioned an activities director that managed the frequency and types of activities offered, and one of the participants mentioned they were responsible as nursing staff to organize the activities. Two participants did not comment about who was responsible for organizing the activities.

Nine of the ten participants stated that there was observed informal socialization outside of the organized events. Six of the participants noted that much of this informal social interaction occurred when residents would sit near each other and converse. Three participants stated that their residents enjoyed watching television together. Others noted informal socialization opportunities included walking around the facility together, eating snacks, looking at the facility pets, and reading the newspaper. One participant stated her perceived benefits of this informal socialization:

A lot of times the majority of people would socialize with their neighbors or in the living room or dining room... I think [informal socialization] would not necessarily improve any dementia type symptoms, but it helped them keep a more social and more normal life than just sitting by themselves in their room and being antisocial and not having anyone around.

One participant stated that she did not remember seeing residents interact outside of the organized social events because she felt the residents all functioned in their own routine and that routine did not cross paths with other residents. Overall, the participants revealed that at all of the facilities, the residents were receiving regular opportunities for organized socialization, and their facilities were conducive for informal socialization opportunities in addition to organized events.

Organized group activity	Number of participants reporting activity
Crafts, coloring, other art-related activities	7
Group exercise, other physical activities	7
Shared meal times	6
Listening to music, live or recorded	5
Card games, puzzles, bingo	5
Religious services	4
Family events	3
Playing instruments	2
Watching television shows or movies	2
Holiday events	2
Community outings	2
Cooking, baking, other household chores	2
Outdoor activities	1
Rummage sales	1
Photo albums	1
Salon activities: nail painting, hair styling	1

Table 1. Categories of organized group activities offered at the long-term care facilities.

### **Factors Affecting Participation in Group Activities**

Next the participants were asked to discuss the level of participation in group activities as well as reasons why residents did or did not participate in the formal and informal socialization activities.

When asked to estimate the percentage of residents who participated in organized group activities, four participants stated that more than half of the residents regularly participated, two

stated half of residents regularly participated, and three said that less than half did. Two participants noted that the level of participation varied widely depending on what the event was. For instance, one participant said that 90% of residents would participate in church services, but less than half of those same residents would participate in crafts. Another said that 75% of people would participate in group exercise or watching television as a group, but activities such as crafts, baking, and group outings had participation rates closer to 25%.

The participants were then asked to discuss reasons why residents did not participate in group activities. The most commonly cited reasons included advanced dementia, behavioral issues, and negative moods. Other reasons included reserved personalities or lower levels of sociability prior to dementia diagnosis, underlying anxiety, physical disabilities, having appointments, having visitors, or simply wanting to do something else.

Six participants cited advanced dementia as a factor that limits participation in group activities. One stated, "I think the higher level of their dementia and needs makes it more difficult for them to socially interact." Another participant similarly stated they think "comprehension of what is going on with that event" is one of the primary indicators of whether or not residents participate in events.

The other most commonly cited barrier to participation was behavioral issues or being in a negative mood, with five participants listing this. One participant said, "If they were in a bad mood, they would always want to stay in their room and do something themselves." Two participants cited reserved personalities or lower levels of sociability as reasons for not participating. One explained,

I think just their personality in general [affected participation level]. Some people are more antisocial than others. Some people enjoy group activities, and some people don't. So mainly I think it has to do with who the person was before the dementia occurred to decide if they were a group activity person or not.

Another participant similarly stated, "Those who maybe weren't married or didn't have kids... they don't really like to be socialized with and like to do their own thing in their own room and kind of sit alone." Two stated physical disabilities, specifically being bedridden, limited participation. One cited underlying anxiety as the reason a few of the residents she worked with did not enjoy group activities. Two participants said that other plans such as family visiting or having appointments occasionally kept people from participating. Two said that sometimes residents simply want to do something else at the times that activities are offered.

In summary, most participants stated that at least half of the residents in their facility regularly participated in activities, but this did vary based on the activity being offered. Participants commonly cited advanced dementia, negative moods, and behavioral issues as the primary reasons for residents not participating in activities.

### **Behavior-Related and Cognitive Impacts of Socialization**

Participants were asked to recall situations where socialization had a positive or negative impact on a resident's dementia-related behaviors.

#### ***Socialization Increasing Dementia-Related Behaviors***

When asked to recall a time when socialization increased a resident's dementia-related behaviors, eight were able to identify times when this occurred and two stated that they could not

recall a time when this occurred. In regards to the specific types of behaviors that were increased during group activities, four participants reported increased physically or verbally aggressive behaviors, four reported increased controlling behaviors, two reported increased anxiety, one reported increased depressed mood or tearfulness, and one reported increased wandering.

An increase in controlling behaviors was one of the most common examples given of a time when socialization increased dementia-related behaviors. One participant stated, “I had a resident who had extreme OCD, so anytime one thing would be out of place or someone would do a puzzle and just wasn’t getting it right, she would come and just start cleaning it up in the middle of them doing puzzles and then that made the other resident mad and then behaviors occurred then.” Another explained, “We have a couple of residents that love folding the towels that we had, and they knew that that was their role... and they got along really well, but if we had other residents that would wander over and want to see what they were doing, not even to take a towel and want to help, but I can't tell you how many fights I broke up over these towels, it was insane.” One participant explained that some residents “just couldn't focus on what they were doing, because they were so worried about what the other client was doing.” Similarly, someone stated “I remember one of the residents always liked to help everybody but it sometimes affected the other resident in a negative way.”

The other most common type of behavior that was noted to be increased during group activities was verbal or physical aggression. One participant explained, “There were a lot of verbal outbursts [during group activities]. I would say more so between men... [it was about] dominance and who could do better.” The same participant also stated “we had a few physical

outbursts during a few games” which was typically related to people taking things from each other.

Two reported that in residents who were prone to feelings of anxiety, group activities could at times accentuate this. One explained:

I had one resident who was sexually abused when she was younger so doing group gatherings, she was very anxious, being close to others she was very anxious, being in a room with men she was very anxious, so sitting next to them during these games and if something loud would occur or if a man would go near her to grab a balloon let’s say for that game, she would freak out and have a behavior and she would start yelling which would then arouse everyone else in the room and make things a little hectic.

A factor that was introduced that had some bearing on the resident’s dementia-related behaviors was the timing of the activities, with activities occurring later in the day more commonly leading to an increase in behaviors. A participant explained, “I remember at one point it was dinner and we had one of the residents who likes to chill out in his room for most of the day ... it was time to try to get them to come out for dinner and he was not having it and the aggressive behaviors came out, swearing and swinging and all of that.” This participant attributed the increase in behaviors to “sundowning” than to socializing itself and went on to explain, “for the most part during... the day, socialization just helped more than it hurt.”

Three participants specifically noted that ending group activities seemed to accentuate dementia-related behaviors more so than the activity itself. One explained that it was fairly common for residents to be “not cooperative, agitated, and tearful” after activities were over.

Another discussed a resident who seemed to become more anxious after activities: “After the group activities she would always sit at her door until all the other residents had gone into their rooms because she was so anxious someone would come into her room.”

### ***Socialization Decreasing Dementia-Related Behaviors***

When asked to think of a time when organized group activities decreased dementia-related behaviors, every participant was able to recall times when this occurred. The most commonly reported activity that decreased behaviors was listening to either live or recorded music with others, with five participants reporting this. Other specific activities that were reported to reduce dementia-related behaviors included church services, physical activities, and shared mealtimes. Participants offered explanations as to why they believe group activities decreased dementia-related behaviors such as socialization offering a distraction from confusion or anxiety as well as offering a sense of routine. Participants reported decreased anxiety, decreased agitation, decreased tearfulness, decreased confusion, increased participation in activities of daily living later in the day, decreased wandering, and decreased hallucinations as some of the types of behaviors that were decreased during socialization.

One participant recalled a situation where a resident helped the staff bake in the kitchen. The participant described the baseline demeanor of the resident as “generally an anxious person” that frequently exhibited dementia-related behaviors. However, the staff realized her passion of baking and allowed her to participate in stirring batter. The participant recalled the following about the impact this socialization had on her:

You could have a normal conversation with her while she was doing her cookie dough. She would talk to you about her past life even though she thought she was still in it. She would talk to you about her shop, she'd talk to you about baking, she'd talk to you about family.

The participant recalls the resident would even try to teach everyone about baking and that during these moments and the evening that followed, the resident's dementia-related behaviors were greatly reduced.

One participant identified the timing of the activities as a factor for impacting the benefit of socialization: "...when people first wake up, they have some extra confusion... in the morning those activities were really helpful in getting them up and moving and decreasing [dementia-related behaviors] and getting their mental brain stimulated in the morning."

Overall, each participant expressed similar scenarios in which socialization allowed residents to resume normalcy and reprieve in a long-term care setting with a noticeable decrease in dementia-related behaviors. One participant stated that these activities were a way of "bringing them back to those times that they do still have memories kind of helps calm and stabilize mood as well". Another participant had similar thoughts stating, "having that social interaction sparked something in the past and I think that is something good to have because everyone needs social interaction."

### **Cognition and Independence**

Participants were asked to evaluate the level of cognition and independence in performing activities of daily living as a reflection of the resident's involvement in social

activities. Of the residents that did participate regularly in group activities, six participants reported that they were overall more aware and alert. Four stated there was a wide range of cognitive levels among participants, with two of these four respondents adding that participation in activities seemed to improve overall awareness in people regardless of their baseline cognitive level. Of the residents that did not regularly participate, six participants identified a lower level of cognition in those residents. One participant explained that as one resident's dementia worsened, her social engagement declined: "I saw a resident that used to be very active in these activities and as her mental capacity and dementia declined, that's when she started separating herself from activities and not really wanting to do anything." Another participant remarked,

Those [residents] who don't really get involved, they don't really mentally click with anybody, they just kind of walk around with a blank look in their eyes just because they don't have that desire to interact. Whereas those who do interact or engage in individual or group activities, you can see the kind of spark in their eye that they're a little bit happier and a little bit higher functioning.

One participant noted that the level of participation in the group activities depended more on the resident's personality and mood rather than their cognitive abilities.

Participants were then asked to discuss the correlation between level of socialization and independence in performing activities of daily living. Of the residents that did participate regularly in group activities, seven participants noted more independence while one noted that they were not more independent. Of the residents that did not regularly participate, six participants stated that these residents were less independent in their activities of daily living.

One added that some residents seemed to function more independently than their usual baseline when they were participating in group activities: “It was always interesting to me how some of them listened so well during the socialization activities, and they would do really well in that environment, but when it came to giving them medications, they were a completely different person.” The remaining four participants said that level of independence did not impact level of participation, largely because staff at the facility encouraged everyone to participate as best they could.

### **Overall Impact of Socialization on Dementia-Related Behaviors**

When asked if overall organized group activities are beneficial, neutral, or harmful for residents with dementia, all participants stated that these activities are beneficial. One participant added “... activities bring them back to those times that they do remember, gives them another form of happiness that maybe they weren’t expecting that day.” Another described how these organized group activities foster friendships:

Even if some people aren’t able to fully hold a conversation, that other one who is just doing all the talking at the other person is able to get their feelings out and vent just like you would to your best friend. So, I think overall socialization and group activities help the residents live a day-to-day life.

Additionally, when about the overall impact of group activities on dementia-related behaviors, all ten participants stated that these activities decrease the frequency of behaviors.

## **Conclusion**

In summary, ten direct care personnel were interviewed over video calls regarding their perspective on the impacts of socialization on dementia-related behaviors. The participants were asked about the types of activities offered at their facility, the frequency that these activities are offered, levels of participation, and barriers to participation. They were also asked to discuss any correlations between frequency of participation and overall cognitive abilities and independence in activities of daily living. They were then asked to discuss times when participating in socialization activities both increased and decreased dementia-related behaviors and what they think the overall impact socialization has on these behaviors. The responses were then transcribed and analyzed for common themes and ideas. All participants in the study stated that group activities were offered regularly, with the most commonly reported activities being crafts, group exercise, shared meal times, listening to music, playing games, and attending religious services. Barriers to participation included advanced dementia and dementia-related behaviors, reserved personalities, underlying anxiety, physical disabilities, and having visitors or appointments scheduled during activities. Overall, all participants reported that they believe group activities decrease dementia-related behaviors and are overall beneficial for adults with dementia. These findings will be discussed further and compared to the existing literature in chapter 5.

## **Chapter 5: Discussion**

### **Introduction**

This chapter will summarize and discuss the results found in chapter 4. This chapter will also compare and contrast the findings from chapter 4 to the findings from the literature review in chapters. These findings will be related to the research question, which evaluates how direct care nursing home personnel perceive the impacts that organized group activities have on the dementia-related behaviors of adults with dementia within long-term care facilities. This chapter will also discuss the limitations and delimitations of the study, implications for caring for adults with dementia, and areas of potential future research.

### **Impact of Socialization on Dementia-Related Behaviors**

This study sought to understand how direct care personnel in long-term care facilities perceive the impacts that organized group activities have on the dementia-related behaviors of adults with dementia. Ten participants who have regularly worked directly with adults who have dementia in long-term care facilities were interviewed about their experiences with group activities and the ways in which they affect dementia-related behaviors.

All participants in the study stated that group activities were offered regularly, with nine reporting daily activities and one reporting twice weekly activities. The most commonly reported activities included crafts, group exercise, shared meal times, listening to music, playing games, and attending religious services. Nine of the ten participants reported that residents in their facility socialize together outside of these organized group activities, typically by sitting in shared spaces and conversing. Barriers to participation included advanced dementia and

dementia-related behaviors, reserved personalities, underlying anxiety, physical disabilities, and having visitors or appointments scheduled during activities. All participants were able to recall times when participation in group activities decreased dementia-related behaviors and eight of the ten participants were able to recall times when these activities increased behaviors. Overall, all participants reported that they believe group activities decrease dementia-related behaviors and are overall beneficial for adults with dementia.

The perceived benefits of group activities for adults with dementia is consistent with prior studies that have found that loneliness or isolation has detrimental impacts on overall health and well-being as noted in the literature review. A large number of studies have found that loneliness is an independent risk factor for worsened physical health, worsened mental health outcomes, worsened quality of life, increased risk of dementia, and increased risk for mortality (Holt-Lunstad et al., 2010; Luo et al., 2012; Wang et al., 2018; Taube et al., 2015; Kuiper et al., 2015; Sommerlad et al., 2019; Cohen-Mansfield et al., 2017). Luo et al. (2012) analyzed data collected from 2,101 adults over the age of 50 years old and found that those who reported the highest level of loneliness were 1.96 times more likely to die within six years than those who reported the lowest levels of loneliness. In addition to this, correlations were found between loneliness and increased depressive symptoms, increased functional limitations, and decreased self-reported health (Luo et al., 2012). These findings were present even when health behaviors were held constant, suggesting that loneliness is an independent risk factor for morbidity and mortality (Luo et al., 2012). The current study added to the existing literature by suggesting that socialization may help to reduce dementia-related behaviors.

The current study also found that advanced dementia is a barrier to engaging in socialization activities, and this finding is consistent with the existing literature. The most commonly cited reason for residents not participating in group activities in the current study was advanced dementia making it difficult to participate, with 60% of participants listing this. Six of the ten participants also agreed that residents who regularly participate in group activities generally have higher levels of baseline cognition and independence when compared to peers who do not regularly participate. This finding is consistent with findings from other studies. For example, a study performed in 2017 by Cohen-Mansfield looked at engagement levels in group activities amongst adults with dementia and found that cognitive function is the most consistent predictor of engagement in group activities. The researchers noted that the apparent decrease in engagement in those with lower levels of cognitive function does not necessarily indicate that people with more advanced dementia are not benefitting from group activities, as these individuals may be experiencing other benefits from the group activities, such as a decreased frequency in dementia-related behaviors (Cohen-Mansfield, 2017). This is consistent with the finding in the current study that all participants found group activities to be beneficial and to decrease dementia-related behaviors. One participant noted that regardless of the residents' baseline cognition and independence, residents often seemed more engaged during group activities than they did throughout other parts of the day.

Another factor that was cited as a reason residents do not participate in activities was reserved personalities or lower levels of sociability prior to dementia diagnosis. Prior studies have similarly found that level of sociability throughout life may impact ability to engage

socially after developing dementia. A meta-analysis of longitudinal cohort studies performed by Kuiper et al. (2015) concluded that low social participation, less frequent social contact, and more loneliness were each associated with a higher incidence of subsequent dementia comparable to other known risk factors for dementia (Kuiper et al., 2015). Another study led by Sommerlad et al. (2019) hypothesized that increased social connection earlier in life may help one to build up a “cognitive reserve,” which may delay or even help prevent dementia. They also hypothesized that those who were less social may have had early decreased cognition that may have contributed to difficulties maintaining friendships (Sommerlad et al., 2019). The study also found that those who spent more time with friends and family during midlife had higher cognitive performance compared to those who spent less time being socially connected (Sommerlad et al., 2019). These findings as well as the findings from the current study suggest that there may be a reciprocal relationship between socialization and dementia, with more advanced dementia making it more difficult to socialize and less socializing making potentially contributing to more severe dementia.

### **Limitations and Delimitations**

As mentioned in Chapter 3, a limitation of this study included sample size and willingness of direct care workers to participate in the interview. The sample size was a result of the qualitative nature of this study to receive saturation of data. The willingness of direct care workers to participate was mitigated by posting to social media in a way to reach these workers more readily, however, their willingness to participate was nonetheless still a limitation. Another limitation was the subjective quality of data due to the qualitative nature of this study. This

limitation may have introduced bias into the responses of the participants. A limitation that had great influence on this study was the impact of COVID-19 pandemic, which inhibited the researchers from interacting with, and interviewing, participants in person. To mitigate this limitation, the participants were interviewed and recorded through Google Hangout or Zoom video chat links. To alleviate possible participant anxieties and hesitations about interviewing online, participants were offered to keep their video off during the interview process after consent was received.

A limitation that was introduced during the study was the inconsistencies in capabilities of the various long-term care facilities to provide activities to residents that may be bed bound or limited by physical disabilities. It was noted that not all facilities had the ability to accommodate these residents and provide enough staffing to allow all residents with certain physical restrictions to be able to participate regularly in the social activities, while others were much more equipped.

A delimitation of this study was the qualitative information retrieved from secondary sources, the direct care workers, and not the residents themselves. Demographics were not distinguished in this research project which created a second delimitation. Participants were able to describe their experience with residents with dementia and their related behaviors in relation to their level of socialization without delineating between gender, age range, and race. Finally, interactions between family members were not included in the definition of socialization of this study, instead, interactions between residents with other residents and staff were documented. This was to allow for group activities and social interaction within the long-term care setting to

be highlighted and reduce discrepancy between residents that do not regularly have outside visitors.

### **Implications of the Findings**

Dementia-related behaviors such as delusions, hallucinations, depression, agitation, aggression, and sleep disturbances are distressing to both those living with dementia as well as their caregivers (Press & Alexander, 2019). While there are a few pharmacological options that may help to slow the progression of dementia, non-pharmaceutical interventions also play a key role in helping to manage dementia and its associated behavioral complications. The current study suggests that socialization can serve as a non-pharmacological intervention to help manage dementia-related behaviors. This study highlights the importance of regularly offering organized group activities in memory care facilities and ensuring that staff understands the importance of resident participation in said activities.

### **Further Research**

The purpose of this study was to identify any relationship between the amount of socialization that adults with dementia in long-term care facilities have and their disease progression. This was done by analyzing the dementia-related behaviors displayed by these residents. Through conducting ten interviews with direct care workers involved in the care of these residents, the amount of activities provided at the long-term care facilities, the level of participation, and the correlation to the dementia-related behaviors have been identified based on perceptions of these direct care workers. The data gathered from this research has shown

correlations between the amount of socialization residents with dementia receive having a direct impact on reducing the amount of dementia-related behaviors displayed by those same residents.

A question was introduced during the interview process that opened an avenue for further research on this topic. This question proposed the idea that there may not only be a correlation between the level of socialization that impacts the dementia-related behaviors, cognition, and independence of the residents, but that there may also be a confounding factor in which the current underlying progression of the residents' diseases could have been the influencing factor for whether they were to participate in the activities in the first place. There is room for further research on this topic that may include documenting progression of dementia via dementia-related behaviors prior to a resident's stay at a facility and tracking their progression as they live in that facility. As previously mentioned by testimonials from participants, a barrier to resident participation in group activities was their preexisting complications of severe dementia. This proposed research would resolve this confounding factor by grouping residents by disease severity and analyzing said groups' dementia-related behaviors based on their levels of socialization.

## **Conclusion**

Dementia is one of the leading causes of disability and death worldwide (World Health Organization, 2017). Dementia-related behaviors such as delusions, hallucinations, depression, agitation, aggression, and sleep disturbances are distressing to both those living with dementia as well as their caregivers (Press & Alexander, 2019). While there are a few pharmacological options that may help to slow the progression of dementia, non-pharmaceutical interventions also

play a key role in helping to manage dementia and its associated behavioral complications.

Existing research identifies a lack of social interaction as a factor of poor prognosis for those diagnosed with dementia (Sommerlad et. al., 2012). The purpose of this study was to explore the relationship between the level of socialization and the progression of dementia in residents by analyzing their dementia-related behaviors by interviewing staff at long-term care facilities.

All participants in the study reported group activities were offered regularly in their facility, with the most commonly reported activities including crafts, group exercise, shared meal times, listening to music, playing games, and attending religious services. Nine of the ten participants reported that residents in their facility socialize together outside of these organized group activities. Reported barriers to participation in group activities included advanced dementia, disabling dementia-related behaviors, reserved personalities, underlying anxiety, physical disabilities, and having visitors or appointments scheduled during activities. Overall, all participants reported that they not only believe group activities decrease dementia-related behaviors and are overall beneficial for adults with dementia, but also advocate for opportunities for organized socialization. The findings of this study suggest that organized group activities have the potential to help regulate dementia-related behaviors and that encouraging socialization is an important part of holistic care for adults with dementia.

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## Appendix A

### Informed Consent

Dear direct care personnel at (insert name of facility):

We are physician assistant students from Bethel University's Physician Assistant Program, conducting research in partial fulfillment of the requirements for a Master's Degree in Physician Assistant Studies. Our study is investigating the impact of participation in organized group activities on dementia-related behaviors.

You were selected as a possible participant in this study because we are interested in studying how participation in group activities affects those living with dementia. As someone who works closely with adults who have dementia, we would like to hear what your experiences have been in regards to this research question. There are no funding agencies involved in this study.

If you decide to participate, participation involves being interviewed by researchers from Bethel University's PA program. The interview will last approximately 30 minutes. Notes may be written during the interview. An audio tape of the interview and subsequent dialogue will be made. If you don't want to be taped, you will not be able to participate in the study.

Most interviewees will find the discussion interesting and thought-provoking. If, however, you feel uncomfortable in any way during the interview session, you have the right to decline to answer any question or end the interview with no penalty.

Facility and administrators from Bethel University will neither be present at the interview nor have any access to raw notes, transcripts, or audio recordings. These notes, transcripts, and audio recordings will be kept on a password protected computer belonging to the researchers for the duration of the study. The information will be analyzed for common themes related to the impact of group activities on dementia-related behaviors. After the completion of the study, the data will be kept on an external storage device locked in the PA program office for a minimum of five years, per securing requirements for Bethel University's Physician Assistant Program.

Any information obtained in connection with this study that can be identified with you will remain confidential and will be disclosed only with your permission. In any written reports or publications, no one will be identified or identifiable and only aggregate data will be presented. After analyzing the results of the interviews, all recorded interviews and transcripts will be deleted from the password protected computer. All participant contact information will also be deleted after the completion of the study.

Your decision whether or not to participate will not affect your future relations with your employer or Bethel University in any way. If you decide to participate, you are free to discontinue participation at any time without affecting such relationships.

This research project has been reviewed and approved in accordance with Bethel University's Levels of Review for Research with Humans. If you have any questions about the research and/or research participants' rights or wish to report a research related injury, please contact us using the contact information provided below.

You will be offered a copy of this form to keep.

We understand that you have an extremely busy schedule and your time is limited. Please realize that your participation is vital to the success of this research. The information that you provide is essential to the validity of this study. Thank you in advance for your participation in this study. If you have any questions, feel free to contact us at the above email addresses. Thank you again for your help.

Sincerely,

Ashley Heppner, Researcher, [ashley-heppner@bethel.edu](mailto:ashley-heppner@bethel.edu)

Caitlyn Jolly, Researcher, [c-jolly@bethel.edu](mailto:c-jolly@bethel.edu)

Katelyn Kunde, Researcher, [k-kunde@bethel.edu](mailto:k-kunde@bethel.edu)

Dr. Mary Schulze Michener, Research Chair, [Mem96552@bethel.edu](mailto:Mem96552@bethel.edu)

You are making a decision whether or not to participate. Your verbal consent indicates that you have read the information provided above and have decided to participate. You may withdraw at any time without prejudice after giving verbal consent should you choose to discontinue participation in this study.

## Appendix B: IRB Approval



**BETHEL**  
UNIVERSITY

Institutional Review Board  
3900 Bethel Drive  
PO2322  
St. Paul, MN 55112

October 13, 2020

Ashley Heppner  
Bethel University  
St. Paul, MN 55112

Re: Project FA-04-20 The Effects of Socialization on the Progression of Dementia

Dear Ashley,

On October 13, 2020, the Bethel University Institutional Review Board completed the review of your proposed study and approved the above referenced study.

Please note that this approval is limited to the project as described on the most recent Human Subjects Review Form documentation, including email correspondence. Also, please be reminded that it is the responsibility of the investigator(s) to bring to the attention of the IRB any proposed changes in the project or activity plans, and to report to the IRB any unanticipated problems that may affect the welfare of human subjects. Last, the approval is valid until October 12, 2021.

Sincerely,

A handwritten signature in blue ink, which appears to read 'Peter Jankowski'.

Peter Jankowski, Ph.D.  
Chair, Bethel University IRB

## Appendix C

### Participant Recruitment Facebook Post

Hello, my name is \_\_\_\_\_ and I am currently a physician assistant student at Bethel University, conducting research to fulfill requirements for a Master's Degree in Physician Assistant Studies. My partners, \_\_\_\_\_ & \_\_\_\_\_, and I are studying the impact of participation in organized group activities on dementia-related behaviors for residents with dementia in long-term care facilities.

We are looking to interview direct care staff (CNA, PCA, LPN, RN) who have worked in a long-term care facility, specifically working with residents with dementia. We ask that you have worked at a facility for at least 2 months or have worked a cumulative 250 hours.

If you are willing to participate, please contact either myself or one of the other researchers in the study DIRECTLY through our email addresses. We ask that you do not comment on or "like" this post to keep the confidentiality of the participants.

All information collected will be anonymous and your decision to participate in this study will not impact your relationship with Bethel University or the researchers.

Again, please contact our emails directly if you are interested in participating.

Our email addresses are:

Katelyn Kunde: [k-kunde@bethel.edu](mailto:k-kunde@bethel.edu)

Caitlyn Hagstrom: [c-hagstrom@bethel.edu](mailto:c-hagstrom@bethel.edu)

Ashley Heppner: [ashley-heppner@bethel.edu](mailto:ashley-heppner@bethel.edu)

Thank you so much, we look forward to hearing from you!

## **Appendix D**

### **Interview Questionnaire**

Script: Hi, my name is \_\_\_\_\_ and I am with Bethel University's physician assistant program. My research group and I are studying the relationship between socialization and behaviors in patients with dementia and are interviewing staff to gain more insight into the caregiver perspective. I will ask several open-ended interview questions about your attitudes, beliefs, and perspectives about residents with dementia living in this long-term care facility and the impact their participation in activities has on their dementia-related behaviors.

Before I begin, I would just like to remind you that all of your answers will be anonymous, and there will be no documented ties to this facility. Your name and the name of the facility will be coded using a number system to remove identifiers and to keep you and the facility anonymous. You have the right to decline to answer any question, and there will be no repercussions by your employer or Bethel University if you choose not to answer any question. If at any time you would like to stop the interview, please let me know and the interview will be stopped immediately. This interview will be recorded so that I can remember the details of your answers. The recording will then be transcribed into a word document by the researchers. The recording will be deleted off of the computer after it has been transcribed and the transcription will be stored on the researchers' password protected computer. The recording and word document will both be deleted off the researchers' computers after the completion of this study. The word document will then be stored in a locked office at Bethel University for 5 years. You have the right to see the transcription if you'd like at any time. To do so, you simply need to

contact me and I will send you a copy. Do you have any questions about the procedure of this study? Would you like a written copy of this informed consent?

Do you wish to continue with the interview? By answering yes, you understand the information I verbally presented to you and consent to this interview.

As I conduct this interview, I would like to reinforce that these questions are directed at gathering information about residents that have been diagnosed with dementia and the behaviors associated with dementia.

If any questions arise during the interview process, please do not hesitate to ask.

1. What types of organized group activities does the long-term care facility you work at offer for people who have dementia (examples may include social events, meal times, church services, and other group events offered by the facility)?
  - a. How often are these activities offered?
  - b. What time of day are these activities offered?
2. Have you seen the adults with dementia at your facility socializing with one another outside of these organized group activities? If so, what does this form of informal socialization look like?
3. If you had to give an approximate percentage, what percentage of the residents with dementia in your facility participate in these organized group activities?
  - a. Of those who do not typically participate, what do you think is preventing them from participating?

For the next few questions I am going to be asking about specific dementia related behaviors.

These behaviors include:

<p>Paranoid and delusional ideation (examples: thoughts of others stealing, “imposter” delusion, infidelity delusion, suspiciousness, paranoia)</p>
<p>Hallucinations (examples: visual, auditory, olfactory, haptic, other)</p>
<p>Activity disturbances (examples: wandering, purposeless activity, hiding objects)</p>
<p>Aggressive behaviors (examples: verbal outbursts, physical threats and violence, agitation, negativity)</p>
<p>Affective disturbances (examples: tearfulness, depressed mood)</p>
<p>Anxieties and phobias (anxiety about upcoming events, other anxieties, fear of being left alone, phobias)</p>

A list of these behaviors will now be shared in the chat box for you to refer to as needed as you answer the following questions:

4. Can you recall an event(s) in which socialization, both in the form of informal interactions and organized group activities, has INCREASED a resident’s dementia related behaviors in intensity, frequency, or duration?
5. Can you recall an event(s) in which socialization, both in the form of informal interactions and organized group activities, has DECREASED a resident’s dementia related behaviors in intensity, frequency, or duration?

6. Overall, do you think that participating in organized group activities decreases, increases, or has no impact on the frequency of dementia related behaviors displayed by residents?
7. For the residents that DO regularly participate in group activities, how would you describe their level of mental cognition relative to those around them? Are they MORE aware/alert, LESS aware/alert, or is their cognition unchanged versus those around them?
  - a. How independent are these residents in performing their activities of daily living?
8. For the residents that DO NOT regularly participate in group activities, how would you describe their level of mental cognition relative to those around them? Are they MORE aware/alert, LESS aware/alert, or is their cognition unchanged versus those around them?
  - a. How independent are these residents in performing their activities of daily living?
9. Overall, do you think that organized group activities are beneficial, neutral, or harmful for the residents with dementia? (*Prompt for interviewer: encourage examples if not already given*)
10. Do you have any final comments or stories about how the role of socialization affects the behaviors in residents that have dementia?

Thank you very much for the time you took for this interview and survey. You are allowed to withdraw your answers from the study at any time until February 28, 2021. If you would like to withdraw your answers from the study, please contact us via email by the stated date. Would you like a written copy of the questions and my contact information?